Transcript – Menopause and cancer: What we need to talk about

Intro music

Liv (00:09)

What if the hardest part of cancer wasn't the treatment itself, but what came after?

Richard Simcock (00:14)

often when women are going through a natural menopause, it's a little like gently applying the brakes on your car and your car slowly comes to a halt and you notice the difference. Therapeutic menopause is like driving that car into a brick wall the transition is very dramatic.

Liv (00:29)

Hello, I'm Liv and my pronouns are she, her.

Carly (00:32)

And I'm Carly and I go by she her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, including health and social care professionals to lift the lid on current issues faced by the cancer workforce.

Liv (00:46)

If you enjoyed this episode, please subscribe, rate and share with your colleagues and friends. We'd also love to hear from you. Please get in touch to ask questions, give feedback or even to suggest topics you'd like us to cover by emailing professionalspodcast at macmillan.org.uk or by filling in our short survey linked in the episode description.

Carly (01:04)

This episode contains conversations about lived experience of cancer, which you may find upsetting or triggering. Listener discretion is advised.

Liv (01:14)

Hello and welcome to the Cancer Professionals Podcast. In this episode, we're talking about a topic that doesn't always get the spotlight it deserves, menopause and cancer. You may already be aware that certain cancer treatments like chemotherapy and surgery can trigger early menopause and that hormone treatments, particularly for breast cancer, can also bring on menopausal symptoms. Whilst menopause is a natural part of aging for women and people with ovaries, experiencing it as a result of cancer treatment can be very different and often much more challenging. Many women say that navigating menopause after cancer is even harder to cope with than the treatment.

Liv (01:47)

October marks Menopause Awareness Month, a month dedicated to raising awareness about menopause and the impact it has on women's lives. That's why I'm really excited to welcome today's guests. We're joined by Dani Binnington, the founder of Menopause and Cancer, who will share her personal experience of menopause after cancer. And we also have Professor Richard Simcock, Chief Medical Officer at Macmillan and Consultant Clinical Oncologist, to help us better understand this topic and how we can better support our patients.

Liv (02:13)

So welcome, Danny and Richard. Could we start by asking you both to introduce yourselves, please? And Danny, I'll start with you.

Dani Binnington (02:21)

Thank you so much for having me. I'm delighted to talk about my favourite topic. As you said, I'm the founder of Menopause and Cancer. As far as I'm aware, we're the UK's and globally only not-for-profit organization to support cancer survivors who are in treatment-induced menopause. I also host the Menopause and Cancer podcast. And I'm delighted to say I've now finally published my book, Navigating Menopause After Cancer.

Liv (02:47)

and Richard.

Richard Simcock (02:48)

Hi, hello, and Danny hasn't told you that it's top of the Amazon book charts that her book she's too humble. So she's done really well. So hello, my name is Richard Simcock. My pronouns are he and him. I'm very proud to be Chief Medical Officer at Macmillan Cancer Support. But actually I'm here really in my capacity as a breast cancer clinician, treating people with breast cancer, where as well, I'm sure we'll talk about menopause becomes an important part of how those people experience their care.

Carly (02:57)

Yeah.

Richard Simcock (03:19)

I'm also part of the British Menopause Society and have just recently reviewed the guidance and evidence for the British Menopause Society of Menopause after cancer and also been part of a very large evidence review for the International Menopause Society. really, like Danny, really glad that you've decided to shine some light on this important topic.

Carly (03:39)

Mm.

Thank you. So Danny, you mentioned that you're obviously the founder of Menopause and Cancer and top of the charts author. I wanted to firstly ask, what is the reason that we're talking about this now? Why is this such an important topic to talk about now for you?

Dani Binnington (03:57)

I think the menopause after cancer conversation is a little tag along on the menopause conversation in general. And it's been beautiful to watch in the UK, so many campaigners and celebrities and celebrity doctors talking more about how to manage a menopause transition for a healthy perimenopause or a menopausal woman.

And it's a really important conversation because we need all women to be well so that we can do well in work, we can lead our countries and we can just globally contribute to our societies, which is super important. When I was pushed into a surgically onset menopause after my own

breast cancer diagnosis, I however felt very excluded from that greater menopause conversation. And so I think it's just natural that everyone with ovaries, whether they've had cancer treatment or not, is now thinking, how can I manage my menopausal symptoms? And so I think cancer survivors are starting to become part of this greater conversation for all.

Carly (04:57)

And you mentioned your breast cancer diagnosis, which I believe was it when you were 30, were you 33 at the time? Would you be happy to talk a little bit about, share a little bit about that experience, what was happening for you around then, if that's okay.

Dani Binnington (05:04)

Yeah

Hmm.

So my identical twin babies turned two and my eldest daughter was four. And we kind of thought with my husband that we'd just turned a corner. The kids were starting to sleep through. They were terrible sleepers. And we thought our life is just getting back on track with three children under the age of, you know, three. It was crazy times when I found my lump. was just sitting on the sofa and discovering a lump under my left armpit. And Initially, I didn't really worry. I just thought I'm too young, I'm too busy. There is no way this can be breast cancer. But I soon found out it was a very aggressive type of breast cancer and treatment started immediately. We were actually on a gap year in my native Austria, where I'm from. And so it was quite mad. My husband wasn't with us. I had to start chemotherapy immediately. Surgeries followed and so like most people I speak to now, life just happened to us.

I had beautiful oncologists and an amazing medical team. And I just did as I was told, and we just got through it as well as possible. And my periods actually stopped, but I had no idea I was in menopause. And I want to mention that because I felt like I'm a relatively okay, educated person. I went to school and I didn't know that with my period stopping, it meant I was in a temporary menopause and it came without a symptoms, but that wake-up call came much later for me, really.

