Transcript

Rethinking neurodiversity and physical disability in cancer care

Intro music

Paul Middleton (00:10)

What if cancer care was designed for every mind and every body?

Ruth (00:14)

And actually to say, to recognise that somebody who's autistic might really struggle to process all those sights and sounds and smells and to say "why don't you come first thing in the morning or last thing at night when it's a little bit quieter, why don't we turn off the lights?". Let's just make some really practical, sensible person-centred adjustments that might enable you to have a really important test that you're entitled to have.

Paul Middleton (00:38)

I'm Paul and my pronouns are he/him.

Liv (00:41)

And I'm Liv 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.

Paul Middleton (00:56)

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Paul Middleton (01:17)

Today we're joined by Ruth, Chair of the Women's Health Forum at the Royal College of Nursing, who has developed a guide for healthcare professionals to support physically disabled women and autistic women with cervical screening. And Jessie Hewitson, who will share her experiences of accessing cervical screening and healthcare more broadly as a neurodivergent woman. We'll explore how we can make cancer care more inclusive and accessible for people who are neurodivergent.

So welcome to the podcast. Would you both like to introduce yourselves and tell us a bit more about your connection to this topic, professionally and personally? Shall I start with you, Jessie?

Jessie (01:57)

Hi Paul, thanks very much. So I am a journalist, author and I'm a Director of a company called NeuroUniverse. So we work with companies and charities to help them better understand neurodivergent people. And more recently, I've been working in the healthcare space, sort of working with doctors and nurses and medics more generally to look at the experience of autistic and ADHD people. I'm also autistic and ADHD myself. I'm a late diagnosed woman. I managed to write hundreds of thousands of words on the topic of autism or ADHD before realising that it was completely relevant to myself.

Paul (02:38)

Lovely, thank you. And Ruth.

Ruth (02:38)

Hello, Paul. Thank you so much for having me on the podcast, really excited to be here. And so my name is Ruth and I use the pronouns she and her and in my day job, I'm an Advanced Nurse Practitioner working in primary care in sexual health, and I support women with their contraception and menopause choices. And I'm very involved in cervical screening. But I also have a role as chair of the RCN Women's Health Forum, which is part of a network that campaigns and advocates for excellence in women's healthcare. And I was very privileged to lead a project which was a project that put together some guidance for cervical screening for physically disabled women and autistic women. And it's a really great opportunity to come and discuss some of the findings and some of the learning from that guidance with you.

Paul (03:38)

Thank you, Ruth. You know, as we continue the conversation, we'd love to hear a bit more about some of that research. So just to kind of kick us off with the conversation, Perhaps I'll sort of start with you, Jessie, but- what are some of the experiences that autistic people are facing today around cervical screening and cancer care more generally?

Jessie (03:59)

Well, just in terms of cervical screening, think the two big challenges I've faced are fairly typical and it's booking it and then once you've booked it, turning up, which I think are quite significant challenges. And then in terms of cancer care, more broadly, there is a huge number of challenges. We know, there's autistic people have far worse outcomes medically than non-autistic people and there's a whole body of research to show that. And the issues that are feeding into that are very complicated, just simply they're often having to make a phone call to start your, you know, whatever that healthcare interaction is. It's a difference in communication. It's the difficult sensory environment of the waiting room, whether it's your GP or whether it's a hospital. And it's also difficulties around being able to identify what's going on in your body and then trying to communicate that to someone else.

Paul (05:03)

And are there any specific aspects that you found challenging?

Jessie (05:11)

Yeah, certainly. So the booking and turning up very much relates to me. So I don't know how many smears I've had, but it's nowhere near as many as I ought to have had by my age. And that is for those two reasons. So I was explaining to my GP actually that, you know, I don't often go to blood tests when I'm being told to go to blood tests and I was trying to explain why and it's to do with the organisational processes that are called executive function and this is certain brain processes that help you start a task and stay on the task and complete it. I wasn't really going into all this with my GP but I was basically trying to say to her- I know this may seem really simple to you but it's not simple to me. And because of that it's meant I don't always get a blood test done and I don't always get my smear done when you text me, in fact I rarely do. So what was a really positive example was the GP said- okay so if I got my secretary or the general receptionist to text you this moment with a link where you could book the date, would that work? And I said yes it would and I had to be really strict with myself to respond to it straight away and get it booked, and we did get it done and actually it was good because there was something out of the ordinary that came from that test so without that interaction with the GP you know it could have easily been years/ I don't think I would have pushed it to never, but it would have been years before that had happened.

