



The Yes to Life Charter for Oncology

'Love as the guiding principle for cancer care'

yestolife.org.uk





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01 Introduction

In the world of healthcare, where the delicate balance between science and compassion plays a pivotal role, the 'Yes to Life Charter for Oncology' aims to bring an inspirational vision for the evolution of the relationship between oncology professionals and patients.

We are in an era marked by remarkable human and medical advancements, and a rapidly-evolving understanding of the intricacies of oncology. To counterbalance this progress, this Charter presents a transformative blueprint for a modern, empathic, and caring approach to cancer care, dedicated to meeting the diverse needs of present and future patients. At the heart of this document lies a commitment to usher in a new era of genuinely patient-centric care within the NHS.

Grounded in the belief that every individual unfortunate enough to receive a diagnosis of cancer deserves not only cutting-edge medical treatments but also unwavering empathy and support, the 'Yes to Life Charter for Oncology' seeks to redefine the standards of care in the oncological arena.

The Charter is more than just a set of guidelines; it is a manifesto for change. It envisions an NHS cancer service that seamlessly integrates the latest advancements in medical science with a compassionate and humanistic approach that will radically improve the experience of cancer care and support patients in meeting the immense challenges of coming to terms with a life that will never be the same. To achieve this, we must transform cancer care to extend well beyond clinical expertise, to encompass a deep appreciation of the emotional, psychological, and social dimensions of the patient's experience.

Yes to Life 2024



Hope



Empathy



Aspiration



Respect



Trust



Open Mindedness

02 About Yes to Life

Our Mission

We provide information to guide people with cancer through the confusing options for care. Our aim is to help them make informed decisions.

With our holistic approach, Yes to Life emphasises the importance of the mental, emotional and spiritual state of those with cancer. Along with physical needs, we feel these should be considered as central to any treatment programme.

Rooted in 20 years of experience working with people with cancer, we know it is vital that everyone seeking options should be empowered to make their own health decisions.

We also believe in the benefits of a positive approach. Of course, a cancer diagnosis is frightening, but instead of talking about 'victims' and 'battling with disease', we feel that forward-looking optimism is crucial. We have seen the realistic hope that results from gaining access to information, and from being empowered to explore your individual needs and make your own choices to manage your condition, as you see fit.

Our role is to help people to decide what they want to do to help themselves – by providing information and referring them to qualified experts – and then to support them in their chosen path.

Yes to Life empowers people with cancer to make informed decisions about their care options. For two decades now, we have provided evidence-based information to those in need.



**We empower
people with
cancer to
make
informed
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about their
care options.**

03 The NHS Constitution for England

Principles that guide the NHS

Seven key principles guide the NHS in all it does. They are underpinned by core NHS values which have been derived from extensive discussions with staff, patients and the public.

An excerpt of Principle 4 is highlighted below, chosen and quoted to contrast with the material shared by patients on the following pages:

4. The patient will be at the heart of everything the NHS does

'It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers.'

NHS values

There are six 'values' set out within the NHS Constitution. Patients, public and staff have helped develop this expression of values that inspire passion in the NHS and that should underpin everything it does.

Three of these values are listed below as a reference against which to evaluate the importance of this Yes to Life Charter for Oncology.

Respect and dignity

'We value every person – whether patient, their families or carers, or staff – as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits. We take what others have to say seriously. We are honest and open about our point of view and what we can and cannot do.'

Compassion

'We ensure that compassion is central to the care we provide and respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for patients, their families and carers, as well as those we work alongside. We do not wait to be asked, because we care.'

Improving lives

'We strive to improve health and wellbeing and people's experiences of the NHS. We cherish excellence and professionalism wherever we find it – in the everyday things that make people's lives better as much as in clinical practice, service improvements and innovation. We recognise that all have a part to play in making ourselves, patients and our communities healthier.'

Important Note: Although the above excerpts have been drawn from the NHS Constitution for England, it is our intention that this Charter be equally applicable to all parts of the United Kingdom.



04 The Charter

The Yes to Life Charter for Oncology sets out the charity's aspirational vision for the qualities that will underpin a modern, empathic and caring NHS cancer service that will meet the needs of current and future patients.



HOPE

Respecting every patient's choice to hope

Hope is intrinsically bound up with the will to live and a critical predictor of both quality of life and longevity.

The certainties of 'no hope' or the dangers of 'false hope' often cited in oncology are inaccurate and deeply unhelpful.

'Reasonable hope' in the face of fear and uncertainty is a precious commodity, a human right that deserves respect and care.



EMPATHY

Helping patients to feel as safe as possible

People diagnosed with cancer are, in most cases, in the most difficult and vulnerable position they have ever found themselves, and they need and deserve enormous care in the way all communications are handled, and particularly in the way their findings are delivered.

