The Cancer Professionals Podcast

Episode 1 (January 2024) – Diet and nutrition at end of life

Music

00:12 Liv: Has a patient ever asked you about nutrition and cancer? Have you not known what to say?

00:17 Natalie: (Sound clip) You know, I found it really hard and I needed support of my colleagues. And you know, I've always worked with really, really great Macmillan nurses who had tons more experience than I did, starting off all those years ago.

00:31 Paul: Hello, I'm Paul.

00:33 Liv: And I'm Liv and 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. Expect to hear discussions of clinical practice, personal experience and practical advice to improve your knowledge and skills in supporting people affected by cancer.

00:55 Paul: In this episode, we're joined by Natalie Harrison, a Clinical Specialist Macmillan Dietitian. Natalie talks to us about diet and nutrition in palliative and end of life care.

01:06 Natalie: (Sound clip) There can be lots of conflict about someone not eating and drinking very well. Relatives might feel quite angry. They might feel frustrated.

01:19 Paul: We learn from Natalie how a person's nutritional needs might change as they approach, end of life, and ways in which all professionals can support people with nutrition. Natalie also shares practical advice on how to approach difficult conversations with honesty, compassion and empathy.

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01:43 Liv: Natalie, Hello and welcome to the Cancer Professionals Podcast.

01:46 Natalie: Good morning.

01:47 Liv: We are delighted to have you with us today to talk about the important topic of food, well, food and fluid, and all things nutrition. So, to start us off, we wanted to know a little bit about what inspired you to pursue a career as a dietician.

02:03 Natalie: So, thinking back many years ago, I've wanted to be a dietician since I was about maybe 15, I first came across sort of the link between nutrition and health and disease in GCSE home economics at school, and I was particularly interested in how you can treat disease with nutrition. I have got a vivid memory of being caught by the teacher drawing a colon with diverticular disease on the board with my best friend and when I was

really little, I remember having a 1970s style book about hospital and even thinking then you know, I'd really like to work in hospital and there's lots of medicine, lots of nursing in my family from, you know, years back. So, I think that was that was the start of it. And then I just studied, went to university. I went to UWIC, which is now known as Cardiff Met. And I now lecture there. So that's gone full circle. So yeah, that's what set me on my path to be a dietician.

03:02 Liv: I love it when a career has come from a really early interest. That's yeah, lovely.

03:07 Natalie: Yeah.

03:08 Liv: And. And could you tell us a little bit about your journey to become a palliative care dietician? So, did you go straight into palliative care, or did you work in different areas before this?

03:17 Natalie: To be honest, when I first started, I wanted to be a pediatric dietician and I've never been that. I didn't really know anything about palliative care. I wasn't sure what I wanted to do, so I started off very generally in medicine and surgery and I've done lots of lots of very different roles because palliative care, even though I've done it for probably nearly 20 years. It's, it's a half time post, so I've always done other things in the other half. So those things are uhm, I had a stroke specialist job. I worked intensive care for 10 years I've worked in surgical specialties, Upper GI and colorectal, worked in lots of medicine. I've just recently done a job working with dementia patients. But all in all of these, I kind of realised I was interested in the ethical and the end-of-life aspect of the condition. So very early on in my career, I was looking into, how appropriate it is to put place pegs in patients being admitted with dementia and quality of life issues. That was very, very early on, so I think my interest was evolving then. I did a bit of a wild card secondment into CAMs into level four eating disorder unit, which was really very different to what I do now.

04:41 Liv: Just on CAMs, is that working with children and adolescents?

04:43 Natalie: Yes, it is, it was people under 18 young adults. Yeah, it really introduced me to the psychology around eating and and the psychological aspects that affect patients and their families and how to manage that. And actually, taught me that a lot of treatment is not just doing things for or to people, it's really the psychological, emotional management and support. So that was really quite groundbreaking for me. I then left this and went back into palliative care but was the start of that area of my practice. So, I think all these things that I've done over the years have been really important in the development of my interest in it, but also they contribute so much to my practice now.

05:32 Liv: And just when we talk about palliative care as well and could you just clarify, I know sometimes there is a bit of confusion about what the differences may be between palliative care and end of life care. Could you say a little bit about what we mean by palliative care?