So it just took quite a fortuitous conversation with the GP who listened to me, who took it seriously, I guess, and found a solution for me.

Paul (06:54)

Thank you, and thank you for kind of sharing such sort of personal, your own personal story and your own personal journey, that'll be really helpful for our listeners. And Ruth, thinking about the guide, what led you to develop this guidance?

Ruth (07:09)

We know that from a national screening point of view, that if we were able to screen everyone who was eligible and we were to meet a target of 80% of people who were eligible to be screened, to be screened, then we would be really successful on our journey to eradicate cervical cancer by the year 2040 and that's our target. But we know that not everyone who's eligible to be screened is. And so this is part of a wider piece of work trying to understand about what it is, what are the barriers that make it difficult for people to engage and the group of people who are underserved with screening aren't homogenous groups, there's all sorts of different groups of people who for whatever reason are underserved in that area and we were approached by Jo's Trust who at the time were really important charity campaigning for cervical cancer and sadly not with us anymore, but at the time they were and they came to us and said, look, we know that there's a real issue with physically disabled women being able to access screening and there isn't any national guidance and would you, as part of the RCN, work with us and some researchers that have explored this area to try and elicit some of those barriers and put some practical guidance into place. And at the time we were also asked to look at the experience of autistic women who were another group of people who were really underserved with screening. And I'm really struck, Jessie, by your story that you shared because really what it took was for a GP to say- can you help me understand the difficulties that you're facing so we can do something about it? And that's the absolute essence of this guidance, to sort of recognise that there are groups of people whose needs are different and we need to do something really practical to address those.

Jessie (09:06)

And also Ruth, I sort of think, like, I don't properly understand why I can't just do that. In my head, it's simple too. Like, you know, I'm a journalist that used to run two, you know, busy desks on the national newspaper. You know, there's a lot of things I can do. So why can't I just phone up my GP practice and book the smear test? It's kind of, yeah, it's not clear to me either. And I don't think I did articulate it to the GP because I'm not clear why I can, even though I've written books on the subject. But what I was grateful for was that she took it seriously. You know, I think, you know, why these organisational problems exist, I think, you know, it's under kind of examined, really. There isn't a whole body of research yet done by medical researchers. I think just having a GP working with the problem, even though she might not have understood completely, was really helpful.

Ruth (10:07)

It was really interesting undertaking the work, the preparatory work for the guidance, working with researchers who had done a huge amount of work with physically disabled women. And the work that they shared with us, on which much of the guidance is based, was looking at those physically disabled women's experiences. And they're not homogenous groups, their needs are different, but they were able to highlight sort of groups of barriers. And one of them was around the environment, and I think you've really illustrated that so it may be really difficult for somebody who's a wheelchair user to physically access the area or getting into general practice and their bed doesn't go up and down and simple adjustments like having handrails or a movable bed would enable that person to carry on with what's a really important test they're entitled to have but there are other people where actually it's the trying to come into a surgery, it's got bright lights and lots of noise and little kids running around and general sort of commotion.

And actually to say, to recognise that somebody who's autistic might really struggle to process all those sights and sounds and smells and to say, why don't you come first thing in the morning or last thing at night when it's a little bit quieter, why don't we turn off the lights? Let's just make some really practical, sensible person-centred adjustments that might enable you to have a really important test that you're entitled to have.

Paul (11:38)

And I think within the guide, are there any other kind of key challenges perhaps thinking wider than just cervical screening, but kind of the whole cancer care and prevention?