Carly (06:41)

Was that because it was something that I suppose, I'm guessing that at the time it wasn't something that when you were diagnosed that was talked about for you that actually this is something that could happen as a result?

Dani Binnington (06:54)

I am sure my doctors mentioned, but I'm also sure as Richard will probably tell you, there's so much information thrown at you and I would have done anything to do my best to survive this and be around for my children. And so I would have had any treatment, I would have given it my all and the side effects and the long-term side effects, they only hit you when they hit you and you don't know what you don't know and I'm sure it was told to me but there is only so much you can absorb and now at work we talk a lot about when is the right time to talk about menopause after cancer to patients because everyone absorbs information so differently and yeah it was just one of those things that I thought well I'm just going to lose my hair, I'm going to lose some of my fingernails and, I've also lost my periods and I didn't know anything else came with it.

Carly (07:44)

Yeah. Were there any, in addition to your period stopping, were there any other symptoms that you were experiencing that perhaps in hindsight you'd realise were as a result of the menopause?

Dani Binnington (07:56)

I have no idea because everything is just so crazily, like a whirlwind, hot flushes and sleepless nights and insomnia. could have all been part of my cancer treatment, of my chemotherapy. It could have been menopause muddling in. And I think that confusion is very real for a lot of people. say, is it still chemo brain or is this now brain fog? And it's very hard to differentiate. When I went through chemotherapy, it was much more apparent when I later had my ovaries removed, but I'm sure we'll come to that.

Carly (08:29)

And looking back at that time, was there anything that you felt was missing or would have been helpful for you perhaps in the form of information or support? What would have been helpful for you at that time that you didn't get, if anything?

Dani Binnington (08:45)

I often look back and I reflect and I think in my case, going through active cancer treatment and chemotherapy and surgeries, I probably had enough information that I could cope with as a patient. I probably didn't need a lot more. I really felt there was a lack of information and preparation when I was planning to remove my ovaries a few years further down the line. And there was a stark contrast there.

In, example, when I removed my breasts because I'm a Brecker 1 carrier, I had a lot more conversation about how would I want to do this? Do I want to have a reconstruction? Do I want to keep my nipples? Will I have implants or which type of implants would I be? And when it was then further down the line discussed about my oophorectomy so the removal of both of my ovarian tubes and also my ovaries, there was hardly any preparation given to me. And I kept thinking, wow, all these campaigners are talking about how important it is to talk about the menopause. Why is no one helping me how I can manage this as a 39 year old? And that's when I was really lacking information.

Liv (09:58)

Thank you for sharing that. ~ Richard, I wonder if we could come to you and could you just explain a little bit more about what the menopause is and also its relationship to cancer and cancer treatments?

Richard Simcock (10:10)

So menopause is the natural transition to ovaries stopping working. ~ Average age for the menopause in the UK is 52, but there's a huge range on that. The way in which ovaries stop working naturally, the speed at which they do that and the impact it has on an individual person will vary enormously. People listening to this will know through their own experience or from the experience of friends, colleagues, relatives, partners, that a woman's experience of a hormonal

environment varies enormously. So there are some women who have very significant premenstrual syndromes, some women who have very difficult pregnancies, and some people have very difficult menopause and some women blink and you've missed it. There is an enormous range of human experience so there is no definition of what might be a normal menopause except to say that it is a transition from the ovaries stopping producing oestrogen. You still produce a little bit of oestrogen after your menopause when your ovaries have stopped working. You produce a little bit of oestrogen in your muscles and fat but that is a very small beer compared to what was there before and oestrogen is a fabulous hormone. ~ It contributes to joint flexibility, contributes to good sexual health, good vaginal health, it has a role in cardiovascular functioning and it may have roles in cognitive functioning as well. So it's a really good hormone and being deprived of it has a number of multiple effects. Its relationship to cancer is probably threefold. Firstly, Life happens to people when they have cancer, so you may be dealing with cancer and you may be having to deal with menopause at the same time and your medical team might be concentrating on one and not the other. So because it's a feature of normal life, may be something you're having to deal with at the same time as dealing with your cancer.

The second issue is what we call iatrogenic menopause. So iatrogenic means a problem caused by medicines. So iatrogenic damage or actually so and the most common reason for that is if we give people cytotoxic chemotherapy and sometimes immunotherapies, these drug therapies for any type of cancer can often be damaging to the ovaries. So regardless of cancer type, a younger woman receiving chemotherapy might experience menopause as a bystander effect it's collateral damage that their ovaries might be damaged irreparably as a consequence of that therapy. And then the third area was therapeutic menopause and so that's particularly important in my area in breast cancer. 80 to 85 percent of breast cancers have an oestrogen positive receptor, they're part in part driven by oestrogen and therefore reducing oestrogen levels or modifying oestrogen levels or blocking oestrogen either by removing the ovaries, blocking ovarian function or taking variants of Eastern blocking drugs is an important part of their therapy. So it might happen naturally, it might be a bystander effect of therapy, or it might actually be part of the therapy. And those are the three ways we most often see menopause affecting people.