05:45 Natalie: So palliative care is holistic care of people with non-curable disease. So, whilst, the bulk of my work is cancer, I see people with neurological disease, people with progressive chronic lung disease, heart disease. So, it involves looking after people who aren't going to be cured, and that we're going to see their disease or their illness get progressively worse approaching them up to end of life. So, I think it's important to clarify that because it's not just cancer and actually I think palliative and end-of-life care is a specialty is really high on agendas everywhere because you know, I'm sure if you think about it, there's a lot of illnesses that people live with that are progressive, aren't curable. For example, you know conditions like dementia we are going to see that really mushroom in our society as our population ages, and I know there's a big focus on non-malignant palliative care as well.

06:46 Paul: So Natalie, diet and nutrition is always a hot topic and we hear so much about why a healthy diet is so important for our overall health and well-being. Can you tell us a bit about the importance of nutrition in cancer care?

07:00 Natalie: I think about it a bit like preparing someone for a marathon. Putting the right fuel in at the right time so you know we might be thinking about people who are just diagnosed who are preparing for treatment, for surgery, for radiotherapy, for chemotherapy, for immunotherapy. We want to get people as fit as possible. So this is where our prehab agendas come in getting people in the best physical state that you can for treatment, we've got the metabolic effects of the disease coexistence or people presenting at diagnosis might have lost weight. They might have lost their appetite. So we're preparing people for that and we're assessing people for that, you know, the rigors of treatment that we know about side effects and and related side effects and how they affect diet and nutrition, but also, you know, things like. Physical effort to attend treatment can be significant for people going daily. Then you've got people you know during treatment, who need might need specific management if they've had, for example, if they've got swallowing issues, they've got absorption issues you're needing to react and respond to that and focuses might change. So you might have someone as I've just mentioned, needing a really nutrient dense diet, you might need someone who needs sort of a really high calorie, high protein diet because they're not eating very well through then to people who are through to the other side of their treatment who might then want to focus on just healthy eating. A really, really balanced diet, thinking about micronutrients and patient groups, and then moving into the area I work in, which is palliative care and nutrition, follows a different trajectory then when we're looking at perhaps symptom management and quality of life in total, so you can see it's really, really widespread and people will have different needs. And this is where, you know, we come in to offer specialised support as a dietician and also, you know, using the expertise of the MDT. So it's, I think you could say, Paul. Nutrition in cancer sort of follows and should follow where that person is in their journey.

09:20 Paul: And you mentioned the prehab agenda in what you just said. Is it worth just for any of our listeners who might not be sure what that is, just a quick example.

09:31 Natalie: Yeah, pre-habilitation, it's a fairly new initiative, but it's looking at getting people into the, you know, the optimum physical state that they can be before they embark on the treatment regime they've been prescribed. And certainly, nutrition is part of that, physical exercise is part of that, psychological management is part of that. So that's a really a new evolving part of looking after people in their cancer journey and nutrition can play a key role.

10:02 Paul: So, nutrition is clearly very important in cancer care and from what you said, there's a lot of different considerations for people living with cancer and how can health and social care professionals support a person with nutrition?

10:17 Natalie: I think it's really about gauging where people are and looking at individual needs and really monitoring and making it part of a conversation. A lot of the areas I talked about there, I mentioned specialists, but we all eat, and drink and we all can ask someone about nutrition and where they are and picking up on cues from patients to know if they're mentioning their appetites not so great, if they're mentioning they've got a sore mouth, you know responding to those symptoms it doesn't have to just be a dietician who does that. It's it's, you know, being aware of it in the conversation and just simply asking people because it is really, really important and from a quality perspective, you know, this is something that worries people a lot. So, all healthcare professionals can play a role in it.

11:13 Paul: So those professionals who are not specialists should, should they wait for someone to ask a question about nutrition or try and bring it into the conversation earlier?

11:23 Natalie: I think it's really useful to bring it into the conversation, not to be scared to mention it because oh, I'm not a specialist. I might get something wrong. As I said, you know, we all eat and drink and it's important to all of us. So, if a patient's highlighting it as a problem or even just working it into a general conversation. How are you feeling? How's your eating and drinking going? Any issues? I think it's within anyone's remit to do it. And you know we work we're in a climate now within healthcare of making every contact count. We're time pressured every, every contact is really precious, and I think you know, just working a simple question in or being aware of things to look for could be part of anyone's role.

12:09 Liv: Just going back to your role, Natalie, can you tell us a little bit more about it as a so your role as a Macmillan dietician, what does a day in your role typically look like?