Ruth (11:51)

Yeah, I guess from the prevention point of view, it's just worth recognising that there are about four million physically disabled women of screening age. I'm talking specifically about screening here. But that's a significant group of people whose needs are different. And that won't be just for coming to have a smear test. That will be coming to have a blood test, it will be coming to discuss a treatment plan. And it's about recognising that and saying, what can I do to make this easier for you? How can we tailor care for your needs specifically? But one of the key themes that the researchers pointed out to us was a barrier being medical healthcare professionals themselves. So, Jessie gave us a brilliant example of where that wasn't the case. And that's something that we should all be working to and to aspire to. But for some people, it's around the attitude or beliefs of healthcare professionals. Now, we're all here to do a good job. We've all come in to try and make things better for people. So, I don't think that some of this is intentional, but it's making assumptions about what people who are physically disabled can and can't do, making assumptions about their experience, talking to their carers and people that are there with them, supporting them, and not the person, really basic stuff. And in cervical screening, people perhaps not offering them because they think that people who are physically disabled aren't sexually active. I mean, that's a massive assumption to make. So I think that's a lesson in that, that chime for any area of care delivery.

Jessie (13:36)

Yeah, I was just going to say that my experience with the GP was a really positive one, but I had had to battle the receptionist for a good two weeks to get to that point. Now, I don't want to blame the receptionist because I think they're given their orders, which they carry out. But basically it was over something else, and it was over HRT really. And the receptionist were telling me I had to go off to get this blood test before I could speak to the doctor. Now I knew that this blood test actually shouldn't have been a barrier to me speaking to the doctor because I'd done my research and I knew the blood test was only indicative of that day, etc, etc. So I was saying to receptionists, well basically I was a bit infuriated because I knew I shouldn't have to go through this blood test, but also it was difficult for me to get this blood test really. So it was even more infuriating me that this was a hurdle because it was a difficult hurdle for me. So I'd kind of got to a point where I was all like in tears with the receptionist before I became so so much of a pain I think they finally put me through to the GP so I guess you know it was a good experience but also there had been two weeks of quite fraught phone negotiations.

Ruth (14:48)

I feel stressed, stressed hearing about it and we're really trying to encourage people to engage with healthcare. So it's incumbent on us to make that as easy as possible and as welcoming as possible as well. So I'm sorry that that was your experience. That's something we should all be really listening to.

Jessie (14:55)

Yeah, I know. Well, I can see sometimes receptionists getting bit of abuse as well from the members of public. So I see how it all happens and I think we're all so busy, aren't we? But I would love, you know, for people to realise how stressful phone calls are for autistic people. And I don't think there is enough understanding around that. So I think if that receptionist, if it was on my file, if that could just ring some kind of bell with her that actually, I mean, I'm actually not so bad with phone calls, partly because I think my career in journalism, I was just forced to do it and I had to get better. But I have interviewed a lot of autistic people and one of them was a man who had a seriously sick baby with a very alarming temperature and he couldn't phone 111 because of his fear of phone calls. You know, there are lots of reasons why autistic people find that very difficult communication, partly because there's no script, you're not quite sure where that conversation is going to go. You know, sometimes people have difficulties with auditory processing, so they're not getting the sort of social cues and lip reading that they're relying on.

But I think it's also because you've had all these interactions that have gone wrong in the past and you're made to feel stupid or odd or all those, like the person who's got the problem and all that anxiety you're bringing to you with these kind of everyday interactions- totally unmanageable for some people.

Ruth (16:37)

I think that's absolutely vital for us to recognise as healthcare professionals. I think it's particularly important and pertinent for people coming for their smear tests because it's an intimate examination and it can trigger trauma that's happened in the past and that might be birthing trauma, sexual trauma or just a really poor experience where somebody's dignity has been challenged in some shape or form. I think we can make a really big difference by recognising that for some people, for whatever reason, it can be a difficult test and there's huge amount that we could do to ease that. I'm really interested in what you were saying around the difficulties of a telephone or auditory processing information and one of the things that we put in the guide is trying to think about giving information in the way that is most appropriate to a person. Sometimes that's taking written information away to read. One of the things that we've suggested in our guidance is having planning appointments where you say, why don't you just come in, we'll just talk about it, and then you decide whether this is something that you want to have. So that the person's got an opportunity to see the room, feel the smear taking brush on the hand, and just sort of play out what's going to happen. And then for the same person, the same health care professional to be undertaking the test, so that you've got that relationship, you've got that a little bit more predictability that can be helpful for some people.