Liv (13:24)

Thank you. And could you share some of the common symptoms of menopause? And are these, would these be quite similar across the kind of three ways

Richard Simcock (13:34)

I may not be the right, I'm going to pass, I'm going to, I'll talk about the similarity, which is to say, and I'll ask Danny to speak to the effect. It feels unfair as a man who witnesses this but doesn't experience it to talk to it. So I'll let the voice of lived experience talk to that. But in terms of its impact, think the thing I would observe about therapeutic or iatrogenic menopause is its rapidity. You will know that many people refer to menopause in jargon as the change, you know, change of life. And I often say to patients that the destination is not necessarily the problem, it's the journey, it's the transition from one hormonal state to the other, which is massively disruptive to a person. often when women are going through a natural menopause, it's a little like gently applying the brakes on your car and your car slowly comes to a halt and you notice

the difference. Therapeutic menopause is like driving that car into a brick wall, the transition is very dramatic and the change I often observe in patients with therapeutic menopause is that very rapid change is quite disruptive. One patient characterised it for me very well, they called it a body shock and I think that body shock is perhaps the most obvious difference. The other important difference is of course the age at which it happens. A woman who's 55 going through the menopause as a consequence of therapy, her body may have been preparing to do that naturally.

Richard Simcock (15:03)

Danny talked about it at 33, her body was not ready for that. But I might ask Danny to talk about what it actually feels

Dani Binnington (15:10)

Hmm, absolutely.

Liv (15:10)

Yeah Danny, could you share your experience a bit more on some of the symptoms you experienced.

Dani Binnington (15:15)

So going to chemotherapy, really didn't know what was my menopause symptoms, what was chemotherapy or other surgery sort of related symptoms. But then later, when I was pushed into surgically onset menopause, I always looked at it from a three sort of...

three buckets of symptoms. There were my emotional symptoms, there were my physical symptoms and there were also like the holistic symptoms in how I navigated all of it and the confusion that came with it and the not understanding and the not being prepared for it enough. And most people I speak to now, they do explain to us that symptoms can feel more severe, than those for women who gradually enter perimenopause and then menopause. Because in my case, I then was without all of those hormones from one day to the next. And that is like being pushed off a hormonal cliff. So it can come on much more suddenly a menopause after cancer because of all the treatments Richard mentioned, but also symptoms can then feel a lot more severe. Some of my most debilitating symptoms weren't very apparent to me at first. It was very much creeping in was a very odd sensation and before I knew it, I was feeling very removed from myself. I was feeling very low. I lost all of my confidence. I thought no one in their right mind would ever want to sit next to me at a dinner party again. I was so boring. I just couldn't believe anyone would want to listen to anything I had to say. So that loss of confidence, that feeling not worthy to be part of other conversations and that real feeling of low mood, all the way to depression, all the way to feeling very removed from myself. And I remember so clearly going on a family holiday and everything was fine. My children were well, my parents were well, life was okay. I had survived quite a few years. I was over five years on from my cancer treatment and I just felt nothing, absolutely nothing. And that took a long time for me to realize these were symptoms of my surgically onset menopause, and some people have severe hot flushes and night sweats and they're the more common symptoms alongside perhaps the joint ache and the joint pain, the insomnia. And then some people have all of those emotional symptoms and it can be very hard to know what's what. And I think that's why we have to really

educate people a lot more about what all of those symptoms are. And a really big bucket of symptoms are the genital urinary symptoms of menopause, the olden term is vaginal atrophy, isn't it Richard? You'll probably explain a little bit more about that. But over 88 % of cancer survivors will struggle with genitourinary symptoms of the menopause and they often don't know it's associated to their menopause after cancer and so they don't bring it up with the healthcare professionals either. So making people aware what those symptoms are, is really, really important so people can then understand what's happening to them and then go and speak to the healthcare professional to ask for their help.

Liv (18:24)

Thank you for sharing that. Richard, are there any other kind of concerns or issues that patients have raised with you? And also, I suppose on the other side of that, like Danny's mentioned, if a patient isn't aware of some of those symptoms, they won't necessarily approach them or bring them up with a healthcare professional. So is there a way that you'd broach that conversation?

Richard Simcock (18:43)

Well, I really like Danny's way of dividing it up. I would just say about the psychological impact that often it's very difficult. A diagnosis of cancer is a massive psychological and emotional impact. And certainly in my practice, I will see people who are distressed, sad, upset, and they have a good reason to be because they're dealing with cancer. And sometimes it takes some care from a professional to unpick what are the ingredients of this cocktail? Am I sad, distressed? There's a great term that psychiatrists use called emotional incontinence, which is when you are suddenly tearful for no reason. Is this because you have just had a very distressing life-altering diagnosis, or is your hormonal storm contributing to that? It takes a little bit of time to unpick that, I think. I'd urge professionals to take the time to try and make that diagnosis. What's going on for this person? The only thing I would just add is long-term and invisible signs of the menopause and the one that preoccupies me most in my practice is bone health. Men don't have this problem but women sadly when they go through the menopause the drop in oestrogen starts to contribute to bone loss so that when a woman reaches her seventh and eighth decades her bones without intervention are likely to be more brittle as a consequence and that's what leads to osteoporosis and fractures and so forth. If you induce an early menopause you will accelerate that process and that is entirely invisible to the person. She won't know that that is happening and it is incumbent on medical professionals, particularly if they've induced an early menopause, to make sure that their patients understand that and as medical professionals you monitor that and supervise that so that in curing a 40 year old of her breast cancer she doesn't fall over in the street at 75 and fracture a hip because of the treatment you gave her 30 years before and so that's a hidden side effect that patients may not necessarily know about that we obliged to monitor and support people with.

Liv (20:53)

That's really interesting to hear about the longer lasting effects of it. Yeah, absolutely. We hear about the common side effects and symptoms like hot flushes and things like that, but actually the longer term impact that it's having on health can be huge by the sounds of it. I wonder if we could move on to treatments and strategies that there are to help patients manage some of these symptoms. Richard, if I come to you first.