12:19 Natalie: OK, it's really really varied. So just to get to give you an outline of it, I work in a in a wonderful Community Hospital on an 8 bedded specialist palliative care unit. It's a beautiful place to work, so I look after patients there and those patients might have come from acute hospitals. They might have come in from the community, they might be patients I've asked to come in for the community because we can't manage them out there. So, I have an inpatient role there and working as part of the acute team. The wider part of my role is I'm part of a community specialist palliative care team which is made-up of all sorts of wonderful Macmillan Professionals, Macmillan Specialist Nurses, Macmillan, OT's,

Macmillan Physios. We've got technical instructors that support us as well and do a really valuable role and we, you know, we work as part of the wider team. So I will go and see patients at home, I will get referral generated from within the team from our specialty care consultants or from other consultants, from GP's, from district nurses. So, I will go and see them at home. I might see people who coming into clinics. So that's kind of the geography of what I do and where people are and I will respond to what they prefer, what works for them. The reasons why people see me are usually things like, weight loss, poor appetite, specialist symptom control. So that could be things like malabsorption relating to their disease. Usually what I find is, is I will be asked to see someone for poor appetite and what I do is almost, almost like unravelling a ball of wool so the poor appetite is the main problem. But I usually work back to try and unpick, what is the cause of that poor appetite? Is there anything we can work on to make it better? Poor appetite is really, really difficult to treat in any condition and I say to people, poor appetite is a symptom and it's a bit like a light switch being flicked off by your body, we can't flick it back on, we manage it, but there are things we can do to improve. So, for example, if someone's feeling very sick, we need to treat that first because there's absolutely no point me going in as a dietitian saying ohh, I think you should eat this, I think you should take that when that person's really, really nauseous and actually, they might and they might be sick and not take that thing again. So that's that sort of core part of my clinical role. My other role is to take part in education, and you know, I'm really passionate about my subject, there's very few of us doing what we do in specialist palliative care as a dietician. So, I'm really keen to spread the message of, of what I do and how to look after people.

15:35 Liv: Yeah, it sounds like there isn't really a typical day. It's very varied.

16:40 Natalie: No, and that that's what makes it really, really interesting. And you know why I've done it for so long really.

15:46 Liv: That's brilliant. And you mentioned there that, so some people's symptoms are possibly quite challenging to manage at home and in the community. Could you give some examples of where somebody would then possibly move into your unit for further support?

16:02 Natalie: I think symptom wise for the majority of people, we can manage them in the Community because we are a team. We're a multidisciplinary team and we're all bringing our individual expertise to that patient. So for example, I would work really closely with the Community Macmillan nurses if we've got someone with a poor appetite and that, you know GI symptoms or gastrointestinal symptoms, may impact on appetite. So common things like managing constipation and nausea and vomiting, pain. You know, as a dietician, pain is not my area of expertise to manage, but pain can really, really knock on to someone's appetite. It can really decrease it. You know, if you can imagine if you've ever been in pain, even for a short time, you don't feel well, you certainly you don't want to eat. I would link in with my community colleagues. There have been occasions where you know we've needed to admit people to the unit, so we've got a more intense focus on that and where they can be monitored by our nursing and medical colleagues and medication,

perhaps titrated to receive optimum symptom management so we can then get them back home. So our really complex patients, the most complex for me are perhaps people with pancreatic cancer where they've got really high levels of malabsorption and we're trying to treat that and we're trying to treat then things like dehydration and diarrhoea and you know all everything that goes with that. So those that might be an example of a patient we might admit for MDT evaluation in an acute setting.

17:44 Liv: And in those in those more complex situations, what kind of advice would you be giving to the person and possibly their families?

