The Top 26 unanswered questions from the Living With and Beyond Cancer PSP (in order of priority as agreed at the final workshop. For questions resolved by the PSP that have already been answered, out-of-scope questions, and other types of question received, please see further down this spreadsheet.

<table>
<thead>
<tr>
<th>Qn No.</th>
<th>Original questions</th>
<th>Category of Respondent</th>
<th>Relevant literature</th>
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<tbody>
<tr>
<td>1.</td>
<td>What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc.)?</td>
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<td>For some patients, newer medicines mean that cancers and leukaemias are treated more like a chronic disease now, so what's the best way for them to get their healthcare - do they always need to see a specialist or can follow ups be done at their GP's surgery?</td>
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<td>What type of long term follow-up/support services would patients value? How can the NHS accommodate this?</td>
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<td>What role do patients see their GP having in their cancer treatment and follow up?</td>
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<td>What would patients like to see in a cancer care review in primary care and at what point does a patient feel it would be appropriate to have a review of their cancer and treatment by their GP?</td>
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<td>What is the role of community pharmacy in supporting patients living with or beyond cancer?</td>
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<td>How can pharmacists better support patients living with and beyond cancer with their medicines?</td>
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<td>How can pharmacy professionals contribute to helping patients live with and beyond cancer?</td>
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<td>At what point do we explore the needs of people following their diagnosis and treatment of cancer?</td>
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<td>How can we get rapid access into the system if a patient is concerned?</td>
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<td>How to avoid overmedicating subsequent care for people who have undergone curative surgery, particularly for low risk cancer?</td>
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<td>In people LWBC, are PROMs improved if they are cared for by RCNP with recognised LMC competencies?</td>
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<td>Ask GPs what would help them in caring for patients who are discharged after treatment in secondary care.</td>
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<td>What is the most appropriate way for GP practices to support patients?</td>
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<td>The relevance of social work in supporting patients with cancer.</td>
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<td>The relevance of social work within an oncology medical team in serving the needs of the patients.</td>
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<td>Post-treatment surveillance strategies: the number of cancer survivors is rising and becoming a strain on resources (clinical time in particular). With increasing reliable detection tools such as circulating tumour DNA (ctDNA, liquid biopsy), and smart phones, could patients monitor themselves using AI (artificial intelligence)? Self directed post treatment surveillance?</td>
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<td>What is the economic impact on the healthcare system of patients who are not coping well with life with and beyond cancer (e.g. health anxious, depressed, agoraphobic, panic, socially isolated)?</td>
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<td>What barriers, if any, would prevent them contacting their GP or practice nurse to ask for support?</td>
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<td>How could health care professionals in primary and community care improve their patient's experience when living with and beyond cancer?</td>
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<td>Living well with metastatic disease: How can allied health professionals support patients in self-managing their disease and symptoms to live well.</td>
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<td>Supporting patients and carers at home and how can carers help manage more with their relatives and can they do more. For example injections with supportive medicines?</td>
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<td>What is the best way to train informal cancer caregivers to support cancer patients during and after treatment?</td>
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<td>How can digital technology be harnessed to support those living with cancer or beyond cancer?</td>
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<td>How are PCNs expecting to transfer relevant clinical information between acute and community to ensure a seamless provision of patient centered care?</td>
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<td>Will cancer patients use digital health adjuncts in their care pathway?</td>
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<td>How can telemedicine (remote / computer based / telephone) support help transform the care of people LWBC?</td>
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<td>How would follow up for long cancer be done? In primary care with specialists support or via respiratory medicine?</td>
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<td>For indeterminate lung nodules, can these be managed in primary care?</td>
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<td>How do we engage primary care with all this? GPs don't view cancer as a long term condition so often aren't happy taking on their management. It can't be sustained in secondary care so how do we change things? Is there any role for oncology specialists in primary care?</td>
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<td>Our local Cancer Alliance wants to see a consistent model for restratified pathways across the footprints. Not surprisingly, specialists favour hospital based programmes while the expertise in management of long term illness in primary care might have more to offer patients. Has there been any investigation of the patient view on this? Are there any shared care models?</td>
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<td></td>
<td>Do they / [PATIENT] have confidence that they can get back into the correct system if they need to?</td>
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<td></td>
<td>Are outpatient oncology review appointments of benefit to patients?</td>
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<td>How can the voluntary eg charitable cancer support work in greater partnership with NHS providers rather than in an often rivalrous relationship. The current commissioning model seems too complex</td>
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<td></td>
<td>How can communication / continuity of care be improved for people LWBC, who access care in NHS / primary / voluntary sector?</td>
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<td>How can the activities of third sector organisations interested in LMC be coordinated to avoid duplication of effort and serve the patients more effectively?</td>
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<td>How and who do you highlight the long term effects you are suffering too?</td>
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<td>Who should be exploring these issues with the affected people? Others, when and how?</td>
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</table>

H = health professional, P = patient, R = relative/ carer, O = other, U = unknown
How can pharmacists better support patients living with and beyond cancer with the late side effects of anti cancer medicines? H

What is the best care model for managing consequences of treatment? H

Should there be a new medical specialty created to manage and deal with late and long term cancer treatment consequences? H

Given the range of late effects includes every system, and given the frequency and epidemiology of the problem, how will all the medical colleges ensure that long term and late effects is a mandatory part of doctor’s specialist training? H

Should cancer patients have an annual review (by the GP practice nurse) of their health taking into account all other long term conditions and any lifestyle needs? H

What ongoing specialist advice regarding symptom control should be available for those who have been treated with curative intent? H

How can we best take a multidisciplinary approach to managing side and late effects of cancer and treatment? H

How can we implement proven interventions that benefit patients into the NHS in the current fiscal climate - e.g. exercise to prevent effects of hormonal therapy or specialist gastroenterological assessment and management for pelvic radiation therapy? H

Who is best placed to advise about late effects? H

How can services be developed to support me with my quality of life beyond cancer? H

How will people affected by cancer be supported to self manage the late and long term effects of cancer and its treatment? H

How do we practically (Health and Wellbeing events in my opinion are not a long term practical solution) deliver good quality patient self management post treatment, that then actually reduces the burden on secondary and primary care? H

I am very interested in Managing Long term effects post Cancer Treatment - I would like to carry out some research on a tool that can be used in oncology clinics to assess and document long term effects and ensure patients are referred to specialist clinics when required. H

What is the best model for investing and managing late effects? H

Are GPs properly equipped to deal with post radiotherapy/chemotherapy side effects? H

Should we be encouraging patients to self manage? Or does the NHS have a duty of care to manage patients in the long run following cancer treatment. How does cancer compare to other long term conditions and what patients are responsible for so? H

How much do GPs understand about late effects of treatments? What tools do GPs need to be able to recognise late effects? H

In 'late effects ' recognised? H

What models of care support people closer to and in their own homes? H

How well are we supporting AYA patients treated for Hodgkin’s Lymphoma in the 1980's, who are now facing late effects and second cancers as a result of their treatment? Can anything be done to reduce their considerable risks? H

How does CCGs, Secondary Care, Primary Care, Community sector and voluntary sector work better together to give cohesive support to those living with and beyond cancer. Especially when there are competing priorities for funding and resources. D

To what extent do people affected by cancer receive adequate, long term support from their primary care team after finishing cancer treatment? What does good look like? D

To what extent do people affected by cancer receive adequate, long term support from community based services (NHS, local authority and third sector) after finishing cancer treatment? What does good look like? D

What are the most effective interventions to support self-management in people living with and beyond cancer? D

What is the role of health charities in working with the NHS to provide support to living with and beyond lymphoma? O CHARITY

Does a yearly check up post treatment meet a recovering cancer patient’s holistic needs? P

The range of advice/treatments applicable to survivors is numerous. Should survivorship be a formally diagnosable condition so that appropriate ‘treatments’ are prescribed? P

NCI identified self management as a key enabler of successful survivorship with a shift from a clinically led approach to follow-up care to supported self management, based on individual needs and preferences. What models of supported self management are being employed which are effective from a patient viewpoint ? P

GCP - why do I have my follow ups with my plastic surgeon instead of an oncologist or dermatologist? P

Could I have an open referral at the hospital after my 5 years of ct scans and consultant appointments have ended? P

Why do GP patients have to ‘see your GP’? When we know where we need to see for the next step in our care pathway, yet we have to waste time talking to a GP /P with no knowledge of cancer care, who is often indifferent and uncaring. In other countries cancer survivors can access the correct treatment in a hospital directly, and don’t waste our time having to get a GP referral P

Why isn’t there a cancer GP where we could go to with concerns who would have expertise to know whether to escalate a situation or if a new symptom is just a common after affect. P

Would patients be better supported if there was better fluidity and communication between primary and secondary care. P

Research to develop and see the effects of an online survivorship course at the end of treatment. This could have units on diet/ exercise/ sleep/ mental health/ sexual health/finance/ etc. and could be tailored for different age groups. It might help people to have a sense of “doing something” at the end of treatment and could be developed as an NHS app for both patients and carers. P

Who do you turn to for re-assurance about minor physical symptoms which nevertheless cause extreme anxiety but are not urgent enough to bother the hospital or GP? P

Fast track referral in place not just for five year follow up but longterm. Patients should not have to go through GP for this. P

Do people who have no other health problems feel they are being adequately followed up in primary care after being discharged from acute care? P
The link between survivor & GP. I feel I could be let down by ignorance & indifference to my previous health problems. I know when my body need medical help. ...

Would it be possible to have a medical person available to patients for ever to answer what might be simple questions - does not need to be a Doctor? ...

Following on from the question above, (worry that, a) I won't be able to get back into the acute system should my cancer rear up again. (b) I worry constantly that my Oncologist, who, I’ve been able to build quite a good relationship with, will leave or retire and I'll be back to square one dealing with complete strangers, who don’t know my history or me personally and will make the wrong decisions on my behalf. I still feel even after 12 years of living with secondary disease that my Oncologist actually controls life and death and that I have little say over my future, such as it is.

The link between hospitals and local services is obscure. My experience of discharge was awful. Local services refused to do injections for me; to the extent that my partner was in tears. I ended up saying that I would travel London to get this done. In the end we used around three separate Leicester services to get simple things like wound dressing and injections done.

Models of follow up to suit various lifestyles - working full time/part time, not in employment. Models needing to request the time of people living with and beyond cancer.

Stop the NHS delaying patients getting follow-up appointments. The system that now makes us return to our GP for referrals is counter productive. Let’s go for European system where patient is deemed intelligent enough to be able to request a follow-up appointment directly with a Consultant whom they are under.

Who is best suited to answer questions on follow up, local GP or hospital.

care post cancer - how to education and involve GPs with issues such as the above - why there seems to be a lack of understanding and knowledge in primary care.

Is primary care equipped to support people in the community after hospital based treatment has finished?

How can I get reassurance that new symptoms are not cancer when my GP mis-diagnosed me with my first cancer?

Appropriate methods to deliver long term treatments (e.g. 10 years of endocrine treatment for Breast cancer) with minimum disruption to everyday life.

Should primary care have a designated 'cancer contact' that specialises in the after care of all cancer patients in that surgery?

Who should deal with cancer treatment side effects? Primary care or secondary care team?

Why don’t GPs and cancer professionals communicate more with each other to benefit their post cancer patients?

Are GPs fully informed of the impact on patients and family members of living with cancer? Things like having access to GP appointments sooner than the usual 3-4 week wait! And up to date medication list from oncology!!

Are the long term effects of cancer often ignored/ underestimated? And how can we better support patients?

Why do the medical profession generally not seem interested in the after effects of radiation treatment? My specific experience is with pelvic radiotherapy (prostate cancer), and my oncologist/radiologist didn’t warn me about many of the possible after effects. Unfortunately I now have three of them - radiation cystitis; proctitis; SIBO. To make matters worse when I told her about my problems after my treatment there was no procedure or process to have me seen by specialists i.e. urology and GI. I had to wait for many months.

How much support can we expect from our GPs as we try to cope with the side effects of the treatments?

Why is there no help for patients living with the late effects of radiation treatment. e.g. Radiation Induced Lumbar Plexopathy?

Should a multidisciplinary approach be introduced to treat late effects of radiotherapy?

Would having a ‘named GP’ (as is done for the over 75’s) improve long term health care for cancer survivors. At the moment primary care is not doing well on late effects or secondary cancers due to people falling through the system?

Is primary care equipped to support people in the community after hospital based treatment has finished?

Are you receiving adequate support from your GP to deal with side issues such as skin complaints, swellings and pain (unconnected directly with your original diagnosis)?
I am really struggling with painful side effects after chemotherapy as well as the physical changes to my body after all surgery so far (I still need more surgery due to brain issues)... the consultants looking after me & BCN seems to have taken a huge step back, now I am left feeling like I have nowhere to turn, my gp says contact the team, my consultant seems insistent I contact my gp, meanwhile I'm expected to take a cocktail of painkillers and just get on with it since the radiotherapy & scans show no bone problems..... So that's it I still have pain, something is causing it, but nobody can give me answers or reassurance which only adds to the anxiety I already feel. Surely more investigation, support & it going help should be available post "active treatment", I was triple negative, so no hormone therapy ongoing, just left to swallow pills/bolus all day with nobody to help me understand why I'm in pain.

When a patient develops Lymphoedema as a direct result of their cancer treatment: Why are cancer patients not being treated by the NHS?

We need a more reliable and robust way for patients to have symptoms and late effects Managed. Too many do not get access to pain management clinics until it is too late. Can we find out why and what interventions would help.

Who do you contact? How can you manage the life long effects of cancer surgery treatment, especially when these symptoms mirror recurrence or new primary cancers? A gp knows very little and doesn’t seem at all suitable, however nice they may be.

How do we best care for those who have had breast cancer? GPs not properly equipped and oncologists only treat ‘active’ disease, but there is unmet need in those who have come through treatment but are now living with the effects of that treatment and the psychological effects of their illness.

Addressing the issue of late effects and getting support for these, particularly when no longer in active follow up.

Ease of access (fast-track) back to medical system if concerned about recurrence.

Once active treatment has finished it feels like a bit of a black hole as to who to contact about any concerns, GP, surgeon, oncologist?

At what point should you look to your local GP / health centre for support rather than the hospital team?

Who is consulted about the support treatments offered by the NHS to cancer patients? I find it quite strange that while – for example- breast reconstruction surgery is offered routinely, getting help with painful tomorrows or dodgy joints following chemo is difficult. For me, the loss of a breast was not particularly difficult and I didn’t the idea of reconstruction. However, holding around with dodgy joints for a year was very, very depressing. Some easily available physio would have been nice – and guess much, much cheaper than the cost of a reconstruction op.

Side effects of medication – for example I am on Tamoxifen with a 10% chance of developing cataracts (which my mum did while on this drug but didn’t realise the link at the time) and everyone else is left to their own devices, when really it should be important to have an eyetest once a year, but no-one has told me this, and I would have to pay for it myself, it is as if you are just prescribed the drugs and then pick up yourself any continuing tests you may need.

No on-going support when living beyond cancer if long term side effects occur and GPs lack knowledge and ability to refer on - "well you’ve had cancer and have to live with it”.

How do you use technology to help people with cancer to live at home?

Following my husband’s diagnosis with stage 4 inoperable maxilliary sinus cancer, he was on an intricate cocktail of pain medication, including morphine, pregabalin, ketamine, etc. etc. It was expected that either my husband (or in view of my confusion and extreme pain level myself) would have the knowledge and education to take this cocktail of medication, sometimes from syringes with very small doses and huge room for error, to the extent that an overdose could very easily have occurred. What support/training for carers is available when such a detailed, complex prescription is made to control severe pain? I was given none and just expected to know what I was doing. Luckily, I was able to do this, but many would not be able to. In fact, some of the nurses in the non-cancer ward hospital setting struggled with dosages, timings, etc.

How do patients and families bypass existing healthcare systems to get the care they need?

Why are the medical profession not trained to recognise the symptoms of pelvic radiation damage? Would save the NHS money as patients would not be put through unnecessary expensive tests. 

Does nurse led follow up improve quality of life for patients?

What is the economic impact of self-management on the patient; primary care; secondary/tertiary care? (including open access telephone and nurse-led clinics)

Why can’t hospitals and GPs work more closely together to ensure e.g. successful secondary/tertiary care? (including open access telephone and nurse-led clinics)

What is the best way for primary care colleagues to support people living with cancer or beyond cancer?

What support is available in primary care for managing long term conditions affected by cancer?

Should there be a specialist nurse to support recovery? With the growing number of cases and CNS’s pulled out already with new cases (and this will rise), should there be an Interim type of specialist nurse - between “remission” and “palliative care”

Once under the care of an Orthopaedic Breast Care Surgeon and subsequently discharged, why does the referral for any further concerns / problems have to be via the GP?

Value of proactive monitoring for hypothyroidism arising from radiotherapy in the year after treatment ends. Several researchers highlight a 40% rate of hypothyroidism. Two thirds of those affected will suffer depressive symptoms as well as physical manifestations of hypothyroidism.

I have heart failure due to Atrial Fibrillation (probably, but not Herceptin which I had to stop after 5 when an Echo was done) which showed up one year on. I am now 8.5 years on (and doing well). What are we doing to stop patients getting heart failure now (the questions, and weighting were a bit random in my case, and I didn’t have an Echo before Herceptin).
Screening post primary cancer treatment - how can screening for late effects be implemented be it by existing technology or new? Particularly thinking heart problems.

What is the best way of following-up people after treatment for cancer. How can we best ensure we detect recurrence in a timely manner, address concerns and long term toxicity without increasing anxiety, falsely reassuring or raising expectations all within increasingly stretched health care resources?

What is the optimum management of cardiovascular/cerebrovascular risk in patients with cranial/craniospinal/neck radiotherapy?

How do we identify whether long term cancer survivors are at significant additional risk of further health problems as a result of previous cancer treatments?

What additional monitoring should be put in place to mitigate any increased risk posed to long term cancer survivors?

What is the most effective way of monitoring patients for late effects of radiation therapy?

How should the health service monitor and support patients living with long term side effects?

What is the best way to monitor patients who have received treatment for thyroid cancer?

I had whipple surgery for pancreatic cancer 7 years ago. There is no protocol for monitoring beyond the 5 year scans. I would like to see a protocol adopted as this is drastic surgery changing the digestive system permanently. I would like to see monitoring for deficiencies before these areas. My gp cannot order these. Monitoring regularly glucose and iron levels both maybe affected longer term by the surgery.

Should there be screening for lymphedema pre and post breast or pelvic cancers?

After screening will occur after treatment on a national basis.

After having a cancer diagnosis and treatment sometimes patients can suffer with depression and this can come out many years after the treatment has stopped - what is being done to monitor the mental health well being of cancer patients?

Also, one (two) might routinely screen cancer patients for osteopenia (for example), a side effect of treatment; the adjective "truly does not.

A known side effect of an osteoporosogram is the risk of vitamin D and B deficiency as well as iron and zinc deficiency. Despite this after care does not include routine blood tests for these problems. Nor are you given either advice by all hospitals or supplements.

Why don’t we screen for treatment related lung cancer? Screening is already in place for breast cancer, but not for lung cancer. Screening for lung cancer using low dose CT has recently shown to be cost effective in the general smoking/ex smoker population, and this question should now be tested in groups who don’t feature in the population risk models due to a lack of smoking but are nevertheless at increased risk due to previous cancer treatment with thoracic radiotherapy and/or chemotherapy. The risk of treatment related lung cancer is multiplied in patients who smoke, and this group in particular warrants urgent research to establish a role for lung cancer screening.

At the end of active treatment for breast cancer I feel that there is no one who specifically keeps an eye on me as a whole. I go for yearly mammograms but don’t see the oncologist at all. If I have concerns I go to GP first and then referrals me if he thinks it’s necessary. E.g. At the moment I suspect I have developed lymphedema in my arm. I wish we could have a yearly all round check up alongside the mammogram.

Should all head and neck cancer patients be screened repeatedly for psychological distress?

How should we screen patients treated with anti-cancer therapies for future risk of cardiac disease?

Should we have more check-ups after chemo? Not seen since before last chemo session over a year ago.

How do we go about developing a protocol for regular monitoring of the rare group of survivors of the massive surgery for pancreatic cancer... there seems to be no organised system for making sure that our nutritional needs are met. eg vitamins, calcium supplements... regular blood checks for essential minerals etc... this must also be true for other survivors of stomach / oesophageal cancer.

Following Treatment for Prostate Cancer I have been left impotent. Fortunately at my age this is not a problem, but for younger men it may be of major importance. My attitude and that of my wife is that as long as the cancer has been stopped it is a price worth paying.

How well informed are patients of the potential long term effects of treatments for cancer?

Why is it not really recognised as an illness as most doctors say before radiation treatment there is not that many side effects yet I suffered from day 1 of radiation to the point were I wanted it to stop.

Now I have wet/dry doctors call radiation burn bowel and bladder are non existent so surely these are common symptoms in side effects of radiation yet your not told this before treatment your given a bit of side effects for chemo an none for radiation wen its clearly damaging to the pelvic area.

Over forty years ago I had radiation therapy for testicular cancer, and no one mentioned radiation induced lumbar/sacral/Plexopathy. I am led to believe that even today this is still the case. Why?

Who is going to really tell me the truth about the after effects of cancer treatment?

Information given to patients during or after treatment about possible long term side effects & how to manage them with treatment options & where to go for help.

Would more time to talk through the implications of cancer treatment have altered treatment decisions?

Is the quality of life following cancer treatment what patient’s had been lead to expect?

Regarding long term side effects: were you suitable prepared and warned of the long term effects of treatment?

Did you worry about the long term effects of treatment at the time you received your diagnosis?
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tr>
<td>Were you concerned about the possible long term effects of treatment whilst receiving treatment?</td>
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<td>If you were/are not aware of the possible long term effects of treatment, would you have accepted treatment?</td>
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<td>the theory of living with is great- reality and resources are completely different.</td>
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<td>Why is there not more information given to patients before they undergo treatment about the possible long term side effects? How can patients give informed consent to treatment if they are not told all the facts?</td>
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<td>Whilst the treatment and information are clear their should be more details of the respective side effects associated with the various actions</td>
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<td>Why were we not told about possible side effects of Chemo and Radiotherapy beforehand?</td>
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<td>Why are the side effects not talked about in more detail?</td>
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<td>How the NHS deals with the risk, and explains the risk of adjunct therapies e.g. radiotherapy and chemotherapy to patients?</td>
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<td>Why don't doctors tell you what could happen after radiation?</td>
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<td>I have no vagina due to radiation damage and i was only 32 when it happened, it has ruined every relationship i've been in. do i think it's important to find a less invasive procedure especially for really young female's who still have their whole lives ahead of them. when i had cervical cancer no one told me that this could happen. so for the sake of all other ladies out there please could you consider this in your research?</td>
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<td>more honest answers when the patient asks questions about their medical problems left by chemo.</td>
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<td>More explanations of the after effects of treatment, especially the late effects</td>
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<td>Where you made fully aware of the side effects of your treatment before you started treatment?</td>
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<tr>
<td>Why are patients not given information about radiotherapy side effects and that many people suffer from them to differing degrees?</td>
<td>P</td>
</tr>
<tr>
<td>What is it that changes, psychologically, when someone finds it possible to accept their cancer diagnosis and become orientated into a position of self-efficacy and hope? What factors bring this about?</td>
<td>H</td>
</tr>
<tr>
<td>I'm also have arthritis, it's been brought on by the chemo, as a side effect it was not mentioned at the start of my diagnosis, will more explanation on treatments be disclosed to patients at the start of treatments?</td>
<td>P</td>
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<tr>
<td>How might patients be better informed about long term toxicity effects of their cancer treatment?</td>
<td>D</td>
</tr>
<tr>
<td>Are we as health professionals giving patients enough information about the long term side effects of cancer treatments to enable them to make and informed decision around what treatment they have to treat their cancer? i.e. do patients say 'if someone had told me this would happen i wouldn't have had the treatment?'</td>
<td>H</td>
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<tr>
<td>Giving cancer patients feedback on what to expect during treatment?</td>
<td>P</td>
</tr>
<tr>
<td>What to expect in relation to long term side effects of treatments and procedures?</td>
<td>P</td>
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<tr>
<td>I believe that emphasis should be made by the consultants on the possible side effects of RP and issues that may be experienced with incontinence and ED.</td>
<td>P</td>
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<tr>
<td>How do you decide - quality of life's quantity of life when prescribing treatment?</td>
<td>R</td>
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<tr>
<td>What consideration is given to the impact on partners / families when treatment such as hormone therapy is given to cancer patients?</td>
<td>R</td>
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<tr>
<td>What influenced your decision to opt for the type of cancer therapy you chose?</td>
<td>H</td>
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<tr>
<td>Are the possible long term effects of treatment made clear to you when treatment decisions were being made?</td>
<td>H</td>
</tr>
<tr>
<td>What treatments may have been declined if the long term/ late effects were spelt out more clearly?</td>
<td>H</td>
</tr>
<tr>
<td>Why aren't hysterectomy patients warned or educated more about prolapse?</td>
<td>FR</td>
</tr>
<tr>
<td>One of the biggest things for me was the early onset of the menopause, following my first chemo regime at age 37. It was never discussed, not actually mentioned as a side effect, and rarely re-visited since.</td>
<td>P</td>
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<tr>
<td>Why was depression never mentioned in the side effects?</td>
<td>P</td>
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<tr>
<td>Do women/pople really give fully informed consent to chemoradiation treatment for cancers affecting the pelvis - my specific concern is treatment for anal cancer, given the huge 'mesityl' impact on sexuality and bowel (and bladder) function?</td>
<td>P</td>
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<tr>
<td>When offered a Cisrectal trial at the start of a diagnosis should we not be told the long term side effects?</td>
<td>FR</td>
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<tr>
<td>Why aren't the long term effects of reconstruction properly explained?</td>
<td>P</td>
</tr>
<tr>
<td>Why do we get neuropathy and why isn't more said about it during treatment?</td>
<td>P</td>
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<tr>
<td>For many patients with advanced cancers there are treatments available (such as chemotherapy or newer drugs) which have marginal benefits but potentially major impacts on quality of life. To what extent do patients feel they receive a balanced choice including 'no drugs'? To what extent do patients regret their decisions in this regard?</td>
<td>H</td>
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<tr>
<td>How do these regrets differ from those of family members? (who often influence the patient's decision when faced with choices).</td>
<td>H</td>
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<tr>
<td>How to properly balance the long term risks of cancer treatment that persist beyond cancer against the benefits of treatments to the time of cancer? i.e. individualised decision making about management at diagnosis with attention on survival.</td>
<td>H</td>
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<tr>
<td>Why do the thes never give you the full information of all side effects and let u experience them and report back?</td>
<td>P</td>
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<tr>
<td>Do patients regret treatments when they are cured but left with the long-term side-effects?</td>
<td>H</td>
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<tr>
<td>Communication between Dr and Patient - an anthropological approach?</td>
<td>H</td>
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<tr>
<td>Should oncologists and multi disciplinary health care teams have formal communication training?</td>
<td>P</td>
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<tr>
<td>What are the best ways to explore with patients letting go of futile treatments and enjoying quality of life?</td>
<td>H</td>
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<tr>
<td>Question</td>
<td>Type</td>
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<td>-------------------------------------------------------------------------</td>
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<tr>
<td>How can information services on various types of cancer that are available be improved to meet the needs of people with particular types of cancer? Linked to this is the need for good accessibility. Also needs to be informative that takes out the unnecessary medical jargon and can empower people appropriately. (This was why former charity CancerBackup was set up.)</td>
<td>P</td>
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<tr>
<td>Whether it is preferable to map out all treatment options for cancer patients or just discuss one step at a time.</td>
<td>P</td>
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<tr>
<td>What information do Teenager and Young Adult survivors of childhood cancer want included in their treatment summaries and Long Term Follow Up care plans and when do they want receive this information?</td>
<td>H</td>
</tr>
<tr>
<td>When do you think is the best time to receive such information? by who? in what format?</td>
<td>H</td>
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<tr>
<td>How does communication across medical and other professional impact or not on someone’s cancer experience; can we improve across professional communication?</td>
<td>H</td>
</tr>
<tr>
<td>At what point is it right to tell patients the positive benefits of supportive care as opposed to treatment and who decides?</td>
<td>P</td>
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<tr>
<td>How should the potential impacts of treatments on cancer patients and their families be communicated?</td>
<td>P</td>
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<tr>
<td>Does routine sharing of results with the patient, help or hinder the healing process?</td>
<td>P</td>
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<tr>
<td>WHY ARE DOCTORS STILL SO POOR AT COMMUNICATING EFFECTIVELY?</td>
<td>PH</td>
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<tr>
<td>Would the offer of continued information and education be beneficial in the first year of receiving a cancer diagnosis?</td>
<td>H</td>
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<tr>
<td>What are the most effective ways of setting people living with or beyond cancer know what support is available to them?</td>
<td>H</td>
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<tr>
<td>How can we best prepare patients for late and long term effects of cancer and its treatment without exacerbating anxiety about the future? How do we give them the awareness of what is “normal” in terms of physical health?</td>
<td>H</td>
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<tr>
<td>What is the best way to advise cancer patients that continuing treatment (e.g. chemotherapy) is not in their best interest?</td>
<td>H</td>
</tr>
<tr>
<td>How can the NHS provide better information to patients about being - hopefully - long term - after hospital cancer treatment has finished?</td>
<td>P</td>
</tr>
<tr>
<td>Are patients happy to receive cancer specific information about their stage/treatment management plan?</td>
<td>H</td>
</tr>
<tr>
<td>How to properly deliver post-treatment information? There are leaflets (but sometimes patients don’t read them) and there are health&amp;well-being events (but sometimes patients aren’t able to attend them), but there does not seem to be an ideal “tool” to deliver information.</td>
<td>D</td>
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<tr>
<td>On receiving a diagnosis of cancer how are the options for treatment discussed with the patient and how long are they given to consider these?</td>
<td>P</td>
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<tr>
<td>How best to impart the diagnosis and prognosis - both to the patient and to the family.</td>
<td>P</td>
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<tr>
<td>What are the lived experiences of people with cancer from diagnosis to treatment and how can communication by medical staff be improved?</td>
<td>H</td>
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<tr>
<td>When is the “right” time to give information to patients and families affected by cancer to ensure they don’t slip through the net and don’t get any support, which can happen.</td>
<td>U</td>
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<tr>
<td>How to communicate the on going effects of a cancer, diagnosis and its treatment when the active treatment phase is completed to manage the expectations of family, employer etc. during the recovery phase.</td>
<td>H</td>
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<tr>
<td>Patients still don’t know how much activity they should do during and post treatment - we run prehab and rehab sessions and this is always a revelation - leaflets don’t get read!</td>
<td>H</td>
</tr>
<tr>
<td>Patients need more than a leaflet when being advised about the impact of the diagnosis on relationships - again this could be short and sweet, I have been in Canada where they do a consultation that hits all key points - this is what I how do on a long toll through your treatment day - we look at cognition, emotional impact, exercise, activity, intimacy etc. - its a short intervention but all patients say they wish they had had it sooner</td>
<td>H</td>
</tr>
<tr>
<td>It’s important to have rapid and clear information about your cancer and the treatment proposed. Shock and confusion means this information may need repeating.</td>
<td>P</td>
</tr>
<tr>
<td>Effective communication and provision of clear, honest, comprehensible information is still a recurring problem in the context of both active cancer treatment and LMC. What can be done to address this?</td>
<td>P</td>
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<tr>
<td>Are Cancer Patients at the point of diagnosis sometimes overwhelmed with too much information that is given at that time?</td>
<td>P</td>
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<tr>
<td>After a very successful laparoscopic by a marvelous surgeon. Followed by tip top post op and recovery nursing. All I wanted to do was get home. Later of course the specialist nurse explained that I had had a TEP inserted. But then there are so many questions that you think of, so you start googling every different support sites, some helpful, some would probably make things worse... my question is could there be more information on the various aspects of care before or after the operation?</td>
<td>P</td>
</tr>
<tr>
<td>Working out when and how best to tell other people about the diagnosis. There were really very few resources available to help us sort out our communication needs. We spent a lot of time trying to manage the impact on them whilst we were dealing with the impact on us.</td>
<td>R</td>
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<tr>
<td>Why is there no honest conversation about cancer? From health specialists, to family, to social network, the communication is crippled by taboos. It leaves everyone in the dark. The patient cannot express their true feelings as they might offend the carers. The carers have to stay strong and positive regardless, sometimes ignore the elephant in the room, with the only result that the patient sometimes feels like in an absurd film. Medical staff is overwhelmed and overwhelmed. Care, especially psychological and emotional, is so fragmented and discontinuous that one has to repeat the same reassuring story again and again. If lack of resources is the main reason, perhaps this should be the very first honest conversation to be had about cancer, and the rest will follow. And if the prospect of one in two people affected by cancer is so close, perhaps the honest conversation should start with let’s stop saving everyone, despite long-term terrible consequences.</td>
<td>PH</td>
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</tbody>
</table>
I think one of the biggest issues for me in moving on / living with, having had cancer was/is confidence in the future. I have managed to find things through Macmillan to help but I did most of the seeking help myself. I feel research is still needed into how best to inform patients of the mental effects cancer and its treatment has and where to get help. I feel the physical effects were fantastically well dealt with but the psychological effects come along later when you are no longer seeing ‘professional’ so regularly.

How can information relating to available services be reliably provided for elderly people and their carers with a terminal diagnosis?

How can we do better to provide easily accessible information about practical matters (e.g. finances, help for those with a caring role, getting back to work) both for the individual and for their family or friends after a cancer diagnosis?

Late consequences. What are the best ways of preparing patients for the risks of developing late consequences of anti-cancer treatments, such as post-surgical pain; endocrine and metabolic changes; long-term bowel complications following radiotherapy?

Can we train surgeons (and indeed other health care professionals) to be better at communicating risk in relation to possible outcomes (both for quality of life and for long term survival) and if so does that change choices patients make about surgery (or other treatments) that can impact their quality of life later on? Indeed do we even know the current ‘real’ practice in this regard in what is meant to happen or is considered best practice. Not all patients want to be alive at any cost and some may be denied the chance to make and informed choice.

1. How can care be better co-ordinated for people living with and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)?

How people are treated by other specialties eg asthma/ breathing dive. I am now seen by many other specialties, not directly related to my cancer and I almost never consider my years of treatment, side effects or psychological effects. They focus exclusively on their area. Also almost never read my notes.

Multimorbidity and polypharmacy in cancer patients - does the oncology pharmacist have a role?

As someone who supports those with Learning Difficulties in the community in the county in which I live I would to know what additional support is or can be provided to those with Learning Difficulties, pre and post diagnosis/treatment, to ensure that they can make their own fully informed decisions as far as possible about the treatment/support they receive?

Ask a patient about their general health and other serious conditions they may have and actually be worried more by that medical condition and the after effects of chemo may have on the other medical condition.

How should people with multiple health conditions including cancer (either as a chronic condition or in disease free survival, not at end stage) be best assessed and managed by health and social care services in order to provide best supportive care within a very tight financial environment for those who need it most?

How do I manage my cancer alongside my other health conditions?

One person who can advise me on options to get better. At the moment I get advice from my Consultant, my GP, the Outbox team, nurses, chemists, but it would be better if there was one person who is the focal point. They may not have all the answers but it would be more efficient if they contacted the other parts.

If the patient has other medical conditions how much cooperation and discussion takes place to bring about a holistic approach to dealing with all the needs of the patient?

I am living with cancer this requires me to see consultants from many disciplines. How does an involved patient who wants to play a full part in managing their conditions make sense of often confusing and sometimes opposing views expressed by different consultants? I am finding the view that treatment is as much art as science. I feel alone trying to manage my main condition whilst minimising impact on other organs or conditions and feel obliged to experiment with my various medications to limit adverse impact in other areas. This is stressful. I work as a volunteer in a cancer charity and see that my dilemma is experienced by many others.

How can improvement be made between oncology and urology teams for people living with complex survivorship symptoms physical and psychological. What is the best pathway to support this group? MDT, GP other?

Living with complex survival symptoms physical and psychological. What is the best pathway to support this group? MDT, GP other

Why are services for people LWBC so fragmented?

How do consultants from various disciplines (or conditions beyond cancer) work with oncologists to optimise treatment for their patients?

I had Prostate Cancer 12 years ago aged 58 and get various anxiety and depression for years after and had to retire with Ill Health. I have once aged 70 been diagnosed with ASD High Performing Asperger’s. Question Is there any special Measures put in place at oncology Centre to cater for Patients with Learning Disabilities and/or Autism ?