Oncology staff must strive to understand the emotional experience of their patients, and to send them away feeling as supported, optimistic and cared for as possible after every appointment.



ASPIRATION

Supporting patients in becoming 'exceptional'

Every patient deserves to aim for the best possible result, and should be strongly encouraged to do so – after all, there are no guarantees in cancer care, and their life is on the line.

The public are increasingly aware of the growing evidence that exists for the crucial role of lifestyle interventions in easing symptoms, enhancing quality of life and contributing to a more successful outcome, and specialists can capitalise on their unique position to encourage them to strive for the advantages that these approaches can offer.

All patients should be supported in wanting to be 'exceptional' patients.



RESPECT

Understanding what matters most to each patient

A cancer specialist's role is to offer their expertise for their patient's benefit, while at all times respecting their autonomy and individuality.

They must never lose sight of the fact that it is the patient who will bear the long-term consequences of treatment choices.

The specialist's role is to listen and understand what matters most to their patient, and any approach that is safe and that could help in some way (physically, emotionally, psychologically, spiritually) must be respected and supported.

Faced with an existential threat, patients need all the encouragement they can get, particularly when it comes to efforts to help themselves.



TRUST

Becoming a trusted ally

Faced with immense challenges, patients need to feel that oncology staff are on their 'team', looking out for them and for the best possible outcome at all times.

This requires clinicians to be interested in, and respectful of, patients' efforts to save their own lives.

A climate of open sharing and trust must be fostered and encouraged in order to support the best outcome and avoid patients withholding information or taking risks.



OPEN-MINDEDNESS

Wellbeing takes much more than good medical treatment

Cancer is not well understood and therefore the ways of supporting recovery are also unclear.

Oncology has much to offer, but so do many other specialities, as do patients and carers themselves, who often become experts on their own condition.

A willingness to embrace the uncertainties of their own profession positions clinicians alongside their patients, supporting them in facing an uncertain future.

A 'team effort', involving a wide variety of support, benefits patient experience and outcomes.

HOPE

Respecting every patient's choice to hope



Hope is intrinsically bound up with the will to live and a critical predictor of both quality of life and longevity. The certainties of 'no hope' or the dangers of 'false hope' often cited in oncology are inaccurate and deeply unhelpful. 'Reasonable hope' in the face of fear and uncertainty is a precious commodity, a human right that deserves respect and care.

In the past, patients were denied the facts about cancer and placated with 'you'll be fine' stories, avoiding the use of the C word entirely. This played perfectly into the patient's, and their family's, understandable hopes, but often ended in feelings of utter betrayal, once it was realised that time had run out, and all opportunities to explore other avenues of therapy were lost.

Thankfully this approach is largely in the past, but what has come to replace it is, tragically, little better. A brutal 'honesty' that confuses statistics with facts and leaves no room for hope is also unrealistic and unkind, and for many can utterly crush their spirit, generating hopelessness, apathy and depression. Even in the most difficult of circumstances, if bad news is delivered with care and empathy, our natural response to adversity can cause the spirit to rally and make the best of things. A massive challenge can induce a massive response, both in a patient and in their family, provided a flicker of 'reasonable' hope can be maintained.

While this may well have a direct effect on the outcome, it will certainly bring a completely different quality to whatever life remains. It must never be forgotten that some people do come through even the most adverse situations, and their own will to live tends to be the key element in motivating them to hope for an extraordinary recovery, rather than anything medicine can offer.

Therefore it is crucial that 'reasonable hope' is respected and supported, even a one percent chance – to do otherwise is to abandon them to a 'certain' fate – an awful, isolating and dehumanising experience. To respond in this way has nothing whatsoever to do with promoting 'false' hope, but is directly in line with our finest qualities as humans in wanting the very best for others.

Quotes from oncology patients

"I asked if I could do anything at all to help my situation such as diet, off label drugs, supplements, and was told they all would make no difference to me and not to bother. "There is no evidence." I am 39 with 3 young children trying to stay alive and this left me in a state of frantic despair."

Jenny, Sheffield

NB: There is in fact a wealth of evidence both for individual integrative treatments and for the integrative approach as a whole[1]

[1] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9740147/>

"I asked what the statistics were for recurrence. "Oh it will come back. It does in nearly everybody." Devastated. It took me months to get over it. I needed to hear a statistic not a cheery 'Oh nearly everybody.'"

Cally, Bristol

"I discussed changing my diet to help heal my cancer. "It doesn't make any difference. Cancer is like a pregnancy, once it's inside of you it just grows and grows." I asked if it was ok to eat burgers and milkshakes, his response was "Yes, eat what you want - it actually sounds quite nice." Irresponsible response. Even if they don't believe in what I'm doing, to encourage an unhealthy diet is irresponsible and unprofessional."