Jessie (18:18)

Yeah I think that's such a great idea Ruth and if it was possible you know. I mean, that is just the gold standard I imagine, but maybe the silver standard could be if you're able to email people if you know they're autistic with a kind of visual story of what a smear test is going to involve really. And I think also the information. I mean, I recently had a gynecological procedure and all the official information said it doesn't hurt. It really did hurt. And actually when I went online, everyone who's done it is saying it does hurt. So I think in a way, you know, I think with autistic people having clarity of information and, you know, sort of expressing it more, I want to use the word honest, but that's not quite right, because it's not that people are trying to be dishonest. But I think it's preferable to say, yes, it can hurt some people, but that pain is, you know, two out of 10, rather than 10 out of 10, and it's likely to last between two and 10 seconds.

Ruth (19:18)

It's hugely important to prepare people and to listen to what their experience is because it will vary. It will vary.

Jessie (19:28)

Yeah, yes that's true and you could say- we welcome fidgets you know if you want to bring a fidget toy to distract yourself please bring whatever you want you know or if you want to bring your weighted blanket or your ear defenders or fidgets that's all good.

Ruth (19:34)

That's what this is about. I mean, one of my key concerns, I think the key concern of the project team was that we know that people who, for whatever reason, are under screened have a higher risk of going on to develop cervical cancer because they don't have the opportunity to have those abnormal cells detected. They don't have the opportunity to be tested to find out whether they've got HPV that will increase their risk in the way that other people will. So that disadvantages them and that if abnormalities are picked up, they're going to be picked up later. So it's a real health inequality that I really feel passionate that we could better tackle with some, what are actually quite simple measures. And one of those measures is recognising that not everyone can come to surgery, even with the best mobility aids and the most well-equipped surgery. And those reasons may not be physical. They may be because somebody has a mental health problem, that they're agoraphobic, or it may be that it's just overwhelming. And we've really asked people to think about offering home visits in those circumstances because it's a simple way to be able to make that adjustment. And ultimately, if people aren't able to come to come to primary care, then we need to think about what provisions we can put in place to enable them to go to secondary care and to have specialist support because it's those people that are under screen that are the most at risk.

Jessie (21:16)

Ruth also what I liked, you know, in your, in your suggestion about coming to have a planning meeting is it's a kind of relationship based approach isn't it saying you've got the planning meeting with me and you'll have me next time and again I know this is down to resourcing but that kind of approach could be spectacular can't it for an anxious autistic or neurodivergent person because you know if they love you Ruth and they're like right I can do it if I've got a Ruth then you know having that consistency.

Ruth (21:45)

I think sometimes it is around consistency and being able to plan. Other thing that I think offers opportunity when we're not there yet is that we are hopeful that we'll be able to offer HPV self testing in the near future. For some women that be groundbreaking, it won't suit everybody and it won't be applicable to everybody. But for people that have been unable to have a test in surgery for whatever reason, may find it acceptable to be to take a self-taken sample. Obviously if they were found to be HPV positive they would still need to come in and have a traditional smear test, but it opens up more choice I think and is a step forward and may offer the opportunity for people to be engaged in screening that previously haven't.

Liv (22:36)

I saw that recommendation from the National Screening Committee who have made that recommendation across the four nations to introduce self-sampling. It sounds like it could really be beneficial to get more numbers screened. Were there any other recommendations from the guidance Ruth that you'd like to touch on? I know you've covered bit of communication, that organisation side of thing. Was there anything else about the environment?

Ruth (23:01)

There's a couple of things in there that I hope will be helpful. This is about trying to be helpful and reach underserved groups. So the kind of things I hope will be helpful is just structuring some of the challenges and highlighting enablers to enable staff to look forward and see what might be applicable in their circumstances. We've offered some prompt questions because sometimes it's around having the language or we're using the right words to suggest opening up conversations like, I can see that you've got mobility aids there that might make a screening test difficult. What is it I can do to make it helpful for you or recognise that you've had a previous poor experience? Is that something you're able to talk to me about? Because I really want to make sure that we don't repeat that and we make the next experience really positive for you. Or have you had any pain or discomfort having sex?