What do Oncology Centres do with Patients who have a severe Mental Health Illness and a Cancer diagnosis ?

How do we ensure people with a learning disability receive equitable support when LWBC?

We know there are specific LWBC long term sequelae that are unique but there are also lots of overlap with other LTC and we know in our areas the flags of patients with one or more LTC. How do patients with LTC inc cancer want their care planning to be - we assume they do not want a care plan per condition - how do patients think of this as being practical? what do they see is GCP? to how would then envisage reviews happening

How can we as Allied Health Professionals demonstrate that our interventions with people are cost effective and benefit patients and family/carers due to the interdependencies involved in their interventions?

Ability of GPs and primary health care professionals to consider complexity of need and how issues interact

Why is there a real lack of joined up working amongst inter-disciplinary teams in hospitals that effect post cancer treatment patients particularly AML? This also applies to other cancers.

Why is there no link or communication between the medical professionals? This appears to be much worse when someone has a more complex case such as dementia and cancer.
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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</table>
Is there more that can be done to manage fatigue when I've been given a cancer diagnosis? R
He suffers severe fatigue some days and can hardly function, how can this be helped? R
What are the most effective ways of dealing with the effects of fatigue from cancer treatment? H
Some days my fatigue is so bad I can't leave my house P
Coping with symptoms: How fatigue? Should I do sport? H
Why does lethargy continue even when treatment has ended years before? FR
How to manage side effects such as fatigue to provide the best quality of life? P
What is the most effective way(s) of managing post cancer fatigue? P
Fatigue - the mechanism for this when all avenues explored and exhausted for some, is never the same again, even if a long time from treatment and they are cured H
How do I manage fatigue? How can I get people to really understand what this is like? What interventions are effective for fatigue? FR
Ever since my cancer treatment (over a period 5 years, ending 12 years ago) I have never regained the same energy levels despite following all national guidance about diet, exercise etc I cannot remember not being at least a little bit tired at all since then. P
Is the cause of cancer related fatigue? H
How effective is fatigue management for palliative patients H
Cancer Related Fatigue is not well documented but is a real and debilitating side effect of cancer treatment. What advice or remedies are out there P
How do I cope with Cancer Related Fatigue when exercise is given as a help method but it is limited because of other problems, example, I now find that due to inoperable exercise is difficult and not advised. P
Morbidity of fatigue post radiotherapy H
Why is fatigue so often reported and experienced after cancer treatment? P
How can we better understand the causes of fatigue and provide better strategies or treatments to cope with it? P
Fatigue is greater after cancer treatment, what can help patients and is there more information? P
Fatigue after working - is there anything I can do to either prevent it, predict it or manage it better - exercise - diet? - "pick me up"? P
How long fatigue lasts and useful management strategies H
How should fatigue be helped? H
Management of fatigue / deep disturbance H
What is the best treatment for fatigue, when going through treatment for cancer and when completed treatment? H

3. What are the short-term and long-term psychological impacts of cancer and it's treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?

Who is a patient's first point of contact after their treatment has finished? H
What psychological support helps people and their carers transition to living with cancer? H
When treatment ended I felt dumped by the healthcare system. How can patients be supported in getting back into their lives after treatment without feeling unsupported? P
Following the completion of treatment, how many patients feel cast adrift and isolated, as the regular contact with health professionals drops off to some degree? P
How does ending of treatment effect expectations of survivors H
What is the most effective way of supporting cancer patients post hospital discharge? H
Effect of lack of support after treatment in overall health P
Is there any organisation that can provide support and information after treatment stage before you go out into the world on your own? P
What support services are the most important to patients and their families in the months post treatment? H
Will you set up an ongoing contact person for patients as they stop their treatment - radiotherapy or chemotherapy? At present it's like being pushed out into the cold, there is a sense of safety while undergoing treatment, if a single person was responsible for contacting the patient once a fortnight to follow up it would give a security now absent. P
Why was it presented with cancer felt abandoned after finishing active treatment? H
How can I support people and their carers through investigation diagnosis and treatment without them feeling abandoned at the end of active treatment. Hospice. Often left to pick up the pieces RH
NHS successfully treated my cancer but I had to seek out emotional support and help myself. I didn't do this until after my treatment had finished but actually it would have helped me earlier on. Why don't Oncologists tell us about the benefits of complementary therapies. It will save NHS having to deal with mental health problems later on. P
The psychological effect of living with cancer particularly once regular treatment has stopped H
How to reduce dependency on health service resources and 'victim mentality' in people who are cured of cancer H
What support is needed/would be effective for those who have had cancer but been discharged after their 2/5/10 year follow up with respect to their mental wellbeing. P
Can they move on H
What is the best way to support patients psychologically finishing treatment for cancer? H
How to cope with the period after the treatment is finished and the 'adrenaline high' has been given. It feels as if professional support has been withdrawn but you still feel vulnerable and anxious. Everyone thinks you should feel great but depression kicks in and it's hard to get back to normal life. You don't want your life to be defined by your cancer but you can't ignore it either. RH
Where to find support once treatment ends without feeling that you are still in the cancer bubble? P
What interventions would help people coming to the end of treatment prepare for adjusting to life with and beyond cancer? H
### Psychological Morbidity of Prostate Cancer Patients

1. **What is the psychological morbidity of these patients?**

   - Often feeling isolated and lonely.
   - Difficulty socializing with those who have not had the same experience.
   - Cancer experience does open up new social groups, but people often find it difficult to socialize with those who have not had the same experience.

2. **How do people regain their social life following treatment and avoid feeling isolated?**

   - People feel unprepared and unsupported after treatment.
   - Once off the hospital conveyor belt, there is nowhere to turn for support.

3. **What support services do you feel you would have benefitted from within 3 months post treatment?**

   - Psychological support is often provided by advocacy or charity organizations.
   - Information on recovering from operation, diet, etc. all faded away.

4. **What are the areas that men with prostate cancer feel unprepared and unsupported?**

   - Patients feel unsupported and isolated.
   - After treatment, there is a feeling of being left to deal with effects on your own.

5. **How can we best support people in the transition period after treatment ends and beyond?**

   - It's important to have clear information about the physical and psychological effects of treatment.
   - Shock and confusion mean this information may need repeating.

6. **What are the resources available for patients during this transition period?**

   - Informational sources, such as pamphlets and websites.
   - Healthcare staff and people with cancer.

7. **What is the psychological support patients feel they need after finishing treatment?**

   - Life as a whole is more worrying.
   - Fear of recurrence.
   - Feeling alone and weak after treatment stops.

8. **How can we best support people living with and beyond prostate cancer?**

   - Psychological support is essential.
   - Information on how to access emotional support.

9. **What is the psychological morbidity of these patients?**

   - Often feeling isolated and lonely.
   - Difficulty socializing with those who have not had the same experience.

### Table: Psychological Support Needs and Services

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>How best to support people in the transition period after treatment ends and beyond?</td>
<td>H</td>
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<tr>
<td>Do patients feel able to attend their GP following a cancer diagnosis and at end of treatment?</td>
<td>H</td>
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<tr>
<td>What are the best methods to support someone post surgery/treatment?</td>
<td>R</td>
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<tr>
<td>Where was having cancer firm (it got lots of support, inserted own website so did end support network) I am still struggling with this lack of support six months after chemo ended</td>
<td>P</td>
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<tr>
<td>Is there an NCS support for platinum patients?</td>
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<tr>
<td>Does access to ongoing psychosocial support reduce A&amp;D &amp; GP visits by patients finishing hospital treatment for cancer?</td>
<td>P</td>
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<tr>
<td>Why are we abandoned after 5 years post Taxotere, follow up on anything</td>
<td>P</td>
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<tr>
<td>Being diagnosed and treated for cancer is a journey. It relies on trust of the medical team. That relationship comes to an end and it is a double grief process. There is a loss due to the cancer and the loss of professional support. How do people deal with this?</td>
<td>RH/H</td>
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<tr>
<td>When you finish your treatment (after 10 years of anti hormone therapy/chemotherapy drugs), what support is given?</td>
<td>P</td>
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<tr>
<td>At the moment, cancer treatment feels as if you are on a conveyor belt. When active treatment ends, it seems as if you fall off the belt and there is a huge void and you are left alone with no support. Can things be improved for those living beyond cancer at that stage?</td>
<td>P</td>
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<td>also between PTSD and living beyond cancer when treatment has finished.</td>
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<tr>
<td>How can people understand and engage with the notion of self-management without feeling abandoned by services or feeling that self-management is a cheaper option?</td>
<td>RH</td>
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<tr>
<td>Why is it that once you are in remission you feel as if you are left totally alone with this big weight on your shoulders?</td>
<td>P</td>
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<tr>
<td>How can healthcare professionals help patients to navigate the transition from active treatment to recovery?</td>
<td>P</td>
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<tr>
<td>Why is there no psychological support, as in counselling, after treatment has ended, in order to adjust to life after cancer?</td>
<td>P</td>
</tr>
<tr>
<td>How and when to access emotional support? Sometimes you don’t realize that you are struggling mentally, it can hit months and years after diagnosis. I found the hardest time was after treatment had finished when all my friends and family thought I should be back to normal! I no longer knew what was normal.</td>
<td>RH/H</td>
</tr>
<tr>
<td>It’s important to have rapid and clear information about your cancer and the treatment proposed. Shock and confusion means this information may need repeating. After treatment, in my case chemotherapy, there remain many questions. Support is not so intense, there is a feeling of being cast adrift. How can the health service best provide links to support groups that will continue to inform patients beyond treatment?</td>
<td>P</td>
</tr>
<tr>
<td>Long term effects of treatment. Had both chemo and radiotherapy for 3 different cancers. Once treatment is over you are relieved but then you need support. It might be emotional support but it seems to be in short supply.</td>
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<tr>
<td>Information on recovering from operation, diet etc all faded away apart from regular (6 months appointment with consultant).</td>
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<tr>
<td>Why are you left in limbo once your treatment and follow up end.</td>
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</tr>
<tr>
<td>How best do we facilitate/ support people living with cancer or beyond cancer when they move from ‘active’ follow up to detect recurrence &amp; morbidity, to the ‘beyond cancer phase’?</td>
<td>RH/H</td>
</tr>
<tr>
<td>Patients undergoing radiotherapy (RT) become accustomed to having daily support from their radiographers. At the end of treatment there is then a ‘black hole’ where there may be no specific support available from radiotherapy professionals and when side effects will be at their peak. How can patients be better supported during this period between end of treatment and start of follow up?</td>
<td>H</td>
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<tr>
<td>A month later after treatment has been completed why doesn’t the patient have contact from a medical professional as this is when it hits most of us.</td>
<td>RH/H</td>
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<tr>
<td>What happens when the treatment stops?</td>
<td>RH/H</td>
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<tr>
<td>As a healthcare professional (within radiotherapy) having ways to sign post patients for additional support post pt would be useful and to have ways of advising patients as they complete their int</td>
<td>H</td>
</tr>
<tr>
<td>Did you feel you had somewhere to go with worries after you were discharged following cancer treatment?</td>
<td>RH/H</td>
</tr>
<tr>
<td>I’ve been taking adjuvant Tamoxifen for 9 years and due to end next year. After treatment, in my case chemotherapy, there remain many questions. Support is not so intense, there is a feeling of being cast adrift. How can the health service best provide links to support groups that will continue to inform patients beyond treatment?</td>
<td>P</td>
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<tr>
<td>Feeling alone and weak after treatment stops.</td>
<td>H</td>
</tr>
<tr>
<td>Living with long term and late effects (see Tintor et al. (2014) for a rapid review). Often there is a lot of support during diagnosis and treatment from healthcare staff and people with cancer are left to actively seek support after treatment which is usually from other sources that are not situated in the healthcare system. This support is often provided by advocacy or charity organisations.</td>
<td>H</td>
</tr>
<tr>
<td>What is the psychological support patients feel they need after finishing treatment? (example)</td>
<td>P</td>
</tr>
<tr>
<td>What support/services do you feel you would have benefitted from within 3 months post treatment?</td>
<td>P</td>
</tr>
<tr>
<td>What happens after 5 year follow up? Tell this date you are monitored, then nothing, is this when you need the support more?</td>
<td>P</td>
</tr>
<tr>
<td>How much support is there as there is plenty before treatment</td>
<td>P</td>
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<tr>
<td>Qualitative look at the transition period between curative and palliative treatment or active treatment then being cured and how this affects people</td>
<td>H</td>
</tr>
<tr>
<td>Once off the hospital conveyor belt I felt there was nowhere to turn for reassurance.</td>
<td>P</td>
</tr>
<tr>
<td>What are the areas that men with prostate cancer feel unprepared/un supported in when living with and beyond prostate cancer?</td>
<td>H</td>
</tr>
<tr>
<td>How do people regain their social life following treatment and avoid feeling isolated. Cancer experience does open up new social groups, amongst fellow cancer survivors, but people often find it difficult to socialize with those who have not had the same experience. When the cancer experience is so all-consuming, you can end up with little in common with those who have not had the same experience.</td>
<td>P</td>
</tr>
<tr>
<td>What is the psychological morbidity of these patients?</td>
<td>RH/H</td>
</tr>
</tbody>
</table>
The psychological impact on patients and how it affects their decision making when deciding, treatment and holistic care

The psychological impact on patients and how it affects their long term decision making.

What is the psychological impact for patients and relatives living with a cancer diagnosis in terms of how their coping mechanisms change and the impact on their life in general. As a professional is there any alternative way of working with this group of patients from the newly diagnosed group.

Why do I feel guilty?

How can we help people move on from thinking of themselves as a cancer survivor and getting a new normal

What is the emotional impact of chronic symptoms related to cancer treatment?

How long is one a survivor before one become a ‘normal’ person again?

What does diagnosis setting effect quality of life?

What psychological support can be offered to patients even 5+ years on, re relationship impact (all relationships - daily, friends, colleagues, significant other etc) - not exclusive to those living alone. People can still be isolated emotionally even if living with others... often not recognised.... as people expect patients to 'be over that by now' and 'getting on with life'.

What is the long term psychological impact of cancer on patients UKBC greater than 10 years post-diagnosis?

What emotional/ psychological changes have you experienced since your diagnosis?

What are the long term psychological effects psychologically for those living with stage 4 cancer?

How are the psychosocial consequences of undergoing appearance changes associated with cancer treatment?

The psychological well being of living with body dysmorphia after major abdominal surgery and having a stoma in place is horrendous not only for the patient but dealing with is fear by the wife or partner puts a strain on the relationship why are they not visited better?

Psychosocial outcomes of immediate breast reconstruction in comparison delayed breast reconstruction following mastectomy for cancer.

Psychological effects of survival

What are the psychosocial long term effects for people following a cancer diagnosis?

How will my mental state be affected

How does a cancer diagnosis impact upon long term mental health.

What are the long term consequences for illness recovery / progression / recurrence of poor psychological wellbeing during cancer treatment?

What are the common long term psychological effects of a cancer diagnosis? I ask this as a Burkitt lymphoma survivor and Psychotherapist, as I see various reactions in practice.

How has coping with the long term side effects of radiation treatment for cancer affected your mental health and well being?

How does a cancer diagnosis affect the person’s mental well being?

What alternative therapies are helpful in dealing with psychological impact of being told you have a slow growing cancer such as CLL and dealing with the waitful waiting approach.

What are the major differences in coping mechanisms with people who require treatment immediately - people who are put on a watch and wait approach?

What is the psychological impact of being on “watch and wait” on those with cancer?

What are the on going psychosocial consequences of treatment for thyroid cancer?

How mentally competent they feel in leading life after cancer treatment

Is it ever possible to ‘go back to normal’? We are told to ‘go about your normal life’ - does anyone understand how impossible that is?

Consequences on ‘normal life’. Moving on and being seen as yourself rather than 10 years post diagnosis.

Will I ever return to the way I was before I had cancer - or do I just have to appreciate my limitations and get used to the “new” (post cancer) me?

What is the difference in psychological impact in being told things during diagnosis and treatment that turn out to be untrue or change us not being told anything unless definite. For instance I was told at diagnosis I would have chemo and if that was successful would have conservative surgery (lumpectomy/ WLE) or if not successful a mastectomy but could have immediate reconstruction (found out (incidentally) 3 months later part way through chemo that although my chemo was wholly successful but that I would have to have a mastectomy with no immediate reconstruction. I still feel instead and it undermined my confidence in my clinicians and sent me into a spiral of despair.

Overcoming a sense of guilt having survived a full cancer experience and reconciling against those that did not win

How it is best to manage feelings of failure, exclusion and disappointment at other people’s inevitable lack of understanding when you feel you have to manage your life differently after cancer diagnosis and treatment?

What are the long term psychological effects of surviving cancer?

How does a patient live with the fact that his prostate cancer was left undiagnosed until it became advanced and spread outside the prostate because of the lack of knowledge and training by the GP’s.

Survival guilt
Why the focus on living with cancer and beyond? We are moving towards a majority of people living with a cancer diagnosis. Whilst accepting that there will be some people who will require on-going support following e.g. disfiguring surgery, please can progress towards disabling people with a cancer diagnosis cease. I have lived with a cancer diagnosis for 25 years. I am a healthcare professional. I am also an academic with expertise in cancer care. Having cancer is ‘normal’ for me. Few people know about my diagnosis. I accommodate the long-term effects within my daily life, consider them trivial and would be surprised if others are aware. Having a child impacts the rest of life there after, but it doesn’t result in life-time support other than for a small minority. So, I suggest a research question such as: ‘What is the profile of someone diagnosed with cancer who will have support needs arising from diagnosis, disease and treatment five years into survivorship?’

what is the psychological effect on having cancer in the following years after treatment. How does that differ between disease sites and are there any similarities. H

How do you adjust to changed life and capacity, for example, if less physically able what psychological processes help people come to terms with this and make successful adjustment, to enable them to live in a meaningful and valued way? H

The psychological impact of treatment. H

The psychological impact of successful / unsuccessful treatment. H

The mental health effects. H

How much are the emotional effects of a cancer diagnosis recognised and talked about with patients prior to their ending treatment, or is the focus solely on the physical and is this helpful? H

In the future will there be more research into the effects cancer has on a person both psychologically and emotionally? P

Is there any way to really prepare people for the realities of life after Cancer? I managed OK during treatment, and in the “recovery” and “recuperation” phase, but now 2 years after treatment I don’t seem to be able to make any more progress. The fear and anxiety of a recurrence are worse, my fatigue hasn’t gone away, although it occurs less often, the side effects of the active treatment and the side effects of hormonal treatment are now an everyday part of life. The more I read the more I realise that this seems to be the norm for most women post breast cancer (and other cancer) treatment. Everything is so different, and it is so hard to get used to, and most of us thought that once treatment was over, given a lot of time and rest and recuperation, we would be almost back to our usual selves. It’s like aging 20 years in 1 year, and the impact of that isn’t something that is dealt with. Sorry that’s a bit long winded! I don’t know how else to explain though!

More research and understanding into the long term impact on people’s mental health and how this can best be supported. H

Being 35 at diagnosis I feel like a stranger to myself now, yet I am expected by everyone to be positive that I have survived... well it’s just that I survived... I don’t feel like I am living, I feel anxious, scared, I am stuck with a strangers body, and I have been told that despite being diagnosed bio-laterally stage 3 aggressive triple negative breast cancer & BRCA1 positive... Moving forward I will not have any routine scans to check for any signs of secondaries.... Why are CT scans or MRI scans not offered to patients post treatment? Surely it cannot be my sole responsibility to just worry about new symptoms? But not given any general info on what I’m looking for?

When will the medical profession realise the psychological effect on cancer patients? It is this side that has the largest effect with very little support or knowledge. P

In the long term affecting attempts at forming some social life because nervous of going out. P

How do you stop that ‘raw door’ opening even years after your treatment? There are some events, things said or an experience that brings the more challenging and negative aspects of having experienced a cancer diagnosis and its treatment flooding back into your mind. As I get older I am finding these thoughts about negative experiences sometimes even more upsetting. I find this quite strange as I would have thought the years would have ‘softened’ the memories.

How can the medical / nursing team better recognise, understand, appreciate and acknowledge the impact of psychological and emotional wellbeing on a patient from diagnosis onwards? H

How do you come to terms with the fact you are one of just a few that have made it. P

what are the psychological issues after a diagnosis of melanoma H

How do I live a ‘normal life’ knowing the cancer is likely to come back at some stage. H

The impact on cancer survivors once all hospital treatments end is enormous. Cancer never leaves your mind, and no one is there to help, in my opinion. P

Mental effects of having cancer. P

what are the likely mental and emotional problems encountered post operative tumour removal? P

Should more attention and support be focused on cancer survivors. Several Cancer survivors have commented to me about the considerable difference in support at the end, or after the end of their journey, compared to the beginning D

Did cancer change you as a person and would you like to have a forum for support locally to your home to express these changes? RH

How do people cope with the initial wait? There’s such a awful time between diagnosis and the start of treatment or the plan for treatment, what long term impact does this have? P

We receive a lot of questions about the emotional and psychological impact of a cancer diagnosis from women seeking support - but we don’t have much data about the type of psychological difficulties women face and ‘depression’ is often used interchangeably with anxiety, sadness, low mood etc. Is there a way to determine the specific impact of a cancer diagnosis on a women’s mental health? H

Does anyone ever really get over the diagnosis? P
How can we determine which patients are at greatest risk of psychological problems during and after cancer treatment, and are there interventions that can be used around the time of diagnosis, during treatment or in the early recovery period which will reduce the frequency and severity of problems experienced?

Things I used to find fun are now boaring. What can I do to change This? Is this normal?

Finding a new norm

Role and status. Regaining and maintaining social equilibrium, issues in transcending the sick role

More research on the mental health effects of cancer

The psychology of living long term with cancer is fascinating. We are told how to improve our lifestyles and live better but little thought or research has been undertaken on how to live with the disease long term. What are the better mind sets? How do you ensure that you remain positive and happy? What works? What is most likely to work? What are the key influencing factors making living with cancer better psychologically?

What research has been done to support survivors best? Is there a country/hospital that particularly does this best and can we use their knowledge to replicate the same system here?

What can be done to support long term survivors? why is the system failing so many?

Does regular social interaction with other cancer ‘survivors’ improve psychological, emotional and physical health?

What is the effect of meditation/ visualisation techniques/ mindfulness on cancer and how are psychological therapies currently being used (i.e. following diagnosis, following treatment) etc.

When should psychological therapy be offered within someone cancer journey (i.e. following diagnosis, following treatment) etc.

What are the psychological therapies most effective for distress associated with cancer and how are psychological therapies currently being used (i.e. following diagnosis, following treatment) etc.

What is the impact of mindfulness training on people with / after cancer

What methods of psychological support are most effective with cancer patients and how can we use this information to inform practice?

What are the benefits of mindfulness practice for people affected by cancer?

Should all patients who have been in intensive care and/or had extended stays in hospital be offered psychological support? Often, when you don’t really know what happened to you in ICU or were very sick, you don’t want to ask your nearest and dearest in case they also find it upsetting reliving what they saw you go through

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How useful are current practices to our patients – we run a Moving On Group but I would like confirmation that it is as useful as it is enjoyable always rated well but consider the impact long term

Is telephone-based CBT counselling a useful service for anxiety and depression associated with cancer?

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<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>What is the most useful psychological support for people living with cancer?</td>
<td>P</td>
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<tr>
<td>What is the most useful psychological support before and during oncology appointments?</td>
<td>P</td>
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<tr>
<td>Assessing the best support strategies, eg regular meetings or online forums or whatever</td>
<td>P</td>
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<tr>
<td>What is the best way to view diagnosis of cancer, this in particular regarding mentally.</td>
<td>P</td>
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<tr>
<td>What is the impact of relaxation &amp; stress management interventions on individual ability to cope? (eg. relaxation sessions, mindfulness, education on coping strategies).</td>
<td>H</td>
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<tr>
<td>What psychological support should be offered to people affected by cancer?</td>
<td>H</td>
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<tr>
<td>What psychological interventions reduce the impact on mental health for people affected by cancer?</td>
<td>P</td>
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<tr>
<td>In my experience after <em>active treatment</em> for breast cancer has led to a shocking down turn and deterioration in my mental and physical wellbeing. I feel very alone and a failure for not &quot;recovering&quot;. What type of support could help women to keep going into the &quot;beyond&quot; whilst managing ongoing consequences (in my case lymphoedema, corded, thoros, menopause, extreme weight gain) and impacts of long term treatment for instance Tamoxifen.</td>
<td>H</td>
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<tr>
<td>What type of support could help women to keep going into the &quot;beyond&quot; whilst managing ongoing consequences?</td>
<td>P</td>
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<tr>
<td>What do patients find beneficial when trying to learn to live with their condition?</td>
<td>H</td>
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<tr>
<td>Does training in basic mindfulness techniques help individuals undergoing treatment for cancer?</td>
<td>H</td>
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<tr>
<td>What support best helps people cope and adjust to life with and beyond cancer? (eg. support groups, counselling, clinical psychology, nurse led CBT, peer support etc.)</td>
<td>H</td>
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<tr>
<td>Who is going to support me to adjust back to life?</td>
<td>H</td>
</tr>
<tr>
<td>How can m-health support those diagnosed with cancer?</td>
<td>H</td>
</tr>
<tr>
<td>How factors help women with breast cancer develop resilience in coping with cancer?</td>
<td>H</td>
</tr>
<tr>
<td>Could cognitive behavioral therapy help people with cancer to deal with mental challenges of diagnosis, treatment and possible recurrence?</td>
<td>P</td>
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<tr>
<td>What support is most important/valuable to people living with or beyond cancer?</td>
<td>H</td>
</tr>
<tr>
<td>Which cohorts of cancer patients benefit most from individual psychotherapy and which benefit most from group therapy/support?</td>
<td>H</td>
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<tr>
<td>How the long term psychological impact on patients be mitigated?</td>
<td>P</td>
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<tr>
<td>Investigate the psychological effects of cancer in the short term to mitigate any long term psychological impact.</td>
<td>P</td>
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<tr>
<td>How does cancer affect patients' self-identity and does the identity of a cancer patient influence social and economic decisions?</td>
<td>RH</td>
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<tr>
<td>How to get psychological support after diagnosis? This is a very traumatic time and it's not at all supported.</td>
<td>P</td>
</tr>
<tr>
<td>Dealing with mental and emotional issues</td>
<td>RH</td>
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<tr>
<td>What self help measures can contribute to recovery of independence following cancer diagnosis and treatment?</td>
<td>RH</td>
</tr>
<tr>
<td>If early counselling is of benefit would confirm and perhaps save future NHS expense when these feeling cause problems months or even years after treatment</td>
<td>P</td>
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<tr>
<td>Is there any psychological help for long after you’ve had treatment as sometimes it hits you all at once as friends and family think you are ‘better’ and seem to have moved on from talking to you about things.</td>
<td>P</td>
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<tr>
<td>Do adapted online psychological support programmes work better than generic ones for improving mental health for people living with and beyond cancer, and their carers/families?</td>
<td>H</td>
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<tr>
<td>Can we demonstrate not just the benefit to patients of good mental and emotional support following a cancer diagnosis, but also the financial benefits to the system in way that influences commissioners to treat it as a priority and not a &quot;nice to have&quot;?</td>
<td>P</td>
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<tr>
<td>What can of programmes is structured or support group (informal) would people want to see?</td>
<td>H</td>
</tr>
<tr>
<td>What support is valued by people during/after treatment for cancer and where is this best delivered?</td>
<td>H</td>
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<tr>
<td>How can arts-based psychological therapies (art psychotherapy) and arts and health interventions help people with the psychological burdens of living with and recovering from cancer, and for those who have a terminal diagnosis, some to terms with death and dying?</td>
<td>H</td>
</tr>
<tr>
<td>How to get psychological support after cancer treatment? I would like to see how people have coped mentally after treatment.</td>
<td>P</td>
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<tr>
<td>Is there any psychological treatment for my sleeping and anxiety issues whilst I'm going through the trauma of pre op chemo, surgery and post op chemo?</td>
<td>R</td>
</tr>
<tr>
<td>what research is there to show the benefits of having psychological support right at the beginning of a cancer diagnosis? I don't think there is enough focus on emotional support</td>
<td>R</td>
</tr>
<tr>
<td>My wife was diagnosed with stage 4 bowel cancer and died. From my experience as her carer, I would like to suggest that there is a huge difference between the novice and the experienced cancer patient and carer - and that the novices may benefit from hearing the perspective of the experienced. It's pretty much a matter of 'the things I wish I'd known from day one'. As a novice, pitched suddenly into 'cancer world', you feel like you have an avalanche of new, complex and strange matters to deal with, and although the OHs, oncologists and GP practices do their best, there are things only other more experienced patients and their carers know. So I guess the question is something like: what do experienced patients and carers wish they had known from day one? The practical question would then be: how to connect novices and those more experienced and willing, so this knowledge can be passed on? Thank you.</td>
<td>R</td>
</tr>
</tbody>
</table>
Is enough practical help available to women dealing with the transition from pre-cancer to post-cancer? (e.g. changes to her physical body; cognitive functioning; energy levels; relationships; changes; emotional distress; lack of sleep; constant worry of re-occurrence; inability to perform/continue at work; lack of sex drive; loss of self; self-image issues; confidence etc.

What are the factors (personal, social, societal) which aid recovery and readjustment after cancer treatment?

How do we ensure we’re support those living with and beyond cancer psychologically especially once secondary care treatment has ended and it maybe months or years later that they need the support?

the role of acceptance and commitment therapy in helping people live beyond cancer

How can the psychological effects of cancer be minimised, and their impact on relationships be minimised also?

How do you get back to normality.

How do people adjust to the loss of function they experience following treatment of the cancer, e.g. loss of fertility following ovarian cancer?

What support is available to help deal specifically with the mental health side of cancer? Do we just mean support anxiety and depression or mean specific specialist support which links in with needs of cancer patients, their carers and their families at different stages.

What long term support is there for people that have had cancer? Throughout life there may be times that consequences of treatment cause mental anguish, this may be years after treatment. For example fertility issues.

How do i cope mentally ifi should Mindfulness or meditation be a part of the support for patients.

What is the role of peer support in reducing anxiety and depression among people affected by cancer?

As treatment improves how will you support the psychological wellbeing of patients living with cancer so they do not impact on clinic time?

Who supports men diagnosed with testicular cancer and their families after treatment has ended?

What psychological support is the most useful for people living with untreated cancer such and watch and wait or terminal cancer?

How best to support patients post cancer diagnosis - by where, when, what services etc.

Many people are now surviving a cancer diagnosis but at what cost? I have lived with a rare blood cancer for 17 years. The impact on work and relationships is huge and life changing. Surviving is not always an easy thing when you have to live with long term effects. What help is there to make these physical and emotional changes.

The value of counselling or cognitive therapy in supporting people after cancer

Are online methods to support people living with cancer or beyond cancer really effective compared with face to face support?

How to promote mental wellbeing after the cancer has been treated and how to focus on the future.

How can people living with cancer be better emotionally supported through the rest of their life?

All cancer patients should be offered some form of counselling before they reach rock bottom, to stop them from reaching rock bottom.

Should all cancer patients routinely be provided with psychological support?

What kinds of support, information and interventions make a positive difference for women before, during and after chemoradiation treatment for cancers affecting the pelvis - my specific concern is treatment for anal cancer, and what has a negative impact? (Include referral to peer support, how peer support is organised and what approaches and activities are included in peer support. Also include professional services/skills/training. Access to psycho-sexual counselling, HRT discussion, and specialist bowel function clinic.)

How best to support patients post cancer diagnosis - by whom, where, what services etc.

Measure outcome from hope courses for patients who live.

Do you want to discuss with her how she wanted to die or where. I was the only one she confided in. I wasn't experienced but I was all she had. Life does go on and outside factors can have devastating effects on families. There is no provisions for the dying & after cancer.

How do you support people who have recurrence even at a later stage.

What evidence is there for group work in cancer survivors?

How do you support people who have recurrence even at a later stage.

What psychological support is the most useful for people living with untreated cancer? I don't just mean support anxiety and depression I mean specific specialised support which links in with needs of cancer patients, their carers and their families at different stages.

What are the methods to overcome the severe psychological aspects of coping with cancer?

As a sibling of a cancer patient and a health care professional I don't know how to help my sister filter all of the information and identify what is really important. This was true during her treatment and now in the period after completion of treatment. She doesn't know her new normal and may not actually want to accept it as such, there appears to be very little in terms of ongoing support that is offered rather than being available on request. She seems not to have a single point of contact who proactively asks her 'what matters to you?'

How can support/help with close relationships be improved?

How can you cope with the emotional effects of having cancer?

Is there a way to identify specific points in treatment pathways where mental health is most likely to be affected and therefore points at which early psychological intervention, or psychological support, would be most beneficial? Often these support services need to be sought out by individuals which means the problem has developed and grown into something that takes longer to reverse from.

What is done for mental strength building after cancer treatment

Who offers support for long term sequelae including depression, anxiety, loss of confidence and physical problems related to treatment.

Why isn't there anybody to call or talk to straight after diagnosis as it's then when your most vulnerable and then rely on Dr Google which in its self is soul destroying
Why is more research not done into, and is not support provided to build in as part of the treatment model, the benefits of peer to peer support both in terms of mental and emotional well being but also in terms of the benefits to patients and clinicians in terms of supporting patients and their families to become better informed and engaged and proactive in making treatment and appropriate lifestyle choices?

Support at diagnosis stage There are not enough specialist nurses to support patients and carers directly with practical questions and solutions Info is good on McMillan site but having a key worker would have helped more

Is there evidence that patients who are part of patient support groups have better outcomes and better overall survival?

What long-term social/psychological support is available to people in the years after treatment finishes?

What long-term professional and social support do people need after treatment?

What are the most effective ways to provide psychological and emotional support to patients who are on watchful waiting programmes, or who are at higher risk of relapse? Can this support be extended to the carers and family?

Is the support consistent throughout the cancer journey?

What are the best strategies to reduce the psychological impact post diagnosis?

My mum was diagnosed with Metastatic breast cancer two years ago and now feels her whole life revolves around treatment. She refuses to plan for the future because she may not be well enough. What will help her to live with MBC?

What benefits would psychological and psychotherapeutic input have for patients living with metastatic cancer?

Is there any specific therapy for people living beyond cancer that is beneficial to the persons wellbeing? If so what is the therapy and how does it differ to other therapy outcomes?

How can I build/maintain resilience through my cancer journey as a patient/carer

Do professionals have a role in building/maintain resilience?

Psychological support and counselling for patients, partners, caregivers and/or families after the cancer experience to enable relationship recoveries and adjustments?

My experience is that people often struggle to accept themselves and their role effects and experiences. How can we evaluate what works well for people to move on, i.e. medical intervention, talking therapies, support group, educational, Hope etc on no large enough scale to count.

How do the needs of caregivers change as patient survival extends?

What can you support carers of people with cancer to help the person with cancer and to take care of themselves?

As a mother/carer for Cancer patient who had a very poor prognosis of Breast Cancer from the beginning, living with cancer takes a very large chunk out of your normal life. Besides trips to the hospital, it is very difficult to “switch off” when returning home to make a dinner keeping housework up to date. It’s easy for Help for Carers families to say about looking after yourself. However, in reality this is very difficult to do. On your mind is the results of last scan, what’s this new treatment they are taking about, does this mean the last one hasn’t worked. Having to talk to your daughter about what kind of funeral she would like. Worrying about what you can afford. Personally I had to spend 3 years paying off my daughter’s funeral & it wasn’t extravagant at all. Very difficult for carers to choose the right time to talk about these personal but necessary things. How do you talk to a 27 year old girl about a “Will” it’s so unnatural especially when it again is very necessary when she has quite a few animals & special things that people have bought her.

What is the best practice in supporting partners, families and carers over the longer term, for example up to five years and beyond?

What support can immediate family members/close friends receive in coping with the diagnosis of their loved ones? E.g. mother struggling to cope with her child’s diagnosis, not measured even if prognosis is good, however, denial–resistance engaging with child’s needs as a cancer patient–ruminating/fear–loss of support towards the child.

Research on how family and close friends are affected with living with someone who is living with cancer or coping with the long term side effects.

The psychological well being of living with body dysmorphia after major abdominal surgery and having a stoma in place is horrendous not only for the patient but dealing with is fear by the wife or partner puts a strain on the relationship why are they not better prepared?

The effect of caring for someone living with cancer, and how carers cope after regular treatment has stopped

What are the most important issues that carers feel they need support with?

What is the long term effect to close family (partner, children, parents) of a person experiencing cancer and could more be done to support them during the person/treatment and follow up screening.

The psychological impact of living with a secondary cancer diagnosis on family members.