Kate, Huddersfield

NB: Studies into the Blue Zones of the world (the healthiest places on earth) confirm that diet and lifestyle are key factors in the regulation of our health.[1] Studies on the CYP1B1 enzyme, which is highly upregulated in cancer, show that it converts compounds found in food, such as resveratrol found in grapes, into cancer-fighting compounds[2]

[1] https://www.bluezones.com/2017/05/okinawa-diet-eating-living-100/?fbclid=IwAR1y-Jz7LRc6g9Oe4vkA9ez-alZgtwdD1OtZ1Tvz_4ZnDqT_sW8XORzHgY

[2] <https://www.nature.com/articles/6600197>

"I had done a ton of reading into taking an integrated approach, such as eliminating sugar, taking supplements, oxygen therapy, vitamin C therapy, cannabis oil, etc. I was told there is no proof that any of these things helped and there was no evidence regarding sugar and cancer; eat everything I can - chemo is the only way. I felt like there was no hope. I felt in my heart and soul these things would help me, but was totally dismissed and made to feel worthless. I became very depressed and felt victimised by them. I left in tears, felt like why bother even trying to live through this if they couldn't help me with how I wanted to be treated."

Sarah, Swansea

NB: Studies confirm that excess processed sugar intake can fuel cancer.[1]

There is a plethora of research indicating that these therapies have efficacy against cancer, eg Intravenous Vitamin C[2]

[1] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1126321/#>, <https://www.sciencedaily.com/releases/2017/10/171013103623.htm>

[2] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9231292/#:~:text=This%20tumor-killing%20phenomenon%20is,therapies%20%5B38%2C39%5D>

"It wasn't a response to a request, more a proclamation on what my chances were: 'There is nothing you or your wife can do.' Then he stalked out of the room leaving us with a startled registrar."

Jeff, London



EMPATHY

Helping patients to feel as safe as possible



People diagnosed with cancer are, in most cases, in the most difficult and vulnerable position they have ever found themselves, and they need and deserve enormous care in the way all communications are handled, and particularly in the way their findings are delivered. Oncology staff must strive to understand the emotional experience of their patients, and to send them away feeling as supported, optimistic and cared for as possible after every appointment.

Excellent processes and procedures, whilst crucial, are possibly not as important as skilful communications when it comes to delivering care for chronic conditions. Our NHS was developed at a time when acute health incidents were the most pervasive threat, and clearly the need for sensitive communications is far lower in a situation of emergency life-saving care. The healthcare landscape has since altered drastically, but appropriate adjustments in the style of care have lagged well behind, retaining an outdated bedside manner of clinical detachment and ‘doctor knows best’.

Patients are highly vulnerable, and while there may still be a few who look to be simply told what to do, on the whole society has moved away from this type of relationship, and the listening ear of a caring professional who can share their experience and knowledge in an empathic way will provide a greater degree of confidence, while playing an important role in reducing the immense stress involved in a cancer diagnosis and subsequent treatment.

Few are aware that PTSD – commonly associated with war experience, sexual abuse, or a serious accident – is extremely prevalent amongst those with cancer. So a mechanistic system of care with little room for emotion or individuality is highly unsuited to this vulnerable population, and will leave them feeling further damaged by the experience of healthcare that is intended to help them.

Put simply, people with cancer are in need of love, expressed through care and optimism. We need to draw from our oncology teams the very best of humanity in order to fulfil this challenging role. This is going to require commitment, a team effort and deep cultural change, but the rewards of a move to increase empathy in cancer care are potentially immense for both patients and staff alike.

Quotes from oncology patients

I just find most of the oncologists I have dealt with over the past year completely uncaring and uninterested in the bigger health picture. They breeze in and breeze out again. Most of them are aloof and standoffish. Only ONE youngish oncologist is lovely. The rest of the team I have no time for. The head of the department, I doubt would know her patients if they dropped dead in front of her, she is that high and mighty.

Debbie, Oxford

"With regard to the prognosis, he said 27 months on average, with no concern, empathy or sadness in evidence. And no indication that he felt he could have done a better job. He barely looked at me during this exchange, looking at his notes more. Once he'd imparted such devastating news he left, and that was the last I saw of him."

Jill, Clatterbridge

"I was told I had cancer so flippantly, with no nurse for support. "You have cancer; you will have to have a mastectomy, chemotherapy and radiotherapy." It has left me so afraid of going to this clinic. I get high anxiety in the waiting room."

Carrie, Stockport

"Not once have I been asked how I'm feeling about my diagnosis or if I need any emotional/psychological support."

Elaine, Huddersfield

"On my very last appointment with him, before I started with my new oncologist, it was very intense. I had made up my mind not to get into conversation with him, just to get him to review treatment which had just ended and leave. But he was clearly expecting me to say something as to why I was swapping, and it took the wind out of his sails when I didn't. I got up to leave and in one final comment he said "Oh by the way your hair isn't ever going to grow back." I was stopped in my tracks and the nurse looked mortified. I turned looking pale, and at that moment I could see he realised no one had told me that gem of information. He backed tracked, but I told him point blank that I thought his manner was appalling."