Richard Simcock (21:18)

Well, the most important part of any medical treatment is you first have to make a diagnosis. And you can't make a diagnosis if you don't ask the question. And Danny's already alluded to this. So number one in your strategy is you have to ask the question because some people won't tell you. They'll think this is normal. There are more important things to, I've got life threatening illness. The fact that I'm having night sweats that are disturbing my sleep is this doctor, this nurse is not interested in that. So we have to build in strategies where we operationalise routinely ask the question. Having asked the question, you have to make the diagnosis.

Do I think this is this person's natural menopause, either accelerated by my treatment, or is it a function of the drugs? And I don't want to... People listening to this podcast will treat a range of cancers, so I don't want to dominate this just about breast cancer, but many of the drugs I prescribe for breast cancer mimic the side effects of the menopause. So particularly, so drugs like Tamoxifen, Letrozole and Anastrozole, drugs that are prescribed in their tens of thousands across the UK for women with a history of breast cancer can cause exactly the same symptoms. Hot flushes, night sweats, vaginal dryness, pain during sex, failure to achieve natural wetness during sex, joint stiffness etc.

So you need to understand is it the disease, is it the treatment or is it the menopause? So you've got to interrogate that. Once you've understood that you then can start building together a plan for people and I'm going to start with hot flushes because that's the thing that preoccupies most of my practice when we're talking about and this is no small thing.

This is not just about helping people have better quality of life because quality of life is what everyone at Macmillan wants people with cancer to have. It's actually about making their therapy more successful.

We know that up to 30 to 40 % of people prescribed hormonal therapies for breast cancer will stop their therapy because of side effects. So if we don't sort these side effects and these symptoms out for people, not only will it mean that they have poor quality of life, it genuinely compromises their chance of cure from disease because they're not able to take the therapy. So it's really important that we do it.

So if I just start with hot flushes and we can see where we go from there, maybe go top to bottom, I am not unhappy for people to try complementary therapies.

Complementary therapies, I think, give people a real sense of control and agency of their own health, that they're exploring. People have worried in the past about plant-based oestrogens, so-called phytoestrogens, being dangerous. We've seen no evidence of that. So, very happy for people. In my practice, I recommend evening primrose oil, and sometimes it works, sometimes it doesn't. It is fair to say that in clinical trials, placebo will help hot flushes about 30 % of the time. And the wonderful thing about the placebo effect is that it's an effect. And if a person gets a benefit, I'm very happy. Acupuncture works at least as well as prescription medications, and I'm very pleased that if you're down my neck of the woods in Sussex, the Macmillan Horizon Center offers up to six sessions of acupuncture free in groups to people and people are taught self-needling. Beyond that we start to move into prescription medications and there are many people in my practice who do not wish to take a prescription medication, particularly if it's for the side effect of a prescription medication.

Richard Simcock (25:08)

One patient told me she felt like the little old woman who swallowed a fly, that she was now having to swallow a spider to catch the fly and so on. But there are so-called repurposed medications, drugs that were designed for one thing that help another. So oxybutynin, ~ a tablet prescribed for unstable bladders, can be very helpful for hot flushes, although it can cause dry mouth. ~ Venlafaxine, an antidepressant, can also help cause nausea. Venlafaxine can also cause a difficult side effect called anorgasmia.

So might help a woman's libido, but when she has sex, she might not be able to reach orgasm as a side effect of the drug. there are no free lunches with prescription medications. What is really interesting is there are now, for the first time, some drugs being developed which are non-deliberately designed and manufactured for the purpose of helping hot flushes with a non-hormonal ~ mode of action. They're called NK3 antagonists. There's only one on the market at the moment.

It is licensed, but it is not approved for use on the NHS. So the only route to that is private prescription. I hope that that might change in the future, but there are some smart therapeutics. Final thing to say about hot flushes is HRT is a fantastic treatment for hot flushes. And there is a very welcome conversation about HRT in the public domain. And that's been greatly socialized. But HRT is often specifically not recommended to people with hormonally driven cancers. so some women are doubly disadvantaged. They've got these difficult side effects. Their friends, their colleagues, their relatives have told them that their lives have been transformed by HRT. They go and see their oncologist to talk about it and they say, I'm sorry, we don't think that's safe for you. So that's a difficult conversation to have with any person, I might hand over to Danny to talk about some of the other side effects maybe.

Dani Binnington (27:08)

You know, I think it's really important to include HRT here in this conversation because anyone who is listening to this conversation might ~ care for cancer patients in different capacities. We might have clinical nurse, practitioners, listening oncologists, surgeons, and people might be helping people with different types of cancer. And it's really important we talk about HRT because there are many, many types of cancer where people are pushed into the menopause, as Richard explained earlier, during chemotherapy or stem cell transplants, where HRT is not contraindicated. And from there hundreds of conversations and we've just recently done a survey with a thousand people replying to our survey questions. It takes people about two and a half years to then access this hormone replacement therapy, which is a very, very long time. And these are people that were not contraindicated for HRT. So it shows us that People fall into this hormonal void, into this hormonal gap after cancer treatment. These are often young people in their 20s and 30s. They really need those hormones back. So the conversation for us as an organization always starts with, do you know if HRT is an option for you? Because so many people just haven't had the conversation. They don't have to figure it all out themselves and it takes them too long to get the treatment they need. And if they then...are being told that HRT is not the first-line treatment for them. We usually open up a massive toolkit that includes so many options, like Richard just explained, lifestyle, exercise, diet, complementary therapies, prescription medicine. And what's the most astonishing for me always, that every person is so different. And you'll see that in your practice, won't you, Richard, with all of your patients. But we have some people that want to know everything about how to eat.