What sort of interventions can be visibly implemented to support family members who care for people with cancer in the short- and long-term after cancer?

The effect of cancer on carer and how they could get help – support to overcome their fear

How do you feel that you living with cancer has affected your family?

What would help your care through your cancer journey?

What support should patients and their carers/partners/family receive from the haematology team providing the medical care?

If you are the main informal carer for an adult with physical/mental health or problems associated with old age does this impact on your route and time to a cancer diagnosis, treatment decision making and survival? If this is the case what can be done to support carers?

Ongoing support for family members of survivors whose lives have changed.

How can unpaid carers be better supported?

What are the best ways to support the families of those affected by cancer and providing care?
What is the most effective, inexpensive intervention we can make to meaningfully support carers of pts with advanced cancer? H
What education and support would best suit the needs of people supporting persons with a cancer diagnosis? H
What are the effects of living with, and/or (b) best treated/managed? H
What help is there for my immediate family to cope with their feelings during and after my cancer battle? P
What is the impact upon adult children and adult siblings of cancer patients, what is in place to support them and how effective is this? (focus of support is often on patient/young children) RH
How can we support carers of those living with cancer or beyond cancer? H

Long term impact physically and mentally, patient and family P

I am supporting my wife through her illness. I found the emotional acceptance of her condition difficult to come to terms with given the prognosis was undefined ... appeared not so good / possibly manageable. My wife voiced the position 'It's happening to me' was understood and was addressed by the professionals and they did their best. I also understood that position. But it did not make me feel better. I suppressed my feeling. But they tended to pop out when I least expected them to. So my question (I) is I understood the stress and distress impacted upon the immediate family of persons blighted by this terrible disease.

How does the cancer cope when the patient lives life as if the prostate cancer is the central issue for both of their lives. R

As a former carer of someone who died of a cancer that was never deemed incurable or terminal, I'd like to ask how carers can be better supported and their opinions listened to much more. I was shut down when I tried to tell the consultant how bad I thought things were for my mum ([I] A positive attitude is half the battle[4]" was what she said to me). So my mother was started on chemo (not palliative but supposedly curative). The first time anyone admitted she might die was two hours before she died, a few days after her first round. The hospital ordered a post mortem which I was horrified about, and she had indeed died of cancer. No surprise to me - what were they expecting? How many people does this happen to, and how can it be avoided? Carers can see what is happening but it is very hard to convey it to the doctors without feeling you might be saying the wrong thing.

How are carers and friends better supported? R

How best to support families H

Where can carers go for help and support? RH

How can we help families understand the emotional and existential changes that might happen for people after cancer and cancer treatment. H

How can we better care for 'cared' and harness the support network around each individual patient to improve outcomes? Is there a need for carers focused clinic appointments to address their needs? H

Is the Concerns checklist an appropriate checklist for the immediate family/friends of people who have been diagnosed with cancer? H

When a woman dies from secondary breast cancer, and has young children, there seems to be very little support for the Fathers. The fallout is huge, and many men have to completely change the structure of their lives to cope. Children may have access to bereavement counselling, but how many Fathers are followed up? P

The development of support for carers and family members. D

How do you support those family members supporting those with CR cancer? R

Were there people available to support your family? H

What support is available for the carers of people suffering from cancer, particularly when the cancer sufferer doesn't accept or want to accept what the likely outcome of the disease will be? R

Although there is some support available for parents of very young children what is happening, I, once again, was left more or less on my own with this one and mid-teens, early 20s children. They struggled to understand what was taking place, didn't know where to turn for support and, as a result, I felt I was very much "doom and gloom" when it came to the cancer diagnosis, whereas my husband was very upbeat and positive. They would also have been better to admit they were feeling, unless someone told them they had to. Would it be worthwhile having some sort of service who could speak to young adults and answer their questions, without them feeling they had to tell me (or their dad) at this very difficult time.

What care is there for carers of cancer patients to be able to live well? R

What is the impact of prostate cancer treatments which affect sexual functioning on the partner/spouse emotional relationship from both the patient and partner perspective? H? This question is not intended to focus on sexual activity but the whole quality of the relationship.

Research the impact of cancer (particularly incurable cancer) on the partners of younger sufferers (ie still working, young children age) P

Impact on family and keeping them in the loop RH

How does a cancer diagnosis and treatment affect partners/families and carers? H

It is apparent that there was relatively little acknowledgement, encouragement or help for members of my family who were also affected by my cancer; and who helped care for me. How can this be improved? R

What are the most effective ways of supporting carers of people with palliative cancer living at home? H

I'm exhausted from looking after my Mum, do we both get help with relaxation, in management? R

I was caring for a son who had cancer. Whenever anyone died from cancer it brought the whole cancer diagnosis back. Is there any way of easing this trauma, my son survived and is doing well.

An RCT of Olanzapine as a treatment for psychiatric disorder caused by high-dose steroids - we currently rely on case series evidence to choose psychotropics in this context, despite the fact that up to 18% of people taking daily dose of dexamethasone over 10mg can expect severe psychiatric symptoms (notably mania, suicidal thoughts). H

There are studies into chemotheraphy and its effect on the brain but not everything is known about it yet. Similar with radiotherapy we know it can affect cognitive function but we don't know how to manage it better.
<p>| How can the long term, including the permanent, side effects of immunotherapy (e.g., ipilimumab) be best managed by patients and professionals? | P | It is possible to have a profile of risks for each treatment but long term data is poor because clinical trials don't collect a) the right data b) long term data. This is an issue to raise with the wider research community. |
| What research is being undertaken to alleviate the harsh side effects of cancer treatment, (e.g. GVHD)? | P | Lots of advances in radiotherapy to minimise toxicity, limiting doses Proton therapy, SABR therapy. Less known about managing effects. |
| Testosterone replacement therapy following testicular cancer and the way to cope with the ups and downs. | P | Publication pending on testosterone replacement therapy. |
| Testosterone replacement therapy and the way it changes the way the body reacts to feed. | P | Long term effects of surgery are known. Getting |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Reference</th>
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<tbody>
<tr>
<td>How to better manage chemotherapy side effects, such as neuropathy, ‘chemo brain’, toxic radiation infections (from biologics). There is very little attention given to the diarrhoea side effects that heavy chemo (such as platinum based) have on patients, it’s a case of ‘get on with it’. For people who cannot be cured, the time they have left is precious and it should be the best possible circumstances.</td>
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<td>What effects do cancer therapeutics have on higher mental function/cognition and how can we mitigate this?</td>
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<td>A lot has been written about ‘chemo brain’ (much of it claiming it doesn’t exist; but a lot of people I know are affected by it). What is being done about this? Is anything being done about only giving chemo to only those it will work for? Do particular chemo regimes affect the brain more than others?</td>
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<td>Are there specific symptoms or body changes which in the longer term after cancer treatment should raise concern to seek medical advice? Ordinarily, these symptoms or changes may be relatively insignificant but does cancer treatment, for example chemotherapy, exacerbate subsequent conditions requiring medical intervention that without having that specific treatment would not have raised concern?</td>
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<td>What can be done to improve outcomes for young people with fertility problems caused by chemotherapy?</td>
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<td>What are the longer-term effects on organ function of anticancer treatment? For example cardiovascular, renal function.</td>
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<td>Does chemotherapy cause cancer?</td>
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<td>What is the long-term impact of chemotherapy (for example FEC) on the immune system?</td>
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<td>What can be done to help chemo-related toxicity health problems after treatment i.e. chronic kidney disease, cardiomyopathy, pneumonitis etc?</td>
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<td>Would it be an explanation as to the damage your nerves suffer due to Chemo</td>
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<td>What are the most effective interventions for reducing ‘chemo brain’ post treatment?</td>
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<td>Can you end up having a perforated bowel from head and neck cancer?</td>
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<td>Muscle pain and aches in thigh: My experience was very painful requiring strong pain killers and continued for a long time after treatment, my normal activities were difficult to carry out, especially walking any distance and going upstairs. I still feel, often the problem linger on despite keeping myself fit.</td>
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<td>What is the real impact in the nervous system for cancer patients who have memory.</td>
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<td>Does VMAT radiotherapy for head and neck cancer have long term affects on</td>
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<td>How do we optimally treat bleeding from radiation psychopathy?</td>
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<td>Why is pelvis radiation disease not commonly talked about by oncologists and why are some patients not warned of the after effects?</td>
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<td>What can be done to highlight pelvis radiation disease and the side effects of it to stem?</td>
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<td>What can be done to avoid it?</td>
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<td>Having had radiotherapy for Prostate Cancer and now having been diagnosed with Radiation Proctitis, what is the best way of coping with this condition i.e. diet etc.</td>
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<td>Why is there so little research interest in the UK into long-term consequences of pelvis radiotherapy?</td>
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<tr>
<td>Why is there so little or no research being done on the late effects of radiation treatment and how to prevent them?</td>
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<td>Long term side effects of pelvic radiation with information on treatments that may alleviate symptoms coping strategies.</td>
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<td>Does stem cell therapy reverse severe radiation fibrosis? If not, what other options are there to reverse (halt the ongoing inflammatory action which is leading to fibrosis of the intestines, bladder, kidneys and sacral spine).</td>
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<td>Is there any treatment for radiation cystitis causing chronic infection and haematuria?</td>
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<td>I would like to know more about how radiotherapy can cause damage to nerves in the body particularly following radiotherapy of the pelvis and abdomen. I have experienced this particular condition and have great difficulty in walking as a result. I have bilateral foot drop and muscle weakness in my hips and buttocks; balance is particularly difficult for me.</td>
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<td>I had radiotherapy follow up because I had a slight increase in PSA reading 6 years after radical prostatectomy, and this resulted radiotherapy cystitis. This condition caused two episodes of bleeding into the bladder, one of which required hospital in patient treatment to flush through my bladder. I have not had any blood in the urine for over two months. The question is &quot;is there any other treatment or medication to treat this condition other than cystodiathermy via rigid cystoscopy as the latter can cause incontinence&quot;?</td>
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<tr>
<td>What are the long term effects of radiation? Especially on the lung and heart.</td>
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<td>What are the longer term effects of targeted radiotherapy.</td>
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<tr>
<td>What is the latest proven treatment for late effect (chronic) pelvic radiation disease.</td>
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<td>How effective is radiotherapy after cancer of the womb? It has ruined my digestion and makes life very difficult (frequent and urgent bowel), and actually killed my mother in the end (total blockage by scar tissue).</td>
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<tr>
<td>How can we manage late effects of radiotherapy?</td>
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<tr>
<td>Why is not more attention being paid to Pelvic Radiation damage? Patients are surviving longer but at a cost, often they have very bad diarrhoea, urinary problems and increasing mobility and bone problems. Much more research needs to be done as to how to help these people.</td>
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<tr>
<td>Why is there not further research into Pelvic radiation disease?</td>
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<tr>
<td>How do I cope with life long pelvis radiation disease, mainly bowel problems that cause incontinence?</td>
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<tr>
<td>Is anyone trying to help people with radiotherapy damage to the pelvic area?</td>
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<tr>
<td>Radiobiology: tissue recovery after radiotherapy (RT). Knowing how to measure tissue recovery from RT over time would allow safer subsequent courses of RT. With increased longevity, people are developing multiple malignancies concurrently or sequentially, and as a result we are increasingly having to deliver multiple courses of RT in a person's lifetime.</td>
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<td>RADIATION PROBLEMS:</td>
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<td>Is there anything a patient can do to prevent/reduce fibrosis following radiotherapy? It's a big problem for patients, it's painful and limits mobility if in leg. Not really discussed at time of consent and GP's not knowledgeable about it.</td>
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<td>What is the possible long term consequences of radiotherapy for cancers in the pelvic area (e.g. prostate, colorectal, gynaecological)?</td>
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<td>Does treatment with radiotherapy for prostate cancer, always mean patients will suffer ED?</td>
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<td>I am 88 and I have been on hormone therapy for my prostate cancer for 6 years. I have a Gleason score 10. I declined to have radiotherapy which was suggested as I felt that the accuracy of aiming the radiation appeared to rely on having a full bladder. As I am not able to estimate just how full my bladder is (I know how inaccurate this feeling can be as I have been self catheterising myself for over 25+ years) I feel therefore that if a &quot;full bladder&quot; is a prerequisite for aligning the X-Rays there is an inherent risk of other sensitive structures being irradiated both unnecessarily and with significant adverse consequences. My PSA score has remained low and is currently 0.6</td>
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<td>How to deal with Trismus (lockjaw) after radiotherapy to cure mouth cancer</td>
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<td>The role of hyperbaric oxygen therapy in late effect management of pelvic radiotherapy bowel problems</td>
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<td>Is there anything patients can do to slow down or stop the progression of radiation cystitis?</td>
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<td>What are the long term effects after radiotherapy that don't get mentioned by medical team. Such as fatigue, rib pains, twitching electrical pulses, burning/swelling, year after treatment. How can we manage it. Brain fog, memory loss, feeling distant from the outside world.</td>
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<td>During treatment I had radiotherapy next to my spine. I have now been diagnosed with osteopenia. Was it the radiotherapy that caused this? 63 year old male no previous history osteopenia in the family.</td>
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<td>What are the relative risks of disease recurrence and exposure to radiation?</td>
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<td>How can the loss of control of bladders be avoided for patients who have radiotherapy and chemotherapy treatment, especially in the pelvis area?</td>
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Why Pelvic radiation disease can be present even when no physical damage to the gut.

How do I live with radiation proctitis?

Research the long term effect of surgery, radio and chemotherapy on bowel and bladder function for patient with bowel cancer. Specifically continence especially bladder (frequency and urgency) and problems with defaecation. I had a low anterior resection for ca colon 13 years ago after radio and chemotherapy to shrink cancer prior to surgery, diagnosis at age of 42 female. Why do I sometimes wet my self when bladder is full so I cannot prevent myself emptying my bladder. Why do I have issues with passing stools, I can feel pressure so know I need to pass stool but can't without pressing on perineum to force out stool. Not constipated

More information about the side effects of radiotherapy

The best way to overcome damage left by cancer treatment in the long term ie radiotherapy burns in breast cancer

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There are ways to manage acute pain but less is known about managing chronic pain. So what can we do as we live longer with progressive disease?

What impact does exercise have on cancer? Can we turn on cell protection/repair mechanisms temporarily, prior to chemo, then, turn them off again after?

Does pre-habilitation reduce length of stay in patients undergoing neo-adjuvant treatment?

What’s the truth about exercising while going through treatment? How does exercise reduce side effects of cancer treatment especially if had radiation through the heart?

What is the impact of Occupational Therapy interventions on quality of life for cancer patients during treatment?

Are there any specific foods, vitamin supplements, or herbal remedies which have a positive or negative effect on how well someone feels?

Is exercise going to help prevent long term effects of cancer especially if had radiation through the heart?

Are there any synergy ways to potentiate the effects of treatments that would mean the longer term side effects could be limited? Can increasing exercise reduce pain from avascular necrosis?

Does regular exercise improve outcomes in cancer patients?

Can exercise help prevent long term effects of cancer especially if had radiation through the heart?

Is cannabis oil useful in dealing with the side effects of treatment?

Does exercise go to help prevent long term effects of cancer especially if had radiation through the heart?

Are patients not advised how to best prepare for surgery, and recovery? For example, for a fortnight before, if you can, take more exercise and sleep, eat proper food, take a quality multivitamin, get some sunshine?

Does pre-habilitation reduce length of stay in patients undergoing neo-adjuvant treatment?

What is the background? To prepare those living with cancer for the long term side effects of medication? Example: Tamsulosin and cataracts: other drugs: neuropaths, fibromyalgia, various aches and pains. Chemo brain and the list goes on.

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3. What specific lifestyle changes (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve outcomes of tests?

How does lifestyle and nutritional factors (eg diet obesity physical fitness body composition) affect outcome from cancer, and how can these be optimised?

Best diet to follow

Do nutritional supplements including energy drinks, omega-3 supplements etc improve quality of life in cancer patients?

Does exercise help with recovery and guard against recurrence?

How can a healthy lifestyle affect cancer outcomes following cancer treatment?

What lifestyle interventions (exercise, strength training) improves quality of life post-treatment?

How to stay strong and healthy?

I need an exercise that is possible post cancer i.e. resist exercise a lot, seek to deal with stress, eat heartily etc. I believe this will give me a better chance of recovering from or dealing with any subsequent treatment/surgery however I have no evidence, other than anecdotal, that this helps. It would be good to have decisive research that showed how best to stay well after cancer.

What's the single best bit of lifestyle advice living with and beyond cancer?

Any good dietary advice.

What can I do to help myself after a diagnosis of cancer?

Are there any supplements which are useful to take?

What can I do to help my health care team manage my condition?

Any good dietary advice, etc)

What role does achieving and maintaining a healthy weight (preventing weight gain and weight loss during and after treatment) have in cancer survivorship?

Does following a healthy diet and lifestyle improve survival after cancer treatment?

How can diet and exercise assist in recovery?

What other exercises and techniques to regain lung and muscle function post-cancer? i.e. does card, resistance or HIIT type exercises work better?

How does the balance of protein, fat and carbohydrate in the diet influence the body’s physiological response in cancer (resistance, efficient use of energy etc)?

European Code against cancer 2016 – overall summary of their guidelines and specifically PR guidelines.

5. How can I improve my quality of life in inoperable pancreatic cancer patients. This will relate at least to pain relief and diet.

The best pain relief for palliative care patients.

When managing pain, are there any alternatives to opioids that do not give the same negative side effects?

Neuropathic pain from surgery is poorly controlled except by paracetamol with side effects almost as bad as the pain itself. What more should be done to arrive at a class of analgesia for neuropathic pain that doesn’t harm the recovering patient into either a zombie or a psychopath

How to manage pain effectively, without recourse to opiates which have very unpleasant mental side effects.

What to do about muscular and nerve pain and how to avoid it after head and neck cancer. 8 years after treatment I live with pain in my neck every day.

Why aren't better pain killers, provided.

Could there be a combination drug therapy which relieved the pain that the actual cancer deft then drug itself?

How effectively is pain managed in some cancer patients? We have had an example recently when because of the siting of a patient’s particular cancer she has been left with the choice of having the pain not very well controlled, or having an epidural which would make her wheelchair bound. Tough choices either way when she is in pain.

Why can’t cancer pain be properly controlled? (And why do so many professionals lie about it being possible to keep pain under control when the evidence of our own experience shows that it isn’t?)

The effectiveness of 1950s or cancer related pain. I see a positive effect in patients with right upper quadrant pain but not particularly found any evidence in palliative care to support this.

Causes of and treatment for chronic pain after chemo radiation and excision surgery for early breast cancer.

Can cannabis oil useful in controlling cancer related pain?

The question of pain relief and the different drugs available for palliative and non-palliative care.

Pancreatic Cancer and the question as to how to deal with the nerve pain which does not respond to the usual drugs.

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<td>Question</td>
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<tr>
<td>What is the incidence of long term side effects or complications of treatment in people with upper and lower I cancers and how does this impact on QOL?</td>
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<tr>
<td>What are the long term effects of radiotherapy?</td>
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<tr>
<td>What impact does chronic lymphedema have on a patient’s life as a cancer survivor and what can the severe effects of surgery and radiotherapy be?</td>
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<tr>
<td>How common is (permanent) chronic tongue following treatment for Ewing’s Sarcoma?</td>
<td>P</td>
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<tr>
<td>What are the long term side effects of treatment?</td>
<td>P</td>
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<tr>
<td>Why my deficit is sometimes worse 2 years after my Wide local Excision, radiological clearance and radiotherapy than it was at the time?</td>
<td>P</td>
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<tr>
<td>What are the actual side effects experienced by ALs patients undergoing chemotherapy? Most certainly, with the benefit of hindsight, I am quite certain that things I experienced were not noted as they weren't things known to be experienced... I remembered...</td>
<td>P</td>
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<tr>
<td>What are the short, medium &amp; long term effects of each of the treatments</td>
<td>P</td>
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<tr>
<td>The impacts of ongoing treatments.</td>
<td>RH</td>
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<tr>
<td>What are the possible long term consequences of the 1st type surgery?</td>
<td>P</td>
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<tr>
<td>3yr post EPN, HER2 breast cancer - and a recent hysterectomy with Bilateral Salpingo Oophorectomy has resulted in significant side effects incl fatigue and joint pain. Is this to be expected living beyond Cancer?</td>
<td>P</td>
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<tr>
<td>My husband has had cancer and is suffering lots of different side effects that are unexplained although he has seen several specialists. He finds this very frustrating.</td>
<td>R</td>
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<tr>
<td>The after effects of hormone therapy such as tamoxifen.</td>
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<tr>
<td>What are the long term implications of cancer treatments?</td>
<td>H</td>
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<tr>
<td>What are the lasting effects of Radiotherapy and Chemotherapy?</td>
<td>P</td>
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<tr>
<td>What are the long term effects of having cancer and of the treatment, e.g. chemotherapy?</td>
<td>P</td>
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<tr>
<td>Research the long term effect of surgery, radio and chemotherapy on bowel and bladder function for patient with bowel cancer. Specifically continue especially bladder (frequency and urgency) and problems with defecation. I had a low anterior resection for ca 12 years ago after radio and chemotherapy to shrink cancer prior to surgery, diagnosis at age of 42 female. Why do I sometimes wet my self when bladder is full as I cannot prevent myself emptying my bladder? Why do I have issues with passing stools, I can feel pressure so know I need to pass stool but cannot without pressing on perineum to force out stool. Not constipated</td>
<td>P</td>
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<tr>
<td>Neurogenic pain - how common an issue is this post surgery and post chemo?</td>
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<tr>
<td>What are my chances of experiencing long term “consequences of treatment” and what can I do about them?</td>
<td>P</td>
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<tr>
<td>What is the most common symptom people LWBC experience</td>
<td>H</td>
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<tr>
<td>Understanding our long term side effects</td>
<td>P</td>
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<tr>
<td>Long term effects of chemotherapy and radiotherapy.</td>
<td>H</td>
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<tr>
<td>what are the long term effects on your teeth</td>
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<tr>
<td>what number of patients suffer long term debilitating side effects of radiotherapy and to what severity</td>
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<tr>
<td>Long term effects of cancer - its treatment - how long do they last, the extent of the effect and its impact on patients lives.</td>
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<tr>
<td>How many people are living with subtypes of breast cancer and how long are these people living in the sub types and what are the side effects people are experiencing?</td>
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<tr>
<td>What are the long term effects of my treatment?</td>
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<tr>
<td>How many people are left with significant longterm effects from the treatment received?</td>
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<tr>
<td>I like more data collection into what happens with people following treatment, eg longer and late side effects, incidence of secondaries, etc as it is only then these issues can be addressed.</td>
<td>PH</td>
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<tr>
<td>Impact of long term side effects like lymphoedema, fatigue, pain, and bone and heart health.</td>
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<tr>
<td>Pain - How can we predict which patients are going to have more pain as a result of their cancer and/or as side-effects of their treatment? This should include screening for phenotype as well as biomarkers and genomic screening.</td>
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<tr>
<td>How are cancer treatment (chemo, adjuvant, radio) and hormone therapy affecting sports abilities of BC patients diagnosed before 40 years old? How is fatigue affecting the patients long term?</td>
<td>P</td>
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<tr>
<td>Now, having received chemo and radiation- what are the damaging side effects long term? I have to undergo dental extractions and cut off all my hair.</td>
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<tr>
<td>Consequence of treatment? Both short and longterm?</td>
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<tr>
<td>What are the most common late effects?</td>
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<tr>
<td>Late effects of bowel &amp; bladder problems - where can patients be signposted for more support? Why do some patients get bowel problems and some don’t?</td>
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<tr>
<td>The impact of late effects on a patient’s life despite treatment success</td>
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<tr>
<td>What is the true incidence of symptoms after various different cancer treatments at different timepoints?</td>
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<tr>
<td>Do acute symptoms predict chronic late effects after pelvic radiotherapy?</td>
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<tr>
<td>What are the long term health related consequences of immunotherapy agents such as bevacizumab used to treat lymphoma and leukaemia?</td>
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<tr>
<td>What is the risk of late effects?</td>
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<tr>
<td>What are the long term, over 20 years past radiotherapy treatment, effects on the body?</td>
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<tr>
<td>What is the stage of disease at Long with &amp; Beyond Cancer?</td>
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<tr>
<td>What late effects can be expected after treatment for the common epithelial malignancies?</td>
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<tr>
<td>How long after treatments late effects can develop</td>
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<tr>
<td>What late effects can develop and for GP’s to be provided with information on late effects and possible ways to deal with them.</td>
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<td>are there any long term LWBC consequences of the immune checkpoints inhibitors</td>
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<tr>
<td>How common are the late effects of cancer and its treatments (prevalence of late effects)?</td>
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<td>late effects of treatment</td>
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<tr>
<td>What are the long-term (like 20+ years) health effects of the chemio and radiation that I received (for bowel cancer) aged only 20?</td>
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<tr>
<td>What will be the side effects of my treatments in the future?</td>
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<tr>
<td>How will my immune system be affected as the years go by?</td>
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<tr>
<td>What are the future implications to my health?</td>
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<tr>
<td>What are the mid and long term effects of chemotherapy and how does this affect the quality of life for the patient and their loved ones, friends and family etc.</td>
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<tr>
<td>What long term health issues can I expect as a result of my cancer and its treatment</td>
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<tr>
<td>Can treatment-related cardiovascular events and deaths be prevented?</td>
<td>FRH</td>
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<tr>
<td>There is lack of knowledge within the healthcare profession, including cancer services, and general public of long term side effect when living beyond cancer. Some side effects do not occur until years after treatment when to others it appears the cancer has been cured so therefore health problems can not related. This is made more difficult as health problems can not be seen e.g. fatigue, pain, neuropathy, cardiac damage, endocrine imbalance. Research has shown long term side effects in children and now that more of us are living longer these same or similar side effects in adults need to be documented.</td>
<td>R</td>
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<tr>
<td>Much is known about late effects of treatment but I am not aware of much if anything that has been done to try to predict the likelihood of particular late effects occurring based on what is likely from the type of treatment, the disease and site treated and the presence of other morbidities. A predictive tool to allow some degree of prevention or early treatment for the range of late effects would make a huge difference to the quality of life of those survivors affected by late effects that could either be prevented by early action or much better ameliorated.</td>
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<tr>
<td>Can we predict who will develop late effects from their cancer treatments?</td>
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<tr>
<td>When is a late effect not a late effect but a consequence of natural ageing?</td>
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<tr>
<td>Late effects of cancer: how the effects people’s lives long term</td>
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<tr>
<td>Can I expect new side effects to appear after my treatment is completed?</td>
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### 11. What are the most effective ways to stop cancer coming back (combining treatments and lifestyle changes)?

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<tr>
<th>Question</th>
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<tbody>
<tr>
<td>What can I do to prevent cancer coming back?</td>
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<tr>
<td>Very large topic and some known answers – not smoking, keeping a healthy BMI etc.</td>
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<tr>
<td>What diet is best for those recovering from primary BC to try to avoid it recurring and avoid weight gain not helped by anti cancer long term medication eg tamoxifen?</td>
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<td>European Code against cancer 2016 – overall summary of their guidelines and specifically FR guidelines.</td>
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<tr>
<td>Stress and recurrence: Do environmental stresses, such as financial concerns following long term sick leave / ceasing of sick pay, have a bearing on the risk of recurrence?</td>
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<td>Is there any proof of high quality nutrition improving prognosis/survival/ recurrence rates?</td>
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<tr>
<td>What can I do to improve my chances of not having the cancer returning or becoming worse?</td>
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<tr>
<td>How can we help people reduce their risk factors for recurrence, second cancers and other health problems after treatment. Eg by reducing obesity and blood pressure and stopping smoking. Preferably also involving the people important to them who are around them. Also to enable them to take control of their own health.</td>
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<tr>
<td>How can I help my chances of the cancer not returning or give me a longer remission?</td>
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<td>Does exercise help with recovery and guard against recurrence?</td>
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<td>There is a lot of confusion about what foods are good/bad for protection from cancer recurring. Is it possible to have a medically approved list of what is best/worst in terms of diet?</td>
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<tr>
<td>Benefits of proper nutritional advice to prevent cancer recurring</td>
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<tr>
<td>Particularly following breast cancer, is there evidence that a red meat-free and dairy-free diet helps to prevent a recurrence?</td>
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<tr>
<td>What can I do to reduce the likelihood of it coming back?</td>
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<tr>
<td>What evidence is there that turmeric mixed with black pepper to increase absorption reduces inflammations in the body of which cancer is one type of inflammation?</td>
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<tr>
<td>In the case of hormone positive breast cancer how important is dietary fat intake and its impact in aromatase production. Is there a recommended percentage of total calorie intake?</td>
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<tr>
<td>Effect of diet on cancer. Effect of milk intake in breast cancer (hormone in milk, which promotes aromatase) and its impact in aromatase production.</td>
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<td>What can I do to mitigate against its return or the development of another cancer?</td>
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<tr>
<td>What can I do to prevent recurrence?</td>
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<tr>
<td>What foods should patients eat that are most likely to prevent cancer recurring?</td>
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<tr>
<td>Does stopping smoking really reduce recurrence?</td>
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<tr>
<td>What is the optimal diet to help prevent cancer recurrence?</td>
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<tr>
<td>What diet changes have the most impact on future prognosis?</td>
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<tr>
<td>Does turmeric help ward off cancer?</td>
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<tr>
<td>Does participating in exercise after cancer treatment reduce the risk of recurrence?</td>
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<tr>
<td>As a PET scan demonstrates that cancer cells thrive on sugar, doso you think it would be helpful to eliminate sugar and refined carbohydrates (which metabolise to sugar) from your partner’s diet?</td>
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<td>Does a vegan diet help prevent cancer recurrence?</td>
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<tr>
<td>Is there any real evidence from previous Research that a “non dairy diet” will prevent the return of my breast cancer?</td>
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<tr>
<td>Is it possible for those of use treated with surgery and chemotherapy up to 7 years ago to benefit from development of treatments to reduce the risk of recurrence?</td>
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<tr>
<td>Will diet affect the chance of cancer returning?</td>
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<tr>
<td>What is the effect of diet on cancer?</td>
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</tr>
<tr>
<td>Which diet is best to follow after a cancer diagnosis? Is there any research that says avoiding dairy and red meat will delay the return of the cancer?</td>
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</tbody>
</table>
How are peoples working lives/earning potential affected by cancer?

What is the financial impact of life after cancer diagnosis?

What are the social, financial and economic impacts of living with and beyond cancer – how does it affect families, relationships, finances, work and use of NHS services?

What can be done to help prevent secondary cancers or recurrences?

How can I prevent a recurrence or metastasis?

Does cannabis oil have anti cancer properties?

Does aspirin reduce progression/recurrence rates?

Does vitamin supplements help cancer patients to keep healthy and/or help to keep cancer at bay?

What are the three most effective things I can do to reduce the chances of the cancer returning?

What are the 3 most effective things I can do to reduce the chance of the cancer returning?

What are the lifestyle choices that can impact the chances of cancer avoidance for the future?

Impact of diet can have on cancer progression

I would like to know how diet can affect my cancer. Would it be better to give up dairy or meat and become vegetarian or even vegan? How about organic v normal-products? Alcohol? I have read about ketogenic diet and how this may be beneficial for cancer patients.

What are the lifestyle changes that can impact the chances of recurrence?

What is the best diet/food for someone continuing on chemotherapy and to help with the best way of absorption.

What can I do to help stop the cancer coming back?

What was the best diet/fat for someone continuing on chemotherapy and to help fight cancer?

What should I have done to prevent the cancer from returning? Change of diet, lifestyle help them recover faster from treatment and reduce recurrence.

Any particular forms of exercise more protective in avoiding a recurrence of cancer?

What can I do to reduce the risk of recurrence?

Can diet and exercise influence prognosis following a diagnosis of cancer?

How best to prevent secondary cancers or recurrences?

What steps can be taken to improve risk reduction for future health problems (cancer and other conditions) after treatment for cancer? Are there lifestyle risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention?

Are there certain foods that have been proven to reduce the risk of recurrence of breast cancer?

What are the lifestyle choices that can impact the chances of cancer avoidance for the future?

There is some research on the benefits of turmeric and green tea on cancer. But it doesn’t explain how to best consume it and how often. It almost just encourages people to pop a curcumin tablet in their mouth when actually that may not be the best way of absorption.

Should I be making any lifestyle changes relating to what carcinogen I had?

How to prevent secondary cancers or recurrences?

What steps can be taken to improve risk reduction for future health problems (cancer and other conditions) after treatment for cancer? Are there lifestyle risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention?

What should I have done to prevent the cancer from returning? Change of diet, lifestyle help them recover faster from treatment and reduce recurrence.

What is the best way of absorption.

I need specific advice about how to reduce incidence of recurrence.

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What can I do to help prevent secondary cancers or recurrences? Is there a special diet to discourage cancer?

What can I do to try and prevent recurrence.

What can I do to reduce the risk of recurrence?

Can diet and exercise influence prognosis following a diagnosis of cancer?

How can I change my diet to improve my chances of avoiding a recurrence of cancer?

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What are the 3 most effective things I can do to reduce the chances of the cancer returning?

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Does diet have an impact on recurrence?

Does stress increase the chances of breast cancer returning?

What are particular forms of exercise more protective in avoiding a recurrence of cancer?

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The financial impact of cancer and how welfare and support agencies respond to this. For example many people with cancer are forced to continue to work due to neglibility for benefits
How does a patient feel about their role within the family unit whilst living with cancer and death?
How might personal health budgets help people undergoing cancer treatments or recovering from cancer treatments?
How has life changed for you as a result of living with cancer?
How have the long term side effects of radiation affected your ability to be in full/part time employment?
What were the financial costs during treatment and ongoing?
How has a cancer diagnosis affected their relationships with partner, family and friends?
I would like to know more about incurable cancers, like I have. There seems to be a focus on drugs and treatments that cure and other remission. Little works seems to be published on the quality of treatments for reducing symptoms, the spread of cancers and on palliative treatments at the end of life. What are the impacts on people generally of living with cancers over the long term?
What are the best approaches to dealing with it for patients, medical staff and carers? How can living longer term with cancers be made more positive.

Financial implications of having cancer
Financial worries and how they affect the patient and their family - how much a cancer patient's income suffers after their diagnosis.
Relationship issues that occur after cancer - I know of some younger women who have survived breast cancer whose partners and husbands subsequently leave them as they can't cope with the wider ramifications. This ties in slightly to my other question, but is also a separate issue that would need to be looked into differently. This leaves the women as single parents which has wider ramifications on career, ability to work, pensions etc. The husbands may need more support in coping with partners who have bad cancer.
What can be put into place to ensure that those living with cancer or beyond cancer are not 'penalised' for having or having had cancer? I am thinking particularly about negative financial impacts or career progression in the short and longer term.
how many people of working age are returning to employment, either, FT or PT after cancer treatment? Have they been supported to return to work? Have adequate adaptations been made for them to return to work?
Support financially adequate or not
How does a diagnosis of colorectal cancer, regardless of treatment, impact on social life, work life and relationships?
How does diagnosis change people's life values - both of patient and of partner/family? In what is important in terms of what they prioritise and value and how they see their life? Equally, if no change, why is this?
What is the impact of cancer diagnosis on the family - short, medium and long term?
what were the main challenges for you on receipt of a diagnosis these should be categorised, family/dependants coping with your illness, financial worries, benefits, progress worries access to treatment locally, communication re the implications of your diagnosis, communication/contact with my GP
I want to understand the comparisons of people with and without cancer diagnosis in relation to ability to take part in social and work lives. How many people living with or following cancer treatments are affected adversely in contexts such as home life, relationships, working/lies and activity. For example, would people unaffected by cancer have less fatigue or is it just that we are getting older and blaming it on the treatment or disease
What is the impact of having a chronic blood cancer diagnosis on employment status/the individual's ability to work? I am specifically interested in indolent lymphomas/leukemias where 'watch and wait' can be an appropriate treatment.
Financial worry and how they affect the patient and their family - how much a cancer patient's income suffers after their diagnosis.
Financial worries and how they affect the patient and their family - how much a cancer patient's income suffers after their diagnosis.
13. What are the best ways to cope with the fear and anxiety about cancer returning (combining self-management approaches, treatments and psychological support)?