17:53 Natalie: Again, very, very, very patient centred, you know, palliative care is holistic care. So we're looking after the patient. We're looking after their families. But this is almost like acute management within palliative care. You know, sometimes we we need to have conversations with patients and families where they've come in and their symptoms are managed, but their appetites haven't improved and their intakes haven't improved and we think that it might not and this is a good place to explore one of my main theories in treatment and management of anorexia, anorexia is a term for loss of appetite in palliative care and cachexic weight loss. So cachexia is a specific term we use to describe metabolic weight loss linked to incurable disease and some of that is around compassionate truth telling. So when people are in-patients or even out-patients, you know, and they're becoming very unwell a big part of my role is opening up these conversations with patients and families because that it's something they can become very, very worried about. And some are not eating or drinking someone visibly losing weight. I think what I've learned over the years is that people don't necessarily know and understand these are symptoms, and so we'll assume that, you know, if someone starts eating again, they're gonna gain weight, they might get better, or they might be able to have a better prognosis and live longer. Those, those are tough conversations and you know everyone in the team is able to have those. But I think that's really important to outline that yes, sometimes we are fixing symptoms for people. Or to help people to eat and drink a little bit better. But it's not always possible. Even when these symptoms are managed. And then comes the role of having that really open discussion with people. And as I said, I call it telling the truth with compassion. And I think in general, as health professionals we shy away from having these conversations, they can be really difficult cause we don't want to hurt someone we don't want to upset someone. We don't want to take away hope, but, in my experience, I found they can be very, very useful. They can be supportive and they can offer relief to patients and families of setting out where we are and what we're able to do. And I think you know the point I made earlier about loss of appetite being a symptom. I say that to people to really highlight, it's no one's fault. UM and I used the example of, you know for example, if you if you felt sick, you wouldn't say to yourself I'm deciding not to feel sick. You can't control it. And it's the same with appetite. Because you know, if you think when you're healthy, you can think, Oh well, I'm hungry. I'm going to eat this or I'm not going to eat that when you're unwell, and when you've got this this uhm symptom we call anorexia. It's the decisions taken away from you and in this whole, the psychology of not being able to

eat and drink. You know, I think it's really useful to outline to the patient. It's not their fault. It's not a choice, but also to relatives and carers that it is a symptom that we're managing like anything else or I'll probably come back to this because it is a thread that runs through my whole practice.

21:39 Paul: You've talked there about a lot of challenges and for our listeners, there might be some common misconceptions or myths about nutrition and cancer. An example of these might be kind of excluding sugar to stop tumour growth, so working in palliative care. Are there examples like this that you're frequently asked about and how perhaps should professionals approach these conversations?

22:04 Natalie: As you said in the beginning, Paul, you know there's tons of information out there on diet and cancer. If you googled it, you'd get, you know, hundreds of thousands of hits and some of it's great information, some of it's not so great. And you know, as a healthcare professional, we're always working on evidence based practice. I do get referrals and I do see people where they've got concerns about nutrients and specifically relating to cancer and prognosis and things like that. So the example you just said, Paul, about excluding sugar to stop tumour growth, I've come across that many times and the way I explain that to people and if I'm looking at any sort of nutrient within their diet is we're looking at a balanced diet. There's specific info about excluding sugars to stop tumour growth, it's not evidence based. There's a really good resource which I do give people from the British Dietetic Association, which has got an information sheet on cancer diet myths that's really, really useful and we can signpost you to that. But basically to to answer that should sugar feeds every cell in your body. So theoretically we haven't got evidence to show that it stops tumour growth but by not putting sugar into your diet, you're not fueling the rest of your body. And if someone is thinking about this and they've got cancer, there's a risk that their diet isn't as energy dense as it needs to be. And sugar as an energy source. So I would be talking to them about the completeness of their diet and where they're getting their energy from, where they getting the nutrients from and and steering it back to that. And usually when we've had that conversation, we've we've made a plan together because it's really important to have core production in, in things like this and they're understanding the theory of where I'm coming from. It's, you know, relayed some of their concerns. And we can move on making sure they've got an adequate and nutritionally balanced diet for where they're at in their cancer journey. That's appropriate as we said in the first question. So that, yes that I've, I've come across that before, there's, you know I meet lots of patients, for example, who might be diabetic or might have previous heart disease and we're all in the space of healthy eating of low fat, low sugar and I might be coming a long time and saying, you know, looking at their diet, carrying out an assessment and signposting them to those kind of foods because I think they need the concentrated energy sources or they might need, you know, micronutrient sources or things like that. And I have that discussion with them about the conflict in that and what's priority. And I sometimes describe it as a bit of a seesaw of what's more important, I meet a lot of patients who are maybe post-admission, and they've been. Been

given some advice in acute settings that they don't understand so that it might be they're totally a light diet. They don't know what a light diet is. It might be a soft diet. And when they come and see me, I'm not really sure why they're on that. So we can undo that. I've got a, a, a recent example of a lovely, lovely man who was told to eat soft diet because of a bowel obstruction. And I went back through his all of his notes, his medical notes. And there was no reason for that. And he blanked out a lot of his diet, actually, no fruit and veg, no meat. But it was very, very limited. And he just didn't know what to eat. And we worked together on this. And he said to me, I just want to have a Creme egg. Can I have one? And I said yes, absolutely. It's a tiny example, but it made a real difference to the quality of his life because he'd come out of hospital. Really worried about eating the wrong thing? And eating very, very narrow range of foods which he didn't need to do, and it was fine. So things like that, I'm often unravelling advice for people bearing in mind their clinical condition and trying to put that into a plan that works, whether that's physically or whether that's quality of life.