And I was one of those patients. I kept hunting down my poor oncologist, asking how many lentils and how many phytoestrogen I need to eat to sort of keep my menopause symptoms at

bay. And other people are not interested at all and they want to go straight to medication and they want to know what their doctor can prescribe for them. And so it's most important actually to find out what person are you sat in front of and what can you then offer them because there are plenty of things they can do but it's finding out what they resonate with and also what their belief system. Some people are really anti antidepressants, for example, whereas for some people they can help with some menopausal symptoms. So it's understanding how people tick is so important.

Carly (29:43)

Mm.

Yeah, and what's important to them, isn't it?

Richard Simcock (29:50)

So people who are listening to this won't have seen...

can't hear me nodding vigorously to when Danny was talking about HRT. I think that message that HRT can be used perfectly safely in a large number of cancers is really important. And actually in breast cancer, it's not an absolute contraindication. The nice guidance is that you wouldn't routinely use it in women with Eastern sensitive cancers, but it can be used in exceptional circumstances when risk has been discussed. there's a good line in medicine, never say never.

Dani Binnington (30:20)

May I add something to when we talk about hormones, it took me a really long time as a patient. And it now takes me a long time as someone guiding other patients through their menopause experiences, that HRT is not just HRT. We, I, took me a while to get my head round that systemic hormone replacement therapy that goes into all of your body is very different to localised.

Vaginal oestrogen for example and and often we have people now in our community say no my oncologist said you can never have hormones again So I won't eat edamame beans. I won't eat ~ phytoestrogens in food I can't have supplements and I can't have local vaginal oestrogen but we see people on a weekly basis that can't go for their smear tests because they have such bad vaginal atrophy that have no sex life, bleed upon intercourse, their relationships are breaking down and they are really, really suffering. And I almost feel that every cancer patient needs to be asked about sexual health related symptoms and they have to have a conversation about vaginal oestrogen. And I don't know about you, Richard, but even with vaginal oestrogen...

Some oncologists are very happy to say to their patients, yes, it's an option for you and other people are less likely to have the conversation. So we're still not there in providing everyone with the same evidence-based information, I feel.

Liv (31:47)

Yeah, thank you for sharing that. That's really interesting. And just kind of on the topic of that kind of evidence-based decision-making and having that conversation with patients about risk, what does that conversation look like? How would you approach that? you know, taking that person-centred approach as well, that it is very personal to each individual. ~ Yeah, kind of what does that look like?

Richard Simcock (32:12)

So, whether you absolutely, so taking the subject of vaginal health and sexual health, that's both personal to the person and it's highly personal, we really need to be giving permission to people with cancer to know that they can ask these questions of their team. Medical professionals should be un-embarrassable and they should make sure that the questions are. So that's the first step. And not everyone is comfortable in doing that. So you need to understand your comfort zone and what you're prepared to discuss. Everyone comes to my clinic gets asked about their sex life. That's a guarantee. And one way to do that to lead into that personal conversation is I will often say to people at the outset that these treatments I'm talking about will often affect a person's sex life and their vaginal health. So that is something I'm going to ask you about next time we meet. we've created an environment where we can have that, a permission has been given and the person with cancer knows that this is something that we can talk about in a safe space. And then approaching it by sharing what works with people so they're unembarrassed. The considerations for someone who is sexually active, particularly for having penetrative sexual intercourse, will be different to someone who's not sexually active. even someone who is not sexually, so we know as medical professionals we first mustn't assume anything about a person's sexual activity, so you always have to ask the question. But we also have to understand that even if they're not having penetrative sexual intercourse, they might still have very uncomfortable vulva and labia. They might still not be able to, I had a patient who couldn't ride a bicycle, she was so sore in terms of vulva and labia. The algorithm for me is to have the conversation, we recommend a wide variety of moisturisers.

Most people are very happy to use moisturiser on the skin of their face if the skin there is dry. So why wouldn't you use a moisturiser on your vulva and labia if they are dry? Not the same moisturiser there. So we give advice on pH neutral moisturisers. For people who are sexually active, then pH neutral lube is really helpful. We could get into a long conversation about silicone versus water-based, but that's a conversation for people. And absolutely, if person is, if sex is painful, If there's contact bleeding then usually from my experience that what those people need is vaginal oestrogen and I am very happy to recommend that to people and GPs are very used to prescribing vaginal oestrogen. They do it every single day, but they suddenly become paralyzed with anxiety about prescribing it to people with a history of cancer. So they'll often need a permission slip from their oncologist to say yes, we think this is okay. The evidence base and you talked about evidence is tricky because you'll never be able to do a clinical trial of sufficient power where you take 2,000 women with vaginal symptoms of the menopause and give half of them vaginal Oestrogen and half of them, you would never be able to deliver that. So we have to base our data on what's gone before and large level population data sets are not throwing up significant safety signals. So very large study, largely done in women in Scotland looking at prescription records, people with a history of breast cancer and history of prescription of vaginal oestrogens showed no evidence that there was any disadvantage from that. there is a, and I do think there is a cultural shift. Ten years ago I think most oncologists would say, breast cancer oncologists would say no to vaginal oestrogen. Nowadays we're hearing more and more that people are very happy to prescribe it. But there's still a bit of pushing against some cultural barriers in practice to make sure that everyone in the ecosystem knows that that's safe to do.

Carly (36:01)

Mm.