Molly, Exeter

"Her last words were that she knows who she is and she is looking after 900 patients and does not have time for 'difficult' patients like me."

Hilary, Maidstone

This was not what my dad wanted. Very upset. He shouldn't have gone through that in his last few days. This doctor had no skill or empathy in dealing with family members during a very distressing time. He totally disregarded what my dad wanted and implied that we wanted my dad to be in pain.

Penny, Derby

I said I'd been stubbing my toes and feeling off balance due to peripheral neuropathy and wanted information about when it might improve. She responded "You signed the paperwork". I was stunned. I actually didn't understand her to begin with.

Frances, Bristol

I felt she didn't listen to me and didn't care about how symptomatic I was.

Susie, Tunbridge Wells



ASPIRATION

Supporting patients in becoming 'exceptional'



Every patient deserves to aim for the best possible result, and should be strongly encouraged to do so – after all, there are no guarantees in cancer care, and their life is on the line. The public are increasingly aware of the growing evidence that exists for the crucial role of lifestyle interventions in easing symptoms, enhancing quality of life and contributing to a more successful outcome, and specialists can capitalise on their unique position to encourage them to strive for the advantages that these approaches can offer. All patients should be supported in wanting to be 'exceptional' patients.

There is a subgroup of 'exceptional' patients who achieve results towards the top of the the bell curve of the average, or occasionally completely beyond it. In the past these were simply labelled 'spontaneous remissions' and attracted little interest. This has changed in recent years, and research has revealed that the remissions are nearly always far from spontaneous.

They involve sustained and focused intention by the patient, and a broad range of lifestyle and complementary interventions, and occasionally unconventional use of mainstream medicine.

Every patient deserves the opportunity to aim for the top end of the bell curve, but this will require their sustained commitment. The enthusiastic support of a cancer specialist can make a world of difference here, and so it is absolutely crucial that the inaccurate belief that it is the oncology team alone that can affect the outcome – which leads to patients being advised to 'leave it all to the experts' – is dispensed with entirely.

Many lifestyle interventions that have been scientifically shown to be helpful are inexpensive or even free, so it is in every patient's best interests that these should be brought to their attention, to increase their chances of a successful outcome, and – critically – to provide them with life-enhancing motivation and hope.

Quotes from oncology patients

"I asked about chemosensitivity testing. "There's no evidence it works in human bodies. Yes, I can help you take bloods, but I wouldn't waste your money. It won't change what treatment I give you."

Pauline, Bristol

NB: It has long been appreciated that while chemotherapy treatments may be effective for some, they are wholly ineffective for others with the same disease. This has prompted the development of chemosensitivity testing to support the avoidance of useless and damaging treatment and to help guide oncologists towards more effective solutions[1]

[1] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8596271/>

"I have found the oncologist just tells you what the next treatment is they will offer. No discussion, no questions really answered. It's totally shocking for a 43 year old man to be so let down by (apparently) the second best lung cancer unit in the country. Maybe we should have gone to the the first... but I have heard that isn't any better."

Carl, London

My Oncologist responded "If there would be anything that would help with cancer I would know. The only thing I believe in is exercise. Everything else is a waste of time. Most patients go after antioxidants, but you can forget about it."

Brigitte, London

I went to a clinic abroad on several occasions. After returning from the first visit, she asked me what I had out there. When I mentioned the vaccine made from my own blood, she commented "Oh, you are a glutton for punishment!" After another visit I said "It would be really helpful if you could liaise with each other" at which point her face darkened and she said "We do not even work from the same premise!" So that was my sign - to shut up and not bring it up again. Fortunately I am strong enough to make my decisions regardless of her opinion and will continue to do so. Really shows the massive gulf there is between conventional and complementary treatment."

Lily, Oxford

"I asked if I could do anything to help myself. "No - I would urge you to go home and enjoy your life. Eat cake, drink, do what makes you happy. I will take care of the medicine, nothing else will make any difference." Initially it upset me, then it made me angry. Now I do lots of things which I know help me and I don't share any of these with my oncologist for fear of ridicule and for fear of being marked as a 'difficult' patient. It was my first formal appointment following a secondary diagnosis. In the same appointment the oncologist also told my mother that she wasn't her patient and her questions weren't important."