26:22 Paul: Thank you, Natalie. And yeah, you can't go wrong with a Cream egg.

26:27 Natalie: I agree.

26:28 Paul: So much useful information there, and you did mention resources and for our listeners knowledge we can signpost to the Macmillan Learning Hub where we do have some resources around diet and nutrition. So Natalie just moving on slightly to talk about. Artificial nutrition and hydration, and this can be complex at the end of life. Can you give us your thoughts and experience of working in this area as a specialist dietician?

26:59 Natalie: I think this is one of the most difficult emotive areas of nutrition at end of life. I became very interested in artificial nutrition hydration. When I was looking after medical patients where we would see perhaps people with end stage dementia being admitted for artificial feeding. And just to outline what artificial nutrition is that involves using the GI tract feeding directly into the GI tract, so it might be using a peg which is a percutaneous endoscopic gastrostomy, or a rig which is another gastrostomy which is a tube that goes directly into your stomach or it might be nasogastric feeding or it might be parenteral nutrition. Where you're using your circulation to put nutrition in in in various forms. Artificial hydration is obviously IV fluids or sub cut fluids. So yeah, I think I think this is really, really difficult as people, especially as people approach end of life. I've had a lot of experience in it in supporting people on medical wards, I've worked in intensive care units and you know I see people now, commonly people who perhaps have had tubes inserted because they've had head and neck cancer or they've had an epigenetic cancer and they're not able to access their GI tract because of various reasons. And I see those patients when they're perhaps out of their acute phase and they've become more palliative. I think it's talking about phases in someone's life in someone's disease and thinking about aims. And whereas in acute treatment aims of nutrition support might be. To aid weight gain to meet 100% of requirements and you're juggling all of that when I when people come to me, our aims might be slightly different in that we're looking at nutrition as maintenance, as

support and limiting side effect of that. Treatment because it is a treatment and it's classed within law now as a medical treatment. So we're looking at aims. What are we trying to achieve for that person? Where are they in their cancer journey? And you know if they are approaching end of life. We're aware that that nutrition and hydration does not prolong life, that it will not promote weight gain and that actually it might cause unpleasant side effects. So we're putting all that together, but I think it's really important to be open about that and again really, really difficult topic. It's hugely difficult for families. It's hugely difficult on times for patients, although sometimes I find patients are maybe more in that space and that their body is telling them they don't want so much of the nutrition. It's also really difficult for staff and I think if you're not experienced in it, if you're not a specialist in it or even if you are, it can be really, really difficult. And I think you need to support people with that. I think you need to be open and have that conversation with people and offer that compassionate truth-telling and that support and say, look, you know, we think someone is less. Well, we don't think their body's using the nutrition. We don't think they need as much and if we're moving into phases of keeping people comfortable being really aware of is that contributing to the comfort. So for example, you know someone on IV fluids who is in last days of life. It might not be appropriate to continue that it might be more appropriate that they don't have a line in their arm. They don't have a cannular and they don't have fluids going in which might exacerbate secretions they might have. It might put additional strain on their on their renal system and what actually might be more appropriate is really, really good mouth care. I think what's important is offering nutrition in this phase of life, because we're talking about comfort and we're talking about enjoyment. And you know, if someone perhaps is on artificial nutrition, it might be that we decide to cut that down a little bit so that they get in some nutrition, but they're not hooked up to a pump for maybe 10 hours a day or 12 hours overnight and they get in quality sleep and you know, they're able to spend that time with families. But again, I think you have to, I think you have to have that conversation. And explain why so everyone's confident, everyone's comfortable with it and they can be open about how they feel in that situation. And I think also what's really useful to explain is, you know, when I do explain this to people a lot is about sort of starvation and loss of appetite in end of life and people will worry about that. Are they starving? Do they feel hungry, you know, in looking after someone you love that is core, isn't it? And that's something you really worry about is their comfort. And I'll use the example of you know for example, if you and I start eating and drinking today being well, we would feel hungry. And as we experienced starvation, it would be unpleasant and we would experience that. We find that people with loss of appetite at this point in the end of life don't feel the same. And sometimes that can offer a huge amount of comfort, coupled with the fact that really keeping on acute nutrition support might actually make them feel a little bit worse, I think you know we're arming people with that information very, very compassionately, very, very supportively. To offer advice and guidance and support at this time. And there's a really, really useful explanation from Catherine Mannix who is a palliative care physician talking about the dying process and the bodies need and lack of need for nutrition and about keeping someone comfortable. Bearing in mind sort of all these points

I've just mentioned. So yeah, it's a difficult one. It's probably one of the most difficult conversations. And like I said, specialist or non specialist, we all need support and guidance with it. But I think it comes back again to this compassionate truth telling to support people.