Yeah, thank you. Is there anything you wanted to add to that, Danny, around that point?

Dani Binnington (36:11)

I think as a patient, you're always a whole person. After a few years of my breast cancer treatment being in the past, you live with your body every single day and suddenly your worry about maybe your cancer returning is a bit more distant, you feel a bit more hopeful about the future and then you might be left with some of these long-term...side effects. And so it's really important to be able to reach out to your healthcare professional at any time. And even at times when you no longer have access to an oncologist, it's really important to realise menopause can go on for many, many years after active cancer treatment is finished. And it's so important that the whole person is treated because in our community, so many people say to us, I'm considering stopping my endocrine therapy, my vaginal issues are just so bad, I cannot go on like this. And so we always wonder as an organization, how many more people could we help stay on their treatments, their endocrine therapies, if we help them with those debilitating menopause symptoms. And that to us is always paramount. And actually, when I looked ~ at our study details that we're just about to finalise, 74 % said they didn't receive adequate information about menopause resulting from their cancer treatment. And when that happens, you don't know which symptoms to bring up to your doctor. So it's really important we inform people about what they might experience, including sexual health related symptoms. And 86 % of people said that their menopause related symptoms had a significant negative impact on their quality of life. And so there is a huge gap, but when you are the person and it affects you every single day, so many people are a at their wits end, so it's so important that we talk about it more.

Carly (38:03)

Yeah, thank you. I think as well, wanted to acknowledge to you, Richard, about the conversation we just had and just, I suppose, being appreciative of talking about that. And I think that's gonna be really helpful for listeners to give them confidence, I suppose, in how to have conversations about topics such as that. So, I wanted to acknowledge that.

Richard Simcock (38:31)

understand that conversations about sex and intimacy...are difficult for some professionals. We can all argue that maybe it shouldn't be, but it might be difficult because of background, culture, practice, you know, just actually you've not done it very often. So, I think it would be unreasonable to expect every single healthcare professional to be super comfortable having a conversation with patients about their sex lives. But I think it is important that every team understands who is going to have that conversation because what we do know is that very often different members of the team think somebody else is asking the important questions. The doctor thinks the nurse is asking, the nurse thinks the GP is asking, the GP thinks the doctors are asking, and actually no one is asking. So, work out who is comfortable and make sure that the questions get asked. Patients will share the most intimate parts of their life with you as long as they know that you're comfortable. I always say that patients are a bit like sharks that can smell blood. If they can smell that you're uncomfortable, they're not going to have that

conversation with you. So, you need to be in your comfort zone. And I am sympathetic to medical professionals who aren't comfortable having a conversation about intimacy but make sure that someone in your team is and that that conversation is happening somewhere in that patient's journey.

Carly (39:42)

Yeah, And I think that's a really, a really great point and also a really good segue into a question I was going to ask next around the role of the professional. So, keeping in mind that the people who are listening to this podcast, our audience, our health and social care professionals and the wider cancer workforce, which spans so many different roles and will come into contact with people living with cancer at different touch points.

So, I wanted to ask, what is really important from your experience, but also the people that you've been talking to through the work that you do, around the role of the professional within this and having those conversations and giving that support? What would you say was most important?

Dani Binnington (40:38)

Last year at Menopause and Cancer, we engaged with all of the cancer alliances in the UK, and it was really, really interesting. Some cancer alliances already provided some services, some PDFs, some leaflets. We spoke to lots of clinics who were establishing Menopause clinics as part of their cancer services within the NHS, so attached to breast clinics or gynaecological cancer services. So really interesting and we also spoke to a large number of healthcare professionals who don't talk about the menopause at all. And when we dug a little bit deeper about why that might be the case, it was usually because they had nowhere else to signpost their patients to that could provide support. And I think all healthcare professionals want to do the best job they can. And I think you open up this can of worms. People have so many menopausal symptoms. People really struggle.

And if you have nowhere to refer them to, if you've got no options and you can't provide support, it must feel awful. And currently we do not have enough access to see an NHS menopause specialist for cancer survivors. The waiting list is up to 18 months long. And some doctors, some GPs don't even refer to those services. And so, I think sometimes the conversation isn't had because there aren't services that can be referred to. What we say as a patient led organization, we always say refer them to us. have 300,000 people listen to our podcasts. People can start the learning journey by watching YouTubes. We have amazing people like Richard on our conversations. We bring the experts to our community. Some people want to read. We've got written resources on the website and it's okay to give the responsibility to the patient as well. Because part of doing better, we need to bring everyone into this conversation. So,So,it's not just the healthcare professional'sprofessional'sresponsibility. It's not just the patient's responsibility. Everyone needs to do a little bit better, including pharmaceutical companies, need more research of course, we need better drugs and then I think we can truly move into a much better informed and better supported future.

Richard Simcock (42:57)

I agree with all of that Dani and I would build on that to say, I think you're absolutely right about being able to signpost. is no one, everyone who's listening to this podcast is listening to this podcast because they are interested in providing high quality cancer care. And some people on this podcast will think, I really want to be better at supporting people in the menopause. And there are multiple ways they can educate themselves to do that. Other people will say this is not for me. But what they need, all I would ask with those people is to work out where you can signpost people to. So, then you can ask the question and even if don't know the answer you can say, I'm really glad you shared that with me, go and listen to Dani's podcast, go and look at this, here is that. And that runs through, I know an awful lot about breast cancer. I know very little about financial benefits for people with cancer. So, I refer them to welfare support at Macmillan. So, it's analogous, work out where your knowledge gaps are and use it to just work where you signpost people to for the gaps.