Nora, Milton Keynes

NB Nutrition is the cornerstone of health, as evidenced by the Blue Zones of the world, the healthiest places on earth[1] It should be noted that oncologists receive a rudimentary few hours' training in nutrition in medical school, so are not qualified to provide dietary advice[2]

[1] https://www.bluezones.com/2017/05/okinawa-diet-eating-living-100/?fbclid=IwAR1y-Jz7LRrc6g9Oe4vkA9ez-alZgtwdD1OtZ1Tvz_4ZnDqT_sW8XORzHqY

[2] [https://www.amjmed.com/article/S0002-9343\(14\)00308-8/fulltext](https://www.amjmed.com/article/S0002-9343(14)00308-8/fulltext) <https://www.theguardian.com/society/2016/oct/19/doctors-know-too-little-about-effects-of-nutrition-and-exercise>

"To my question about whether I could do anything to improve my chances beyond 27 months, he said no, there was nothing I could do."

Jean, Clatterbridge

"I asked about making an impact on disease progression with diet and supplements. "Don't worry, just make sure you keep your weight up. Don't stress about it. Whatever you do don't spend thousands of pounds." I'm amazed the NHS is still adopting this position, and the advice in the official guide to neutropenia (eat small chocolate bars, crisps, scones etc) is incredible."

Cora, London



RESPECT



Understanding what matters most to each patient

A cancer specialist's role is to offer their expertise for their patient's benefit, while at all times respecting their autonomy and individuality. They must never lose sight of the fact that it is the patient who will bear the long-term consequences of treatment choices. The specialist's role is to listen and understand what matters most to their patient, and any approach that is safe and that could help in some way (physically, emotionally, psychologically, spiritually) must be respected and supported. Faced with an existential threat, patients need all the encouragement they can get, particularly when it comes to efforts to help themselves.

Along with empathy, respect is an essential building block of trust. Every oncologist knows this – that if a patient doesn't respect their skills and knowledge it makes the task of helping them almost impossible. A trusting partnership is built on mutual respect.

The conviction the specialist may have concerning the best way ahead may not always be exactly shared by their patient. While this is frustrating when wanting to do one's best, it is crucial not to lose sight of every person's individual right to make their own healthcare choices – for themselves, as they see fit. It is their life that is on the line, and it is they who will bear the consequences of treatment choices, even if they choose to fully accept the recommendations of the specialist.

Maintaining respect for personal choice is central to the NHS Charter, and if this can be achieved, then an ongoing open dialogue is possible, which holds the potential to lead to more compliance towards the specialists' recommendations, as trust in the relationship increases.

Furthermore, many patients nowadays will want to engage in a range of proactive lifestyle strategies to combat the serious side effects of treatment and to help work towards a healthy future. Although these are not incorporated in NHS guidelines, most are almost entirely safe, and the areas for genuine concern are very limited. Given this, any 'blanket' ban on lifestyle or complementary approaches, however well intended, is quickly read by the patient as an indication that the specialist is not on their 'team', that they don't really care about their experience or the outcome. This leads to mistrust and rapid waning of respect.

By showing due respect for a patient's efforts to help themselves, and by making an effort to accommodate as many of their own suggestions as possible, trust will grow exponentially, and a far safer environment for the patient will be generated, in which they are honest and open about their ideas and will far more readily accept and appreciate the genuine concerns around a particular lifestyle intervention.

Quotes from oncology patients

"No explanation, no discussion or negotiation - just a point blank 'No.'"

Iris, Milton Keynes

"I asked my oncologist whether my cancer would be hormone driven, about metabolic pathways, fatty acid synthesis, ketogenic diet, ferritin levels, vitamin D and vitamin B levels, thermography, detailed functions of PARP inhibitors. Most of these questions have been dismissed by smiling and not answering or high level answers with insufficient detail. Other questions she brushed off saying she does not have time for these irrelevant topics."

Aileen, London

"I got more and more frustrated and annoyed as I was looking for a conversation with content, but I was treated and silenced like a five year old child. I got so upset days before every appointment and my stress level has been up to maximum every time I had to go and see him. I also have been crying in his rooms, and he even ridiculed me for crying in front of his PA."

Fiona, London

"My first oncologist told me that "Mr Google can kill. Don't tell me you are going to cure your cancer with coffee enemas." I hadn't even mentioned that topic. His lack of empathy was evident. I tried to speak to his young registrar but she was clearly frightened by him. He doesn't like anyone that stands up to him."

Rose, Wirral

"I was never allowed to answer questions, but the oncologist used all his time to talk about his private life such as his holidays, racing horses, his other businesses... This has been the tone of conversations for over 8 months. I cannot describe all his insults and dismissive behaviour, but my impression was always that this person is beyond care. He even ridiculed me in front of his PA, for my wardrobe, asking her "would you wear this?"

Joy, London

"I was asked if I was on any medication. After much deliberation I said "Not things you'd class as medication.... supplements and vitamins." "Oh those insignificant things." he replied. In the next breath he told me to stop taking them before my operation, to which I replied "When they are so insignificant?" He dismissed my confidence in my research, made me feel I was worthless. This interchange made me disrespect the clinician and decide never to share anything I am doing in the future."