Can you talk to me about that? Those kinds of things. We've put some practical resources. We've highlighted some training. So the Oliver McGowan training is mandatory. I know very well that not everyone who could have benefited from that training has had it, but it is excellent and full of practical tips. certainly learned to do that. So it's just advocating the resources and training that is available.

And one of the things that I hope will be useful to people is a checklist at the back of the guidance so that people can just work with their own teams to see what have they already got in place because there's pockets of excellence across the UK. There really are. There's really some huge, fantastic, innovative projects, but they're not everywhere. So what is it that we've got that we can celebrate and what is it that we need to build on? And what are the things that would make this very difficult in our practice? Because they're the starting point, really.

Ad

Paul Middleton (24:54)

Before we hear more from Ruth and Jessie, here's a quick message from Liv about additional learning in this area.

Liv (25:01)

Lots of people with cancer have other needs or health conditions too, as we've been hearing about chatting with Jessie and Ruth. This can have a huge impact on the level of care and support that a person needs. If you want to learn more about cancer and other conditions, there are a range of resources on the Macmillan Learning Hub, including the Cancer and Other Conditions eLearning course. If you'd like to know more and access the Learning Hub, see the episode description. Now let's get back to the conversation.

Liv (25:26)

Jessie, coming back to your experience, what kind of difference would those, if those kind of different measures had been implemented and adjustments made for you, obviously you've spoken about having to really have that conversation with the GP to explain your situation and what would help you. If that had kind of happened without you pushing for it, what difference would that have made to your experience and kind of other interactions with healthcare as well?

Jessie (25:48)

Well, do you know, I would absolutely love it if, you know, everyone could book a smear online. You didn't have to phone up, you know, I think. But also, I think also it needs to be recognised that ADHD people are absolutely certain have a low uptake compared to other groups because of these organisational difficulties. And in a way, you know, for those people, you might need someone phoning up or emailing saying, OK, book now and you've got to do this. Let's do it together. You know, to I mean, we talk about a lot in ADHD about body doubling and it's like having hooking yourself to someone else who's going to help you achieve the outcome you need to. I sometimes think actually explanation if people have got time is really helpful because I recently did have an experience that taught me why I absolutely do have to have smear tests regularly. And I know we do get them in letters, but there's something about hearing it from the person. The reason why we ask you to do is this, this is a very unlikely outcome, but if you don't come back in however many years time and there is something to be picked up, this could be the consequence. I think sometimes hearing that in person can be helpful.

But you know, this isn't, I think this is less of an issue, but in the past I have found that as a mum actually that I've had to kind of only justify my son's autism to the particular doctor. I don't know how relevant this is in this conversation but because I don't look autistic neither does my son. In a way I think we've I've sensed a certain barrier when we're asking for adjustments because you know I can feel and then there's follow-up questions asked really I feel like it's someone sizing up how autistic are you and I think in this day and age I'd like to think we're more aware of the fact that this kind of spectrum isn't normal to not normal. Autistic people are very varied, just like neurotypicals. if someone has a diagnosis, it needs to be respected.

Liv (27:55)

Yeah, absolutely, it shouldn't be something that you have to justify at all. Yeah, that's quite shocking really. Ruth, if I could come back to the guidance again, what kind of feedback have you had since it was released and have you kind of measured any impact that it's had as well?

Ruth (28:08)

It was published at the last part of last year and we've very recently had a webinar to launch it, which we did in partnership with the Eve Appeal. So the Eve Appeal are a charity that do fantastic work advocating for five gynaecological cancers. And they've very much worked to try and the space left by Jo's Trust. And the Eve Appeal have inherited the rights to Jo's Trust patient literature, which was fantastic, and that's being updated. So, we had great response to our launch, and it seems to be guidance that people have welcomed, so that's great. It's early to be able to evaluate its impact.

And ultimately, its impact is going to be how people run with it and put it into practice. And it may be that an individual service doesn't put all of it into practice. They pick on one bit, perhaps, that's particularly resonant to them. Jessie, I've scribbled out some ideas as you were talking- yeah, my goodness, that would be great to do an audit. How many people have you got registered as autistic? And let's have a look and see how many of them are up to date with their smears.