- Do you always think that every pain in your body is cancer after a diagnosis?
- What is the best way to support patients living with the fear of recurrence?
- What are the best ways to deal with “scanxiety”? (Anxiety relating to follow-up scans)
- My cancer, multiple myeloma, is treatable, but not curable, I’m always looking to the next 3 monthly clinic appointment. How can I put these thoughts aside, or, who can help me do this in order to live my life to the full?
- How can I stop the worry of a cancer recurrence becoming overwhelming?
- I’m still concerned after nearly twenty years, why I’m still having polyps removed. Every time I wonder if the cancer is coming back
- What can you do about the fear of recurrence?
- Help how to get through each day and have an unknown future
- To what extent can digital resources (videos / blogs / files etc.) help patients cope with fear of recurrence, uncertainty and the psychological problems of cancer recovery.
- How can we help people to cope with living with the anxiety of recurrence. What strategies help and in whom?
- How can health professionals effectively work together with patients and carers to manage the chronic uncertainty and long term treatment of relapsing cancer?
- Cancers vary considerably and some are never considered cured - how do people live with that worry of recurrence?
- How can healthcare be delivered so every time I come to clinic I don’t get scared?
- How do I best deal with anxiety about the disease returning?
- How can people best be supported to cope with the fear of their cancer returning?
- Best way to deal with uncertainty or worry of cancer coming back
- What can be done to alleviate “scanxiety” (i.e. Anxiety around scans and results)
- How to cope with the knowledge
- The benefit of having follow up appointments for patients who have achieved complete response from chemo.
- How can I deal with the worry and uncertainty of cancer returning?
- How is anxiety about cancer relapse in these patients? And what are doing about this?
- Trying to be positive is a constant battle and individual. Is cancer is it normal feel always hang over you even if cured?
- How do I live with the concern that cancer will come back?
- The anticipatory dread with follow up scans etc.
- What are you long term anxieties and concerns about living with cancer and beyond, and how can health care professionals best support you through this?
- I have been diagnosed with a blood cancer but have been put on ‘watch and wait’ but I have these constant feelings of anxiety and tearfulness, especially around the time of my blood tests?
- How do patients live with the uncertainty of their future?
- How do they deal with uncertainty.
- I am most interested in the psychological impacts of living with cancer, long term. As someone with follicular lymphoma, I am well aware that, despite being in remission for 7 years, my cancer is most likely to come back at some point in the future. Not knowing whether that might be in 6 months or 6 years time can be a strain and I know that there is very little support available on the NHS for people like me. How can this situation be improved for those of us with a chronic but indolent cancer condition?
- Does counselling help with the anxiety about the cancer returning?
- How do you feel when you have a scan coming up?
- How do I cope with the fear of cancer returning?
- How do you deal with the fear that the cancer will return when you felt perfectly well before the cancer was discovered and you now feel well again?
- How can you trust your body again?
- How can I cope with scan anxiety?
- What is the most effective method to address the fear of recurrence experienced by patients at the end of treatment?
- How can you reduce the inner fear of the cancer coming back?
- Where can I find help to assist me with coping with the negative feelings and thoughts of recurrence after finishing treatment?
- Has it spread, You say no but how do I know that? Every tingle ache or pain might be another tumour.
- What are the best ways to cope with the fear of cancer returning?
- How do I know on whom? have been told I have a 2% that the cancer will return for the rest of my life. I feel like a ticking time bomb
- How is it possible to try and live a new normal life after cancer? without it ruling your every day and fear that it will come back?
- How best to support post-treatment cancer patients in coping with the fear of the disease returning.
- What is the best way to manage fears of cancer recurrence
- Is there an evidence base for group based psychological therapy to manage fears of further deterioration or spread of disease in people living with metastatic cancer?
- When do you stop worrying about recurrence?
- I’m scared of cancer returning
- What CBT exercises might be available and helpful to assist with anxiety and fear of recurrence?
- How do you manage the anxiety about recurrence?
- How to manage the issue with thoughts of recurrence of the cancer
- What are the most effective ways of dealing with fear of recurrence?
- Mentally I can never rid the thought of getting cancer back
- How can people be supported with health anxiety related to cancer recurrence?
- How can health care professionals be trained/educated in the importance of not sending anxious people for multiple investigations as this worsens them and maintains anxiety about recurrence
How do you take away the fear if the word cancer?
P
How can people cope effectively with the worry that the cancer may return sometime later in their life?
P
What additional methods, support, strategies are proven to help with living with the fear of recurrence in the future?
H
What tools are effective in helping people who have been through treatment to manage their fear of recurrence?
P
What do professionals need to do to help support patients living in constant uncertainty?
H
How do you cope with the uncertainty of the cancer returning?
H
I’ve also struggled over the years I’ve lived with secondary disease to find a way to overcome the knot of fear that still remains in my stomach about when and how this disease will raise its ugly head and do its worst again. What to look for, and when to know it is the cancer and not the other usual illnesses and issues we all suffer when ageing. i.e. I often worry when I have a bad headache or migraine that I have a brain tumour. Or, what I believe to be arthritis often causes pain where I know the cancer could be causing me issues, and therefore I always fear that it has kicked off again. (I have bone secondaries, and have already had a replacement hip).

What are the most useful strategies to manage the psychological impact of outpatient appointments?
P
Will the fear of cancer returning ever go away?
P
Living with uncertainty is hard. How can I make this easier? P/R
How to manage the worry of a cancer diagnosis returning once in remission.
P
Returning to (a) clinic is quite stressful and brings the whole initial diagnosis/treatment back as ‘if it was yesterday’ it feels like post traumatic stress disorder. If this happens to others it would be great to know and to develop or be given coping mechanisms. Triggers are not just the clinic visit but as little as the bleep of an alarm on an IV pump. None of this seems to get better with time

How do you look forward and not back?
Not become permanently worried well?
P
How can we learn to cope with the thought the cancer might recur?
P
How can primary care professionals help patients who have had cancer deal with the ongoing worry of recurrence?
H
How do you forget the fact you are living with cancer and try to live a normal life when you are being monitored every 3 months? I find I rarely switch off from thinking about it.
P
How do you help people when the future is really still unknow post primary treatment?
F/R
How mental support is available to aid recovery. Dealing with doubt and uncertainty is one of my biggest issues.
P
Does it help to have full information e.g. re prognosis predictions in order to be able to be more fully with cancer or does this restrict the ability to ‘get on with life as normal’?
H

The fear of recurrence
This is by far the most difficult problem for me and is something that never completely leaves you. I think anything that could be done to dispel many of the myths about cancer such as its always terminal and there is no cure would ease the fears of many patients.

How do you get over it? How can you not spend the rest of your life worrying about whether it will come back?
P
How will you be able to fully relax?
P
Dealing with the next PSA and the time when PSA will start to rise again.

What is the best way to deal with ‘has it returned’ fear every time you feel under the weather?
P
Fear of recurrence is talked about by many researchers as being important but I am not aware of any practical approaches having been developed to help those sufferers who suffer extreme anxiety from this.

Resilience fears - and reality - and how we fare with these challenges physically and psychologically.
P
Coping with fear of recurrence. Are there sufficient mental health support services/counselling to support both cancer patients and their families or those going through diagnosis. Having a diagnosis of cancer often creates a PTSD reaction - a threat to life and therefore recovery includes the need for supportive activities, such as art therapy, laughter, sharing stories and one to one counselling for both patient and relative.

How can I stop worrying about it coming back?
P
Living with uncertainty?
H/R

How do you cope with psychological side after treatment and when you are cancer free with the unrelenting fear of it coming back?
FR
How to live with the fact that the cancer may return. Who would you seek support from?
P
Managing personal and family anxiety regarding fears of relapse.
R

14. How can we predict who is at risk of developing mental health conditions in people living with and beyond cancer (e.g. depression) and what are the best ways of supporting those with mental health conditions? P

What is the answer for long term fatigue and anxiety as a result of surgery and radiotherapy for head and neck patients?
P

And after 2 years am now having some black thoughts.
P
Surviving cancer is a lonely, scary place for the patient and their support.
R

I can sometimes feel like additional pressure for patients to feel grateful/happy as certain milestones post treatment are achieved but sometimes as time goes on the anxiety levels increase and often patients are on their way ‘out of pathway’ when it matters.

How likely is it that someone with a cancer diagnosis will experience mental health problems as a result?
P
What impact does a Cancer diagnosis have on mental health?
P
On ALL patients need some intervention - what proportion can just get on with life and which cancers?
H
We all have mental health, good or bad, and I would like to know what additional support is given for those with mental health needs, existing pre or post diagnosis, it order that they may manage both their mental health and cancer?
FR
How can I cope with a mental illness e.g. depression after my cancer diagnosis? P
What are the most effective ways of managing anxiety following treatment? H
What is the best way to deal with anxiety and depression following a cancer experience, particularly when the mental effects are felt long after the physical experience? P
How to deal with those dark thoughts in moments when every parent must get and how to copy with those periods leading up to reassessment by the professional staff, whilst positive thinking may help the constant media bombardment about Cancer and its consequences does little to help!!! H
how best to identify and manage symptoms including depression and anxiety H
How many breast cancer survivors who are on hormone treatment such as tamoxifen and zoladex, suffer with anxiety or depression H
ongoing anxiety issues around recurrence for younger patients who have had cancer. concerns about having children, looking after young children and the expenditure. My younger brother has had melanoma, now clear, but it has left him with lots of on-going anxiety and he is seeking counselling 8 months after definitive treatment. H
Where can I find help to assist me with coping with the negative feelings and thoughts of recurrence after finishing treatment? P
What are the most effective psychological interventions for patients with long term fatigue and depression? H
It is difficult to deal with psychologically/ mental penchant of ‘I don’t know’ ( pessimistic rather than optimistic ) when trying to be positive. It wears you down. (?) i have that patient optimism can be kept at a good level and how best can the family of the patient be made aware of the problems likely to be encountered and how at least to deal with this or at least how best not to be overly stressed by not knowing... H
At the end of treatment it becomes increasingly difficult to live with the uncertainty and preoccupation with my diagnosis. i would have liked to have been offered without me having to ask or search for sources of support which are practical P
is post treatment depression common? P
Why the depression never leaves. Why do i no longer feel like a whole woman. P
Why do hundreds abandon you after breast cancer why is your life never the same again. Why am i angry all the time????? P
What does the link between PTSD and cancer diagnosis - and... P
What suggestions do you have for coping with the anxiety after being diagnosed ? P
links to cancer survival and long term depression PRR
I have CML, i would like to understand more about support for mental health, anxiety and depression. Coming to terms with having a chronic condition. Are there plans to provide yoga/meditation/meditation training? I have found these very helpful. P
How can i deal with my mental health as thoughts are consumed with cancer and the what if's? P
Learning how to live with uncertainty. Cancer moved in with us, we didn't move in with cancer. Abandoning time horizons without abandoning hope. Trying not to think too far ahead - particularly during the treatment(s) phase. H
Why is mental health ignored when it is as damaging as cancer? Especially with "non sexy"/not socially acceptable cancers like bowel? If you are already vulnerable in some way and have ongoing post cancer symptoms it can lead to serious depression: P
Would like to see more help given to people with stress and depression after treatment P
Are taking therapies the only way to deal with my unending propensity to cry all the time? Isn't there a pill or injection to balance me? P
How many survivors of cancer go on to develop depression or other mental health conditions? P
I suffer from anxiety and taking antidepressants - will it ever subside? P
10. What are the best ways to support people living with and beyond cancer to make lifestyle changes to improve their health?
Does a health coaching approach to self-management support make a difference to key survivorship outcomes? H
How can we promote self management of cancer after care? H
I have found that by continuing a fitness regime through and after my treatment it is of benefit both physically and mentally,what is the current position on helping cancer patients with this? P
More evidence and practical application of exercise in patients following treatment H
What interventions are effective in encouraging healthy lifestyles for this group? H
What can i do if other health conditions i.e. arthritis stop me from even walking briskly? What other resources are available to help me get more exercise? P
What's the best way to lose weight post treatment factoring in fatigue, changes to body and general lack of confidence in body? P
How important is it to a cancer survivor to have control of what they do after cancer? Do we mean job, activities, lifestyle etc H
How can we facilitate more holistic treatments such as gardening therapy, meditation/meditation, yoga being widely available as part of supported self management and regaining a sense of control to everyone who would find them useful? RH
Why is exercise considered to be a universal cure for cancer-related fatigue when many patients suffer extreme "payback" after all forms of exertion? P
How and when is the best 'teachable moment' to create change behaviours in patients - particularly with respect to increasing exercise H
How can we best achieve weight loss in the obese breast cancer patient post diagnosis? H
What resources and support can we offer to patients to help them recover their fitness after treatment. P
What cancer patients are most likely to respond to self care interventions which can impact and optimize wellbeing? H
What strategies work best to enhance patient activation to undertake self care activities? H
Can intentional weight loss help cancer patients with overweight or obesity? H
How to exercise without causing exhaustion or further damage. P
What is the best exercise prescription for cancer survivors? D
Why is there so little support to improve lifestyle (physical activity and diet) and therefore my chances of living a long and healthy life? H
What is the ‘teachable moment’? How soon or long after ‘end of treatment’ is most effective for patients to attend educational events RH
Should self management programmes be mandatory? H
Why is there no fitness/physio programme to help people recover from cancer? P
How can people best be helped to stop cancer coming back? PRH
What are the most effective methods to teach people what they need to know living beyond their cancer in respect to how to manage their health and wellbeing? What is most effective in terms of emotional well being and physical health. i.e. teaching when to contact different professionals, what happens next, what new normal will look like, what symptoms/ side effects are normal, what should be investigated, what activities to be cautious over or to definitely try, where to access support, financial implications of treatment/ recovery. P
Using behavioral change/health coaching approach, how can we help patients to be more physically active on and after treatment? H
How much support do people living with cancer need to be physically active? Or Do people living with cancer receive the support they need to be physically active? H
Does teaching self management techniques during treatment (such as active lifestyle, fighting fatigue, early advice or anxiety management) have a longer term impact on a person’s physical and psychological wellbeing and quality of life. H
How can we encourage nurses to continue to exercise in the long term to maximise secondary cancer prevention and cardiovascular outcomes? H
How can we encourage all patients to participate in exercise programmes, particularly those who live far from cancer centres and cannot easily participate in supervised exercise trials or programmes? H
Are many people are exercises post cancer treatment? do they find macmillan never more beneficial? do they know about it? U
What behaviour change interventions related to lifestyle factors work for who and when. H
How can we best support those living with and beyond cancer to be physical active. We know there are huge benefits to be gained through regular exercise but we don’t know - 1. when is the best time to discuss ways to become physically active and who should lead these discussions 2. how best to support people to be active through their treatment 3. how best to support people to be active in the months and years following treatment completion H
Should wellbeing support be offered to all people diagnosed with cancer or living beyond cancer if we could get it? R
How can patients who have lost significant muscle and mobility post treatment for cancer be supported to build muscle and mobility? P
Should cancer rehabilitation and support be part of other healthy living and survivorship programmes? RIII
Would a exercise/fitness or physical function assessment as part of the usual treatment ‘work up’ prior to commencing chemotherapy treatment facilitate early positive lifestyle (exercise and/or physical activity) behaviour change in people with cancer? H
Does giving the cancer patient a healthy lifestyle plan e.g. physical activity plan, diet, lifestyle changes make the cancer patient feel empowered and positive about something they can do to beat cancer. RN
How does gender influence access and engagement with supported self-management services and activities for those living with cancer? R
Are Cancer patients able to access leisure activities on ‘prescription’ to enhance their overall wellbeing eg swimming, gym, art class, choir, book groups etc? PRH
Do people living with cancer receive the support they need to be physically active? Or How much support do people living with cancer need to be physically active? H
How can patients who have lost significant muscle and mobility post treatment find help to self manage a recovery package such as advice on exercise, diet and dealing with a fear of recurrence? PR
What factors influence people living with & beyond cancer to make changes in healthy behaviours linked to diet and physical activity H
Do Motivational Interviewing skills in nurses/staff affect/improve outcomes in people attending health & well being events eg readiness for change or actual change. H
Support for people (healthy lifestyle, psycho-social support) for people in full time employment. Not having to take time off work to access this. P
To investigate weight loss techniques in men after treatment for colorectal or prostate cancer H
Try to exercise regularly as per national guidance (over the last 12 months my average is approx. 105 mins per week of vigorous exercise as measured with a chest strap heart rate monitor). However, it never integrates me. Whenever I read about exercise in the media, or see people on TV they always say how they struggled at first but after a couple of weeks they really feel better etc etc. This isn’t how I feel at all if it is how I used to feel though. None, I do it because all the evidence seems to point to it preventing all sorts of things but I just struggle through it. P
How much can a person exercise during and after cancer? H
How can we best support these patients to enable them to more effectively self-manage and get their confidence back?

How much do you value exercise advice from a physiotherapist?

What is the optimum way to deliver health & wellbeing support - timing in pathway, context, e.g. generic versus site specific?

Why are physical activity guidelines becoming more tailored and proactive in identifying potential risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention?

What steps can be taken to improve risk reduction for future health problems (cancer and other conditions) after treatment for cancer? Are there life-style risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention?

How do we best advise patients regarding nutrition?

How can we make patients and their supporters aware of the importance of exercise in managing disease and improving wellbeing? And, also importantly, how can we better facilitate people taking advantage of this knowledge bearing in mind their lack of energy and their possible issues with body image?

What is the benefit of 'exercise prescription' in cancer survivors? i.e. Evidence for Exercise Oncology?

What type of exercise would be beneficial for patients with secondary cancer and how what would encourage more patients to participate?

Who can help me follow a vegan diet while I’m on chemo?

What types of support are most effective - and most cost-effective - in enabling people LWBC to enjoy good mental wellbeing, be physically active eat a healthy diet etc. There are a multitude of apps, and self-help resources...but which really work in enabling effective self-management?

Is the same true of patients who are actively involved in their own healthcare decisions [better outcomes and better overall survival]?

What are the barriers to patients participating in MDT meetings that discuss their care? How can these be overcome?

What is the impact of experiencing a parent with cancer on the child’s life chances?

What is the impact of experiencing a parent with cancer on the child’s life chances?

Is there a long-term change in family dynamics after a cancer diagnosis and cancer treatment?

Include also effects on children, they both worked at weekends and holidays from age 16, affecting their A level results. Our middle feriends paid their children so they could study.

Psychological impact on children of those with parents living with cancer/ repeated cancer

I am a GP. Cancer can have a devastating effect on the mental health of the children of parents with cancer.

The psychological impact on school-age children of having a parent with cancer

What are the key considerations for children of parents diagnosed with cancer?

Impact on children when a parent dies from cancer

I would like to see what the impact of cancer has on children of a parent who has cancer, not just the short term impact but the long term. How do they manage the cancer of a parent? If and when should they be told? How are their emotions met? Do they fully understand? Do they need to fully understand? Should the parent die from cancer, is there a service dedicated to children whose parent has died of cancer, rather than a general bereavement service?

Are there long term psychological effects for children who have had a parent diagnosed with cancer?

How do I best support my children financially and emotionally?

What is the long term emotional impact on children and teenagers when a parent has cancer?

Anxiety in children and their perception about cancer and their own health.

Family impact where cancer causes early death

How can we support children and young adults who have lost a parent to cancer?

How can a parent’s cancer impact emotionally and psychologically on their teenage children?

How can children whose parent has been diagnosed be supported?

What type of support is currently available to dependent children who’s parent have been diagnosed with cancer. What impact does this have on them long term?

Why is there very little done to support teenagers / kids who look after their terminally ill parent. I’ve been talking to young lads who’s mum is near the end of her cancer journey... she screams and says hateful words and although there’s home help twice a day, there’s no one there talking and counselling her. I know she could phone help line but she had no info on this. Why can’t young carers have someone go visit them so they can talk about how they are suffering...

What is the optimal way to deliver health & well-being support - timing in pathway context, e.g. generic versus site specific?

Why are physical activity guidelines becoming more tailored and proactive in identifying potential risk factors (e.g. smoking cessation, dietary improvement, increasing exercise) which could be reduced by post treatment or post diagnosis education or intervention?
16. What is the best form of rehabilitation and other support to help people living with and beyond cancer return to or maintain their usual activities (e.g. work)?

How can we better support patients who are hoping to return to work?

P

Back to work support programmes.

P

How can people be supported to regain confidence and return to normal activities, such as work, once cancer treatment is over?

H

What support should be offered to patients returning to work after/during cancer treatment?

P

A list of men / women do physical work and are unable to return to their previous jobs this comes as a shock to them and affects their whole lifestyle and adds financial burden and stress so need all their options explained

HH

How should the health services monitor and support patients living with long term side effects?

H

The age of retirement is increasing. Cancer is a disease, in the main, of older age. How can people of employment age, a growing group, be best supported to return to work? What kind of rehabilitation programme for return to work would be most cost effective in the short term and long term?

HR

What is the most effective way to help people return to work after cancer treatment, especially those who weren’t working at diagnosis (in education/parenting/unemployed)

H

Impact of non medical habits are on getting people back into the workplace (e reducing numbers claiming benefits etc), or particularly young people back into education and having fulfilled ‘normal’ lives

H

Quite a few of cancer patients have to go back to work full time after treatment and have trouble accessing help with regards to health and wellbeing out of normal working hours, what can be developed to help working cancer patients to gain access to support especially around copmg and dealing with fatigue.

P

What is the best way to support those with cancer to continue working?

FR

Employment support, whether returning to previous job or seeking work after cancer experience

P

What help would be most useful (RETURNING TO WORK)

RH

What do we need to include in a support/rehabilitation program for end of life cancer patients that are no longer classed as end of life?

R

What are the key components of cancer rehabilitation for optimum outcomes?

H

If each cancer MDT had access for its patients to a cancer rehabilitation team (PT, OT, clinical psychologist) would a) clinical outcomes b) patient reported outcomes be improved?

H

Do you feel there would be a place for more support/rehabilitation for patients living with cancer and beyond?

RH

What is the value of early rehabilitation interventions in people who need treatment for musculoskeletal cancer

H

How does OT input facilitate discharge

H

How many OP appointments can be saved by patients attending community cancer rehabilitation?

H

To what extent do people affected by cancer require specialist rehab versus generic rehab services? It would be helpful to know this for key areas such as lymphoedema, pelvic radiation disease, cardiovascular disease, osteoporosis, and sexual dysfunction.

D

Does early rehabilitation help after surgery or should this wait till after radiation therapy?

H

19. What are the best ways to manage the consequences of nerve damage caused by cancer treatments?

Peripheral neuropathy is a major ongoing side effect of some chemotherapy drugs. How can it be avoided?

P

What new drugs can be developed to reduce the pain of those who already have it (peripheral neuropathy), given that steroids often cause more problems than they solve?

P

How do I best manage peripheral neuropathy long term?

H

What can help patients live with peripheral neuropathy?

R

Is research being done into effective pain management of nerve damage resulting from cancer treatment?

R

How do I prevent or manage postural hypotension related to chemotherapy – autonomic neuropathy?

H

Does chemotherapy have any effects on peripheral neuropathy?

P

What can help in the management of peripheral neuropathy which begins to be noticeable 5 plus years after treatment and becomes progressively worse, causing difficulty lifting up feet properly when walking and particularly using fingers for some of the fiddly every day tasks such as tying up buttons, doing up zips and belts, putting on shoes and doing them up, writing, using cutlery, holding food to prepare and to eat, holding handles of cups, washing and drying up, picking up small items, opening cards and so on. This impacts so much on daily living, causing dependency eventually.

R

Would a programme of fine exercises, concentrating on hands and feet, started immediately after treatment, with ongoing encouragement to continue, help patients with peripheral neuropathy?

R

If we know what causes peripheral neuropathy, can adjustments to treatments prevent or lessen it?

R

Late side effects of chemotherapy e.g. late onset peripheral neuropathy

RH
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tbody>
<tr>
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<td>H</td>
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<tr>
<td>How much is sex life disrupted by a cancer diagnosis and treatment?</td>
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<td>What support needs of people with rare and less common cancers differ</td>
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<td>How do the support needs of people with more common cancers, and how</td>
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<td>What can be done to reduce and manage the impact of cancer treatments on</td>
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<td>Are vaginal dilators used during/after radiotherapy for pelvic cancers?</td>
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<td>What Psychosexual support should be provided for patients who experience</td>
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<td>Long term effects on sexual relationships following a cancer diagnosis</td>
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<td>How are treatment supportive interventions advertised (i.e. psychological</td>
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<td>10. What are the best ways to support people living with and beyond cancer who live alone?</td>
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<td><strong>What should the priorities be for patients living with and beyond cancer, particularly those living by themselves, to maximise quality survival?</strong></td>
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<tr>
<td><strong>What is the best way to support older patients who live alone through chemotherapy and recovery?</strong></td>
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</tr>
<tr>
<td><strong>How do we reach those facing cancer alone who find it difficult to access help, and who would benefit from professional support?</strong></td>
<td>H</td>
</tr>
<tr>
<td><strong>There is not enough after care for people who are on their own, this in turn leads to depression &amp; a possibility that the cancer will return, will more care be available to single people?</strong></td>
<td>P</td>
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<tr>
<td><strong>How will I continue to cope with daily living and cancer on my own - I have no family nearby - as the end comes nearer?</strong></td>
<td>P</td>
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<td><strong>How do I know when I am not getting the right help to live with cancer and who would benefit from professional support?</strong></td>
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<tr>
<td><strong>Who do I turn to for help and support if I/e live alone?</strong></td>
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</table>

**Part 2:**

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<th>23. How is cancer perceived across multiple black and minority ethnic groups – what are the similarities and differences?</th>
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**Part 3:**

<table>
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<th>24. Can lymphoedema be prevented? If not, how is it best treated/ managed?</th>
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<tbody>
<tr>
<td><strong>What interventions could be made to help with hypertension caused by untreated lymphoedema and fibrosis?</strong></td>
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<tr>
<td><strong>Are aquatic and/or exercise effective in managing lymphoedema?</strong></td>
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<tr>
<td><strong>Prevention if possible (interventions better now than 10 years ago) on possible development of lymphoedema?</strong></td>
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<tr>
<td><strong>Why has lower limb lymphoedema been ignored? And why are those suffering with this life long legacy from radiotherapy and/or surgery not being referred to musculoskeletal specialists for possible help?</strong></td>
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<tr>
<td><strong>How can I prevent my lymphoedema in both legs from getting worse? And will there ever be a cure for it?</strong></td>
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<tr>
<td><strong>What is the best way to support people to empower and manage themselves living with and beyond cancer, particularly with lymphoma which becoming akin to a long term condition.</strong></td>
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<tr>
<td><strong>What can I do to lessen the risk of lymphoedema?</strong></td>
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<tr>
<td><strong>What information about lymphoedema, reducing its risk and early intervention should be provided for people with gynaecological or male genitourinary cancers?</strong></td>
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<tr>
<td><strong>How can I prevent any delayed side effects of treatment in Lymphoedema?</strong></td>
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<tr>
<td><strong>Has the treatment you received for cancer caused other ongoing medical conditions e.g. Lymphoedema?</strong></td>
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<tr>
<td><strong>Does early physiotherapy help prevent lymphoedema in limbs following surgery and/or radiotherapy? Some patients get very limited access to physiotherapy, is this varying among the country?</strong></td>
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<tr>
<td><strong>Does early referral to a Lymphoedema Clinic make a difference to development of lymphoedema? Especially thinking of leg lymphoedema in sarcoma.</strong></td>
</tr>
<tr>
<td><strong>Why is the subject of lymphoedema not properly covered during and after cancer treatment?</strong></td>
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<tr>
<td><strong>Lymphoedema care?</strong></td>
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<tr>
<td><strong>Preventing lymphoedema following breast cancer surgery - we need a much better evidence base on what would help</strong></td>
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<tr>
<td><strong>Any benefit in offering ‘rare’ self-help solution in basic massage techniques? Specialist help was available in our case but has now been withdrawn.</strong></td>
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<tr>
<td><strong>Lymphoedema issues and treatment and more general knowledge from those who don’t know of the complications for living beyond cancer.</strong></td>
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<tr>
<td><strong>Are patients with potential lymphoedema aware of the early symptoms? What should they do if they become apparent? How to avoid the condition as much as it is feasible?</strong></td>
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<tr>
<td><strong>How can patients with chronic lymphoedema get help, support and training to manage the condition so they can lead a full life socially and professionally?</strong></td>
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<tr>
<td><strong>How can we better help people with cancer-related lymphoedema to successfully self-treat and control their lymphoedema symptoms and live as normal a life as possible, unrestricted by lymphoedema and its treatment.</strong></td>
</tr>
</tbody>
</table>
Despite improvements in cancer treatment which will reduce the incidence of lymphoedema, cancer related lymphoedema clinic caseloads appear unchanged or increased. Treatment is generally focussed on self management, and educating the individual to successfully control and manage their swelling. But is this the most effective use of resources? Is it possible to use therapist-delivered treatments to more effectively reduce the swelling? Symptoms and return the swollen limb to as near normal as possible for the patient to manage long-term? Would this ultimately be more cost effective if, by achieving a smaller and less complex swelling, the ongoing treatment and follow-up costs were reduced/minimised and more patients could successfully be discharged earlier?

Would offering ICG to people post cancer treatment, particularly for breast and gynaecological cancers, prove effective in identifying those who have or will go on to have lymphoedema so that early management strategies can be implemented sooner to prevent or slow down the progression of the disease?

Would offering IVA microsurgery and lymph node transfer on the NHS to suitable candidates who go on to develop lymphoedema post cancer treatment prove cost effective by reducing the cost of future hospital stays and antibiotic use for cellulitis?

Could offering ICG scans to lymphoedema patients post cancer treatment with personalised self management techniques taught specific to the outcome of the scan reduce the incidence of complications?

I want to understand more about lymphoedema care. This information is available but is it understood by the medical profession?

Treatment and management of lymphoedema secondary to cancer and cancer treatments. As there is only little research in regards to Mansell Lymphatic Drainage therapy, it would be very helpful to have more research in this area. There are clear, visible and measurable outcomes but as there is not enough research to show the effectiveness of this treatment it is difficult to obtain on the Nhs.

Management of chronic lymphoedema

will my body become immune to prophylactic antibiotics for repeated cellulitis attacks?

The psychological aspect of living with lymphoedema as a consequence of cancer treatment needs further research. Some of my patients tell me it is worse than the diagnosis of cancer itself.

How can lymphoedema be prevented?

Is it necessary to take out lymph nodes if sentinel node biopsy shows cancer, especially as chance of getting lymphoedema in arm afterwards

How can we prevent lymphoedema and/or shoulder/arm pain caused by lymph node dissection and sentinel node biopsy? Self help works, so why are breast cancer patients not told about it before the arm starts to swell? Pain killers are not the answer. We need to start prevention immediately the wound from surgery is healed.

Why is there no organised specialised treatment for Head and Neck lymphoedema post radiotherapy?

How can I help myself avoid lymphoedema after surgery without taking up NHS resources.

Why is cording reoccurring despite compression sleeve and massage? Why isn't it resolved/minimised and more patients could successfully be discharged earlier?

Is it necessary to take out lymph nodes if sentinel node biopsy shows cancer, especially as chance of getting lymphoedema in arm afterwards?

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Drainage therapy, it would be very helpful to have more research in this area. There are clear, visible and measurable outcomes but as there is not enough research to show the effectiveness of this treatment it is difficult to obtain on the Nhs.

Manual Lymphatic drainage therapy, it would be very helpful to have more research in this area. There are clear, visible and measurable outcomes but as there is not enough research to show the effectiveness of this treatment it is difficult to obtain on the Nhs.

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Is it necessary to take out lymph nodes if sentinel node biopsy shows cancer, especially as chance of getting lymphoedema in arm afterwards?
What levels of medication and follow-up is necessary.

Having had cancer, I would like to be regularly monitored for reassurance.

Should we be monitored beyond 5 years (maybe at 2-yearly intervals)?

Is the current follow-up schedule for melanoma patients effective in identifying recurrence and new lesions or would a more risk-stratified, individualised approach be better?

How often should I be monitored for recurrence/secondaries after a Whipples procedure?

Should PET scans be available every 5 years for life for cancer survivors?

Should treatment ever stop? For peace of mind should checkups be available for life for cancer survivors?

How do we stratify patients for psychosocial factors - rather than genetics

What is the current follow-up schedule for melanoma patients effective in identifying recurrence and new lesions or would a more risk-stratified, individualised approach be better?

Is there any benefit to making the surveillance more uniform?

Should I have repeat CT scans and is benefit outweighed by risks?

Are there any standards applied for considering a person for imaging for mole checks post melanoma?

Are the follow up processes adequate and sufficiently quick once a person has been discharged following the initial cancer?

How often should I be monitored or seek check up advise.

Benefits or not of remaining in long term follow-up

Benefits of regular screening ie ct scans which may pick up secondaries early, as opposed to waiting until symptoms are apparent by which time treatment may be too late or more costly or invasive. If regular mammograms are recommended why not regular ct scans?

Does stratified risk at discharge increase or decrease anxiety for patients (e.g. clinic vs discharge or shared care)

Benefits of not of remaining in long term follow-up

When and how often blood tests should be made , to assure people that things are going well.

Would patients and their families like active follow up or just to be given information of who and where to go to get support once they complete treatment.

I would like to be able to know if the GLL is no longer in my lymph without 4 monthly CT scans and the risk that entails

Why patients how to attend follow-up at hospitals

How do we stratify patients for psychosocial factors - rather than genetics

What type of follow-up/aftercare do people want following completion of therapy?

Is a new follow up protocol needed for survivors of PNETs who have undergone a Whipples procedure?

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Benefits or not of remaining in long term follow-up

Benefits of regular screening ie ct scans which may pick up secondaries early, as opposed to waiting until symptoms are apparent by which time treatment may be too late or more costly or invasive. If regular mammograms are recommended why not regular ct scans?

Does stratified risk at discharge increase or decrease anxiety for patients (e.g. clinic vs discharge or shared care)

Benefits of not of remaining in long term follow-up

When and how often blood tests should be made , to assure people that things are going well.

Would patients and their families like active follow up or just to be given information of who and where to go to get support once they complete treatment.

I would like to be able to know if the GLL is no longer in my lymph without 4 monthly CT scans and the risk that entails

Why patients how to attend follow-up at hospitals

How do we stratify patients for psychosocial factors - rather than genetics

What type of follow-up/aftercare do people want following completion of therapy?

Is a new follow up protocol needed for survivors of PNETs who have undergone a Whipples procedure?

Should PET scans be available every 5 years for life for cancer survivors?