Ellen, West Yorkshire

"I mentioned that I was considering contacting a clinic to discuss their repurposed drug protocol. He burst out laughing ... 'Oh I could say a thing or two about that. You should hear what me and my colleagues have to say about that lot. Oh I have to be careful what I say here,' still laughing. I felt dismissed and ridiculed. I was sharing my thoughts in an effort to have a collaborative relationship with my doctor, but it was made very obvious to me that she thought very little of what I was considering"

Angelo, Tunbridge Wells

NB: The protocol of repurposed drugs was developed and administered by conventionally-trained doctors, and has demonstrated a doubling of life expectancy in glioblastoma patients [1]

[1] <https://www.frontiersin.org/articles/10.3389/fphar.2019.00681/full>



TRUST

Becoming a trusted ally



Faced with immense challenges, patients need to feel that oncology staff are on their 'team', looking out for them and for the best possible outcome at all times. This requires clinicians to be interested in, and respectful of, patients' efforts to save their own lives. A climate of open sharing and trust must be fostered and encouraged in order to support the best outcome and avoid patients withholding information or taking risks.

If a cancer specialist shows disinterest in, or actively ridicules or dismisses a patient's clear ideas about how to aid their own recovery, then the message received by the patient is that this person is not on my team, they are more interested in just doing their job than they are in saving my life – they may even be my adversary.

The effect of a single activity that engages a patient's will to live and gives them a part to play in their own recovery cannot be underestimated – and this applies equally to something that is purely a psychological intervention. Unless such efforts are openly and actively supported, patient's will naturally keep information concerning other strategies they are pursuing to themselves, creating the unnecessary risk of complications occurring due to adverse treatment interactions.

The focus and concern of the specialist in relation to other interventions being considered by their patients should be solely in regards to safety – and a blanket ban on all other approaches, communicates not concern, but disinterest and disrespect. Careful consideration is required, particularly when there is strong scientific evidence behind the patient's interest, and provided there are no genuine safety concerns, then any proactive approach by patients should be strongly encouraged.

As in all walks of life, there are those who seek to exploit the situation of desperate and vulnerable patients by 'peddling false hope'. Nonetheless, patients must be trusted and respected to make their own informed decisions, and supported in exploring the therapeutic opportunities that present themselves with a critical eye.

Such activities will support a kernel of 'reasonable hope' that can result in a forward-looking, optimistic and hopeful day-to-day experience, and, occasionally, an unexpectedly remarkable outcome.

Quotes from oncology patients

"I asked about diet, whether any foods should be avoided or cut from the diet. The Oncologist responded: "Nothing makes a difference, just eat whatever you want". I will not ask them anything other than questions relating to conventional treatment. I will never again discuss diet, complementary therapies, alternative treatments etc. It is futile as they are stuck in the dark ages!"

Jilly, Sutton

NB: Contrary to this advice, processed foods and overconsumption of certain vegetable oils as well as processed sugars promote low-grade inflammation throughout the body, encouraging the development of chronic diseases such as cancer. Inflammation is one of the fundamental hallmarks of cancer said to drive the disease - eating whatever you want will likely exacerbate cancer progression[1]

[1] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10058108/> <https://health.clevelandclinic.org/5-foods-that-can-cause-inflammation>

"He barely looked at me, more interested in his notes. I still trusted him at this point; I realise with the benefit of hindsight that he was the worst type of oncologist, old-school, intellectual, ie not interested in me as a person, just as another statistic in his busy schedule; zero bedside manner, very difficult to obtain meaningful answers, because of course he had all the info, cancer was complex and I didn't need to know anything except what he was going to do to me."

Evie, Clatterbridge

"I said that I'd changed my diet as part of an integrative treatment plan. "Diet has nothing to do with treatment. It can help with prevention but nothing else." I was angry, as the same clinic had a research arm that is studying diet as both prevention and treatment of breast cancer. I fed back to the Breast Care Nurses and my surgeon in a feedback form about how no one had even mentioned diet even as a preventative and I've had to find out all the research information from their clinic myself."

Rona, Bath

NB: Apart from the negative associations between processed foods, inflammation and cancer, studies show that everyday organic food compounds show promise against cancer stem cells[1]

[1] <https://pubmed.ncbi.nlm.nih.gov/27609747/>

"Following this exchange and previous ones with this oncologist, where she either dismissed or ridiculed thoughts I had about treatments, I decided I'd had enough and sought a new oncologist."

May, London

"I asked him what he could do for me emotionally and nutritionally. He just laughed at me and said he could help me scientifically."

Evelyn, Bristol

"I asked for the Consultant's opinion of a clinic [run by conventional oncologists and doctors and delivering a programme of repurposed drugs to cancer patients]. He said they are 'Scammers!' I'm unlikely to discuss anything non-conventional with this particular doctor again."