33:44 Liv: And so staying on that topic of those quite difficult conversations and that compassionate truth telling what communication skills would you take into those conversations and what advice would you give to other professionals about having them?

33:58 Natalie: I mean, it's tough, isn't it? You know what I've just said? It's tough. And I've done it. I've done it for 20 years and it's still tough. I'm really, really lucky that I've had a lot of communication skills training through Macmillan. I've done advanced communication skills and a course called SAGE & THYME. And when I first started in this role you know, I found it really hard and I needed support with my colleagues and I think it's having, really empathic intuition. I think that's vital. And what I mean by that is looking behind what someone is saying or is too scared to say, and it's about interpreting emotions. So, for example, there can be lots of anger. There can be lots of conflict about someone not eating and drinking very well. Relatives might feel quite angry. They might feel frustrated. You know, I've made you this. You used to enjoy this. Why don't you like this? I don't know why I'm bothering. You're not trying. There's fear behind that. There's fear and and really I think to myself what they're saying to me or what they're saying to the person they love or themselves is I'm worried I'm going to lose you quicker. And that's really difficult and I think it's about being brave and having those conversations with compassion and understanding and assessing or asking how much info people want to know, I think we're very good at that in palliative care about being open but also you know, some people don't want to know. Some people don't want these difficult conversations. It's about, it's about sitting with that think it's about sitting with your own discomfort. And like I said, being brave. I think some of it has to be inside you? Yes. And you know I am that person and certainly in. Reflection and self development I. I've facilitated myself to say kindness is my superpower because it is it is in me. Advice to my colleagues is the fact you want to have these conversations. It means it's in, you know, the fact you care about people means you're able to do it. And I think it's having support around you.

36:30 Paul: Thank you. And at what point would you recommend that health and care teams involve the dietician?

36:40 Natalie: There's really, really few of us and working in dietetics in palliative care. There's two of us in Wales, so there aren't many of us. I think ideally it would be as someone's entering, perhaps a palliative care phase if they're involved with a specialist palliative care team, if they've got specialist needs to sort of have early intervention and assessment and really, you know, enhance the quality of care there. In an ideal world, perhaps it would be a lot earlier than I see people, but the resources you know aren't there at the minute so I. Think in that respect. It's being aware of. Like you said empowering other people to provide some of that input and some of that advice and some of that

support and triggering a proper referral when they come online. And I think that's a really key role in being a specialist. It's not just the clinical intervention you offer with people, but networking and educating to empower because you can't see everyone. So that's a really important thing to consider. There are newer models of care coming in now in things like supportive care, where we're seeing AHP, dietitians meeting people earlier in their journey and working with acute teams so that care becomes even more seamless. So they're staying with the same person throughout their journey and supporting them, so that's really exciting and that's new.

38:16 Liv: And leading on from that question, Natalie. So we know that research is so important for informing best practice and improving outcomes for patients. Just thinking about any recent advances or research findings in palliative care and nutrition that may benefit people. Are there any that you find particularly exciting or promising at the moment?

38:34 Natalie: There's a couple of areas that I'm really interested in studying and locking up and integrating into practice, so I'm aware that there are initiatives around palliative care rehabilitation, which is really, really exciting and new and not something we've maybe thought about before. So I'm currently looking up information on that and that is thinking about keeping people well and as fit as you can in palliative illness. So that's really really interesting and exciting and also leads me into something else I'm working on looking at the moment, which is different ways to manage cachexia. So as I said earlier, cachexic weight loss is a metabolic phenomenon syndrome of muscle wastage and we see it in people and when they become more and more and well as they approach end of life. If you can maintain muscle mass you can maintain things like strength, mobility, well-being, quality of life aspects you know such as you know even things like being able to get to the shops, being able to watch your grandson play football. All these quality of life indicators we look for in palliative care. And that's looking at managing cachexia with exercise and nutritional therapy. So that makes me hopeful that there may be more dynamic ways to manage that in the future and linking up sort of multidisciplinary teams to support people with that. So I'm actually really quite excited about that. And and looking into it with sort of leading experts to see how I could integrate that into my practice today and how I can share that within the organisation so that it reaches as many people as we can. So watch this space on that, maybe I'll come back in a year and let you know where I am and be really excited.