Carly (44:02)

Yeah, absolutely. Dani, can we talk a little bit more about your organization, Menopause and Cancer, because you started to talk about some of the services and some of the resources, written resources, but could you tell us what are some of the amazing things that you can offer to people living with cancer, to perhaps even healthcare professionals?

Dani Binnington (44:28)

I think we figured out very quickly that every person that came to us had such a different need. so, within the first month of being an organization, we knew that our services needed to be holistic. And we really are very passionate about providing that holistic wraparound care. so, services are very much from where people just want to tap into a Facebook group and be part of a Facebook private group where they suddenly are met with thousands of others from around the world after different kinds of cancer and they can just chat but be quite anonymous. And for some people that's a really great support. Some people never even post a question. They're just there in the background reading everyone else's experiences and that is beneficial to them. All the way to now providing specialist free menopause appointments which is absolutely incredible. So, we try and give people the option of how much do they want to engage and they want to engage at different times. We also run weekly workshops healthcare professionals where people can come in, and we have different topics. We might just bring GPs in to educate people how they can support different experts. We talk a lot about how to manage endocrine therapy for breast cancer. So many people have real struggle with those. And we always say to them, before you give up, come on one of our workshops, let's see what else you could do. What could your next question be? And often it's just making sure people know they're not alone, because when they start this journey without having the adequate preparation, most think it's just them that do badly. And when you listen back to what Richard said earlier about how many people can't stay on the endocrine therapy, for example, because of side effects, there are millions of people struggling. And as soon as they're on Zooms where they see others,

I think a weight gets lifted off their shoulder and so our services are partly bringing the experts to our community, but partly also creating that community and making sure they're not alone. And there is no point in everyone being on social media, following people that are brilliant about the safe prescribing of HRT when perhaps they've been told they can't have it. It's like barking up the wrong tree. So, we need to create our own conversations where people are met and meet people with similar needs.

Carly (46:29)

Yeah.

Yeah, sounds brilliant and very, very important.

Liv (46:51)

Yeah, sounds like such a needed organisation and that you've filled such a gap by setting it up. That's amazing. Just thinking a little bit more about kind of practical strategies and what healthcare professionals could be doing when supporting patients. Kind of thinking about the importance we've spoken about kind of normalising the conversation and bringing it up and asking questions about menopausal symptoms. Dani from your perspective, what can healthcare professionals be doing? Like what's that most important kind of takeaway that you'd like to see put into practice?

Dani Binnington (47:23)

I think we sort of have a three-pronged approach we always talk about. It's better preparation. So, it's warning people and preparing people that menopause might become part of their cancer treatment at whatever stage they feel that is the best. It may not be when you're first diagnosed and the person receives their cancer diagnosis, because there's a lot going on, but definitely at one point to better prepare people for menopause being part of perhaps as a result of their cancer treatment, then to provide more acknowledgement that this can be a very difficult menopause conversation. And sometimes people just want to be heard. We often say to people, what was the best about seeing our menopause specialists? And they said, gosh, just someone to believe me how much I'm struggling. And that's really interesting. And then to provide better support, which I know we can't dream up billions of pounds. But I think by providing the first two steps, we can already better support patients.

Liv (48:24)

Lovely, thank you so much. Richard, is there anything you'd add to that?

Richard Simcock (48:28)

Yeah, as I say, I'm not asking for everyone to be an expert in menopause, but I'm asking everyone to be aware of it.

So, if we can ask the question and if you can take stock of your local situation, who here, what is it, what menopause services do we have? What GP, there are many, the British Menopause Society has a list of specialists in every area, many of them are GPs. Where could we refer someone for specialist advice if we needed it? Who in our, who in our team has an interest in this? Is there someone in our team who would like to go off and learn more and upskill so that we can provide better in-house support for people with cancer and menopause. So, it's just understanding the priority of the conversation, understanding where the skills gaps are and stop taking what the support is so that you can signpost people. My very first week in medicine I remember working with a palliative care doctor who said the worst thing you can ever tell anyone is there's nothing you can do. There's always something you can do even if it's signposting to you know so that you can go to Dani's podcast and listen to people who've lived

through this, and share lived experience and understand the commonality of that experience. Even that can be supportive and nurturing and helpful.

Dani Binnington (49:47)

Last year with Richard, we piloted our first healthcare professional training course, and we had 150 different experts from all across the world joining us. And it was really interesting because at the end of the conversation, people didn't want to leave. They wanted more. So, I think there are a lot of brilliant doctors that really understand.

People need more support, people need more answers. They might not have them, they might not have the resources to signpost to, but it's that want to do better and to understand their patients better. And I think that was the most exciting thing for me, that there is this big cohort of patients and doctors alike that want to do better for everyone. And we all have a little bit of that responsibility, I think, because some of my friends who are menopause doctors, they said, we didn't get any of that taught back in medical school and no one talked about the menopause then. And I always say, well, fair enough, but I'm sure my mechanic also didn't learn how to fix electric cars back in the days. And people upskill along the way, don't they? And I wonder whether now with the menopause conversation being much more out there and in everyone's of households, whether everyone needs to upskill a little bit, patients and doctors alike.