Kelly, Harlow

NB: The protocol of repurposed drugs has demonstrated a doubling of life expectancy in glioblastoma patients[1]

[1] <https://www.frontiersin.org/articles/10.3389/fphar.2019.00681/full>



OPEN-MINDEDNESS

Wellbeing takes much more than good medical treatment



Cancer is not well understood and therefore the ways of supporting recovery are also unclear. Oncology has much to offer, but so do many other specialities, as do patients and carers themselves, who often become experts on their own condition. A willingness to embrace the uncertainties of their own profession positions clinicians alongside their patients, supporting them in facing an uncertain future. A 'team effort', involving a wide variety of support, benefits patient experience and outcomes.

The science of Integrative Oncology is rapidly opening up an increasing number of fresh avenues for patient support that, in many instances, are very unlike the disciplines traditionally associated with cancer care. Not the least of these is the now well-established arena of mind-body therapies, which places care for the mind and spirit on an equal footing with physical care. To a service built around the premise that healthcare means care of the physical body, this is foreign territory,

To embrace such concepts and science and thereby help patients gain the benefits they can offer, an attitude of open-mindedness is fundamental. Without needing to become experts in disciplines beyond their own, oncology clinicians must keep abreast of the development of promising and safe unconventional approaches – that will understandably be of interest to their patients – so as to be able to give accurate advice about any safety concerns in regards to interactions with their own treatments. It also needs to be appreciated that in the current climate of intense research, these will be moving targets.

A personalised programme of exercise, to give one example, can rival or even, in some instances, outstrip the capacity of conventional oncology to prevent recurrences, and will benefit almost every patient in some way.[1] So this is a low-risk, highly effective intervention that oncology specialists are ideally placed to recommend to practically every patient as a means to improve their own outcomes, even though the specialist will not deliver the service themselves.

This is equally true of many other therapeutic avenues, and there are a raft of expert practitioners, trained to meet the needs of cancer patients and to appreciate the safety concerns around oncology treatments, who can be signposted by organisations such as Yes to Life.

[1] <https://pubmed.ncbi.nlm.nih.gov/32239145/>

Quotes from oncology patients

"I asked about taking supplements whilst taking chemotherapy. "We don't want you to take any supplements, as advised by our specialist pharmacist, whilst on chemo or radiotherapy." Despite giving them full background on the supplement, which is rice bran and shiitake mushroom, I felt they didn't read the info or check on any database, but just said no."

Shayne, Sutton

"I was detailing the wide range of approaches I am employing to beat my stage 4 colorectal cancer: off label drugs, diet, exercise, stress reduction, supplements etc. My comments were mainly greeted with smirks and shrugs, before spitefully (I felt) telling me that my condition was 'incurable'."

Roger, Yeovil

"I tried to probe around different options eg delaying the start of chemo. My oncologist responded "If you don't have chemo straight away you'll be dead in a few months. Nothing you can do will make any difference. Just eat a balanced diet." She didn't listen to anything I had to say and dismissed all my questions as irrelevant."

Jane, London

"I asked the Oncology consultant about her opinion of the benefits of taking Iscador. She dismissed this treatment with a shake of her head. Her verbal response was that she would not recommend it as there was no evidence of it having any effect on cancer tumours."

Thali, London

NB: There have been more than 60 trials,^[1] and one involving 10,266 patients demonstrated significantly reduced treatment side-effects and a one third or more increase in 5-year survival

[1] <https://www.ncbi.nlm.nih.gov/books/NBK69731/>

"He added 'These drugs... it's not a trial, and there's no evidence these work.'"

Caroline, Bristol

NB: The study he was referring to is published, demonstrating a doubling of the life expectancy of glioblastoma patients [1]

[1] <https://www.frontiersin.org/articles/10.3389/fphar.2019.00681/full>

"Regards the ketogenic diet I got the response she would neither be interested in reading about it, nor would she know anything about it. However, within the same conversation she mentioned later, that the ketogenic diet has proven not to be effective in mice."

Vendra, London

NB: On the contrary, researchers found that 60% of mice on a ketogenic diet survived. This increased to 100% in those that got a ketone supplement in addition to the ketogenic diet. None survived on a regular diet

"I told my oncologist that my neuropathy in my toes has improved dramatically since I commenced medical acupuncture before chemo. The pain had practically disappeared. He said that was good news, because I would be able to have more rounds of chemo. I asked him if he wanted the name of the medical acupuncturist for his other patients with bowel cancer and he said "No." Just no. I was so sad to hear that as he is in the best position to know who needs this kind of help."

Holly, London



Important Note - regarding patient commentary

Whilst we appreciate fully that the examples of patient-clinician interactions we have included above are not representative of all such interactions, they are, however, far too common for us to ignore(*). One of our aims for our 20th Anniversary year is to build a library of positive interactions, and to that end we are launching a new section on our website which will give patients the opportunity to show appreciation for excellent support from their clinical team.