So that's a great quality project. But I think we need to be mindful that many people who are neurodivergent are underdiagnosed. So I certainly see in my clinical practice, families coming forward saying- look, my child has been diagnosed with ADHD. Actually, I think I've got that. That resonates with me. So it's about us being open and not being judgmental and not having fixed ideas, which I think is what you're talking about, Jessie, you know, this picture of what the autistic might look like or behave like.

Jessie (29:58)

100 % yeah, 100 % because I feel like the whole healthcare system, like the whole education system, like banking, everything's been set up for neurotypical brains. So, you know, it often doesn't work for us and causes us immense stress to access. So I think, you know, I think it's about being open-minded. Does it have to be this way? You know, is everything an easy task for everyone equally? Yeah, yeah, and also, you know, a lot of people are autistic and ADHD. They're often, I think we're realising increasingly, you're often not one thing or another, you tend to be both.

Ruth (30:40)

I think that reminds me of a section that is inherent in the guidance which is around intersectionality, which is actually quite difficult to say, but I think what it means is that people don't fit into just one group, and actually physically disabled women may also be marginalised because they're living in poverty we know that more disabled people live in poverty. And that might be because of their ability to work, or all sorts of reasons. Ig they come from a different underserved area in the country. If they are women of color, then they might have inequalities in their access to care. And of course, they may be autistic as well. it's about looking at what are the unique needs of this person and what are the unique barriers that they're experiencing to cervical screening and what can we do to work with them to find a solution. And I think it is about asking, as your GP asked you, Jessie, what is it that I can do to make this manageable?

Jessie (31:47)

Yeah and sometimes it might be that question that the person doesn't have an answer at the tip of their fingers so it might be that you both need to work to what the solution is and that could be by asking supportive questions and like we're doing like kind of brainstorming but I also think you know my world is more neurodivergent people but I'm assuming this is true with a lot of the other groups that you're discussing Ruth, that the reality is sadly a lot of these people haven't had a great time, know, school life, doctors. So it may be that you're getting people who are slightly, you know, defensive, worried, anxious, whatever. And I actually, I was getting a train yesterday and there was a man who wasn't helping me and he was getting really agitated and cross at me. And then I suddenly realised he's autistic, and I just kept placing all these demands on me. I lost my tickets, then I found them and then, and also it was all under a time crunch because my train was at like seven minutes. I was just stressing him right out, but actually his behaviour to me was getting my back up. But then I suddenly realised what was going on and sort of stopped using so many words and language because I think I was just overwhelming him and just said- I'm really sorry, I realise this isn't easy for you and just kind of he got through it and we got through it together. But I guess the moral of the story is that actually his behaviour was actually angering me. But then once I think it's just having that voice in your head, like is this person actually being difficult or is there something else going on? And if so, just having that open mind to if they're autistic people, have they had a lot of negative interactions in their life? Have they got really upset at just not being heard by doctors? Probably their stressors could be very high because of the sensory environment and you know what it's like if one more thing happens, you just feel like you're gonna cry or something. So it's just like maybe that person's not meaning to be rude or feeling slightly abrasive, maybe they're just completely overwhelmed or stressed out.

Ruth (34:03)

I think you're absolutely right that people who are physically disabled or marginalised in any area, if they've had a poor experience of care, they're not going to be in a rush to have a routine smear test. But that smear test might save their life. So that's what we've got to always come back to.

Liv (34:23)

That's so important and really nicely summarised there Ruth, thank you. If we could kind of move a little bit beyond screening, so obviously at Macmillan we're supporting people who have a diagnosis of cancer, going through treatments and beyond. What kind of challenges, I know your guidance is specifically around cervical screening, but what challenges do you think people are facing through the cancer pathway? And what are some of those opportunities for healthcare professionals to really support people and take that person-centred approach?