40:36 Paul: Thank you, Natalie. Yeah, huge things to think about for the future. Just back to your career journey really and in your 25 year career, you'll have supported loads of people who've benefited from your nutritional advice. Just thinking about that. Are there any standout examples of where it's made a real difference to them?

41:02 Natalie: I do. I do like to think that yes and that that's why I do what I do because I want to make a difference to people because I really care about people and that's why I started this 25 years ago. I think standout examples are from patients where I make a clear

and fast improvement in their symptoms which enable them to enjoy eating and drinking again. So for example, it could be something really really simple, like noticing they've got a sore mouth, like noticing they've got sore tongue, or they can't taste very well and I'll zoom in on that part of my assessment and I might think to myself, have they got a vitamin mineral deficiency. Lots of them have because they're a little bit of run down, they haven't been eating so well, their system's depleted from treatment or whatever, and even doing something simple like that, like getting them to vitamins and minerals, getting them a preparation to treat oral thrush, things like that can make a huge difference. Or as I said, working with my team to work on a symptom, which then might mean for example, they can leave the house again. So if they've had malabsorption for a long time, they might worry about going out in case they need the loo and they can't access the loo and things like that. We don't, we don't want people in their last months of life to be restricted by things like that, we want to enable them to do what they want to do. And you know, I think because of my previous roles, all of my previous experience in surgery, intensive care, that type of thing, I've got so much banked in managing patients who've had all sorts of resections malabsorption, that can make a huge difference. So I think you know off the cuff that makes difference. But I think for everyone, it's the fact that someone is interested and willing to work on this and go the extra mile, and that's what I try to do with people. And I think that makes a huge difference and offers a sense of relief. And you know, I feel that as I'm leaving that person's home. Thank you so much, you know? And I know that's made a huge difference. From a quality of life perspective, although not as instant I know the discussions I have with patients and families offer a sense of relief and support at, you know, one of the most difficult times in their lives. And I think overall, you know, knowing I'm on their team and I do say that to people sometimes, you know. I'm listening and responding to what matters to them, is really, really valuable and a core part of the job. And it gives me huge job satisfaction actually, to have that rapport with people and to have that feedback.

43:53 Paul: And that all sounds absolutely amazing. And what about for you? What are some of the joys and challenges of working in this field?

44:02 Natalie: It's much more than a job to me. It's a vocation. It is really my heart and soul. And and I'm really privileged to do it. And I meet incredible people, patients, relatives, carers. I work with incredible people. The communities I work in I've worked in them for 20 years. They're unique. They're absolutely wonderful. You're really privileged. Going into people's homes and they welcome you and I'm not easily phased. Let's just say that and it comes with a sense of humour and a belonging to the communities I serve, they welcome me and that's special. That's really, really special. The challenges I think you have to look after your own well-being and mental health and that's something I've really had to learn and sometimes the hard way, you know. Ee are working with people who aren't going to get better. Every single person we work with and that can be challenging the most difficult times are if you're looking after someone that resonates with something in your own life, then it can feel really personal. So you have to, you have to be mindful of it. You have to

take what you can you know the joy is that I've just said, but be mindful of the other stuff. But I love it. I absolutely love it. Yeah, I'm very lucky.

45:28 Liv: Your passion for the role and the people you support and your team absolutely shines through. That's so, so lovely to hear. And just thinking about some advice for our listeners, what top tips would you give to professionals who are supporting people in palliative care when it comes to people's nutritional needs?

45:45 Natalie: I think I think there's two things here, I think it's individual assessment. So finding out, you know, real person centred care and conversations. So finding out what's important to that person about their nutrition at the time. Can we make it better? Can we improve it? And looking at that? Think it's very easy for us as healthcare professionals to go in and see people with our own agendas. We've got boxes to tick and we've got things and performers and things like that. That, but I think that's a core skill is finding out what's important to that individual about nutrition and it could be something totally different to what you're assuming. And then when you've done that, you know, I would revisit my compassionate truth telling theory about, OK, this is important can we improve it? If we can't, being honest and explaining that and supporting within that, and I think those are probably the two key strands, what's important to them? What can we do about it? If we can't have that conversation and be honest and support them.

47:05 Liv: That's really helpful. Thank you. And just to mention on those two topics as well for anyone who is looking for more information about person centred care and communication skills, there are a lot of resources on Macmillan's learning hub to find out more.