Should treatment ever stop? For peace of mind should checkups be available for life for cancer survivors?
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>Is there a way to support patients that are %s&amp; as they don’t feel alone? Is it isn’t always necessary to see a physician in clinic and yearly appointments can be done via a phone call?</td>
<td>H</td>
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<tr>
<td>For endometrial Cancer, following my CT scan at 1 year 4 months post hysterectomy, why am I not being given a routine annual CT or MRI? I know that breast cancer patients get annual mammograms for 5 years post treatment; instead I am only to be investigated if I report further symptoms. Surely by the time I notice symptoms the new cancer will have spread already?</td>
<td>P</td>
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<tr>
<td>How will I be monitored after treatment?</td>
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<tr>
<td>How do patients feel about risk stratified follow up, do they feel supported or isolated?</td>
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<tr>
<td>People are surviving longer after initial diagnosis of breast cancer, but just because they are surviving doesn’t mean they always feel well; many will have recurrent, numerous treatments over several years. What can be done to make these people feel less isolated and more “actively monitored” during lengthy periods of disconnection from the healthcare system.</td>
<td>R</td>
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<tr>
<td>Protocols around scanning and monitoring and describing the situation to patients: why do different trusts follow up differently, why does grade of cancer not influence screening regimes, why is the mix up of language around remission/NED cancer free survival etc - Grade 4 (terminal) progression.</td>
<td>R</td>
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<tr>
<td>Why isn’t routine follow up with CT scans done across the whole body instead of just certain areas, is money better spent on prevention rather than treating patients to prevent a premature death?</td>
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<tr>
<td>What methods of follow up can be effective but least intrusive into everyday life?</td>
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<tr>
<td>Why are patients with breast cancer not routinely screened via CT scan etc following completion of treatment? Surely better checks post treatment will allow metastatic disease to be identified sooner and in turn prolong life &amp; be more cost effective?</td>
<td>P</td>
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<tr>
<td>I find living beyond cancer scary at times. &amp; Think a yearly scan for at least the first 5 to 10 years should be available to everyone living beyond cancer but it seems to depend on each individual consultant or nhs area can there be some set guidelines on this to give us all the same chance of peace of mind and/or catching a secondary cancer quicker?</td>
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<td>How do patients feel about risk stratified FU?</td>
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<tr>
<td>Quality of life impact on patients and carers of shorter v. longer monitoring - e.g. CT, MRI, intervals.</td>
<td>R</td>
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<tr>
<td>Evidence to support remote surveillance following curative intent intervention for cancer, rather than clinics hospital based follow-up.</td>
<td>H</td>
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<tr>
<td>Why do we get regular scans?</td>
<td>P</td>
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<tr>
<td>Do Health and Well being events provide cost effective support to patients? Do patients/what proportion of patients diagnosed with cancer find these events helpful? What are patients perceptions of Health and Well being events and has attending these events changed patients ability to live with their cancer diagnosis, perception of their illness, treatment and or prognosis?</td>
<td>H</td>
</tr>
<tr>
<td>How do patients feel about risk stratified follow up, do they feel supported or isolated?</td>
<td>H</td>
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<tr>
<td>Spiritual care comes up frequently as a need in cancer, including survivorship. Every patient has questions, some well articulated others less so. The very few research papers in the area of care have been dominated by Church of England clergy, yet over 50% of the population does not admit to any religious belief let alone Anglicanism. Studies which set out to consider the needs of the “no religious” patients would encompass those with a religion. The research need is not “what” or “why” but “how” and “who” and should start from a rational base rather than a belief base.</td>
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<tr>
<td>What is the evidence that each of the individual components of the Recovery Package makes a significant improvement to a) clinical outcomes and b) PROMs?</td>
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<tr>
<td>What differences in spiritual support needs during active treatment, compared with when active treatment has stopped?</td>
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<tr>
<td>How do different faiths or being an atheist assist or undermine living with cancers?</td>
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<td>Do Health and Well being events provide cost effective support to patients? Do patients/what proportion of patients diagnosed with cancer find these events helpful? What are patients perceptions of Health and Well being events and has attending these events changed patients ability to live with their cancer diagnosis, perception of their illness, treatment and or prognosis?</td>
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<tr>
<td>Does the recovery package really make a difference to patients?</td>
<td>H</td>
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<tr>
<td>The impact of different aspects of the Recovery Package</td>
<td>H</td>
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<tr>
<td>do Health and Well being events help patients and carer’s adjust to life after a cancer diagnosis? What is the optimum time for these to take place.</td>
<td>H</td>
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<tr>
<td>does a health and well being clinic produce long lasting benefits in terms of knowledge, activity, engagement with services, reduced cancer anxiety?</td>
<td>H</td>
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<tr>
<td>What are all the elements that need to be lined up for people to tap into in order to live their lives beyond cancer (e.g. physical, emotional/ psychosocial, social, spiritual)</td>
<td>O CHARTY</td>
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<tr>
<td>Have your holistic approaches to cancer treatments been supported by doctors?</td>
<td>R</td>
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<tr>
<td>Health and Well Being Events are intended to provide patients with the information and confidence to live their lives well following their cancer diagnosis, but what should be included and at what point in the patients pathway (e.g. Is it on discharge from acute care too late? , a missed opportunity in terms of introducing patients to beneficial self management techniques)?</td>
<td>H</td>
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</tbody>
</table>
What is the long term impact of attending a Health and Wellbeing Event? Does it improve the quality of survival in terms of physical and psychological health?

Are Health Needs Assessments accurate in addressing patients concerns?

How does the recovery package work in does it help people to self manage and identify resources/services that will help them to do this?

What proportion of patients completing treatment engage in health and wellbeing activities and what factors influence this?

How effective are holistic needs assessment and support planning on outcomes for people with cancer?

How does Health & Wellbeing Events reduce unnecessary clinical appointments?

What is the evidence that the recovery package is being delivered and that it makes a difference to people’s recovery from cancer?

Health Service treatments, while excellent in their medical input, sometimes miss the ‘whole human’ input, what some might call emotional and spiritual needs of patients. How can busy professionals encompass these aspects of care in their practices?

The impact of holistic needs assessment and support planning on outcomes for people with cancer.

Do health and wellbeing events reduce unnecessary clinical appointments?

What proportion of patients completing treatment engage in health and wellbeing activities and what factors influence this?

The value of Holistic Therapies Holistic therapies are of proven value but it’s definitely not a one size fits all scenario and some in my opinion can actually be detrimental to recovery. I know most of the assessment is done by the CNS’s and I’m not sure how much training they receive.

In a caring for patients UHNS - what do patients want to see in their treatment summaries as a professional we are not getting to summaries - we are do not know what to look for - when should a patient come back etc. fundamental to this if the communication of HNA and Tx summaries - how can we use research platform to explore with patients - how they want to be communicated to on these 2 things - do they want hand held records - can patients become more integral to these documents so they are useful and can also be a group advocating these docs being sent to GP/between professionals

We have noticed that there is quite a high rate of patient DNA’s to attend health & wellbeing clinics despite being told it is part of their pathway. How can this be addressed, improved, what information do we need to be getting across to patients to help their understanding of importance of these events?

How do we evaluate the effectiveness of HNA and health & wellbeing events and other types of self-management support?

How useful are holistic needs assessments in managing patient need?

How can we utilise the patient data collected as part of the electronic holistic needs assessment tool which enables the delivery of care to better understand patients’ needs, outcomes of interventions and to improve services in a way that makes this simply, routine and emotional embedded into clinical practice and service development?

We need to understand from patients and staff how we can ensure the offer of an holistic assessment (HNA) can be viewed as having the potential to enhance the care and support provided to patients. As one of our challenges in implementing the electronic version of the HNA remains understanding why patients may not undertake the offer of undertaking the assessment

Understanding the value of providing health and wellbeing events for patients and how to offer this to ensure patients will take up the offer to attend. For example we need to understand what information patients and carers need and how they want to receive it i.e format, venues, topics etc. As currently locally and nationally we are seeing only small numbers of patients attending events. We would like to understand how we can make them more accessible to the wider cancer patient population and their carers.

Screening for holistic needs and specialist care - what are the best ways of screening for patients’ and carers’ holistic needs at all stages after diagnosis and the start of anti-cancer or palliative treatments, up till the point when patients enter the end of life stage?

What is the long term impact of a one off health and wellbeing event in changing patient health behaviours?

What is the value of an eHNA?

What does emotional support mean in cancer services - are we applying it correctly? - Used HNAs but means different things to different people - Sometimes it turns people off
How can we measure the impact of attending a Health and Wellbeing event?

How could palliative care service/hospice play a greater role in caring for people living with and beyond cancer?

Why are patients with incurable cancer not referred sooner to specialist palliative care services when the research suggests this would be to their benefit?

How can palliative care be offered as a therapeutic option for treatment for some people?

Would patients who are not ultimately going to be cured benefit from earlier referral to hospice?

Would services be more efficient working more closely, i.e., hospice and cancer services? To dispel the myth of patients “just being referred to hospice to die” and to allow greater access to specialist symptom management.

What are the best service models for providing both general and specialist palliative care to people living with cancer?

Who do they feel should be supporting patients with a non-curable illness even when the prognosis may be many months or years. Does the Hospice have a role at this time?

How do people who have embraced survivorship notions transition into Palliative Care services without feeling like they have failed?

How can we facilitate earlier referral to specialist palliative care as this seems to contribute to better survival in incurable cancer?

Do clinicians feel confident in delivering palliative care?

How can quality of life be measured in a way that is relevant to people living with and beyond cancer?

What is the cost to the NHS, society and patients of not optimally managing the long term consequences of treatment, such as bowel & bladder incontinence/urgency/bleeding, lymphoedema, pain, fatigue, swallowing/speech difficulties, etc.

What are the costs/benefits to the NHS of better managing the long-term and late effects of cancer treatments?

How have long term consequences of cancer treatment affected your quality of life?

Do people with a learning disability report a poorer quality of life after cancer that is less systems based. more truly person-centred care.

Do palliative care services only get involved at the very last minute (literally)?

Misconceptions about the hospice.

We know that supportive and palliative care given early to cancer patients (not just at end of life) improves symptom control, leads to better quality of life and can even prolong life - how can we better integrate earlier supportive and palliative care into routine patient care [I mean the whole package of physical, spiritual etc. not just pain relief]

What is the impact on quality of life of long term cancer treatment. We currently have the cancer treatment affected the patients quality of life?

How can we measure the impact of attending a Health and Wellbeing event?

How can quality of life be measured in a way that is relevant to people living with and beyond cancer?

Do people from the BME community report a poorer quality of life after cancer than the whole population?

Do people with a learning disability report a poorer quality of life after cancer than the whole population?

How does poverty effect quality of life after cancer? I e. if I come from a poorer background am I more likely to report a poorer quality of life than if I come from a richer background?

Impact of cancer on patients Global QOL and long term changes in this.

How can we balance chronic toxicity of targeted agents against response when evaluating quality of life?

Is there one quality of life methodology which can be used in Survivorship to provide a single tool capable of delivering results which patients can understand, can use to draw comparisons, and which help inform choices between different therapies?

Has the cancer treatment affected the patients quality of life?

Impact of treatment side effects on quality of life.

What are the most important issues affecting people living with and beyond cancer from the affected peoples perspective?

What is the impact on quality of life of long term cancer treatment. We currently treat aggressively putting up with side effects but long term life with cancer can be ruined by the chronic impact of intermittent steroids for example.

The changes in quality of life experiences.

and how the treatment affects life afterwards?

Quality of life assessed by patient and relative(s), rather than just Overall survival/PFS, particularly in the setting of onerous/toxic treatments, eg HSCT

Do blood transfusions for anaemia improve quality of life?

How have long term consequences of cancer treatment affected your quality of life?
<table>
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<th>Question</th>
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<td>Where is the gap between the quality of life of those living with and beyond cancer compared to similar individuals who do not have/have never had cancer?</td>
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<tr>
<td>What are the quality of life implications after radical chemotherapy/radiotherapy for squamous cell cancer of the oesophagus?</td>
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<td>What are the quality of life issues for men after treatment for testicular cancer</td>
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<td>How will quality of life be affected following cancer treatment and thereafter?</td>
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<tr>
<td>Quality of life of cancer survivors?</td>
<td>RH</td>
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<td>What are the mid and long term effects of chemotherapy and how does this affect the quality of life for the patient and their loved ones, friends and family etc?</td>
<td>PR</td>
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<tr>
<td>What are the quality of life issues for women after treatment for breast cancer?</td>
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<tr>
<td>How to quantify outcomes for improvement projects/interventions/new services</td>
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<tr>
<td>Does living with and beyond cancer affect a person’s quality of life?</td>
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<tr>
<td>What are the best measures/standards to assess quality of life for people living with and beyond cancer? (Most tend to focus on symptom reduction or mood/anxiety changes rather than measures of quality of life).</td>
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<tr>
<td>What is the quality of life of people living with advanced and recurrent bowel cancer? And, how can we improve it?</td>
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<tr>
<td>Quality of life questionnaires need to be holistic but ensure cancer components covered? It may be QOL questionnaires and cancer survivors - how can patients contribute/mould/how can these be “tested” etc</td>
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<tr>
<td>What makes the biggest difference to quality of life in the recovery phase 2-5 years after treatment?</td>
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<td>How can we measure/quantify/qualify participant psychological improvements in health and well-being programmes?</td>
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<tr>
<td>How much does the effective management of side effects and long term consequences of treatment improve quality of life and survival? (In both those who are NED and those who have relapsed but are not curable)</td>
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<tr>
<td>What is the quality of life and the worth living with and beyond cancer? quality of life and side effects of treatment</td>
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<tr>
<td>When measuring QoL, how can we properly measure and account for the emotional, financial and practical impact on family life (children, partners, parents, siblings etc) when a person is diagnosed with metastatic disease.</td>
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<td>What are the safest and most effective ways of managing early menopause caused by cancer treatments?</td>
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<tr>
<td>How can younger women with BRCA1 and BRCA2 patients who have undergone risk-reducing oophorectomy have their menopausal symptoms best treated and managed?</td>
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<tr>
<td>What is the best form of oestrogen replacement for young women: HRT or OCP? looking at effects on bone density, fertility is preparing the endometrium, symptoms, sexual function. And side effects/safety of secondary breast cancer, thrombotic epidodes, lipid/CVs events.</td>
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<tr>
<td>How can I control menopausal symptoms without hrt?</td>
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<tr>
<td>What is the optimal HRT in young patients following premature ovarian failure secondary to cancer therapy? (mainly transdermal or oral vs OCP) Considering fertility issues, uterine size, cardiovasculare/termesascular risk</td>
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<tr>
<td>Treatment of menopausal symptoms on Tamsulosin.</td>
<td>RH</td>
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<tr>
<td>What are the physiological and psychological short and long term effects of not having any oestrogen and not having hormone replacement therapy?</td>
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<tr>
<td>What are the long term side effects of being put in an early, chemical induced menopause?</td>
<td>P</td>
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<tr>
<td>How many breast cancer survivors who are on hormone treatment such as tamoxifen and zoladex, suffer with anxiety or depression. Compared with those not on those hormone therapies?</td>
<td>P</td>
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<tr>
<td>Following Distant cancer diagnosis and a complete hysterectomy I had to live with early menopasue. I would have like support about supplements that are safe to assist with menopausal symptoms and longer term effects of this. I would have liked the support to be aimed at younger women.</td>
<td>P</td>
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<tr>
<td>What are the alternatives to tamoxifen for premenopausal women with hormonal breast cancer, and how effective are these alternatives in terms of disease free survival compared to tamoxifen?</td>
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<tr>
<td>If men get menopausal symptoms would there be more drugs available to counteract the side effects of tamoxifen</td>
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<td>What are the real consequences of starting HRT in your 25’s due to cervical cancer treatment? How long is too long to be on HRT? Will we even see a shift away from tablet form to something similar to contraceptive implants?</td>
<td>P</td>
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<tr>
<td>Hormone replacement after gyna cancers (premenopausal women)</td>
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<tr>
<td>Do complementary therapies benefit people living with and beyond cancer (e.g. improving treatment outcomes and quality of life post- treatment)? What role do complementary therapies have for patients living with and beyond cancer?</td>
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<tr>
<td>Can massage affect negatively cancer patients? I’m talking about deep tissue, aromatherapy, therapeutic massage the kind one can get at a spa.</td>
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<tr>
<td>Patients often attribute survival to a complementary therapy they take without reference to their clinician(s) and reluctance to tell them. How can we gather that information and use it to help determine research questions which look into such therapies?</td>
<td>P</td>
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<tr>
<td>Benefit of complementary therapy for positive outcomes</td>
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<tr>
<td>What are the most effective complementary therapies, adequate for cancer patients? We need more research on these.</td>
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</tbody>
</table>
How useful are holistic treatments in complementing medical treatments?
P
Benefits of various forms of alternative/complementary therapy
P
Can alternative therapies such as high dose vitamin C help alongside traditional treatments such as chemotherapy?
R
Is it safe to use of treatments such as reflexology and massage when being treated for cancer?
R
Does acupuncture help in recovery from breast cancer?
P
How important are self care therapies in living with and beyond cancer? (things such as yoga, massage, reflexology, acupuncture)
P
Does taking using complementary therapies or treatments improve survival?
P
What impact can alternative therapies have on my wellbeing during cancer treatment?
H
Which alternative or complementary therapies improve/extend quality of life post cancer treatment?
FR
Can complementary therapies speed my recovery? Are they beneficial in more ways than providing relaxation and in palliative care?
H
How can yoga and mindfulness support people with and beyond cancer?
P
Apart from conventional medicine what help is available to patients to access complementary therapies in the UK? (Aromatherapy, Acupuncture, Mindfulness/Meditation) and is there research which can demonstrate if there are any measurable benefits.
H
I would like to know about the effects of complementary and alternative therapies on being with cancer - homeopathy, reflexology, osteopathy, acupuncture, amrit etc.
P
How effective is holistic and complementary cancer care such as reflexology or mindfulness?
FR
Research on massage and bodywork therapies for people living with cancer and their carers.
D
Which complementary or alternative treatments really help cancer patients and side effects of treatment.
P
What are the benefits of complementary therapies to people affected by cancer in the UK?
H

What are the best ways to maintain healthy bones and teeth during and post-cancer treatment?
Bone health in young adult cancer survivors, mode of treatment, bone density, fracture rate, if hypogonadism, use of high dose steroids.
H
dental issues after chemotherapy: more support needed from dentist - and an awareness of dental issues which continue 20+ years after chemo
FR
Bone health - what can be done to provide more targeted & effective treatment to maintain bone health while reducing side effects (particularly thinking of post menopause ER+ breast cancer)
P
Can assessment of risk and optimisation of bone health prior to/during cancer treatment/pelvic radiotherapy prevent vertebral fractures and insufficiency fractures?
H
There is a big question around consideration of optimal bone health in patients LWBC. I saw a number of young patients cured from their cancer who are totally debilitated by vertebral fractures induced by high dose steroids/underlying condition and this becomes their major problem. We do not currently have any evidence for optimal management of these young/premenopausal patients in terms of risk stratification/calciu/vit D status and use of bisphosphonate/anti-resorptive therapy
H
The other major bone issue is pelvic insufficiency fractures post pelvic radiotherapy. This is common and a significant cause of morbidity in these patients. There are a number of descriptive studies but none that actually allow us to understand pathology, consider bone density/risk factors and no evidence for any intervention that works (and theoretical concern that bisphosphonates, which are reflexly used may actually worsen healing). It might be that early bisphosphonates (ie at start of radiotherapy in certain at risk subgroups might be of benefit)
P
If, at some point, bisphosphonates become a prescription drug funded by the NHS (or indeed, if women are given the option to pay for their own), would these be available to, and benefit people living beyond cancer?
P
Are these people who suffer from damage to pelvic bone damage and accompanying pain offered any form of support package?
P
BONE PROBLEMS
Can I eat anything or take supplements to help with the loss of bone density after chemotherapy?
P
Is there any research into osteoradionecrosis
P
Can you do anything to improve/slow down bone density damage from pelvic radiation given to someone in their 20’s?
P
What effect does Chemotherapy have? I had bowel cancer and 30 weeks Chemotherapy. I was diagnosed with Chronic Lymphocytic Leukaemia and this year alone I have had 16 dental appointments, 2 abcesses under teeth 2 root canal fillings I tooth re-crowned and numerous fillings, I have facial pain and may have Sjogrens Disease are these things related?
P
Radiation damage to bones ( following pelvic radiotherapy/brachytherapy/surgery)
P
How does radiotherapy affect strength of bones in weight bearing bones?
P
Why are there no National Patient Leaflets about the benefits of Bisphosphonates eg Zoledronic acid infusion in prevention of bone metastases in relation to breast cancer in particular but maybe relevant for other disciplines also? The only leaflet available talk about metastatic disease treatment rather than prevention. They also don’t mention that some of the younger ladies have horrific side effects with lasting bone pain and fatigue. Observationally it is the older ladies who take this that have less side effects.
RH
After having osteoradionecrosis on my left jaw, what are chances of getting it at a later date on my right jaw? Is there anything I can do to prevent recurrence?
P
Does having a positive attitude influence the outcome of cancer and improve quality of life?
H
How much does a positive attitude - to both the cancer and its treatment - aid recovery after chemo therapy and/or radiotherapy?
P
How well do we apply known research on bone health in prostate cancer across the UK?
H
Does having a positive attitude influence the outcomes of cancer and improve quality of life?
How does mental health impact on physical health e.g. Does anxiety lead to more experience of symptoms?

How can be supported through identifying positive outcomes improve psychological wellbeing?

How much does a positive outlook/positive mindset affect outcomes for cancer?

What effect does positive attitude have on avoiding recurrence of the cancer?

Does monetary and mental wellbeing improve the patient’s outcome?

What role does expectation have in someone’s experience of chemotherapy/surgery - does the expectation that the treatment will work make any difference, or is it more about positive mindset leading to positive behaviours after treatment?

Understanding the impact of the things I can control as a patient: Can your mental attitude really impact your survival / quality of life with metastatic cancer? (i.e. does having a positive attitude make any difference?)

What are the best ways to deliver chemotherapy in the short and long-term, and/

How can bowel obstructions be prevented in people surviving bowel cancer?


What is the effect of media campaigns or the portrayal of cancer in TV drama/soaps on individuals living with cancer and their families?

What is the true incidence of symptoms after various difference cancer treatments at different timepoints?

What role does the return to a workplace environment play in psychological wellbeing following cancer treatment?

What are the best ways to support people living with and beyond cancer and their families if they experience prolonged insomnia?

How long does the chemo stay in your system and are the side effects permanent?

How much fibre should be included in the diet when a person has a blocked bowel as a result of cancer?

How long does the chemo brain last after treatment?

What is the best way to deliver chemotherapy in the short and long-term, and/or when there are problems delivering it via an arm?

What effect does positive attitude have on avoiding recurrence of the cancer?

How common is (permanent) chronic fatigue following treatment for Ewing’s sarcoma?

How long does the chronic fatigue last after radiation?

How much does it take for recovery to the best achievable level?

Is chemo brain long lasting after Treatment finishes?

Is tinnitus permanent for head and neck radiation patients?

How long does it take for recovery to the best achievable level?

Does monetary and mental wellbeing improve the patient’s outcome?

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How long does the chemo brain last after treatment?

Will any damage caused by radiotherapy slowly get better Or do we have to live with the pain the damage has caused.

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How is radiation/chemotherapy treatment like R-CVP or R-CHOP and what type of timescales are involved?

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How common is (permanent) chronic fatigue following treatment for Ewing’s sarcoma?

How long does the chemo brain last after treatment?

Will any damage caused by radiotherapy slowly get better Or do we have to live with the pain the damage has caused.

How common is (permanent) chronic fatigue following treatment for Ewing’s sarcoma?

How much does it take for recovery to the best achievable level?
Risk of recurrence for each cancer is known through certain that their cancer will not return? How can diagnosis of the likelihood of a cancer returning be improved? What are the chances of my cancer coming back? When will it come back? When will I be cured? Mine did! What is the true likelihood of my cancer returning after being given the all-clear? When after time period can one feel confident that cancer is unlikely to return due to initial diagnosis - either Breast Cancer or Bowel Cancer as they seem to be referred to differently ie Breast as 'in remission' and Bowel as 'cured'....how can we be clear what these terms mean to individuals to enable them to lead fuller lives after a cancer diagnosis. Research element would be to utilise up to date data to underpin policies to restrict practice that takes advantage of the disadvantaged. Do we have this data? How can we reassure insurance companies that living with cancer is not necessarily and life sentence as in wanting to travel and take short term risks in the future? For those who don’t have a stoma bag, do changes that occur to your normal bowel functions due to surgery, ever improve, or do you have to accept that your body is different forever? Has the chemo permanently damaged my body? Are there long term affects from Radiotherapy that will continue to affect me for the rest of my life? How long do aftereffects of chemo usually last? Where can I find prognosis rates beyond 5 year survival? Does terminal cancer even though she has been discharged and has had a number of operations to remove Breast Cancer my mind took a while sort itself out. I didn't have Chemo. Minor forgetfulness. Occasional wrong words. Slight slowing down in responses. Ability to focus on more than one thing at a time. After ten years either I'm getting used to myself or thing are starting to get better.

Where can I find prognosis rates beyond 5 year survival?

I would like more in depth understanding of the long term side effects of cancer treatment and how it affects people, not just in the immediate phase, but in 5, 10, 15 years etc. There needs to be evidence that employers can use to gain a more objective understanding of the needs and adjustments needed for people going back to work post cancer. For example, my OH doctor quoted MacMillan research that says 75% of people take 6 months or more to go back to full time working. However, that isn’t enough to quantify an early retirement and so the individual is faced with making many changes to their life in order to work less hours if at all and even move home or become homeless as a result of that. Does terminal cancer even though she has been discharged and has had a number of operations to remove Breast Cancer my mind took a while sort itself out. I didn't have Chemo. Minor forgetfulness. Occasional wrong words. Slight slowing down in responses. Ability to focus on more than one thing at a time. After ten years either I'm getting used to myself or thing are starting to get better.

Has the chemo permanently damaged my body?

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How can we reassure insurance companies that living with cancer is not necessarily and life sentence as in wanting to travel and take short term risks in the future?

Can you ever fully recover from all the treatment? That isn’t enough to quantify an early retirement and so the individual is faced with making many changes to their life in order to work less hours if at all and even move home or become homeless as a result of that.

Has the chemo permanently damaged my body?

For those who don’t have a stoma bag, do changes that occur to your normal bowel functions due to surgery, ever improve, or do you have to accept that your body is different forever?

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What is the true likelihood of my cancer returning after being given the all-clear?
<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>How great are the chances of cancer coming back in any form when you have had it once?</td>
<td>R</td>
</tr>
<tr>
<td>How likely is my cancer to return after my treatment is complete?</td>
<td>P</td>
</tr>
<tr>
<td>Time before we know for sure about expectancy for the future</td>
<td></td>
</tr>
<tr>
<td>Why is the length remission such an unknown factor is it the lack of empirical data for treatments such as FCR?  It was put to me I could have up to 7 years before relapse, is what I was told</td>
<td>P</td>
</tr>
<tr>
<td>Remission length for various treatments for ClL, this can assist in planning likewise.</td>
<td>PR</td>
</tr>
<tr>
<td>My daughter was diagnosed with stage 3 cervical cancer 6 years ago. So got the all clear in January of this year. How likely is it that the cancer will return?</td>
<td>R</td>
</tr>
<tr>
<td>How likely are cancer cells to break away and appear many years later in other parts of the body?</td>
<td>P</td>
</tr>
<tr>
<td>What is the risk of my cancer coming back, or me getting a different cancer?</td>
<td>P</td>
</tr>
<tr>
<td>The chance of recurrence depending on the type/tissue of breast cancer.</td>
<td>P</td>
</tr>
<tr>
<td>Will it come back?</td>
<td>PR</td>
</tr>
<tr>
<td>How accurate a prognosis can I get?</td>
<td>P</td>
</tr>
<tr>
<td>How often does a good result in cancer metastatic cancer?</td>
<td>PR</td>
</tr>
<tr>
<td>How long the treatment keeps cancer at bay</td>
<td>P</td>
</tr>
<tr>
<td>Progression rate and life expectancy</td>
<td>P</td>
</tr>
<tr>
<td>After 5 years, are we clear?</td>
<td>P</td>
</tr>
<tr>
<td>If you have underlying autoimmune conditions too what is the chance of it coming back?</td>
<td>P</td>
</tr>
<tr>
<td>Does cancer ever truly go away if you had it once?</td>
<td>P</td>
</tr>
<tr>
<td>Stage 3 breast cancer after five years are you then all clear?</td>
<td>P</td>
</tr>
<tr>
<td>What are the chances of cancer coming back?</td>
<td>H</td>
</tr>
<tr>
<td>I’d like to know recurrence rates for my cancer. I can find survival rates and the fact that 75% of recurrences happen within three years but not the actual rate of recurrence.</td>
<td>P</td>
</tr>
<tr>
<td>What chance have I got in suffering a secondary cancer episode?</td>
<td>P</td>
</tr>
<tr>
<td>How likely is a recurrence once you had cancer</td>
<td>P</td>
</tr>
<tr>
<td>Is it not the longer in remission the likelihood of it remaining so</td>
<td>P</td>
</tr>
<tr>
<td>How soon can you have a recurrence after cancer?</td>
<td>P</td>
</tr>
<tr>
<td>What is the percentage of cancer recurring after a colectomy at 21/2 years ago?</td>
<td>P</td>
</tr>
<tr>
<td>Will it return?</td>
<td>P</td>
</tr>
<tr>
<td>What are my chances getting cancer again?</td>
<td>P</td>
</tr>
<tr>
<td>What is the likelihood of my cancer returning?</td>
<td>P</td>
</tr>
<tr>
<td>What are the chances of developing metastatic breast cancer?</td>
<td>P</td>
</tr>
<tr>
<td>What is the incidence of second primary cancers after treatment for a first primary cancer?</td>
<td>H</td>
</tr>
<tr>
<td>When you are in remission does this mean that you are cured or is this just a period of uncertainty until you are given the “all clear”?</td>
<td>P</td>
</tr>
<tr>
<td>In which way we can say that cancer are cured to who living with cancer?</td>
<td>U</td>
</tr>
<tr>
<td>Why is an all clear given after 5 yrs when we know there never really is an all clear?</td>
<td>P</td>
</tr>
<tr>
<td>Uptake of the likelihood of my breast cancer returning</td>
<td>P</td>
</tr>
<tr>
<td>I’d like more data collection into what happens with people following treatment, eg longer and late side effects, incidence of secondaries, etc as it is only then these issues can be addressed.</td>
<td>PH</td>
</tr>
<tr>
<td>I’d like you to be able to tell me that the cancer has gone, not likely to have gone. I want to be no risk, not low risk. (Maybe this would stop me crying)</td>
<td>P</td>
</tr>
<tr>
<td>How likely is it to come back in a few years? After stopping tamoxifen?</td>
<td>P</td>
</tr>
<tr>
<td>After completing immunotherapy treatment for 3 years how long would you expect the treatment to continue keeping new mets away?</td>
<td>P</td>
</tr>
<tr>
<td>the incidence of relapse</td>
<td>P</td>
</tr>
<tr>
<td>Recurrence rate</td>
<td>P</td>
</tr>
<tr>
<td>What is the life expectancy for longer than 5 year research if you have grade 2 or grade 3 cancer. Do we talk for longer than 5 years?</td>
<td>R</td>
</tr>
<tr>
<td>What is the probability of estrogen sensitive breast cancer to return if you are in fertile age and you get pregnant. What is the mortality rate in such circumstances.</td>
<td>P</td>
</tr>
<tr>
<td>Had ovarian cancer stage 1C I had a totally hysterectomy. Will I ever get a secondary cancer recurrence?</td>
<td>P</td>
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<tr>
<td>Are people living with and beyond cancer at risk of developing another type of cancer, different from their first cancer?</td>
<td>H</td>
</tr>
<tr>
<td>Are patients at risk of developing a secondary cancer? (New Primary)</td>
<td>H</td>
</tr>
<tr>
<td>What is the risk of recurrence of new primary? When factoring in complex genetics such as having a Lynch-like syndrome? Why is this group not being tested for double somatic mutations, to distinguish them from Lynch/sporadic, when the psychological impact is so great?</td>
<td>P</td>
</tr>
<tr>
<td>Is someone living with and/or beyond cancer more likely than someone without a history of cancer to have a second/new cancer?</td>
<td>P</td>
</tr>
<tr>
<td>We know that are treatments cause malignancy, item malignancies following chemo and solid cancers following radiotherapy. There is plenty of literature on this.</td>
<td>P</td>
</tr>
<tr>
<td>Could I get cancer else where than the other cancer for which I was treated?</td>
<td>P</td>
</tr>
<tr>
<td>Why are people with CLL more susceptible to skin cancer?</td>
<td>P</td>
</tr>
<tr>
<td>Is Chemotherapy be the cause of Chronic Lymphocytic Leukaemia? Had breast cancer and after operation had 30 weeks of Chemotherapy. I was diagnosed with CLL is there a link?</td>
<td>P</td>
</tr>
<tr>
<td>What does treatment of radiotherapy for breast cancer have any relation to diagnosed with CLL?</td>
<td>P</td>
</tr>
<tr>
<td>What are the absolute risks of being diagnosed with other forms of cancer after having been tested for another form?</td>
<td>P</td>
</tr>
</tbody>
</table>
Are people living with and beyond cancer at risk of developing another health condition (e.g. dementia and osteoporosis)?

Ph: Yes by virtue of the risks of their previous cancer history

Incidence of Cancer and Dementia sufferers.


Is "watch and wait" associated with developing apparently unconnected co-morbidities?

Ph: Co-morbidities. Is there a link between a particular cancer and other illnesses?

Co-morbidities, is there a link between a particular cancer and other illnesses?

Ph: Yes by virtue of the risks of their previous cancer history and treatment.

Is there an algorithm, like Google’s search engine, that relates interrelated diseases with a particular cancer?

Ph: I want to know the long term health effects that my cancer treatment can cause

What health risks do I face as a consequence of cancer and treatment

Ph: Having been diagnosed with melanoma do I have an increased risk of developing any other health related diseases and conditions? (What should I be especially vigilant of?)

Physical effects of cancer and their impact on other illnesses

Ph: Would I like to ask about the connection between living with cancer and the susceptibility to catching and getting dear of the side effects of stingles?

What do I call my situation watch and wait. I know my cancer will come back (had it twice already) but emotionally it does not help to know you are watching and looking out for?

What is the best way to diagnose Graft Versus Host Disease (GvHD) when you have returned - apart from general aches and pains?

How can patients be better informed about possible early signs of their cancer coming back?

Ph: The signs of cancer coming back are well known but there may be an issue because FLWEB are not aware of them.

What is the risk of my cancer coming back, or me getting a different cancer?

Ph: Instead of I have any new or unusual symptoms then I should contact the team, what are the symptoms that I need to look out for? If the primary cancer spreads are the symptoms different to another primary cancer forming?

What are the indicators of decline and how to stay one step ahead.

Ph: Having had a cancer diagnosis, breast cancer in my case, the fear that a breast cancer might recur or another primary cancer might develop, is very real. What are the symptoms that I need to look out for? If the primary cancer spreads are the symptoms different to another primary cancer forming?

How do I know what to look out for after scans?

Ph: How do I look for or identify the signs of recurrence?

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Ph: Information relating to what to expect from specific secondary cancers

How can patients see a role for patient involvement in the “safety-netting” of vague symptoms or do they feel this should be solely down to the clinician?

Ph: Ho am I missing the early signs of a return of my cancer?

What are the symptoms of the cancer returning

Ph: What cancers are linked, if any and what ones increase your chances of developing a secondary cancer? What is the relationship between different cancers? What effects does Chemotherapy have? I had bowel cancer in and 30 weeks Chemotherapy. I was diagnosed with Chronic Lymphocytic Leukaemia and this year alone I have had 16 dental appointments, 2 abcesses under teeth 2 root canal fillings I tooth re-crowned and numerous fillings, I have facial pain and may have Sjogrens Disease. Are these things related?

What if, any, links are there between different types of primary cancer? I had breast cancer, but am worried about other types of cancer being more likely as a consequence.

Having had pancreatic cancer does this make me predisposed to having another type of cancer?

Ph: For check ups? for example I go through periods of worrying if I have aches and pains, canal fillings I tooth re-crowned and numerous fillings, I have facial pain and may have Sjogrens Disease are these things related?

What should I look out for 5 10 or more years post treatment?

Ph: How will I know if cancer has comeback?

How do patients see a role in patient involvement in the “safety-netting” of vague symptoms or do they feel this should be solely down to the clinician?

Ph: Information relating to what to expect from specific secondary cancers

Are they aware what symptoms to look out for, which need medical attention and which can be self managed? What cancers are linked, if any and what ones increase your chances of developing a secondary cancer? What is the relationship between different cancers? What effects does Chemotherapy have? I had bowel cancer in and 30 weeks Chemotherapy. I was diagnosed with Chronic Lymphocytic Leukaemia and this year alone I have had 16 dental appointments, 2 abcesses under teeth 2 root canal fillings I tooth re-crowned and numerous fillings, I have facial pain and may have Sjogrens Disease. Are these things related?

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What are the best signs to look for to see if my cancer has come back?

What signs should I look out for regarding my cancer returning or spreading? Is there a hotline I can call for advice?

The signs of relapse

Can treatments be developed with fewer side effects, including short-term, long-term and late effects?

Treatment that does not make you ill

The signs of relapse

I would like to know how the side effects of Tamoxifen can be reduced. I am to take this drug for 10 years and it is causing muscular/joint aches and pains, bladder issues, nausea, mood swings and hot flushes.

I have been prescribed an American Inhibitor (Lemtrada) to take for the rest of my life. The side effects (or effects as I call them) are quite dramatic. The fatigue is sometimes overwhelming. And my life has been seriously changed by the painful and restricting arthralgia I get.

Having the cancer was not as bad as living with it post surgery and there are side effects to the treatment. For example, it has been proven for some that the meds can have an impact on the heart. Again, similar to Question 2, what is research doing to minimise these adverse reactions?

What are the possibilities for future treatment of prostate cancer which will obviate the risk of ED?

How can treatments be made kinder and less damaging?

Why haven't more targeted treatments been trialled?

Trying to reduce side effects of treatment, both short and long-term.

Does extending the treatment intervals of say an immunotherapy treatment such as Nivolumab from 14 to 21/28 days impact on the treatment efficacy, side effects and survivability?

Continue search for treatments to modify (reduce) treatment adverse effects - in particular radiation.

How can radiotherapy be improved for head and neck cancer sufferers?

Can neuroSERMs (eg Raloxifene or similar) protect younger women who have had breast cancer from the increased risk of depression, anxiety and dementia in later life?

Can neuroSERMs (eg Raloxifene or similar) protect younger women who have had bilateral oophorectomy from the increased risk of depression, anxiety and dementia in later life?