Ruth (34:51)

Oh my goodness, that is a big old question, but I'm going to do my best to respond to it. I think that the key things in anyone's cancer journey really are about recognising that uncertainty is incredibly difficult to manage. And we as healthcare professionals, I think can go a really long way in being able to provide clear information as clear as we possibly can in a way that somebody can digest it to enable people to really understand what's going on and to give them as much as information as possible to be able to negotiate their care and to be able to ask questions. And that I think can be incredibly supportive, obviously being there to listen to people, to listen to their concerns, to acknowledge them and actually hold space for people and recognise that actually as healthcare professionals, we don't always know the answer. And sometimes that's because the answers aren't there. We can't always make things better, but we can always, always listen. And that in itself can be incredibly supportive. The guidance that I've talked about today is about cervical screening, primarily what that does is look for HPV because we know that HPV causes over 90 % of cervical cancers. People don't have HPV, then that's straightforward. They're re-screened at an appropriate interval, which might be five years or it may be one year of their having had treatment. However, having a result that's not normal, so that might be simply that they're HPV positive and there are no abnormal cells, but they need to repeat the test in the years time. Or it may be that they're HPV positive and they have abnormal cells and then need to go to colposcopy. That isn't a diagnosis of cancer. It's a diagnosis of risk. But it can be very, very worrying for patients. And it's important that our patients really understand that that is a diagnosis of risk and that the further investigations that they're going to face are very helpful and that treatment at that stage is very robust. If they have a diagnosis of cancer then that's very difficult. It's often a great shock, it is accompanied with all sorts of emotions and often it's a time of turmoil and it's for us as healthcare professionals to really recognise how difficult it is and to be able to provide clear information and to be able to put support in place. It's important that we provide information in a way that is accessible. think Jess has really helped us understand what that might look like for different people with different needs. It might be that it's in a different language or that it's in a different format. It's also about understanding the nature of support that people need. I've talked about emotional support, about information support, but actually it might be practical support as well in terms of financial support, in terms of organisation. Who's going to look after my children while I'm having treatment? How am going to make those adjustments at work? So I know that you guys at Macmillan do enormously important work around that and being able to sign people so that they can tap into that, I think is incredibly helpful.

Jessie (38:27)

Yeah, I mean, I think in terms of information, giving information, I think it's also to remember to avoid euphemisms or and I think, you know, often we use these in, think particularly in the English language, if I'm right. I think we've got loads of them in without always realising. I interviewed someone who was a doctor, an autistic doctor, and actually she's, well no sorry, she's a consultant, an esotist, and even she couldn't make a phone call in order to book a biopsy for something that did turn out to be skin cancer, so that I think that's just a helpful reminder of even people working at a very senior level in healthcare find those, you know, phone calls difficult themselves. But she did some research, Dr Mary Doherty, and she found that somebody, a doctor had told an autistic patient to sit tight. Now what she meant was, we'll get back to you, I think, but this person asked where should they sit. Now obviously that's quite an obvious example, but I think there's lots of interactions that I have with doctors that are milder, but I don't quite know what I'm meant to do. I spent loads, like, I don't know, decades really being given a piece of paper by my GP and not knowing what I do with the paper. I mean, I feel daft saying it to you because but it was only when I got to like 30 that someone said I plucked up the courage to say what do I do with this paper she said you give it to the receptionist but people had assumed I knew that bit and I didn't know that bit or I was zoned out when that information was giving so I think it's just being really clear and also I was thinking you know for for autistic people in particular I think why we love logic is I think it makes us feel safe I think it makes the world feel less confusing you know I think when you're born into somewhere that can be quite hostile to you in a sensory way and also doesn't always make sense to you and sort of doesn't understand you know you're thrown into a class of 30 kids which is just a really difficult situation for you to be in if you register noises in a more chaotic way. So I think really that role of logic for autistic people, I think why we sort of lean into it so much is because it makes sense of things for us. So I think if you're able to give an autistic person like numbers 1 to 10, okay this is the process, I can imagine that would be really helpful. And to give someone something to take away, because when it's too verbal I think a lot of it is missed in the moment but if you could just fill in- okay these are the 10 things that should happen in the next two three months and then saying- if at any point these don't happen this is when you flag it, this is the number you call, just making all that stuff explicit because a lot of neurotypicals, and I know not all neurotypicals, but there's a lot of neurotypicals that will figure that stuff out for themselves or will have the ability to phone someone out to say- this hasn't happened. You know- what do I do? But a lot of autistic people won't be able to read between the lines in that way and make the system work for them quite in the same way. But also, like all these things, even basic appointments just take up so much energy for neurodivergent people for a whole host of reasons. So, you know, it's such an admin heavy process, isn't it? Having something like cancer. So I think as much as people are able to help, you know, make the admin simpler and that could be like trying to collate all the information in one place and now handing it over to someone in a spreadsheet for example.