We hope this will help foster a move in culture towards the values set out in this Charter.

Below are some examples of patient responses that clearly reflect a good relationship with their care professionals:

"I felt comfortable having a conversation about my needs and the oncologist addressed my real concerns. Even when I discussed nutrition and supplements, I was not judged, rather I felt I was treated like a unique individual."

"The whole team, from the oncologist, specialist nurse and pharmacist were wonderful, they communicated with me well and involved me in all decision-making. I feel I can trust my clinical team."

"The doctor made me instantly confident in him and I feel happy that I can ask questions."

"Communication was outstanding and my online appointment... was very helpful... His care and compassion to my condition had set myself and my partner at ease."

"I came away from my consultation with the Doctor feeling really positive."

"Had very good communications with them and a lovely interview with the doctor, who was empathetic and put me at ease straight away."

"I am able to ask questions anytime and the consultation reviews are thorough and support my emotional as well as physical health."

"I feel that my doctor treats me with compassion and kindness. I find it helpful to obtain their opinion before I make decisions about changes that I might need to make to my lifestyle."

"... hope is a wonderful thing."

(*) A Yes to Life survey of difficult interactions between patients and their oncology team revealed that of nearly a hundred respondents, approximately half described their practitioners as 'extremely narrow-minded', 'extremely unempathic/cut off' and 'extremely ill-informed'.

Champions for The Charter



Prof Sir Sam Everington, OBE

Dr Everington practices at a GP partnership which is part of the Bromley by Bow Centre, an innovative community organisation with more than 100 projects under its roof supporting wider determinants of health.

Considered a founder of the social prescribing movement, he says "...it focuses on what matters to patients. This increases satisfaction, delivers better health outcomes and reduces prescribing and referral costs."

Under his chairmanship of Tower Hamlets Clinical Commissioning Group, the Group was awarded Clinical Commissioning Group of the year by the Health Service Journal in November 2014, receiving praise for "strong leadership, especially clinical leadership, while retaining patient focus."

"The Yes to Life Charter for Oncology will improve the early diagnosis of cancer and provide holistic care to those living with it. "



**Dr Penny Kechagioglou
MBBS (Hons), MRCP,
CCT Clin Onc, MPH,
MBA, DBA**

Dr Kechagioglou is a Senior Consultant Clinical Oncologist practising at University Hospitals Coventry and Warwickshire.

She has experience in advanced radiotherapy techniques for breast cancer including proton therapy, personalised chemotherapy and immunotherapy treatments based on genomic testing, as well as integrative oncology.

Dr Kechagioglou currently serves as the Chief Clinical Information and Deputy Chief Medical Officer at UHCW.

She has also recently served as Co-Chair of the British Society for Integrative Oncology.

"As an oncologist, passionate about health creation and patient empowerment, I support the Yes to Life Charter for Oncology; the latter advocates for an Integrative Medicine approach to cancer care, supports patients to navigate health and care choices, and inspires a compassionate and inclusive culture in healthcare"



Chris Lewis

Chris founded Chris's Cancer Community in 2007 out of a personal need for practical support during his own cancer experience.

He has transformed the cancer support landscape by advocating for patient inclusion and breaking down silos among charities.

He has played a pivotal role in ensuring patients' voices are heard and championing their rights within the industry through speaking engagements, worldwide presentations, and collaboration with clinicians. Chris is recognised as an influential figure, driving change and disrupting the sector. Chris is also COO of YourSimPal, an innovative charity supporting individuals affected by cancer.

"The Yes to Life Charter for Oncology will help create a crucial working 'partnership' between patient and clinician, as the numbers affected by cancer increase rapidly. I am proud to have my name associated, and wish I could claim that I created it!"



Sheila Dillon

Sheila is well-known as a pioneering broadcaster who has presented the BBC Food Programme for more than 20 years.

Amongst the enormously wide-ranging content of the show, she has presented some of the very first UK public broadcasts ever to tackle questions around nutrition and cancer, and in 2011 she spoke with Jenni Murray on BBC Woman's Hour about her own experience of cancer, and shared her views on the role of nutrition.

Sheila has never fought shy of asking the hard questions, whether about government policy or medical dogma.

"I support the Yes to Life Charter for Oncology because, after 13 years of cancer treatment in the NHS, I see the limitations of the conventional medical model in treating cancer. I have a remarkable open-minded oncologist in charge of my treatment, but around him a shredded system that damages, sometimes kills, people with its certainty that patients have nothing to contribute to their recovery except obedience."

05 Get involved

If you would like to support our Charter, there are several ways to do so. You can become a Supporter, sign the petition for the Charter to be seriously considered by the NHS, or send the Charter to your doctor, practitioner or anyone you feel may be interested.

Scan the QR code below to find out more about the different ways you can get involved and support 'The Yes to Life Charter for Oncology'



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