Please note: The above document is a collection of multiple questions and answers related to various medical topics. The questions cover a wide range of subjects including cancer treatments, side effects, workforce shortages, and other health-related issues. The answers are provided in the form of references to scientific studies and reviews.

For example, one question asks about the side effects of a treatment and the answer cites multiple studies and reviews. Another question inquires about the best method for treating a specific condition, and the answer references several studies that explore different treatment options.

The document appears to be a compilation of extracted text from various sources, possibly for the purpose of summarizing or referencing important medical information. Each question is followed by a list of references, which likely contain more detailed information on the topics discussed.
Single question

Do partners and carers influence the decisions of patients and healthcare professionals?


Single question

What are the biological changes associated with complementary therapies?


Single question

How can we prevent, cure or improve the symptoms of people living with GVHD?

H 10 separate Cochrane reviews on GVHD treatments.

Questions that are out of scope

Questions about access to services

How do patients access QoL improvement/support/assistance services?

P Why is it so difficult to get treatment for long term effects post cancer treatment?

Unmet supportive care needs of cancer survivors: Beyond breast cancer, and is this different to women without breast cancer?

R Depend on type of cancer why does level of support differ.

R Why is there so little psychosocial support to improve psychological adjustment post-treatment?

R Why isn't there more support available for people who want to have palliative care in their own homes?

R Why is it after diagnosis it is up to the patient to find support services available to them?

R Why is there so little psychosocial support to improve psychological adjustment post-treatment?

R Why after receiving news of new or changes to tumours there is a lack of support available to patients?

R Why are there less well being activities built into treatment for adults.

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R Why after receiving news of new or changes to tumours there is a lack of support available to patients?

R Why are there less well being activities built into treatment for adults.

R Why is it so difficult to get treatment for long term effects post cancer treatment?
Why is there no effort to put cancer patients in touch with people who may be able to help, or give information EG support groups, MacMillan, etc, and why is it apparently impossible to contact the consultant supposed to be in charge of your treatment?  

P

When planning treatment and access to appropriate ancillary services, how can it be right that a late stage lung cancer patient is given an appointment for physiotherapy 6 months hence? So perhaps a question like “How do patients feel about the length of time they are waiting to access physiotherapy services which have been clearly identified as being necessary as part of their treatment planning. And what has been their perceived impact of this?”.  

O

Why aren’t the health services utilising all available screening resources for the purposes of earliest possible detection of cancer risk?  

P

Do people get access to palliative care when they need it?  

H

Appropriate advice w.r.t. patients with cancer - I’m finding that there are items not available on the market that would meet the needs of my patients comparatively particularly with increasing obesity within the population, taller patients or petite patients.  

H

As patients and main carer giver (ages 30-60) there is not enough community support  

H

Why are some treatments only available in a few places forcing patients to travel for hours?  

FR

Why are 11 inch disposable pads not available to prostate surgery patients? Thicker, bulkier pads are available, but don’t improve confidence.  

P

Why is there not enough emotional support for cancer patients  

RH

Why is there no psychological support available during the initial 12 months post surgery?  

P

Why is dental care and follow up not part of the standard after care plan post radiotherapy?  

P

My mother was given a diagnosis of stage 4 pancreatic cancer yesterday but no CNS available. I know guideline say this should be happening but there are clearly loopholes. I am a CN in a different cancer discipline so hard to transfer necessarily the relevant information other than the fact I know the procedures and time lines.  

RH

Why is the service offered to patients different depending where you live. Should it not be a National standard for everyone?  

P

There seems to be serious inequality in terms of supportive and palliative services available to patients in different areas of the UK - given we know they make a difference to the quality of life of patients why is there such variation and how can it be solved?  

R

Why isn’t there a fast track system in place for the mental health of those diagnosed with cancer, especially when the diagnosis is life threatening? There should be an offer of immediate referral, no wait.  

P

Why is there such a long wait when six weeks can be very bad for some cancers  

P

Access to psychological support services  

P

Why is there not a consistent approach to psychological care of cancer patients from one NHS trust to another? Compare the Fountain at Surrey Hospital that is supported by counsellors and listeners ex RHB which has none.  

P

Equity in the management of complex and rare cancers, especially surgical management.  

H

At no point have we as a family been offered any emotional support following my mother's diagnosis of cancer and dementia. WHY?  

R

Why has my mother (the patient) never been offered any counselling or emotional support? She is so scared.  

R

How can a supportive infrastructure be set up for each patient who has/had metastatic spread?  

P

How can we integrate support for emotional/mental health issues during/after oncology treatment  

FR

How can I get emotional support as well as medical care  

P

Why isnt only offered medical care and not a holistic, patient-centred package  

P

Should counselling be a mandatory part of treatment for cancer patients  

P

How to improve psychological support to empower the patient and carers  

H

Can a counsellor be classed as part of the treatment process?  

P

Patient leaves hospital and usually there isn’t any one to ask questions of as they don’t get to be seen for 6 months by this time the patients have often sunk in to depression why isn’t counselling automatically given it shouldn’t need to be asked for it should be automatically arranged.  

RH

When is the emotional and psychological aspects of a cancer diagnosis going to be taken into account and patients get the support and help they need? Many suffer for years with the after effects of a cancer diagnosis.  

P

When an individual has other medical difficulties or diagnosis on top of cancer how are they treated and supported holistically with everything being taken into consideration? A personal example. I have a serious heart condition (5 heart attacks), severe asthma and complex mental health difficulties as well as prostate cancer (6 years so far) and have found that medical professionals focus only on their expertise. This is particularly true for having my mental health needs ignored by those addressing my physical health needs.  

FR

I’m a three times survivor of cancer, my mental health has been affected, trying to get help from the hospital has been traumatic, will this research make it easier for cancer patients to receive the counselling before & after a diagnosis?  

P

Should all cancer sufferers be offered counselling to help come to terms with what happening?  

P

Cancer counselling  

R

The treatment and side effects of treatment I received for Breast cancer was without question excellent. However I do feel help for the short and long term impacts on mental health are something which is lacking. A cancer diagnosis changes the way you look at life and life experiences. Friends I have spoken to have confirmed this especially feelings around confidence issues. Research into these mental health impacts, if earlier counseling is of benefit would confirm and perhaps save future NHS expense when these feeling cause problems months or even years after treatment.  

P
I feel there are certain cancers that get a lot of research funds and focus, but less is known about the experiences of those who have less researched cancers. I had endometrial cancer at a young age (37). Care was not great (if we compare it to the gold standard of breast cancer treatment, which has psychological support in-built). Treatment had huge impact on my quality of life. I would like to see these issues warrantied because they matter to the individuals affected.

How can we treat the whole person during cancer treatment, not just the physical illness? Is emotional support, managing shock, reducing PTSD etc. still required.

How is the mental health and wellbeing of patients and carers considered as part of the post cancer recovery?

Would it benefit cancer patients & their partners long term to be offered sex and relationship counselling automatically as an adjunct to any form of cancer treatment i.e the counselling is offered to everyone not just those who ask for help.

How can support services and the promotion of them/accessibility be improved? What other therapies/treatment have you experienced and would recommend to other people living with the effects of cancer?

Is the postcode lottery still exist for drugs to help with living with cancer and beyond?

Would it be possible to create a more central/less桀骜不驯 inclusive advise service that would allow cancer patients a clearer understanding of suitable trials that may be available. My own experience is that this information can be quite dis-jointed and open to individual perception.

Why isn’t there psychological / emotional support regarding developing individual consequences of having cancer?

Why isn’t there more support regarding emotional and mental health well being? Why is counselling so hard to access in order to “learn to live with” the treatment still required.

A job post treatment for recurrent disease and/or where regular (adhoc) trained profession (eg. disability affecting ability to do job) or difficulty in securing term effects as a result of treatment? i.e. if patient unable to return to their

Is there adequate support to facilitate the return to work for those suffering long term effects as a result of treatment? I.e. if patient unable to return to their trained profession (eg. disability affecting ability to do job) or difficulty in securing a job post treatment for recurrent disease and/or where regular (adhoc) treatment still required.

Why isn’t there dis-jointed support regarding emotional and mental health well being?

Why isn’t there psychological / emotional support regarding developing individual resilience from the point of initial diagnosis or pre treatment? Cancer has an immediate impact psychological.

Would you have a key contact throughout your cancer investigations, diagnosis and treatment?

What is your experience of being able to share your experiences?

What other therapies/treatment have you experienced and would recommend to others?

Would you have a support plan that were tailored to your needs?

Can online resources adequately compensate for a lack of workforce in Survivorship / LWBA?

How is the mental health and wellbeing of patients and carers considered as part of the post cancer recovery?
Questions that could be answered by audit

What is the availability and quality of NHS resources specific to young adults with cancer to help them to deal with the mental health effects of a cancer diagnosis?

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What mental health/counseling provision is in place for those given the "all clear" but who are concerned about their cancer returning?

Is there any further help possible for more acupuncture to help people with dry mouths as a result of their treatment? The acupuncture course I went on was beneficial yet too brief and I have heard nothing more about it and I am anxious to get more of it.

What is available to help people with mouth consequences of cancer treatment? A course is advertised and readily available to all patients or is it location dependent?

Macmillan cancer support nurses are spread thinly throughout NHS hospitals. If the hospital sees the value of paying a charity to supply their expertise and knowledge, why don’t the health trust employ specialist nurses?

Is there any physio offer as part of treatment and after finishing treatment and being discharged back to GP care and are these services be provided outside office hours?

Why is counseling not offered with treatment and after?

Is it the not any physio offer as part of treatment and after?

Why does there seem to be no-one at the weekends, support lines, Cancer nurse specialists if I need to ask questions or get advice?

Equipment for endoscopy and expertise varies widely. Is this being addressed?

What numbers of patients successfully claim benefits they are entitled too having been diagnosed with cancer?

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What percentage of women under 65 years of age return to usual employment after a diagnosis of breast cancer treated with curative intent? H

What percentage of women with metastatic breast cancer under 65 years continue in active employment? H

Did you get help during their treatment? H

What support is there for those wanting to change career after cancer? U

Is provision of support services (LWBC, e.g. e.g. by primary care, or by social care) available? How should services be tailored / designed to minimise any variation? H

How many women diagnosed with oestrogen positive breast cancer go on to have a baby after treatment ends? And what are their survival rates? P

How many In-patients experience a delay in their discharge from hospital due to waiting for discussion at cancer MDT? Sometimes for a management plan which recommends simple best supportive care? H

Do you receive adequate support to manage any such condition? P

What improvements could be made to support you in managing any condition which has resulted from your cancer treatment? P

What is the experience of 'open access follow up' (i.e. stratified pathways) patients who develop metastatic breast cancer H

Is compliance of endocrine treatment affected or impacted by open access follow up? H

What services do people access up to 5 years post a cancer diagnosis? H

What are patient perceptions of rehabilitation received / undertaken since undergoing treatment or following treatment? H

Do patients feel that there should have been greater access to rehabilitation during or after their treatment? H

Are people who have experienced pelvic radiation being offered physiotherapy to help with secondary more long term effects that may impact on bladder / bowel? Sexual dysfunction? Pelvic floor? How early are these people being referred? U

What psychological support is available for people during diagnosis and treatment? H

We know that patients who are 'cured' are left with complex post treatment problems. What services are really available for these patients? H

What community services are available to support patients/families/carers LWBC in each locality? H

How are local PCT’s aiming to fill these inequalities in community support? H

What support is available for families/relatives following a diagnosis of cancer? H

What services are available in the community for patients with a recent cancer diagnosis? H

What support is available to carers? H

Are the psychological needs of people with Head & Neck cancers under met in comparison with other cancers e.g. breast? RH

Differences in care, wellbeing and treatment between those who live in cities and those who live in rural parts of the UK. Issues include transport; travelling time, access to wellbeing services and access to support for families and carers. R

What support is available for people who have finished their treatment? D

What support is available in the community for people living with cancer and need emotional support? D

What support is available in the community for families and carers that are affected by cancer? D

What support is there for people living with and beyond cancer in the community when their cancer treatment has completed? H

Is there access to rehabilitation in the community for people who are going through and who have completed cancer treatments? H

Have you had any rehabilitation offered during your illness (physio, OT etc) during or after their treatment? D

What support exists for the immediate family who have a cancer sufferer in their midst? P

Are people likely to travel very far to access support eg in rural areas? H

What are the experiences of those diagnosed with conditions considered uncommon or rare for their age group? What is their experience of care (poor I suspect)? P

How available is counselling for people diagnosed with cancer? P

What is available for managing the side of living with cancer? RH

Do all cancer patients have access to specialist pain teams to optimise pain control? H

Are there regional differences for patients living with and beyond cancer and how can local services support these differences to best help patients and families, and to meet their needs? U

How are you supported by your employer in your return/phase approach to work? RH

Did you have access to a specialist nurse for the duration of your treatment was this support beneficially and in what way? RH

What services do people living with cancer accessing H

How many people living with cancer, who are not actually EII are in our community? Broken down into countries. I feel there isn’t enough information on people living with cancer who are currently not accessing secondary care H

What are the needs of local counties, what do people want access to? Whether it’s psychological, benefits etc what do they actually want? H

What support is there for those in long term remission? P

What help is available for people who are cancer treatment causes them long term problems even after their cancer treatment is finished? H

What are people LWBC saying they are struggling with? H

Does every person LWBC have an holistic needs assessment and are they told of what services are available in the community? H

What services are available to meet the needs of this patient group? H

How many extra appointments with primary care do patients, in the 1st year after completing (hopeful) curative cancer treatment, make as compared to pre diagnosis. ie how much extra demand is generated for primary care services? H

What support is available for people with cancer? P

Did you receive advice on fatigue and breathlessness management? H
### Questions about employment

**How to make healthcare professionals and employers acknowledge the effects of living with fatigue following cancer and not just say it's a side effect to live with.**

Patients are told to pace themselves but employers still expect the work to be done so no allowance is given for fatigue hence the patient is unable to pace themselves. Fatigue should be categorised like any other disease that has to be treated for. The idea is to consider and maybe capture information to encourage clinicians - we hope we are helping our patients but maybe alongside the big things we do the little things are so important.

**Do patients feel confidence in their cancer care?**

What aspects of your care during your cancer journey have been most helpful (e.g. information, timely response to referral, the person who sat and listened, changes to medication …….). The idea is to consider and maybe capture information to encourage clinicians - we hope we are helping our patients but maybe alongside the big things we do the little things are so important.

**What influences equity of access to (1) medical services (2) other support (e.g. psychological, financial, community nursing) for patients living with life-shortening cancer & uncertainty about prognosis?**

As a working carer, I have been lucky in that my Company and management have been supportive. But then I am able to work at home and can catch up at weekends. My experience is not necessarily what other carers have the support and flexibility that I have relied upon. Lack of support could be ruinous to the patient experience. Fatigue should be categorised like any other disease that has to be treated for. The idea is to consider and maybe capture information to encourage clinicians - we hope we are helping our patients but maybe alongside the big things we do the little things are so important.

**What psychological support is available for partner of person with diagnosis?**

Patients experience of a Holistic Needs Assessment (HNA): was it helpful, were any particular support needs identified, were you offered/signposted to the appropriate service/support, did this service/support help, was the outcome of the service/support followed up in any subsequent HNA.

**What is the biggest worry after treatment?**

Cancer Care Review in primary care: following your discharge after your main course of treatment were you offered an Cancer Care Review by your GP. If yes, was it helpful, was a care/support plan developed jointly with your involvement, was any follow up care agreed.

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Employers - Why do they feel that they can’t help you when you have cancer?

What help is available to people struggling with the emotional impact of ‘watch and wait’?

Have patients been asked if they would prefer an oncology appointment just with other secondary cancer patients rather than being mixed with primary?

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Apart from the Equality Act how can employers in the UK be encouraged to compose long term absence policies to cover Cancer with some 'humanity' incorporated? Some of the wording such as taking further action is quite crude in the 21st century.

P

I have found that once having cancer when going for jobs I believe I have been discriminated against because of my long term health conditions and side effects of cancer. I now do not mention the fact I have had cancer when applying for jobs.

P

Flexible working arrangements for those not feeling 100% but who still can work.

R

Can there not be an employer's pack giving them the information needed for them to ensure their employee's return to work is smooth and not stressful?

R

Currently it is down to the person living with cancer to find out about their entitlements and cancer isn't a quick fix. My daughter has had successful treatment but because of the nature of the cancer is under her consultant's care for 10 years.

P

Questions about financial support

Why does travel insurance have to be so expensive after a cancer diagnosis?

P

Patients feel they are being penalised for wanting to have a holiday after getting through what can be very tough going treatment.

R

Given the unpredictable nature of recurrence and also the effect of cancer drugs, how can we provide financial support to people unable to continue working because of this?

R

I am aware one established side effect of chemo is damage to gums and costly dental/treatment following chemo. I am in this position yet on half pay, live alone and my priority is paying the mortgage. Why is there a disparity between pregnant women who receive free dental care during pregnancy and the 12 months after because of the risk yet cancer patients on chemo who are at high risk of gum damage receive nothing. Surely any research would establish chemo is a greater risk than pregnancy. Following completion of my chemo I will need to get my gums and teeth repaired yet it's not able to afford it until back on my feet and working full time again. I can't understand why there is no help available unless you are on benefits yet we qualify for free prescriptions.

P

Financial support when suffering with late side effects and struggling to stay in employment

PH

Why don't (pip) assessors understand the on going impact of fatigue and anxiety on activities of daily living?

P

What changes need to be made in hospital based welfare and benefit support for those undergoing treatment and living with side effects of disease or treatment.

P

Financial problems I am afraid I slipped into Patient Rep mode for this one as I did not suffer from financial problems due to the generosity of my employer, however it is a massive problem for many patients and more help and advice needs to be provided.

P

The financial side of living with cancer is a problem. With few exception, the wealth of the patient will change, specially if they cannot get back to full time employment. So why are the ethics around financial help so rigid and horrendous? Financial help should be adapted to the needs of someone who has had to shift their mindset from inactivity to short term future. Helping with monthly housing benefits is not real help, it is business as usual adjusted to such radically different circumstances that it simply cannot work. Lump sums could perhaps better cater for financial struggle. E.g. one could go and recover in a sunnier, happier place, for a bit less money, rather than stuck at home, where every single corner reminds one of their life before and after diagnosis, and how it can never be the same.

PH

How can applying for IP be simplified for those living with and beyond cancer and be made less stressful?

P

Travel and other Insurance are affected by a cancer diagnosis but I am not convinced that the insurance industry's actuarial base for increasing premiums is based on evidence of the actual likelihood of survivors having problems related to their cancer. As a result survivors are discriminated against by either not being able to get insurance or by premiums that are much higher than reasonable.

R

Should there be easier access to financial support? Fast Track Funding without the need for mountains of form filling to support both patients and carers? Simply! The CAR provide a very good service, but MacMillan could do with stopping ramming down people's threats their own agendas. Marie Curie provide a high quality service, but there are not enough of them.

RH

Benefits and other allowances advice available within a hospital setting... as a walk-in. I realise this could potentially be a very busy service with the option to make an appointment to return.

P

When you have an inoperable Tumour... mine is in the brain... and are life limited... and have been approved for ESA and other benefits... why do the DWP make you fill in "suitability for work" questionnaires. approx every three years... and often make you attend ridiculous "health" check appointments... ATOS... that really have no relevance to our condition?

P

Will the government ever give travel allowances for hospital visits for cancer treatment?

P

Why is there no financial assistance from government when people have to take time off work due to the effects of cancer?

P

Help with claiming benefits where the affects of the surgery have no diagnosis. I have debilitating fatigue and many other issues. As there is no diagnosis as such for the affects of the surgery there is great difficulty claiming for benefits.

P

Insurance implications when patients do better in trials than those who don't enter - how come insurance companies do not like insuring patients in trials.

P

How can we encourage Insurers of Life, Critical Illness & Income Protection to enter - how come insurance companies do not like insuring patients in trials.

R

The lack of financial support.

R

why should people living out f the uk not get help our grants i have lived their all my life its not fair

R

Is there a way that we can insure ourselves against the costs and financial burdens that are posed by living with cancer and being unable to work? For example, a short term disability living allowance?

P
we need to make sure that patients are supported so that they can access all the potential financial benefits available to them. Young people services do this well but I worry that the vast majority of patients do not get this support

Has the governments drive to reduce certain benefits affected cancer survivors ability to manage financially?

P

Having cancer can cause real financial hardship; charities are good at helping out but there really should be a more co-ordinated approach for anyone suffering; because they are ill, it is bad enough dealing with the physical and emotional stress without worrying about money.

FR

Holiday insurance is very difficult to get and feel confident with. They certainly don’t understand returnships. How can we make it simpler for them and us to understand and also obtain so we can feel secure when our consultant says we can go on holiday.

P

Difficulties obtaining travel insurance due to ignorance on the part of insures about current/new treatments whereas clearly they think I am a high risk I always use specialist sites for those offering insurance for existing conditions and use comparison sites such as ‘paying too much?’ that compare several offers - still very expensive and an annual policy is unavailable for me meaning I pay much more.

FR

Why are there not short term benefits for those cancers that only incapacitate for a few months such as leukaemia?

H

What financial assistance is there for cancer patients. Especially around getting private healthcare and life insurance.

P

Insurance Companies - why do they believe that everyone with living with cancer is a high risk?

P

Why is Pelvic Radiation Disease (PRD) not made a tariff?

P

Why are there not travel expenses for those cancers that only incapacitate for a few months such as leukaemia?

H

What financial assistance is there for cancer patients. Especially around getting private healthcare and life insurance.

P

Insurance Companies - why do they believe that everyone with living with cancer is a high risk?

P

Why is there no money set aside in the NHS for pelvic radiation damage?

H

I feel that financial support for people with cancer is completely inadequate. I am a young, single parent to 2 children, I’ve never been in debt until cancer. I applied for PIP to be refused as I am not disabled enough, only my MP getting involved made them offer me the lowest living element of PIP which is a pitance, the universal credit system is inadequate & the 12 week delay left me in debt, so now I have to go back to work even though I don’t feel ready, because I can’t afford not to. I have been told of funds like British gas hardship…. But I’m expected to give them my entire income & outgoing everything down to my food bill even then I may not get the help, it’s feels degrading to have to justify my need for this help to that depth…… I already feel bad enough that I can’t even take my kids for a simple day out, that some weeks we eat the minimum because that’s all I can afford, never mind having to send my entire 6’s & 6’s…… Make me feel ashamed when actually I’ve fallen on hard times due to cancer treatment but I’m young & was fit so I’m not as physically immobile as someone would be in their 60’s with my symptoms & diagnosis, surely more can be done ?

P

Questions about funding cancer services

Why after living with long term effects from my cancer treatment for life - because I am no longer taking specific drugs to do with Cancer but all the treatments I had caused me to have long term health effects requiring regular treatment I now have to pay for my medication for life.

P

Why can’t dental treatment be free for head and neck cancer patients?

P

What is the NHS going to be able to offer new, cutting edge treatments when they’re so expensive and therefore become controversial? Many of the new research projects produce amazing results, but then are only available to those who can afford it. Britain cannot trail behind other countries, as we’ll be in danger of losing our brightest researchers.

FR

How do we deliver cancer care most effectively in the community at a time when General Practice is so overstretched

R

How can we ensure that patients and families receive all the support they need with the ever changing horizon of a cancer diagnosis and long term treatment and scans etc. I e. A Macmillan nurse. It’s vital that access to informed support is available to as many people as possible, Perhaps the drug companies, who now have created long term immunotherapy treatments, can contribute financially to this?

H

What is the impact of using old machines in radiotherapy for treating cancer, and how can an effective rolling replacement programme be successfully implemented and funded regardless of future Government politics?

FR

Why is Pelvic Radiation Disease (PRD) not made a tariff?

P

Are all G Phs going to be given the training and resources to support patients with long term side effects.

P

In the last five years I have had constant problems with my teeth, this year alone I have been to the dentist 16 times mostly as emergencies having lost fillings, crumbling teeth - 2 abscesses - 2 root canal fillings etc. I am currently awaiting an X-ray on my face due to having jaw ache for 8 months, on my last bone and marrow biopsy 1 year ago it showed I had 80% CLL infiltration in the bones & marrow, is this related to the CLL and if so why isn’t dental treatment free?

P

Why are cancer drugs so expensive? It seems immoral for drug companies to profit through the suffering of others and for NICE to withhold drugs which may work from patients when it is often linked to cost

P

Why is there no money set aside in the NHS for pelvic radiation damage?

P

Possibly the above would not have happened if funds were available for adequate training. I appreciate that the Government have little money for extras in the NHS but will you research put pressure on the Government to improve funding?

R

Research has shown that people living with cancer is on the increase. This is excellent news. However, research has also shown that people with cancer have deep seated psychological problems. As frequently reported, the NHS is in crisis in respect of funding and resources. How can we be certain that sufficient resources will be available in the future to prevent this epidemic spiralling out of control? Action is required now not just recommendations.

H

Why can’t dental treatment be free for head and neck cancer patients?

R
Whether care was experienced as truly MDT (or very medically led)

What support has your healthcare team provided you in 'holistic' support and free up appointments with GPs and hospitals.

Counselling/complementary therapies (working with breast cancer nurses) would

Dreams and Maggie's Cancer Caring Centres. Why are GPs and oncologists

moment this is undertaken by charities like The Breast Cancer Haven/Future

diagnosis. This will only be adopted by the NHS if there is funding in place. At the

There is evidence - and a growing understanding by oncologists - that it is

information and should be reviewed as my treatment progresses?

Why wasn’t I given a written cancer care plan so that I could refer to for

to help me through a very stressful time?

Why wasnt I allocated a care key worker when I was first diagnosed with cancer

Staffing resources in the 3 Radiotherapy centres - are they appropriate

RH

after operations. I

Research has to be done to get better response to patients after operations. I

found this by myself . Why wasn’t I directed to this site by the NHS. It offers more

I do a lot of reading and use the kidney cancer support network KCSN. However I

It’s a time when dignity is being promoted by health authorities I have found it a

is no privacy or dignity for

on chemotherapy drips whilst I am asked questions about my bowels, sores on

my body, my bleeding mouth and then have bloods and weight taken. This is my

Shocking about the total lack of privacy when being assessed for my next chemo

cycle. There is no private room and I sit with all others plus their family members

in front of the patient. Do THEY get a chance to ask these privately and separately?

Clinicians say that a drug is available, but not funded by NHS. Why is the

NHS so 'dog-in-the-mangerish' that is difficult for us to find the way to buy a

drug ourselves?

Questions about care quality

Whether care was experienced as truly MDT (on very medically led)

Did you feel that you had the relevant support throughout - in what way - what was most beneficial?

Information about side effects of treatment short term and long term and whether support was available?

When first diagnosed, many people are given very little information and have to

look for it themselves. How can the NHS deliver a tailer made information

package from day one of diagnosis?

What the shock of the initial diagnosis is over or diminished, do you as

professionals feel that there is enough time to re-iterate the information and to re-

explain everything, which may not have been taken in, in the first place.

Cancers or partners may well have questions which they don't want to utter in

front of the patient. Do THEY get a chance to ask these privately and separately?

I had a reading and use the kidney cancer support network KCSN. However I

found this by myself. Why wasn’t I directed to this site by the NHS. It offers more

support and knowledge than any other website as it’s specific to my cancer. These

patient led sites among with NHS representatives are fantastic. They offer

support, facts , and lots of data regarding treatments. The NHS could really learn from these.

It’s a time when dignity is being promoted by health authorities I have found it a

shock about the total lack of privacy when being assessed for my next chemo

cycle. There is no private room and I sit with all others plus their family members

on chemotherapy drips whilst I am asked questions about my bowels, sores on

my body, my bleeding mouth and then have bloods and weight taken. This is my

biggest shock since my cancer diagnosis that there is no privacy or dignity for

cancer patients. It is so public that I find myself whispering in response to the

nurses.

Is spiritual care information lost in the plethora of information given as a person is

diagnosed?

Research has to be done to get better response to patients after operations. I

found that very poor but that was a long time ago.

After being given pain killers to ease the pain after treatment, why did no one tell

found that very poor but that was a long time ago.

NHS why has to do this. It’s just not there for us. Why do doctors not explain their

“Treatment Plan” from the end of

whether support was available?

also concerned about funding of the NHS and is the country investing enough in

research for new treatments, equipment and would they be available on the

NHS?

Why can’t rare cancer patients are left floundering - fewer clinical trials, less follow up and

less support, fewer treatment options - further to travel. fewer experts. Where is the

quality in that?

ARL /LR have more funds available

When Consultants say that a drug is available, but not funded by NHS. Why is the

NHS so 'dog-in-the-mangerish' that is difficult for us to find the way to buy a

drug ourselves?

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less support, fewer treatment options - further to travel. fewer experts. Where is the

quality in that?
Have you felt supported on your journey by HCPs options?

During her treatment I was asking questions as to why the chemo had changed. We got no answers.

When my daughter had been in hospital with a collapsed lung I was not allowed to be kept informed obviously due to the fact that it wasn’t written on her notes. She was in a totally different ward. I could see her deteriorating, & was certainly not kept in the loop. I had no one to talk to about her condition.

How can care particularly for elderly people with cancer be better co-ordinated, even with the new cancer teams? Communication continues to be poor at times, particularly cross-over points like failure of curative treatment, people can feel they have been dropped, are in limbo etc at an extremely vulnerable point.

Why is the hotel Discharge process so long-winded? Get patients off hospital sooner once they’re ready to go and NHS will save loads on catering and unnecessary bed blocking. On my 2 admissions I was waiting until 7pm for meds after being told at 9-10am ready to go home.

Be it lots of HCPs over drop after drop, such a waste. Is there a way to reuse them or not give so many out. Could Patients manage their meds.....?

Were you provided information about local services available to support you?

Why do cancer MDTs not comply with national cancer rehabilitation guidelines despite the evidence?

Seen that womb cancer is the fourth most common cancer in women why is there not much awareness?

Gynaecological cancers, specifically womb/endothelial cancer are often seen as an "easy cancer". Many women who have been diagnosed have been told this by their Consultants or Gynaecologists. Why do they do this? If you are still of child bearing age and are told you have to have your womb removed, become incapable of having a child of your own, go into sudden menopause and deal with a cancer diagnosis there is nothing "easy" about it.

As a carer why was I not told of the likely affects of treatment on the patient?

As a "carrier" of CML for 7 years why was I not given any advice on what to avoid and what to eat?

In NHS hospitals how can communication between haematologists, medical doctors on the wards and the pharmacy departments be improved to ensure drugs that have been prescribed are received on the wards quickly to patients who are hospital because their immune systems are compromised by their cancer and treatment?

What training will be given to those giving news about cancer to patients and friends (we were told to go home and say everything you ever wanted to say to one another - that was quite a shock!)?

Not to shy away from a patients question about some of the diagnostic tools used to detect cancer and the return of cancer.

Why was I not told the risk of side effects?

Why did it take a year of being in constant excruciating pain before being referred to a pain clinic with follow up appointments taking between 3/6 months.

Why do cancer MDTs not comply with national cancer rehabilitation guidelines despite the evidence?

How do cancer care professionals maintain the compassion in delivery of care I see very much need?

The treatment of relatives ( close family) get from the Hospital it varies a lot depending on what area you are in

Quick win results

Proper, written statement of diagnosis. It's only given verbally or in the form of a release letter if patient is hospitalised.

How can we encourage all professionals managing patients with Cancer to use the word 'cancer' instead of using avoidance tactics? How can we encourage them to be more open and transparent as without this is leads to more patient anxiety.

Why can’t there be a much more clearly defined care plan for patients? Something tangible and easy to refer to at any time. Something I can update and so can the NHS staff looking after my care. This could be as a hard copy which can be routinely updated and/or on an app accessible online via your phone or tablet which is electronically updated.

Can there be more detailed information into exactly what happens from start to finish with any surgery or treatment? Not just told you will be here on that day, that time and you will have treatment. Well, what is the exact process? Who is who and what are the roles in your position. Because if you can visualise it, you can take some of the fear out of the situation and how it’s making you feel.

How to make sure cancer are kept in the loop. I understand patient confidentiality, but I found it very hard to get info when my mum was an inpatient because they did ward round outside visiting hours, and she was confused and couldn’t remember what they said well enough to tell me.

Why was my fertility not discussed with me and that I might be able to have children?

When given the diagnosis of cancer, the options for treatment follow on very quickly even if the need is not immediately urgent. How long is given to the patient and relatives to carefully consider these options?

How much counselling is given to the patient to carefully consider the treatment options?

Have you felt supported on your journey by HCPs options?
Why, when diagnosed with cancer initially, do oncology departments at hospitals disappear into a black hole and tell patients nothing about what their plans are, when is the MDT meeting to discuss a cancer, what are the treatment options, what are the pros & cons of those options, when will treatment begin, and how long will it probably last? Locally the oncology department think it is quite appropriate to get patients in within the govt target for first appointment then forget about them altogether till they then get to the top of the next list.

Having seen mother, sister, sister in law and wife all suffer with cancer, the common thread for them all was transport, parking and time taken with treatment. Looking to the future, will it be the same when mobile units may attend the residence of the patient and administer treatment. Obviously this sounds a fanciful idea but it would solve the parking problems, put down on waiting times for the patients and reduce the stress levels for the patients change of practise and a lot more thought required I know...just thinking outside the box.

When in hospital to have surgery for cancer why is the food not nutritious?

Why do people that have multiple cancers and where everything is failing, still get terms / radiation treatment... I've talked to a few older patients who feel they aren't given quality over quantity but have felt pushed to have more treatment... it gives false hope and often has no effect on a late stage... I respect if they ask for it... but there has to be more respect back, to have minimal interference, and not made to feel guilty...

When my daughter & I were brought into an empty room which was "found" in Fracture Outpatients and told. Verbatim. All your treatment is now stopping we can't do any more. My daughter asked "How long have I got? About 3 months the Oncologist said... could there not be a more empathetic way to tell a girl if 28 years of age who already knew from the beginning it was terminal, for example perhaps a nurse or a Macmillan member or even a Marie Curie member could have been there to answer any questions. This was very cold. We walked out of the hospital not knowing what to do next.

Reference to the above. Three days later I had to take her to hospital for oxygen. I knew she was really ill at this stage. Another Oncologist said oh no she's got weeks & weeks. I disagreed & she asked me what I thought. I said I thought she wouldn't survive the weekend. She died on Saturday. Doctors do not see patients 24/7. Parents need to be involved in the prognosis based on their home experience.

Can surgeons giving bad news receive much better training? I was given 12 months and it felt like the news was pretty much delivered in 1 sentence. With realistic training the surgeon could have said something like you'll feel awful for a few days, then you'll start to pick yourself up and work on what's best for you. Just the slightest hint of positivity would ease the news, I didn't receive that till I saw my oncologist 3 weeks later.

Can the benefits of receiving first dose of chemotherapy Monday to Thursday be explored? I received a first dose on a Friday and had nausea and vomiting for 4 days with a variety of UC24 doctors visiting me at home at great cost to the NHS. If I had received my first dose Monday to Thursday my GP would have been able to visit and provide personal and improved care which would have benefited both myself and the NHS.

Is it luck as to whether or not you get to see an oncologist that specialises in your particular cancer? My husband had a NET in his pancreas. The oncologist seemed to know very little about it.

Upon my surgery in this country it feel far short of my surgery in in Boston, America. There are a number of reasons for that however nurses speaking in Hindi to each other whilst I lay in bed and nurses not knowing what medication to give to me.

The patient knows best. After my first surgery I knew I did not di not take well to steroids. However the surgeon and the doctor put me on them as a result I had to spend 10 days on hospital and I got clinically depressed because they would not listen to me and did not know how many pills to administer. I had to set multiple alarms on my I phone to nurse to administer my pills, they were not enough of them on duty and up to the day I left was unable to answer me when I was in to go home.

I had to spend 12 months on antidepressants all because the hospital did not listen. This would have been longer if I had taken matters in to my own hands. Which again leads me to the Doctor / patient relationship.

why do medics treat survivors with discrimination? I have had health issues since cancer, but once tests for mets are concluded nothing else is done. Cancer history obscures everything. If a non cancer survivor presented with other conditions they would get full investigations which wouldn't end at only, 'well it's not cancer, goodbye'.

Why are private hospitals and consultants allowed to ignore clinical guidelines? Regulators are not inspecting on this. The nurse in charge of care can't answer questions we have.

Why do Appointment so far apart 3-4 months is not good enough. Why are there no regular 'follow up' tests for patients who have previously been diagnosed with prostate problems and continue to have symptoms?