Carly (50:40)

Mm. Yeah, that's a great tip and a great

Richard Simcock (51:06)

So, if I was to pick up on Danny's point about building teams, there's lots of different ways to do that. So, I run a clinic with non-medical prescribers run a clinic where patients having oral chemotherapies or therapies are seen by Fiona, a pharmacist on the team, and Fiona has developed a huge interest in the menopause and she has become our go-to expert and that's a model in one of my sister hospitals down the coast, one of the clinical nurse specialists has got a particular interest in menopause and she's become the go-to person. So, it doesn't have to be a particular person the team. I would say that menopause is everybody's business, but it doesn't have to be everyone's expertise we can develop there. There are different services within the hospitals. Most hospitals will have some access to women's health physio for people who've got pelvic floor problems. Most hospitals will have some input into dietetic advice and support for people who are seeking advice on that. So, stop taking what's available and taking stock of where the interest is and then working out who is going to be local champion, whether that's a pharmacist, a nurse, a physiotherapist or a doctor, is your route one I think to starting with a successful service.

Carly (52:27)

Yeah, that's what I was thinking when you said a sort of menopause champion. thank you. So, we'll move on then to our regular feature, which we ask for all of our guests. So, they are three questions, and we tend to look for just sort of fairly short and snappy answers. So, I will start with you, Richard. So, the first question is, if you could go back in time to the start of your career, what piece of advice would you give yourself?

Richard Simcock (52:56)

Don't worry about getting there too quickly. I've had a slightly squiggly career. I thought I was going to be a psychiatrist when I was at medical school. Then I did well in exams and thought I was going to be an obstetrician and gynaecologist. Very quickly decided I wasn't going to be that. I then just briefly flirted with surgery, but anyone who's ever seen me handle anything delicate would know that would have been a disaster.

I briefly went into palliative care, but I eventually arrived at oncology. And I don't know how good an oncologist I am, but I know I'm better at being an oncologist than I would be at any other kind of medicine. And it took me quite a long time to decide that. And I think I picked up some really useful things along the way. medical professionals, don't feel like you have to get to where you're going as quickly as possible taking the scenery as you travel through your career and I think you'll be a better-rounded professional as a result.

Carly (53:57)

Great, having a squiggly career, thank you. And Danny, to you, so if you could go back in time to when you were first diagnosed, what piece of advice would you give yourself?

Dani Binnington (54:07)

I would say that cancer treatment is not over when actual cancer treatment ends. I felt a cancer patient for a long time after active cancer treatment finished, and my physical health and my mental health took an awful long time to recover when everyone around me had celebrated the active cancer treatment and everyone was sort of looking towards the future of, wow, this is amazing. You've done it now. You can look into the future. That's when really my healing journey started and to just be patient because it took so much longer. And especially my mental health was on slow motion recovery to my physical health.

Carly (54:51)

Thanks for sharing that. So, the second question is, and I'll come back to you Richard, what change would you like to see to improve the lives of people living with cancer?

Richard Simcock (55:02)

So many, but I'm going to focus on one which I think is at the heart of what we've always tried to do at Macmillan and a lot about what we've been talking about today, which is trying to ensure that every person with cancer has a good conversation about what matters to them and Macmillan have pioneered that around the holistic needs assessment and care planning. But it doesn't have to be a holistic needs assessment in the care plan. But if every person with cancer could have a good conversation about what matters to them, so that we could deliver truly personalized care, that would be an extraordinary achievement.

Carly (55:38)

And that's a really theme that comes through so strongly in so many of our episodes, asking that question about what matters to you and that personalised care. So, thank you. And Danny, what change would you like to see to improve the lives of people living with cancer?

Dani Binnington (55:52)

When I answer that, I can't stop thinking of the many, many, many hundreds of people that have said to me that managing menopause after cancer is harder than the active cancer treatments. I feel I would love for everyone to be asked about their menopausal symptoms at one point during their cancer journey so that people then had more awareness and received better support.

Carly (56:18)

And lastly, and I'll come back to you Richard, what would you like listeners to take away from this episode?

Richard Simcock (56:25)

You don't need to be an expert in menopause; you just need to know how it importantly affects people's lives. So, ask the question and take a stop take of how you could support and signpost those people to services.

Carly (56:38)

Short and sweet. And Danny, what would you like listeners to take away from this episode?

Dani Binnington (56:44)

That even though if their patients may have been told they can't have HRT, there are many other things that they can do. And as Richard said earlier, never say there is nothing you can do. That's incorrect advice. Can I remind everyone? And also, really unhelpful. There is lots of things people can do and just to open those doors and possibilities for people.

Carly (57:08)

Thank you.

Liv (57:09)

Lovely. Thank you so much. That's such an important message to end on, I think, and really beautifully put, Dani. Thank you. Yeah, that brings us to the end of today's episode. So, thank you both so much, Richard and Dani, for joining us today, for sharing your experience and your expertise. You've really helped to shine a light on this often overlooked, but hugely, hugely important topic and given us some really practical ways to better support people navigating both cancer and menopause. Thank you both.

Richard Simcock (57:37)

Thank you for having us.

Carly (57:38)

You have been listening to the Cancer Professionals podcast, which is brought to you by Macmillan Cancer Support. If you work in health or social care, visit macmillan.org.uk forward slash learning to find out more about our learning hub where you can access free education and training.

For links to the resources mentioned, see the episode description.

Liv (57:58)

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Ruth Bailey, Chair of the Women's Health Forum at the Royal College of Nursing and Jessie Hewitson, Director of NeuroUniverse, author and journalist to discuss the barriers and challenges faced by neurodivergent people in accessing cervical screening and cancer care more broadly.

Carly (58:17)

We'd love you to rate our show and share with your colleagues. Get in touch with us by emailing professionalspodcasts at macmillan.org.uk. New episodes are released on the first Wednesday of each month.

Liv (58:27)

I'm Liv.

Carly (58:28)

and I'm Carly and you have been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.