47:19 Paul: And Natalie, just just reflecting back on one of the challenges you just talked about in terms of well-being. You're supporting people as they near the end of the life, which as we've talked about can be very emotive, just maybe a little bit more about how you balance that personal professional life and your own well-being and any examples you've got of or tools that you might use.

47:47 Natalie: I think it's. I think that's really important. It's it can be difficult. I think I think formally I'm supported I have a psychology session every six weeks with a clinical special psychologist who has supported me for a long time and knows the ins and outs of my working and personal life and that's really really useful. And to be honest, quite often when I go to see him, I think I'm not sure what I'm going to talk about. And then at the end of the hour, I haven't stopped talking and you know, I always leave there with food for thought and feeling a lot better. So formally I have that set up. Informally, the very nature of the team that we're in. We chat, I've got colleagues. I share an office with my OT colleague and Physio and our next door. We're in the centre of the ward and we have really informal support there, so we'll have a chat, we might have a laugh in our office, we might have a cry. You know, we might come in and say I was tough. It was a tough visit. Oh, this is so sad or I don't know how to help this person. And we might have a bar of chocolate. I might trot up to the Macmillan Nurse Office and, you know, have a chat with them. And it's really,

really informal debrief. I think. In my personal life with more experience, I've just become mindful of if things start to creep in and and you know I'm, I'm busy. Full time jobs, got two lovely children, busy life and you keep going and you're running on the hamster wheel, aren't you? And I think I've become better at maybe noticing if I'm getting a little bit of run down. If things are getting on top of me and doing something a bit sooner than maybe I used to, I think as a person I'm quite tapped into well-being resources into sort of mindfulness and you know well-being resources that are out there from within the health board within Macmillan and just using apps and things like that, I might do a bit of yoga and I might avoid anything to do with sadness in my own life. My sister works in oncology as well. She's a specialist radiotherapist and is someone I can talk to a lot because she understands. I think it's about being mindful of your well-being. And I think we all need to be mindful of that.

50:19 Liv: Yeah. well-being is so important, isn't it? And I think you shared some really, really helpful advice there that that people can take forward. And just to bring us to our final section of the podcast and our conversation today. So we have three questions that which we've titled what three things just to for us to finish off with. So firstly, if you could go back in time to when you first started your role as a dietician, what one piece of advice would you give yourself?

50:46 Natalie: Wow, OK, I think. I think the advice I give myself is you're doing the right thing because it's been a it's been a wonderful career. I've absolutely loved it and it was it was definitely the right choice for me. I've never doubted it really, but I think I would say to myself that that sticking with things is the right thing to do and it'll all work out in the end, and what I mean by that is, you know having been in a specialty for so long and the same place for so long. Perhaps I've put a little bit of pressure on myself should I be doing something else and where I am today in my career? I'm really sort of standing on the edge of amazing things. I've had an incredible year career wise and I'm really sort of catapulting into the expert field of palliative care, which I never thought would open up for me. I really want to take that full word to spread my love of this speciality and my mission within it.

51:53 Liv: Yeah, that was. That's so good to hear. And our second question is what one change would you like to see to improve the lives of people living with cancer?

52:02 Natalie: I think there's so much positive work going on in research, in cue, in cures, in supporting people with cancer. It's so, so holistic. I think the one thing maybe I feel is that we're still really seeing and feeling all the post covid after effects. Everyone is trying their hardest. We're working 200%. But there are still gaps, and there are still delays and that's what I would like to see improved for people, really, it's not for the want of trying, but if I could be in an ideal world, that's what I would like to see. Because it there's. There's a lot to recover from, I think.

52:49 Liv: Yeah, absolutely. And finally, what one thing do you want our listeners to take away from this episode?

52:55 Natalie: I want to empower you to be brave and to feel comfortable and confident in compassionate truth telling. And I want you to know that saying the difficult thing can be kind, it can be empowering for patients and it then will enable us to move into individual person centred treatment, care and support. So I think if that's the one takeaway you can take from this is that sometimes being honest is the right thing to do.

53:32 Paul: Wow, Natalie. So many great pieces of information that you've shared with us today. Thank you so much for the time you've given us and for really the the passion for the subject that you've shared with us today. It's been a real pleasure to meet you.

53:50 Natalie: Thank you both.

53:53 Liv: You've 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/learning to find out more about our learning hub, where you can access free education and training. For links to the resources mentioned in this episode, see the episode description.

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