Why were patients not warned of the dangers of metal examination?

Why was I not warned of risk associated with prostate biopsy?
Receiving written test reports and not having to wait many months for results further surgery which could have been avoided with more in depth testing. I feel that proper scanning and tests for diagnosis should be improved to avoid especially financially!

McMillan advertise all this "help" - my experience was that there was no help - prescription requests!

I'd like doctors to write to me, rather than just copy me in when writing to GP. Do people within the NHS realise how inefficient they are.

Lack of information and support for sufferers of very rare cancers 

Like this should never happen without clear unequivocal discussion with the patient and family.

My husband experienced misdiagnosis several times with the second of his major cancers. The hospital merely tried to sweep this under the carpet. The hospital should realise its responsibility towards patients and any errors that are made in treatment or lack of them, and be honest enough to admit they were wrong.

If patients and their families clearly state they want resuscitation, this should be respected. Instead in my husband's case, although the medical and nursing staff knew this, some doctor called in the death squad (end of life team) and within 24 hours he was dead, although he had previously responded to a couple of earlier resuscitation treatments. This action totally over-ruled all our wishes and actions taken. He was dead, although he had previously responded to a couple of earlier resuscitation treatments. This action totally over-ruled all our wishes and actions taken.

Why was I told they were taking four biopsy'es and they took Seventeen.

Why did my GP refer me sooner when I had had a lump which was growing for over six weeks? Why didn't my gp refer me sooner when I had had a lump which was growing for over six weeks.

Cancer of surgery?

Why because my tumours were rare I had to wait for over 6 weeks after diagnosis for an outcome?

Information wasn't given all in one go there was no one to contact to ask. Why?

Support wasn't offered. Just a pale of information given, with go and read. You read but don't understand. Why is there no automatic support given. It is a scary time, and no one there.

The confusion after your primary cancer has spread, more talking to the patient and caregiver to explain what is going on and what treatment options there are available.

question: Should you have complete control over what treatment you have. Plus be involved? Example I attend Dartney Valley which is 85 miles away for my treatment. My choosing. But I could for example do pre ops in Canterbury south east Kent, just as I am officially under Dartney Valley west Kent. This is not allowed in today's world of technology, there is no reason why every appointment has to be at a given hospital.

Taling of side effects: Why is more not being done to warn about the possibility of a lymphoedema diagnosis?

The length of time for results, living in turmoil and high anxiety

Cancellation of surgery?

I had womb cancer why are the very painful examinations done with out anaesthetic?

Lack of information and support for sufferers of very rare cancers

Why was I seen by a doctor who said to me this is not my field rather than explaining in medical terms.

Why do doctors explain the diagnosis in ways that can be easily understood rather than explaining in medical terms.

why was I seen by a doctor who said to me this is not my field

Why didn't my go refer me sooner when I had had a lump which was growing for over six weeks?

I went home the day after my hysterectomy and was told to go back in 6 weeks in that 6 weeks I never had an appointment for my dressings and when I phoned up they said I was to go to the clinic securely just to be reassured by a visit. This would help me to put out my mind at risk.

When a patient moves from Terminal to not terminal, it should be wonderful news. Instead there is confusion between your staff on how to deal with this patient. In Hospital staff treat a patient as if they are dying, let things slide and lack respect when a patient should be treated as a chronic patient.

Why was I told they were taking four biopsy'es and they took Seventeen.

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Why was I told they were taking four biopsy'es and they took Seventeen.
I am very concerned about hospital closures, bed closures, long waits for appointments and treatment. Patients not being seen quickly enough to get a good outcome.  

Do cancer care professionals make their patients feel supported? 

How do you tell people the severity of the cancer in “layman’s” terms? 

I feel that sometimes, perhaps many, relevant and valuable information is not conveyed at the appropriate time, even not at all. I have picked up this comment from several Cancer Patients.

I wonder if it would be more helpful if patients were treated more as individuals by doctors. Each person has an individual response to their disease and I don’t think doctors give enough credence to this. I think it would be more helpful to give a range of outcomes instead of an amount of time someone may have left, especially as the information given is based on research findings 5-10 years old and averages not what might happen to you. People may be misled and think what the doctor says is what is going to happen to them and thus they accept all the doctor says without realising what they can personally contribute to outcomes. 

People with Serious Mental illness present late in a cancer diagnosis and are usually given a terminal diagnosis. HCP profs do not know how to manage their needs. 

Should more support be offered to those of a child bearing age as like myself I was told I had to start treatment straight away and that there was no time to freeze my eggs. It was never spoke about since and it was not being able to have my own kids which was actually harder than getting a cancer diagnosis.

My GP seemed unaware that I should be given daily Tadafenil for two weeks prior to my prostate surgery, in order to improve erectile function after surgery. Should GPs be aware of guidelines?

Why don’t clinicians in general in general hospitals know that pancreatic pain, as a nerve pain, may not respond to opiate?

How can the cross-county issues regarding Hospital/surgery/finance transfer, communications, etc. be overcome for the benefit of patients?

The vast majority of health care professionals (GP, dentists, hygienists, max-fax doctors, consultants, head and neck doctors, nurses) dealing with me whilst suffering with ORN symptoms pre-diagnosis (approx 7 months) had zero understanding of ORN - this resulted in pain, infection, damage, delays. I had inappropriate community care advice - resulted in further damage and infection, whilst hospital doctors treated me as a simple run-of-the-mill rather than the more significant ORN case. can this be improved.

Why aren’t mastectomy wounds finished off with at least a nice well seen scar?

Why aren’t health professionals such as Drs, Health Visitors able to help you?

Why don’t someone contact you after you leave hospital to see how you are doing rather than living.

Why doesn’t someone contact you after you leave hospital to see how you are doing rather than finding someone yourself?

Why doesn’t someone explain about colonostomy and ileostomy and what can go wrong, i.e. leakage, bad skin like nappy rash, pain.

Why can’t radiotherapy be mandatory after a radical hysterectomy? I had wrong. i.e. leakage, bad skin like nappy rash, pain.

When a patient has zero quality of life due to over 100 hot flushes a day, and then being told I am not worth the cost implications? I do not feel my doctors tells me everything- he has not provided any treatment, is this because of my age (80 years) and I am not worth the cost implications?

Why isn’t radiotherapy used to treat post-gelation leakage, bad skin like nappy rash, pain.

When do you tell patients you are going to stop anti-hormone treatment?

Why are there no trials/pilot work in radiotherapy to treat post-gelation leakage, bad skin like nappy rash, pain.

Why isn’t radiotherapy used to treat post-gelation leakage, bad skin like nappy rash, pain.

Many decisions about treatment do not require an insane level of rush. Why can’t most patients be encouraged to research get 2nd opinions and be placed in the driving seat.

Why aren’t health professionals given a list of organisations to help patients and their families.

Do you feel that your GP is aware of the potential long-term effects of your cancer treatment?

Do GP’s have the knowledge and skills to help people live the best lives they can with their cancer?

Do community care health care professionals have skills and knowledge to support people to live with their cancer to the best they can?

How do you get health professionals to deliver true personalised care and have time to listen to people with cancer?
**Questions asking for advice**

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<thead>
<tr>
<th>Question</th>
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<tr>
<td>How to cope with telling others, especially work colleagues</td>
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<tr>
<td>Who can I go to to talk about me, and the problems I have, having survived the DFSP - why did I not get a full body scan to check it had not spread?</td>
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<td>DFSP, it’s a rare cancer. I had surgery to remove my tumour. Why is it not treated comprehensively, can I be treated to be more aware if this condition PRH</td>
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<td>What are the likely side effects and how do I overcome them?</td>
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<td>What's the best way to measure the competences of GPs to ensure they have a basic knowledge and clinical skill to look after people living with or beyond cancer with treatment consequences?</td>
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<td>How to build relationships with others following a life changing event such as having a diagnosis of cancer</td>
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<td>What benefit do and can they claim?</td>
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<td>What long term financial and emotional support is available for patients?</td>
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<td>Is there still a stigma attached to telling work colleagues, friends and family that you have cancer?</td>
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<td>My treatment has finished and my doctor tells me I am cancer free, but I'm still so fatigued. What are my rights at work when I'm still struggling with treatment related tiredness?</td>
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<td>How can I let my family know that I'm still struggling with the impact of cancer even though my treatment has finished</td>
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<td>What projects are locally available to young people post treatment</td>
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<td>How should I return to work after treatment? How long should I stagger it?</td>
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<td>What is the best way to educate HP's regarding caring for patients LWBC?</td>
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<td>How do I plan for my future?</td>
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<td>Dating after cancer - when to tell someone? How to start that conversation.</td>
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<td>What are the options available for people who were diagnosed with cancer as a young adult and are unable to have a biological child who would like to start a family?</td>
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what is the criteria etc?
tasks and self-care is becoming difficult for them. What are their entitlements and
Both parents with Terminal cancers, living together in their own home day to day
wish to go through my uncaring GP?
Can prescriptions from CNS be faxed through to my local pharmacy as I do not
Can I request a copy of my Healthcare records?
were diagnosed several years ago and whose treatment (apart from hormone
basis. My question is does the success of this type of research benefit people who
Thankfully, so many new findings regarding the behaviour of breast cancer and
therefore have no sick pay or benefits?
How can I manage financially if the cancer returns-I am self employed  so
Do pelvic exercises improve continence?
Prevention of hair loss during treatment
Is there any support/help for mums with young children
Are the any cancers that are hereditary
embolisation followed by a 75% resection?
What long term or late onset health/lifestyle issues might I expect from a 25%
large bowel resection ?
What long term issues might I expect from having a course of oxiplatin and 5FU?
What support should be given to patients and their carers if hearing deterioration occurs
as a consequence to treatment?
How do you rebuild intimate relationships living with cancer
how do I advise patients and carers on local living with and beyond cancerservices?
What support is given to patients and their carers if hearing deterioration occurs
as a consequence to treatment?
Are there any specific guidance for prescribers in medication to avoid in patients
with a history of cancer
Did the radiation treatment cause scarring of my lungs when treating my upper GI
cancer?
Why are all the research figures only quoted at 5 years after diagnosis?
Are enema really necessary when undergoing pelvic radiotherapy?
Is any research happening in the UK to improve current treatments for chronic
peripheral neuropathy? (e.g. ‘Scrambler’ treatment currently being tested in
the Mayo Clinic)
Does wearing a prothetic breast have an effect on security if I fly. Do I have to
If I'm worried about something can I request a scan?
I have erectile dysfunction after prostate cancer. I take tadalafil but still I can't get
an erection. What also can be done for me?
How can I access psychological support when I've been discharged from
treatment?
If Blood Cancer is one of the bigger killers in this country, why are so many people
unaware of what to look out for, to enable a quicker diagnosis?
How can I find out if others have the same symptoms and what medication they
are on that helps .instead I feel like a Guinean pig.
Should I be concerned about doing physical activity after finishing chemotherapy
treatment.
What support is available after I stop treatment.
How likely is chemotherapy to work?
suffer from life long fatigue.
How can we educate those around us more about the side effects of treatment -
what that means long term for our health and that we aren't 'fixed' but actually
suffer from life long fatigue.
How can we connect cancer survivers of rare cancers?  Especially for those not
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unaware of what to look out for, to enable a quicker diagnosis?
If I develop secondary Lymphoma, what treatments and care will you provide me with? [Are all treatments/procedures available on the NHS?]

What support, both emotional and practical, are available to help me after treatments?

How much research is being done on CLL?

Do breast cancer survivors suffer more in the heat?

Can I challenge the consultant to use worldwide knowledge and treatment expertise or a generalist.

Having reached normal blood levels with CLL, I would like research to tell me if reducing or cutting the daily dose is safe and effective in maintaining the good health I am now enjoying.

How do I carry on living with these symptoms?

Where can I access information about how effective different cancer treatments are at prolonging life and improving/maintaining quality of life?

What happens in the later stages of CLL? There is very little information on this apart from giving rough guides to life expectancy.

How long will it be before I need treatment for CLL?

I have been diagnosed with a blood cancer but have been put on "watch and wait" so how do I explain this to my employers, especially the fatigue?

I have been diagnosed with a blood cancer but have been put on "watch and wait" so how do I carry on living with these symptoms?

Why can't we have a full DNA profile done with clear profiling of the mutated gene causing cancer?

Finding out or upgrading to alternative therapies that are accredited or affiliated to respectable professional bodies.

What support can you get within the community where you live to support a patient and/or carer?

What help can you get assessing information on financial support if you became a cancer/patient in work etc receiving treatment for cancer?

Why is CLL only treated when white blood count is high?

Do I have the choice of what hospital I can attend if I'm not happy with current choice?

What support is available for single cancer patients, during and after treatment?

How do I find an expert in my kind of cancer and how will I know he/she is an expert.

What other changes occur (such as to the immune system) in relation to the primary cancer and are these related to actual blood results? For example I have low level CLL but joint pain which is really affecting quality of life.

I am not on watch and wait. I want to know what are my best options in my treatment.

What characteristics are the most indicative of phyllodes tumour metastasising?

What characteristics are the most indicative of local recurrence of malignant phyllodes tumour?

I like to participate in groups that offer information and interesting speakers. Post up three years ago the physio suggested I target days/meetings to keep my brain alert. This has worked but now meetings tend to come on the same day. Yes, you have to draw a line but how do you decide what not to attend? When you enjoy all these meetings.

After three years post colostomy does one's stomach shrink or have I made it too big?

What is the maximum paraprotein count before Myeloma becomes treatable?

What are the side effects to be assessed for at the smouldering myeloma stage? It compromises the auto-immune system, so what places or events should I avoid to keep safer from infection?

How can it be treated?

If my periods don't return after 2 years does that mean I have gone through the menopause?

Do I have the choice of what hospital I can attend if I'm not happy with current choice?

What characteristics are the most indicative of local recurrence of malignant phyllodes tumour?

What characteristics are the most indicative of phyllodes tumour metastasising?

I worry that the cancer is hereditary, how difficult is it to have genetic testing?

Cervical cancer can cause cervical incompetence - how will this affect a person's ability to get pregnant and or carry a baby and what can be done about it?

How can it be treated?

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If my periods don't return after 2 years does that mean I have gone through the menopause?
I am infertile due to cancer treatments. I take the regular pill instead of hormone replacement therapy. Is this the best long-term solution and what else should I be doing?

What symptoms do you have when undergoing chemotherapy and what should your daily routine be? Is it best to rest all day in bed, or get up and try to stay active even if you are in pain?

Radiotherapy treatment 30 years ago have caused nerve damage, muscle wastage and burning sensation in back. Was not told when going through treatment about possible side effects. I would like to know if there is anyone that can guide me through symptoms I am now experiencing?

Gene corrections is my child safe

What avenues are available for financial help and assistance when off work for a long period and receiving reduced pay?

What support or new skills training is available if I have to give up current career after treatment which includes limb amputation?

What non-medicinal treatments are available to compliment the sometimes harsh treatments of chemotherapy and radiotherapy?

Why does the patient having hormone therapy smell musty despite a high standard of hygiene, it doesn’t seem to affect him but the carer finds it very off putting?

How many different types of prostate cancer are there and which are least and most aggressive?

Having been recently diagnosed with PC, I am amazed at how just how many of my friends and colleagues seem to think it isn’t much worse than toothache which can be easily treated! So I guess my question is how do official organisations promote the reality of awareness of, and treatments for PC. I now accept I’m on a mission to do my bit!

When I finish all my treatment chemo what do I find out when I go into remission?

How can a person jump from stage 2 to stage 4 cancer without any node involvement and clear margins after surgery?

What are the effects of having lymph nodes removed (eg long term pain/discomfort)

How fast must your PSA be to start to be worried about the spread of the disease?

What are the latest treatment for a rising prostate.

What supplement do you recommend?

What makes the risks associated with surgery too high to make it an option when the cancer has not spread beyond the capsule of the prostate gland?

Are there any new treatments available for dry mouth

What are the chances of me getting cancer with having the brca1 gene

How to support and relate to close friends and family during and after cancer treatment?

Why do Medical professionals refuse to accept that there are alternatives to treatment or preventing the spread of prostate cancer by means other than Radical Prostatectomy surgery or “watching and waiting” involving repeated painful biopsy sampling.

Prostate cancer is said to be slow growing (compared to some other cancers). But how slow is slow? Having been diagnosed with an “aggressive” form of the cancer, it took six months to “act” at which point the initial diagnosis of a localised tumour i.e. confined to the prostate gland, was “upgraded to locally advanced, and further scans then “upgraded again to metastatic, outside the normal area treatable with wide area radiation. Is this because the cancer had progressed in the nine months or so since first diagnosis or because it is moving faster than the correct treatments can be identified

Just how does Prostate Cancer spread from inside the Prostate

What makes Cancer aggressive

When a hospital order a post mortem, they should tell the relatives why. And they should meet the relatives afterwards to explain the findings. Instead of it all being handed over to the coroner.

How can side effects of chemo especially hair loss be prevented?

If I have breast cancer can I breast feed?

What questions do you ask the consultant when you see them every month. It is hard when you know very little about the topic, and the progression of the disease when every one is different and you do not want to frighten yourself when you look at the internet

I can’t get to grips with pelvic floor exercises, is there anything else that can help me with bladder control.

I am still using pads 3 months after having my operation is there anything that can be done to reduce/stop my incontinence?

How can patients and their carers find out what is available to help them and them access them?

Why immunotherapy is ineffective according to the degree of cancer classification.

How realistic is metastasised treatment for advanced cancer.

Why are men aged 60 or over not automatically offered a PSA test?

Diagnosed with Prostate Cancer and given radiotherapy then aged 65. I ask if it is true that the average survival rate is approx 10 years

How are survival rates calculated?

Recently completed pace that, psa dramatically dropped to 1.6. Will it rise?

After successful treatment what happens if one’s PSA goes up again?
What are the possible treatments available if prostate cancer comes a second time?  
How will my chemotherapy treatment affect my nutritional needs, and how can I ensure that my needs are met when I have problems with nausea, diarrhoea and or von anorexia?  
What services are available for family/relatives following the death of a loved one?  
How do I know I am receiving the best treatment?  
What innovative treatments might be coming on stream and how can I access them?  
How can I go about hunting for a job if after having leukaemia I don't want to go back to what I used to do. Will people still want to take you on if they know you might get your cancer back at anytime and allow you out of work for all the appointments you still have to go to.  

Some of my side effects seem trivial. Is there someone you can ask about them without having to wait to see or bother the consultants.  
I have survived 2 brushes with breast cancer; DCIS and invasive. I am a person who "needs to know" so I would appreciate being told what my statistical chances are of surviving into old age. I am 74 yrs old.  
I have 2 daughters and I would like more information on what health screening is available for them; both in their 40s; and also how it can be determined whether they have a genetic tendency to developing breast cancer.  

How can I have control over my end of life care and death?  
What are the chances the same thing could happen to our children?  
If you suffer from low grade Non-Hodgkin follicular Lymphoma is it inevaluable or potentially dangerous to take herbal remedies like Echinacea?  
Is it potentially harmful for lymphoma sufferers to drink diet fizzy drinks as some articles intimate that it is?  
is the NHS planning to use freezing caps to help prevent hair loss during chemo.?  
After a auto SCT is the immune system still compromised and can you have a second auto graft if you relapse?  
What benefits are available to cancer sufferers and those in remission when you've lost your job  
How can patients with ongoing hair loss post treatment for leukaemia be supported to find hair loss solutions  
If the patient and relatives ask for time to consider the treatment options how is this recorded in the notes?  
Due to only being 30 doctors are reluctant to start any form of treatment other than medications. Why is this?  
Can regular help be achieved for routine chores such as shopping, when patients are housebound?  
Who can help me with financial support and tell me what benefits I can access?  

Is there a specialised cancer care mental health service?  
What are the chances of returning to work?  
How easily would it be to create a "one stop shop" for the latest research findings on cancer or have a contact who could provide a "fast check" re latest research findings to stop "reading the web"?  
What trials or studies can those living with and beyond cancer take part in to help the medical profession which has helped us so much, to help others, short of actually searching for such trials, is there any way to register my interest and willingness to join?  
Are there any regular blood tests that I could pay for privately that might act as an early indicator of cancer (particularly melanoma)  
Will there still be continuous support from the NHS while living beyond cancer?  
Raised liver function results... do they preceed liver cancer?  
What are the chances of returning to work?  
How can patients who cant go back to work get benefits?  
Where does one find support to help ones adult child with Special Needs/ Autism?  
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Where does one find support to help ones adult child with Special Needs/ Autism?  
Who can help me with financial support and tell me what benefits I can access?
Who ensures admission to national guidelines, such as the BNF, as far as prescribing medicine goes? P
Does the treatment for Prostate Cancer also treat any areas it could have spread to? P
You often hear of Prostate Cancer spreading to the bone, is it possible for it to spread to other organs / parts of the body? P
What treatments are available to me & how much input do I have on choosing the right treatment to suit me? P
My case is with The University Hospital North Staffordshire. Q. Will the oncologist be fully versed regarding latest research and, therefore, would my consultant be in a position to advise me on future treatment options based on current thinking? P

Q. What is the expected duration for the ongoing hormone therapy? P
Does the therapy impact blood clotting? R
Will I get cancer if you have a enlarged prostate? R
If so what is the treatment? R

Can you have your prostate removed if it’s enlarged? R
Does taking opioid painkillers such as codeine whilst on tamoxifen affect how well tamoxifen works? Do all opioids have a similar effect on tamoxifen, or are some more or less likely to affect how well it works? P
What long term effects work for? P

What vitamin deficiencies are likely after removing the duodenum? Are we prone to b12 deficiency? How many develop bile acid diarrhoea? For soluable vitamin deficiencies? Doctors are too reactive, waiting until deficiencies have already developed before providing any supplements. P

likelihood of developing diabetes? And what sort of diabetes - type 1,2 or 3? P

I had pancreas cancer and then had a Whipple operation followed by chemo. What should I eat/drink to ensure that I absorb all the required nutrients and vitamins after my operation? P
I had pancreas cancer and then had a Whipple operation followed by chemo. How much Creon should I take with my meals? P
I had pancreas cancer and then had a Whipple operation followed by chemo. Should I take a PPI e.g. Omeprazole? P

How best to help a partner cope with living with a ‘death’ sentence. A bit dramatic, I know, but having cancer means that one loses what will kill one and appropriately when rather than it being a random event. R
Is testosterone supplementation safe? P
How can artificial testosterone be administered to enable spontaneous rather than contrived intercourse? P
Where can I get support for side effects of the treatment? P

On you keep having cystitis on a regular basis? P
Is the use of medicinal cannabis oil likely to be approved for cancer patients? P

How long will jaundice work for? P
What are the different types of radiotherapy and why do they use that type on me? R

Does dark nail varnish stop your nails peeling during chemo? P

Why is there no register of doctors who specialise in treating long term side effects of cancer drugs? P
Agent acting as an involved patient I read the leaflets associated with medication and realise that these are really produced as a back covering exercise for pharmaceutical companies. How is a patient to understand the impact of medications like antibiotics on germs conditions? P

Why aren’t there more support groups for bladder cancer, and how are support groups set up? FR

Why after 5 sessions of ONCOTICE treatment have they stopped it? FR
Aren’t making the correct progress after my surgery? R
What are the different types of radiotherapy and why do they use that type on me? R

Does dark nail varnish stop your nails peeling during chemo? P

If I have a recurrence, what issues will any future treatments bring? P

How can I maintain health and wellbeing be supported? P
How to assist with private education when the cancer patient is the money earner. R

How common is parastomal hernia? P
Is there a national database which can give information on social, emotional and psychological support available? P
What will the end be like for me with my present multiple cancers? P
When and what can I do exercise wise when having treatment? As told to avoid gym and pools due to infection - what are the other options? P
How do you manage other people’s comments which sometimes add to your fears? P

Your loved one or maybe a colleague or fellow school parent or friend is being treated for cancer. What are the things that you can say or do that are actually helpful? P
What are the side effects of having a hysterectomy on your body, physically, what damage can occur during the surgery i.e. Hip problems? P
I have been diagnosed with uterine carcinosarcoma. There is literally no easily available information about this. My question is that information on this rare form of cancer is urgently needed. P

Dealing with your partners emotional distress when you barely have the energy to hold it together yourself? P

Lack of confidence - Dealing with the worsening weaknesses in your body after being quite fit for your age and the lack of confidence this brings (e.g. Your leg going out with no warning and landing in a heap on the ground and unable to help yourself up). P

What provision is made to support families manage their finances and cover the costs of post cancer treatment? R

My mental stability seems to have changed considerably to the point where I do not recognise myself and my feelings, could this be hormone related as the oestrogen is being artificially restricted? P

How many people live more than 5 years with lung cancer? R
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>Is it true that once a nodule is cancerous, all other nodules in the lung will eventually turn cancerous? And why?</td>
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<td>what is flare up or exacerbation? And what do you do about it?</td>
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<td>Given that relationships can fail with the effects of a cancer diagnosis, how can they best be sustained and renewed after cancer, particularly when fatigue and depression may be issues?</td>
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<td>I’ve had a double mastectomy and I find it very difficult to find bras that are comfortable with my scars and don’t ride up and are affordable, can anyone suggest any company to contact to help?</td>
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<tr>
<td>Can I struggle with lymphedema in my left arm and I can’t find anything to help with the pain and discomfort? I’ve tried banks of different sleeves including ones that include the hand they are all painful. The doctor has given me painkillers but they don’t touch the pain? I have also tried reflexology and massage which is pleasant but the pain and the swelling return within hours. Has anyone got any suggestions as to what might help?</td>
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<td>Can you get help at home?</td>
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<td>What benefits can you get?</td>
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<td>Can you get help with depression?</td>
<td>P</td>
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<td>How soon should you return to external and what exercises are safe when recovering from major abdominal surgery, should you wear support to prevent hernias?</td>
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<td>Even though I have been &quot;signed off&quot; by the Oncologists are further checks done on you to make sure cancer has not returned?</td>
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<td>How do I tell my family the truth? or possible truth?</td>
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<td>How do I help myself cope in between tests to see if the cancer has waned?</td>
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<td>In light of evidence demonstrating health care professionals should be encouraging vigorous exercise to improve survival rates, are we not?</td>
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<tr>
<td>How can I cope with having a rare brain tumour and not being able to research it and its pattern of growth and how it takes different types of treatment? I have a rare central neurocytoma.</td>
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<td>When do I have to try to be on remission?</td>
<td>P</td>
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<td>What treatment is currently available other than chemo and radiotherapy?</td>
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<td>How does the medical team balance the priorities of “getting the numbers down” with rescinding side-effects?</td>
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<td>How likely is it I have children after chemotherapy? (I am a 40 year old woman, two years after last chemotherapy for oesophageal cancer).</td>
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<td>What were the benefits of of before starting cancer treatment?</td>
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<td>What can my workplace do to support me after returning to work after cancer treatment and what are my rights?</td>
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<td>How can I ask for my path of care re-assessed.</td>
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<td>How do I support myself financially?</td>
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<td>Are there local support groups in one's area?</td>
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<td>What was your experience of going through remission?</td>
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<td>Is Scottish research as good as British, European or worldwide research?</td>
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<td>Is there a way that we can publish the public how their donations to charities like are spent on research?</td>
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<td>How can patients access research on differing preventative approaches?</td>
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<td>In whom can I turn for practical day to day support if family can't cope?</td>
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How long does it take to get over the physical effects of my prostate removal?

What support / training is available to patients who can no longer do the job they

How do you de-jargon the terminology?

What effect do hormone injections have on prostate cancer?

Would you like to know who is the responsible health professional for your own care of

the patient? Feel that after treatment you seem a bother so you do nothing

Reporting and analysis of rare cancers in statistics of survival and quality of life.

Often cancer types are not even broken down into rarer sites e.g. head and neck

cancer and extremely rarely do we see head and neck sub-types such as salivary

gland cancers

What if patients are doing well and don't want to attend Health and wellbeing events and Cancer Care reviews?

If I have a relapse, what treatments could I expect to be available, and will they be effective? (M0)

Why doesn't every cancer patient have a genetic profile, including analysis of their

cancer for future reference, given the emphasis on developing targeted treatments that may yet come to fruition...?

Dealing with comments from clinicians that 'you look well' when I am describing

my symptoms/edema or am able to walk about in hospital compared to much

older patients as if not taken seriously due to the efforts I've made to regain fitness [and steroids making me gain weight and appear well]

How to relate to some people who don't seem to know how to treat me as a

person anymore since cancer diagnosis

My mouth is vulnerable to bacterial and fungal infections following intensive

radiotherapy. I find a salt mouthwash twice daily works wonders, and I now only

experience soreness if I forget the treatment. However, this has never been

recommended by professionals as, I am told, research has not been carried out,

which might support this. If research did support it a lot of people might benefit

from a simple, safe and cheap treatment

Head & Neck Cancer patients, especially Laryngectomies, often wish to make a

suggestion or a complaint but so often there emails go unanswered by the

professionals. It is not known who to approach. And there is a fear that it might

derogate their future treatment if they make too much noise about anything.

How can this best be rectified and how can the patients be reassured?

How long can someone keep taking chemotherapy tablets for four tumors which

cannot be operated on?

Taking antidepressants: what happens when you gradually come off them does it

come back?

What suddenly happens to the body immune system when someone dies of cancer in how does it happen so quickly and why suddenly does one get an

internal bleed

What is the cumulative effect of TURP and radiotherapy, in terms of impotence?

Where can support be found to deal with these issues?

Why is there not a full scan/examination at the end of treatment?

How can you support a relative who has previously been diagnosed with cancer who is

waiting for tests results to find out if the cancer has returned?

What support will I get emotionally?

Is there any chance that my bowel cancer will affect my lung cancer?

What support will I get financially?

How can this best be rectified and how can the patients be reassured?

Do people get enough information about support groups in their area?

Where do people with learning disabilities diagnosed with cancer get support and

information? Do they use opportunities such as Macmillan information centres and Maggie’s? Do they rely on carers to provide support and information? This question comes from some initial discussion in the North East and Cumbria where the Macmillan and Maggie’s had not had any people with a learning disability use services.

What reasonable adjustments are available to support people with a learning

disability manage UNMC?

How do the public find out About the most up to date research about cancer?

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What support will I get financially?
If my consultant can't answer my questions to my satisfaction, who else can I turn to? P
How can I best prepare myself for possible side effects of cancer treatment and where do I find this information/support? P
How do you cut through the mass of information that is found online and separate the right from the wrong? P
What is the best way to approach telling family & friends you have cancer without them instantly thinking you will not survive? P
Do I give up work? P
Can more be done to 'coach' those that require colostomy/bags after surgery? R
Getting patients involved with research, e.g. my mum had vaginal cancer which I understand is very rare - but there appeared to be no interest in her apart from as a patient H
More about the inherited/passed on nature of cancer - e.g. doctor's suspect my mum's cancer was due to an STI she had years before I was born - what is my risk? R
Are RFA and cryosurgery available under NHS for treatment of metastases after first ACC treatment and if not why not and what alternatives exist or are likely to exist over the next decade? R
How do I explain this to my family? RH
How do I deal with the reactions/feelings of close family and friends? H
Given that the statistical chance of having cancer is higher if one has had a cancer already, how could I access periodic "whole body" reviews to detect any other new cancer early and hence enhance the chance of beating and surviving the new cancer? P
As a sibling of a cancer patient and a health care professional I am unsure of what questions to ask her to help her manage her condition/return to work/living life without feeling patronising or lacking in compassion. RH
How long can people stay in hospice care? P
Will I be able to return to breastfeeding my baby after surgery for cancer? And if so, can I have help to maintain my milk supply until then? P
What are the risks/effects on my unborn baby of diagnostic tests for bowel cancer whilst pregnant? P
What are the risks (to both mother & baby) associated with remaining pregnant once diagnosed with a cancerous bowel tumour? P
I need more help in understanding when to move to supportive care and stop treatment with long term blood cancer. FR
Where do I get help for counselling/mental health, help adjusting to life living with cancer? P
Are there differences between the brands of Tamoxifen and causes of side effects? P
Do employers, friends etc ever get over you having cancer? Are you constantly treated like a victim? P
I experienced 3 specific terrifying mental episodes during chemo, NOT depression, but some sort of drug episode. My doctors dismissed it. What was it? P
What already exists in the local area that people can access? H
Lots of the Cancer support groups do great work running support groups/courses for their patients but it still seems quite hard to find out about these courses Do they give enough info to people should one central organisation coordinate all info about local courses/help available? To make it more easily accessible For example if you go onto a MacMillan website you will find loads of info on how you can help them/Trek Himalayas/ volunteer etc but no info on local support groups? Again this info would have to be collected into local geographical areas P
Is it okay for breast cancer patients to vigorously exercise their arms after axillary node surgery? RH
Why are neuroendocrine tumours/cancer not included for funding from CRUK? My family gave money on the assumption that Nets were included in research funding. R
My husband died of cancer 7 years ago and I learned him through the chemo etc. He was very poorly. I now have cancer and have no surviving relatives to take care of me. I have therefore refused any treatment as I don't want to end up in a care home earlier than I need. What else can I do? FR
Since the Meals on Wheels service is no longer there, I am living on ready meals from the Supermarket as I am too ill to cook. Any suggestions PR
After a prostatectomy which was followed by a session of conformal radiotherapy, my PSA levels have steadily risen to 22 now. If PSA readings can only come from prostate material, why am I getting such readings when the prostate was removed and was followed by the chemo? P
I would like to ask about the support available for couples where the person with cancer has become infertile due to cancer treatment and the postcode lottery for the availability of free NHS IVF treatments? P
What drugs are on the Priority Buying list for specific cancer? P
Do I have the right to request a second opinion from a centre of excellence? FR
Can I request an MRI scan if I haven't had one? FR
Support with practical things like continue to work and financial matters w/fip and five large organisations. R
Help for relatives when they say they did not need any, my husband/carer is very depressed even though I am now well but will not admit this or seek help and when I have asked for help on his behalf I am told 'if he doesn't ask he cannot get any' P
Where can you get information from about eating well when you have cancer? P
Where can you find out what new drugs are available in your area or what new drugs are available to the patient? R
What medications and supplements can you take with your medications/chemo/therapy or not? E.G Turmeric supplements need to be avoided with Breast Cancer and avoiding herb supplements with Tamoxifen / Anastrozole. RH
Why are the investigations different for each cancer diagnosis, eg. MRI/CT scans not for all? RH
What follow-up tests / examinations are there for patients once given the 'all clear'? U
Why is Britain lagging behind rest of Europe in survivorship, and what should we do?

Who monitors internationally all the research into breast cancer?

Where can I find specialist counselling to help me to cope with my diagnosis?

To what extent is urinary retention a problem following a radical hysterectomy for cervical cancer?

When should a patient be assessed/start treatment for lymphoedema resulting from treatment for breast cancer?

There are so many charities working for cancer patients. I don't know how many of these are actually benefiting cancer patients or their families. I lost nearly everything when my teenage son was diagnosed with cancer. Now that he survives, after going through all these experiences, and amputation of leg, he has to face educational and his parents' financial difficulties.

Why chemotherapeutic agents are the same as they were 25 years ago?

What experiences can a breast cancer survivor expect from pregnancy and childbirth?

Lack of energy and tiredness due to nausea is most disconcerting. Is this due to radiotherapy / damage or continued hormone injection?

Thinking about work age patients, are employers making allowances for hospital appointments? Not all employers give time off for such appointments and I know of patients who have to take annual leave to attend outpatients.

Why is post cancer care so bad in UK? Why don't we learn from other countries?

Why is it that UK is 25th out of 27th on table of ratings for European hospitals for cancer?

Why are other countries better in helping cancer survivors to handle long term side effects for cancer treatment?

How do you measure financial impact of a service development? Both impact on Patient experience. Secondary care costs including a and e. Primary care costs, patient costs, other cost.

How are the different needs of young adults recognised and met during and post treatment?

How do you measure financial impact of a service development? How soon will new treatments be available?

What new treatments are in development for primary bone cancer?

How soon will new treatments be available?

What are the prejudices faced by young adults with cancer: in the work place and the home?

How do we support those from the younger generations for health and wellbeing?

What impact of being diagnosed with cancer as a young adult.

How are the different needs of young adults recognised and met during and post treatment?

Which of these are actually benefiting cancer patients or their families. I lost nearly everything when my teenage son was diagnosed with cancer. Now that he survives, after going through all these experiences, and amputation of leg, he has to face educational and his parents' financial difficulties.

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How do we ensure that there is enough community psychological support after treatment for Teenagers and Young Adults?

What are the long term (worldwide) effects of moving to more targeted therapies?

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Somatic issues. Massive education issues.  "Oh my friend had ‘cancer and they’re doing really well now’. Thanks but was it leukaemia? ‘Oh at least your hair hasn’t fallen out’. Nevertheless I am going to die without a transplant. And the worst thing are charities - with the possible exception of Macmillan - with their happy clappy positive campaigns. Being positive does not improve cancer survival.  
(There’s a large US study of over 40K people that disproved the positive connection to cancer survival.  

The biggest pain is not when the person dies. There is deep down a release from the pain (both yourself & others) but specific the patient is pain is filled.  
Afterwards the pain begins slowly at first then it becomes the most acute pain you have ever experienced in the empty days ahead knowing you won’t see them again. It’s a hole in your heart where the emptiness can never be filled.  
Side effects of the disease and treatments some of which occur much later than the treatment date.  
Better coping environments during and after treatment.  
Long term survival research rather than cure could be done  
What about returning to work post treatment?  
Why have my doctors surgery not put up any leaflets or posters that I have taken to them?  
There is nothing in my surgery relating to Blood Cancer - why not?  
What support would be beneficial to help with survivorship?  
Psychological/financial/social/physical/OT/SALT/dietetic  
Is it normal?  
Course of treatment  
What are the steps to developing cancer services so that they reflect the needs of people with cancer who use them and leading to good shared decision-making?  
Linked to this is the way research is developed: which may at present rely too much on pharmaceutical companies’ priorities rather than people’s real needs.  
How do I get through the confusion and anger *(DIAGNOSED AS A CHILD)*  
Issues regarding support for post cancer treatment issues e.g. In my own case renal cancer,  
why don’t I get any when telling you about your problems?  
I often find the effect of positive support bottom of like ‘nothing can be done to ease pain infections content etc.”  
unable to tell you when diagnosed long term effects of treatment  
Is there anything I can do to make my issues more able to cope with?  
Support and encourage all patients to be enrolled in inexpensive follow up studies (like the University of Washington Core Study) as a default with opt out option and share findings with participating patients.  
Does the treatment age your body or is it the drugs that are given that can be highly additive to relieve certain symptoms of the treatment?  
How to control your symptoms better with medication.  
How long can you live?  
Statistics of how long you can live on average with a certain cancer  
Shower survival rates for Breast Cancer and other cancers.  
I want effective treatment for secondary cancer that even if the diagnosis is terminal gives a good quality of life for whatever time left.  
Who delivers more effective care: primary care or secondary care?  
Who delivers more cost-effective care: primary care or secondary care?  
Who delivers better patient experience: primary care or secondary care?  
Whether patient and cancer diagnosis can be linked more widely to GP and hospital records to look at long-term effect on health, with attention to appropriate control groups.  
If doctors don’t know how to deal with issues, say it. Don’t ignore what parents have to say they see their children every day & know exactly what is happening. Ask them questions. Don’t leave patients & parents in limbo.  
If doctors don’t know how to deal with issues, say it. Don’t ignore what parents have to say they see their children every day & know exactly what is happening. Ask them questions. Don’t leave patients & parents in limbo.  
Person my daughter & I were told she had 3 months. I knew she did not have 3 months but no doctors or staff asked me why.  
The diagnosis.  
The treatments  
Is there any research regarding subcutaneous abscesses resulting from diverticula in a defunctioned rectum becoming infected and resulting in a fistula and abscess and why this can happen?  
WHAT PROVISIONS ARE BEING PUT IN PLACE FOR THOSE PATIENTS LIVING FOR YEARS WITH ADVANCED CANCER WHO ARE RESPONDING WELL TO MONOCLONAL ANTIBODIES?  
How to take the profile of radiotherapy for patients and clinicians, and make it an attractive prospect for AHPs and clinicians to want to specialise within?  
What problems if any are you having  
How are you coping  
How would have been the single most important thing that could have been done to improve your QOL following cancer treatment?  
As a patient why are we told we have cancer - if we have no symptoms, we are well, there is no need for any treatment and no cure?   ‘Like many others, I was diagnosed with CLL following a routine blood test. I have been on Watch & Wait for 11 years. I would have preferred not to be told until I need treatment)  
How will research help deal with the many Side Effects of treatment? - Cure is not the end!  
How is research helping to improve the QoL (Quality of Life) post treatment?  
Once and for all, independent peer reviewed prejudice-free talks on nutrition roll on oncology. I know oncology institutions serving sugar drinks and croissants to patients on daily basis, others advise you to avoid too much sugar. Please, just some consensus  
The effect of workplace culture on supporting cancer patients to continue to work and return to work; and also on supporting carers  
Is the oncology workforce ready to deal with the needs of the ageing population?  
Practical help for patients who have been debilitated by the consequences of cancer treatments but are cured of their cancer
Why are there only limited funding, resources etc for this type of research?

How is the food/diet regime for these patients?

What type of interventions will reduce cancer inequalities and how can these be pursued/delivered?

How can transitions of care be improved between the NHS, social care and other agencies?

In past I was misdiagnosed and carried for 6 months TB. It felt like I had Aids. 2 years later I got cancer - people treated me differently is that normal.

I had test done family test high not I was under 50 what do people think about lowering the age 50 testing?

Why is the current model of care for cancer patients leaving so many with unmet needs?

How can we move away from a kind of blaming of people who have had cancer which is exacerbated by public health messages about prevention? It's not helpful for recovery.

Do cancer patients want to talk about their cancer - or would they rather forget it and carry on as normal.

How can we have a life beyond cancer when there is no cure for it - why are we side lined and brushed under the carpet?

What are my responsibilities as a patient?

How can we best support the NHS and ensure efficient use of resources?

Why is CLL not taken seriously?

Why is there no cure for CLL so there is no life beyond cancer - where is the help we need

Long term side effects after treatment

What do people living with cancer really want? A lot of my patients don't want to be constantly reminded of their diagnosis and just want to get on with life.

What helps people most when faced with a life limiting illness?

Charges and support given by NHS

When should quality of life be prioritised above quantity of life?

Managing the long term side effects post treatment, chemotherapy, radiotherapy etc.

How can these long term side effects be managed & treated?

How do we best support those patients with really poor prognoses, such as CUP (cancer of unknown primary)?

How can we best minimise and treat psychological distress and comorbidity?

Understanding of the tests

As the pharmaceutical companies are primarily interested in treatment and cure, how can we ring-fence research funds to properly investigate the effect of changing diet on quality of life?

What are the problem beyond cancer?

How can we help with these problems?

Containment or cure is the big issue

How to reduce iron content of regular blood transfusions in order to prevent iron overload?

What is the best way to identify what patients need?

What is the most difficult factor for you in returning to work, day to day living and resuming your hobbies?

What's the worst thing about living with cancer?

Why has there not been any research into CUP? There is no information to speak of that is in anyway satisfactory at present.

How can people be helped to feel as well as possible generally after cancer?

How can people be best supported socially if they have left work after cancer?

Will there ever be more options for fertility with a quicker egg freezing process

Could the cocktail of drugs that need to be taken be made easier, as you are often in a place where it's difficult to concentrate on what needs to be taken and when.

Although I had transport eventually I was unaware that this was available initially.

How can transitions of care be improved between the NHS, social care and other agencies?

What type of interventions will reduce cancer inequalities and how can these be pursued/delivered?

How can we have a life beyond cancer when there is no cure for it - why are we side lined and brushed under the carpet.

What helps people most when faced with a life limiting illness?

Charges and support given by NHS

When should quality of life be prioritised above quantity of life?

Managing the long term side effects post treatment, chemotherapy, radiotherapy etc.

How do we best support those patients with really poor prognoses, such as CUP (cancer of unknown primary)?

How can we best minimise and treat psychological distress and comorbidity?

Understanding of the tests

As the pharmaceutical companies are primarily interested in treatment and cure, how can we ring-fence research funds to properly investigate the effect of changing diet on quality of life?

What are the problem beyond cancer?

How can we help with these problems?

Containment or cure is the big issue

How to reduce iron content of regular blood transfusions in order to prevent iron overload?

What is the best way to identify what patients need?

What is the most difficult factor for you in returning to work, day to day living and resuming your hobbies?

What's the worst thing about living with cancer?

Why has there not been any research into CUP? There is no information to speak of that is in anyway satisfactory at present.

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How can transitions of care be improved between the NHS, social care and other agencies?
How can we make sure there's less prejudice towards lung cancer sufferers?

How can we make sure people don't start smoking in the first place?

Oesophagectomy

How can I help current and future patients recover from their operations

individuals LWBC and their carers

therapeutic yoga, mindfulness higher up the agenda of "treatments" beneficial to

How can we get more holistic therapies such as nature/garden therapy, workplace yoga, meditation, mindfulness, music, art therapy, and other therapies beneficial to patients and their carers?

Why does womb cancer not get more publicity/ its own awareness day? It is the 4th most common cancer in women.

From the moment I was diagnosed with cancer I had very good treatment but it came at a price. Pancreatic cancer patients need long-term care as other cancer patients do. What is my life span expected to be and how can I plan for the future? Will a cure be found for my particular cancer? How can professionals better understand the patient's experiences and perspectives?

How can we prevent swallowing difficulties after H&N treatment?

Dry Mouth after H&N treatment

Psoriasis: the type of cancer patients would find most beneficial

How will this affect our relationship?

What is the biggest concern for people living with and beyond cancer?

What are the best ways to support people with cancer and their relatives - not just in relation to the treatment but to the emotional and financial advice/support they may need?

What have I said that I could wait for the surgeon to have their summer holiday before I needed my surgery? I couldn't help wondering at what point a cancer will start to spread as opposed to not? I always felt my cancer could well have decided to go walkabout while the surgeon took their (perfectly entitled, I'm not complaining about it) leave. Thankfully, it didn't.

Are patients yet acknowledged as their own carers? I caused much head scratching and disquiet when I insisted I was my own carer too.

Relationships:

Continuous investment in research to help improve outcomes for recurring cases.

A year after finishing chemotherapies still not feeling well. Tired and having breathing problems had chest x-ray and that was fine. Was diagnosed with bowel cancer.

Why not listen to patients - and find out from us people who have bothered to find out how to help us. As far as I know, the doctors whom I mention above receive no help in funding their extra research to undertake to help us.

There needs to be more focus on rare cancers but because there are so many people who come forward due to it being rare, does this prevent research in these areas being a priority?

Why do you follow up questions exclude people with MPNs [leukaemias] from these areas being a priority?

How is it that people are not put forward for trials because of the way they are framed?

Why are some cancers so underfunded when it comes to research targeted therapy?

What are the interventions which will help people live well on immune and targeted therapy?

Why are some cancers so underfunded when it comes to research targeted therapy?

Another consequence of having radiation to my neck has been a jaw spasm with severe pain. At times when my salivary gland is stimulated with the sight and smell of lemon or chocolate the signal gets confused to a motor nerve response to cause cramping. Yawning can have the same effect. The pain is acute but fleeting, lasting around a minute.

Why are some cancers so underfunded when it comes to research targeted therapy?

I would like to know why there are no accurate statistics for long term survival for Ovarian cancer in Wales?

Why is sclc not researched as much as nsclc there seems to be a lot more for patients with lung cancer.

Why are so many Doctors want to focus on extending life as long as possible?

What are the long term effects of different cancer types on communication?

How to properly assist BME communities?

Are they still accepting of dietary advice post treatment

What information do patients want

Are there needs to be more focus on survivorship programmes

How to help patients who survive cancer - we currently don't offer any survivorship programmes

What support do children need when they're returning to school?

What are their needs to be more focus on survivorship programmes

How can we improve outcomes for children with cancer?

What are the most important aspects of care for people living with and beyond cancer?

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What are the most important aspects of care for people living with and beyond cancer?
I was diagnosed with cancer of stomach after complaining of burning pain in the stomach for a week. The pain was worse after a meal or a snack. I tried to treat myself by drinking milk and gaviscon because I thought I was developing ulcers. I suffered from stomach ulcers a long time ago.

I went to the GP. From my complaints and other medical history the GP decided to send me for investigations. Endoscopy and CT scan. The results were bad and shocking. I thought that was the end of my life. I imagined all sorts of things including the suffering from pain, death and my funeral. I also thought that there was a mistake in the diagnosis. The stomach was inflamed and cancer on a tumour. I was put on antibiotics to treat the infection first then referred to a specialist team.

The consultant surgeon who was going to treat me explained very well the state of the cancer and how I would be treated. This raised my spirits and hope. I developed a positive attitude towards the treatment and my life. My family was there for me throughout the treatment up to now.

Research seems to be ongoing across many areas but I

Why do no one believe that colonic resection for colon cancer can induce diarrhea?

How can quality of life be improved?

The ongoing side effects of treatment.

Many help with research.

Why did I get Cancer?

The feeding and process for it is usually acceptable place.

These types of cancers to appear in more forms than showing lists of cancers

Awareness of such cancers needs raising as a matter of urgency.

Fertility

When I left school with 2 A levels in biology and chemistry I became a Junior Medical Laboratory Technician. I first did a Pre -HNC course in Medical Laboratory Science.

When I completed this which involved spending 6 weeks in each of the medical health subjects I went onto to gain and complete a HNC in Med Lab Sciences in Histology and Cytology.

I was preparing to get married and changed to work in a Microbiology Lab in Histology and Cytology.

Health subjects I went onto to gain and complete a HNC in Med Lab Sciences in Histology and Cytology.

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<thead>
<tr>
<th>Question</th>
<th>Section</th>
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<tbody>
<tr>
<td>The use of kinesiotape in pain and posture reinforcement within cancer patients?</td>
<td>H</td>
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<tr>
<td>Why are patients sometimes told not to look up research and use the internet?</td>
<td>P</td>
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<tr>
<td>How can we minimise long term side effects of cancer?</td>
<td>H</td>
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<tr>
<td>What is the best time to attend an event, does this vary by site or diseases stage?</td>
<td>H</td>
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<tr>
<td>How do oncologists discriminate against old people?</td>
<td>R</td>
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<tr>
<td>How does the NHS manage to cope &amp; Care for the ever increasing amount of cancer patients?</td>
<td>P</td>
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<tr>
<td>When a cancerous tumour is removed how then does it spread to other organs or parts of the body?</td>
<td>H</td>
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<tr>
<td>Accessing personalised information and continuity of care</td>
<td>RH</td>
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<tr>
<td>What better research there is?</td>
<td>P</td>
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<tr>
<td>How important is occupation and what does that mean to patients and carers?</td>
<td>H</td>
</tr>
<tr>
<td>What has living with cancer improved over the years for patients?</td>
<td>H</td>
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<tr>
<td>Can't we stop the body from producing mutated cells once we know it is cancer?</td>
<td>R</td>
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<tr>
<td>How to help bloat and flatulence</td>
<td>H</td>
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<tr>
<td>How can information about clinical trials be best disseminated so that all relevant cancer patients are informed?</td>
<td>H</td>
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<tr>
<td>How can the post-effects of a normally treated patient be reduced?</td>
<td>H</td>
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<tr>
<td>What is the best way of supporting patients living with incurable but treatable &amp; asymptomatic breast cancer?</td>
<td>H</td>
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<tr>
<td>How can we best manage the side-effects of endocrine therapy in early breast cancer patients to ensure compliance, improve quality of life &amp; overall survival?</td>
<td>H</td>
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<tr>
<td>What support should be available 2 years + post treatment?</td>
<td>P</td>
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<tr>
<td>After treatment IMMUNE support is currently held in the hospital Can it be considered to offer support sessions in regional hubs, possibly Church or Community Halls which have facilities such as toilets for disabled and cafe facilities?</td>
<td>RH</td>
</tr>
<tr>
<td>Can it be considered to have peripatetic Advisory Staff visiting Health Hubs on a once a week, fortnightly or monthly basis to meet OUTSIDE of the hospital premises in such a Health Hub? Can such peripatetic advisors answer specialist questions about symptoms and what to expect regarding surgery, physical recovery, radio therapy, chemo, effects on diet, dietary advice, financial advice Can there be regular visiting speakers and sessions run by specialists for gentle exercise, nutrition, skin care , and those coping with financial implications, stress, anxiety, loss and isolation. Body and Mind therapies CBT Alexander Technique Reflexology CranialSacral Acupuncture, Massage Reloc/Healing, Mindfulness, CBT, Counselling</td>
<td>RH</td>
</tr>
<tr>
<td>It would be good to find out the quality of life once in order to gain a few extra months, would it be better to go for quality rather than quantity?</td>
<td>R</td>
</tr>
<tr>
<td>If over 80% of those diagnosed with a primary brain tumour die within 5 years, why has research into brain tumours been given such a low priority by the NCRI and larger cancer charities?</td>
<td>R</td>
</tr>
<tr>
<td>If brain tumours are the biggest cancer killer of children and young adults under 45 yrs old, why is so little being spent on research by the Government and larger cancer charities?</td>
<td>R</td>
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<tr>
<td>In a recent report on recurrence it says cancer can lie dormant for years. What is the plan for those who have already gone through this hideous disease?</td>
<td>P</td>
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<tr>
<td>What outcomes matter most to patients living with and beyond cancer?</td>
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<tr>
<td>Please look at all the projects/questionnaires already started in France by this organisation - they seem to try to answer what I feel I would like to know <a href="https://www.sentinelles.com">https://www.sentinelles.com</a></td>
<td>P</td>
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<tr>
<td>What reduces chest pain?</td>
<td>H</td>
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<tr>
<td>Better Chelation therapies</td>
<td>P</td>
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<tr>
<td>Faster access to drugs</td>
<td>P</td>
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<tr>
<td>Better and greater research into low risk MDS</td>
<td>R</td>
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<tr>
<td>Having lost both mother and father to metastatic cancer - father to prostate and mother to breast - how close are you to finding a cure and what advances have been made?</td>
<td>P</td>
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<tr>
<td>Exercise is so important</td>
<td>P</td>
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<td>Accessing personalised information and continuity of care</td>
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<td>Why are we offered support with counselling but never any feedback with our concerns? More upsetting than anything</td>
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<td>Are there any new developments for the treatment and cure of cancer?</td>
<td>P</td>
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<tr>
<td>Support for the patient once discharged with long term side effects from the cancer treatment</td>
<td>P</td>
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<tr>
<td>Managing longer term treatment effects</td>
<td>H</td>
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<tr>
<td>Management of Endometriosis</td>
<td>H</td>
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<tr>
<td>Management of cachexia</td>
<td>H</td>
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<td>What do you mean by a cure?</td>
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Questions about causes of cancer

- Is there any less invasive ways to find microscopic traces of cancer?
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- What kind of tests can be carried out on eventual metastasis?
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- How can we prove efficiency and effectiveness and influence future care?

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- Importing new research into existing survival, with a view to preventing whether there are communalities of benefit others, especially the exceptional early succumbers?

- Is there any less invasive ways to find microscopic traces of cancer?
- Can limb salvage methods be improved, to retain maximum muscle mass, so aiding post-salvage recovery and long-term function?

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- What are the best methods for coping with the physical effects of the condition before treatment, such as how to deal with the discomfort of swollen tender and painful lymph nodes?

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- How do the different treatment options for renal cancer (surgery, radiotherapy, watch & wait) compare in terms of bowel function, sexual function and overall acceptability to the patient?

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- How to identify accurately if cancer had metastasized?

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- The experiences and support of LGBT individuals with cancer

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- What prophylactic approaches can be put in place to prevent disability or loss of quality of life caused by serious or frequent infections?

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- Can primary bone cancer be addressed through other site research?

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- What is the effect of exercise on cancer survivors?

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- How can we reduce the cost effective of treatment of cancer?

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How can prostate cancer be more accurately identified?

More research into oesophageal cancer and its causes, especially in younger people and regions other than London.

What is the actual impact of the FNH on breast cancer? Why are people not made aware of it at the time when its so readily prented and even encouraged.

What caused my cancer?

I feel that I have always looked after myself and been health aware as a health professional and that I was given a HRT medication that triggered my triple negative breast cancer. I don't have breast cancer in the family except one cousin who had dcis. I feel when I mention this to nurses etc. It is dismissed. I only had one application of Gynest but it certainly fits in for me as I have never taken any hormones in my life prior to this. I feel this is a very dangerous product and could affect more women. Please look into this to prevent further devastation of lives.

I went through a very tough divorce and wonder if this contributed to me getting breast cancer?

My mother died of ovarian cancer aged 70; my maternal grandmother died of multiple myeloma aged 60; my maternal aunt died of lung cancer aged 70; my father died of lung cancer aged 78 after being cured of bowel and skin cancer. I am aged 57 and go for all mammograms and cervical screening when called. Am I at increased risk of getting cancer with my family history. I do not have any siblings.

What causes Brain Tumours to grow?

Does being overweight (rather than obese) increase your risk of developing a cancer?

Is there a link with the teaching profession and cancer?

Is there a link with nonsteroidal anti-inflammatory drug use and cancer?

Is there a link between excessive consumption of meat spirits etc. (brandy, whisky etc. in, say, one's twenties, and the development of Barrett's Oesophagus turning into oesophageal cancer later in life?

What caused my cancer to develop and who?

Was it inevitable that I would develop cancer?

Is there a link to lymphomas and HIV? Can it be passed on genertically?

Cause of disease.

Looking at the genetic links and familial risks

Genetic links and risks. Breast cancer at 10 yrs of family history but tested negative for lynch so told not genetic. But I think that it may be a differnt gene defect that is not identified so could my children still be affected?

How soon will it be possible to get an answer on if familial CLL is genetic and could be tested for?

Is any research being undertaken to find out if there could be a link to the development of brain tumours in patients who have served in the armed forces? My elder brother and I were diagnosed with similar brain tumours; he died as per his prognosis e.g. 12 months. He served via NAAFI with the Royal Navy for 30 years. I served for 8 years with the Royal Navy and 22 years as a Reservist.

I would love to know if there was anything I could have done or avoided that would have led to me NOT getting cancer.

What triggers a cancer which has reached NED on scans to start growing again?

How do brain tumours begin and what causes them?

What caused my cancer? Was it stress, smoking, diet, lifestyle?

Does diet or lifestyle contribute to getting cancer?

Is any research being undertaken to find out if there could be a link to the development of brain tumours in patients who have served in the armed forces?

How can diagnosis be speeded up

Would PET CT scans be helpful in diagnosing cancer of the stomach?

Are there any other ways of diagnosing the presence of cancer more accurately

Can more support be given to educating GPs in detecting at an earlier stage the first signs of cancer?

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More accurate and quicker diagnostic process.

I was mis-diagnosed as having Mantle Cell Lymphoma and treated as such, receiving CHOP chemotherapy. It is only transpired that I had CLL after moving and then being re-diagnosed at Mount Vernon Hospital. They could not understand why I was still alive after more than 10 years. I am still alive after 16 years but my experience with GPs has generally been disgusting. Should they have more training in recognising potential concerous conditions?

In my experience the symptoms of CLL were/are unknown at the local GP level. Why is the diagnosis of CLL so difficult, i.e. why aren't blood tests compulsary at a regular diagnosis.

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In people who have brain tumours can accelerating diagnosis reduce the risk of progressive brain damage?

When will an early detection method be produced for pancreatic cancer?

When will G.P.s be quicker in diagnosing pancreatic cancer

What is it the first appearance?

Why couldn't You find out sooner?

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How did I contract the disease & what advice is available to best avoid 'catching' cancer

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Does referral to palliative care services prior to symptom development improve treatment and improve the odds of survival?

Are paraneoplastic syndromes underdiagnosed?

Why does many GPS not recognise symptoms of bowel cancer and make referrals for further investigation?

How to diagnose brain tumours earlier (rather than only when a seizure or other major symptom occurs)

How to get an early diagnosis?

Why wasn’t my Neuroendocrine cancer (NETs) sooner? Although the symptoms were present for years, it eventually needed emergency surgery to save my life. Now I will live with the consequences of metastatic cancer for the rest of my life.

When the diagnosis was made my one fear was a partial oesophagectomy. It is important that symptoms are believed and an early diagnosis is made in order to avoid major surgery. Can research produce a more refined test for the diagnosis of adenocarcinoma of the oesophagus?

To stage cancer more quickly

Find an early detection test for pancreatic cancer

Why isn’t genetic screening offered to females as soon as possible from the date they are sexually active?

I had a scan on my breast, which showed a fibroglandular growth. Why is it that I’ve had to turn to google for answers as to what this is? And secondly, why are we no follow ups for this despite a history of breast cancer in my family. I’ve not been offered genetic screening either despite my maternal grandmother being young when she was first diagnosed and I still have a lump in my breast.

When will there be an alternative to bone marrow biopsies in order to diagnose stage lymphomas? An alternative to trephining would be very welcome!

Differences of a diagnosis in childhood and adulthood

Has any research been undertaken to find out if the onset of a brain tumour could be picked up during routine eye check ups? Prior to my sudden illness, during a routine eye check up an Optician, he noticed something at the back of my right eye, which he was concerned with. He didn’t know what it meant, so made a referral to the NHS for a specialist check up (Preston Hospital). At my hospital appointment, the person who conducted the check up identified something that concerned him and had to leave the room to consult with someone else. I was subsequently given an appointment to see a Specialist. Over the following several years the appointment to see the specialist kept being cancelled at short notice! A few days prior to the onset of my first tumour, my wife noticed a yellow substance appearing from the tear duct of my right eye. As a result of the above, I do wonder if the potential development of my brain tumour could have been picked up at a far earlier stage.

Did you feel your GP was well-informed about your genetic disposition to bowel cancer?

Why are links between endocrinology and cancer not explored or strengthened:
certain small details of people’s medical history could provide clues or relevant information but don’t seem to be explored routinely at all. They aren’t captured as relevant to allow further research and that feels like a thick is being meshed in terms of finding more early warning signs.

Better understanding of how early detection of kidney cancer can be achieved. It’s diagnosis often happens once it’s too late.

As my cancer was discovered by screening (I have a BRCA2) but I had no symptoms yet had cancer in both breasts - my concern going forward is that people like me have a higher risk of other cancers too but there is no screening for anything other than breast. Therefore my question is - ‘would people like me benefit from a whole body scan at perhaps 2 yearly intervals’. If so what type of cancer would be most useful.

Would early diagnoses and prognoses be improved by full body MRI at primary cancer diagnosis?

When will an early diagnosis test be developed for pancreatic cancer?

Do those with a caring role present later with their cancers? and if so how can we support cares better in a time when carers are getting older in an ageing population?

How can we improve early detection of cancer? My cancer was not identified until it was locally advanced. Should we start to be tested routinely for various cancers using circulating tumour cells?

My GP misdiagnosed my case as a slight infection - once pushed for an MRI, subsequently given an appointment to see a specialist. Over the following several years the appointment to see the specialist kept being cancelled at short notice! A few days prior to the onset of my first tumour, my wife noticed a yellow substance appearing from the tear duct of my right eye. As a result of the above, I do wonder if the potential development of my brain tumour could have been picked up at a far earlier stage.

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What is the likely progression of my NETs with Lanreotide injections?

How to overcome professional death anxiety so they can talk more openly about this with patients?

How often do oncologists use euphemisms for cancer and death and what is the impact on patients and families?

How do we deal with grief after losing a loved one to cancer?

How should I be supported if I am diagnosed as terminal, what support services should be offered to their families?

Should there be more support available for families of those who have lost someone to cancer? This includes all types of support from help with wills and paperwork, emotional support to help with maybe moving, downsizing etc.

How will I know that doctors are offering me the best possible end in terms of pain and comfort?

It’s really important to me that I don’t die in pain. My question would be. Would you prefer at the end of your life to be spared a painful death?

Do bereaved carers want to support other people faring less and does it help with their grief?

What is the best way to support elderly people who choose to remain at home without treatment for a terminal cancer diagnosis?

How can we reduce unnecessary hospital admissions for patients reaching the end of their life?

Dying with dignity as a general question but also with specific emphasis for LGBTQ+ people.

How do we improve access to healthcare for those with terminal diagnoses? (On a diagnosis of 2-3 months to life, we were still told the only available GP appointment. Was in 30 days - if we wanted a referral letter to a different hospital)

Counselling for terminally ill patients

Counselling for family once patient is deceased

Support for loved ones after a cancer patient has passed away

Counselling for a terminally ill patient

Many cancer survivors are elderly. What should we be considering as they move towards non-cancer-related end of life care from a position of living well-with-cancer, especially when late recurrence is frequent cause of death?

Questions about cancer prevention

What interventions should education in schools be including to ensure a healthy immune system as much as possible? NB, I might have my wires crossed here!!

Are not currently available (to me), what can I do, or who can help me improve my immune system as much as possible? NB, I might have my wires crossed here!!

Immunotherapy seems the way forward for some cancers, given that such drugs are not currently available (to me), what can I do, or who can help me improve my immune system as much as possible? NB, I might have my wires crossed here!!

Is being given a poor prognosis a self-fulfilling prophecy? If you believe that your going to die in one year for example does it make it more likely to happen or is death time out of the patients control?

How often do oncologists use euphemisms for cancer and death and what is the impact on patients and families?

What could have prevented me developing cancer?

How can the risk of my children being affected by the same cancer be reduced?

If we all regularly took immune boosting medications would this prevent cancer developing?

Much is done to alert parents to the dangers of the sun on children’s skin. Adults developing?

What is the criteria for treatment to move to Palliative - Pain relief only care. It sometimes seems to be the easy option taken by oncologists. Whilst my husband was in Guy’s hospital with advanced prostate cancer, there was another man in an opposite bed with throat cancer, we heard his family being told exactly the same as what we had been told, palliative care, reasons why etc etc. Different cancer but same words and explanations. We were astonished. Sometimes it seems the oncologist sign up rather than the patients... The moment you take away hope and go to pain relief only, it is little wonder the cancer is allowed to spread and become terminal. Palliative care assisted suicide but with pain.

Why is the information emphasis put on care rather than prevention again?

What is the likely progression of my NETs with Lanreotide injections?

How long will the Lanreotide work in slowing down NETs?

If prevention is better than a cure, effort should be put into prevention surely in the long run it would save money?

Why is there not more emphasis on prevention and support in the NHS in order to reduce/negate their risk developing ovarian or breast cancer.

What can my blood relations do to reduce their chances of having my cancer if it is hereditary?

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Questions about cancer prevention

What interventions should education in schools be including to ensure a healthy future generation in their older age?

How can the risk of my children being affected by the same cancer be reduced?

If I can genetically programmed to have cancer mutations/family members who died with cancer are there steps I can take to lessen my chances of getting cancer again?

What can try blood relations do to reduce their chances of having my cancer if it has a genetic component?

I am BRCA 2. If I would be good if when my relatives were screened for this genetic mutation there was then something they could do - other then radical surgery - to reduce/negate their risk developing ovarian or breast cancer.

What risk do my blood relatives have? What can they do to prevent cancer developing?

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some patient trials next. Could we be looking at e.g. genetic testing to see if there are commonalities amongst the women who live longer after (in this example) a breast cancer diagnosis.

How to measure any improvements in length of life (after palliative chemo for 37%) and balance this with toxicity of treatment

Does treatment for cancer - chemotherapy and radiotherapy - whilst treating the cancer: ultimately shorten your life.

I would like to know how far we are from curing all types of cancer

What is the efficacy of using cannabis oil after chemotherapy - to help kill cancer cells. Would like to see

A cure for myelodysplasia is needed, other than a bone marrow transplant, for the elderly.

of the currently ineffective drugs?

If every cancer patient was given vitamin D supplements, to a high level, would very fatalistic (understandably) view about it and this often seems reflected in the

Innovative ways of managing and treating stage 4 cancer; there seems to be a

How to treat metastatic pancreatic cancer, particularly in the liver.

Will there be more research into Lung Cancer? Still one of the most common of

a baby after treatment ends? And what are their survival rates?

disease. It so often shows no symptoms until advanced.

areas?

What progress has been made with some of the rarer cancers e.g. pancreatic, brain etc.? What advances have been made for targeted treatments to these areas?

Will there have been any advances in the treatment of this small, rare disease - it so often shows no symptoms until advanced.

What is the evidence that improved psychological wellbeing extends the life of people 'recovering from cancer'.

What is the effect of multiple drugs for comorbidities on the effectiveness of primary cancer drugs.

Is the period between initial visit to a GP and the diagnosis of cancers reducing?

Is ongoing TSH suppression necessary for patients who have been successfully treated for myeloma.

Well obviously I would like a cure

have not seen the disease before and two relatively short series of anti Myeloma

NEWS: After a month in hospital which could have been avoided by the GP who called 999. I did not do so as the NHS was stretched. This was a STUPID move on

Is the period between initial visit to a GP and the diagnosis of cancers reducing?

Is the level of the expectancy after the mean forecast has been reached i.e. 75% chance of living 10 years? What happens once the 10 years has been reached, as you have been discharged to the oncology department by then. Is life expectancy then back to the normal levels?

How can treatment of cancer be personalised?

whether a patient’s attitude to life has an effect on their survival rates

What are the benefits of taking cannabidiol oil as a natural treatment (non-pharmaceutical) to assist with pain reduction, improve sleep and contribute to treating cancer?

Access to information about your cancer treatment and options appears to operate on an individual location basis. How can it be fixed so that everyone receives the same information and support irrespective of where they live?

Whilst I appreciate the professional concern about going-estimated life expectancy and the many variations, the most prudent and concerning problem is estimation of the remaining life upon following diagnosis.

Realistic choice of treatments available.

Other than tiredness and night sweats, I would not know that I have a CLL problem. Is there any likelihood of reversing the white blood cell problem that is the root of the diagnosis?

What effective treatment for myeloma is there?

What psycho-social barriers might there be to people accepting or being fully compliant with active treatments e.g. distance from the treatment centre, social support, finances?

WILL THERE EVER BE EARLY TREATMENT FOR PATIENTS WITH CLL STAGE A incurable cancers like leukaemia, how important is cost in the final decision on treatment.

Why are some cancers given such low priority for treatment

How can the healthcare systems provide a clear explanation of the survival statistics in relation to the patients personal condition? As opposed to bland assurances!

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What’s my life expectancy?
How long does the hormone therapy control the cancer and what happens when it stops working? Do breast cancer patients have any chance of complete remission? Is there a correlation between historical tumour markers and current tumour growth?

How much does hormone therapy reduce the risk of clinical recurrence? How much benefit do I get from neoadjuvant radiotherapy in rectal cancer? How to weigh up treatment options when a patient is diagnosed with a rare form of disease, or one that differs from the norm?

What treatments can be developed to address genetic syndromes, like Lynch? What are the priorities for treatment from the patients’ perspectives? How can we improve the quality of decision making for patients with musculoskeletal tumours?

How to treat brain cancers more effectively with drugs/chemotherapy? What is the prognosis when you don’t complete the number of chemo cycles due to side effects? What is the prognosis when you don’t complete the number of chemo cycles due to side effects?

Is there any chance of a complete cure for grade 4 cancer within the next 25 years? What treatments can be developed to address genetic syndromes, like Lynch?

For women facing a much higher risk of breast cancer as a result of Hodgkin disease who are diagnosed with cancer, what is it all about our treatment that gives us such a poor outcome?

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What is the lowest dose of treatment required to kill the cancer but minimise damage to other cells?

What is the best treatment? Still too many unanswered questions.

What is the most effective treatment? Triple therapy or hypobaric? I had triple therapy for 18 months, but it didn’t work and I ended up having surgical treatment.

What are the main drugs that can help?

Better identification of patients who will receive benefit from different therapies and those that will not.

Why Cancer is controllable in some patients and others not, despite similarities in illness, staging and treatment etc. What makes the difference.

Are all treatments post surgical intervention necessary e.g. chemo and radiotherapy? Who would and wouldn’t benefit.

Would my survival odds have been very different if I had chosen not to have surgery and radiotherapy? Who would and wouldn’t benefit.

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<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
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<tr>
<td>Explore in more detail why/what is facilitating super responders to respond to treatment</td>
<td>P</td>
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<tr>
<td>Is staying positive in attitude and thought and feeling likely to help a cancer patient fight the cancer better than someone who doesn’t stay positive? Is there any real substance to these ideas? Does positivity act as a ‘medicine’?</td>
<td>P</td>
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<td>To what extent does ‘maintaining a positive attitude’ contribute (or not) to improved clinical outcomes?</td>
<td>P</td>
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<td>Who much work has been done around exploring the fatalistic attitudes of some groups of patients with diagnosis where there is a very poor prognosis? We see that there is often a very different approach to seeking additional support services for people with a lung cancer diagnosis as opposed to women with early stage breast cancer. Perhaps this is another factor which impacts on quality (and perhaps quantity) of life post diagnosis.</td>
<td>D</td>
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<td>How important is a positive mental outlook to survival rate</td>
<td>II</td>
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