Paul (42:07)

Thank you, Jessie, for really kind of unpicking some of that and really kind of helping to get to the root of some of the challenges that as a neurodivergent person you're experiencing. Jessie, can I ask a question? What advice would you give to a healthcare professional listening who wants to improve how they support someone who is neurodivergent? Thinking about practical tips.

Jessie (42:34)

I absolutely love Ruth's suggestions about offering the first or the last appointment of the day. You know, trying to offer people appointments when it's quiet are amazing, you know, but also maybe if you ask, you know, asking questions of your neurodivergent patients, because it is going to be quite a range of things that people are going to ask you to do and lighting definitely is going to be helpful, but just be interesting to hear what other people say. Like it could be like that radio in the background makes it even more harder for me to work out what the receptionist is trying to say to me because often there's a difficulty filtering out background noise. So maybe just asking those questions like- what are the things that make it stressful coming into this GP practice, or, I guess you don't have time for a huge conversation but can you just give me two things and then if you ask that of you know 20 people I think you're going to start to get quite a good, you know, overview and then, you know, nobody's expecting you to do everything but if you can experiment doing a few of those things and find out what that's like for people, that's brilliant. And I also think, you know, you don't have to be an expert in autism and ADHD. And I think sometimes maybe people feel like they should be because they're in this role. But I think actually what I'm guessing as well, Ruth, broader disabled people want is for someone to say- I don't know it all, but I'd love for you to tell me or-

Ruth (43:59)

What's the problem here and what can we put in place together to enable you to have care that you are entitled to have?

Jessie (44:11)

But I wonder if you have to be quite confident to say that. I don't know, Ruth. I wonder if younger healthcare professionals don't always feel it's okay to say that. And I'm here to say it's absolutely okay to say that

Ruth (44:24)

Yeah, I mean, I mentioned the Oliver McGowan training. I think that's absolutely fundamental. Part of it is saying- you're not the expert, the person with autism is the expert and their family. So listen to their family, look at their care passports because you know, this is about working, working in partnership and it's around not making assumptions. And we really tried to express that in the guidance that, whatever image you've got about somebody physically disabled, get rid of it and ask them about them without assumption because you don't know what's going on for them.

Paul (45:01)

I think you both summed that up really well I just wonder, Ruth may be aimed at you, any kind of anything new, any new developments, any hopes for the future?

Ruth (45:12)

Well, I feel really hopeful about the changes in the cervical screening program, but I think are going to be more sensitive and better shaped at identifying people at risk. I'm really excited about the introduction of HPV self-sampling. So they're things that I'm really hopeful for.

Paul (45:33)

Thank you. And Jessie, anything you want to add?

Jessie (45:35)

Yeah, I mean, we're talking about a lot of the barriers, but I just do feel really positive that we're at least having these conversations. I mean, we weren't up until very recently, so it makes my heart sing a little that we are.

Liv (45:47)

That's really positive, thank you. So that leads us in quite nicely to our three questions feature. So these are three questions which we ask all of our guests who appear on the podcast. So the first question is, Ruth, if you could go back in time to the start of your career, what piece of advice would you give yourself?

Ruth (46:04)

When I started nursing, I was 18, I thought I could really do, you know, I knew everything and it would all be fine. And struggled on so many times where I've learned along the journey that if you ask for help, there's some really brilliant people out there to support you. I wish I'd done that a earlier on.

Liv (46:23)

That's really good advice. And Jessie, if you could go back in time, what piece of advice would you give yourself?

Jessie (46:28)

Yeah, I actually think Ruth's is the best. I would totally agree with what she said. But certainly related actually, I think sometimes I felt like if I couldn't do something that was my fault really. And I think just like learning more about yourself as you get older, you realise actually it's not to see it that way, do you? And yeah, but also I just tell myself, you know, girls can be autistic and ADHD, and go and get yourself assessed earlier.

Liv (46:54)

Then the second question is what change would you like to see to improve the lives of people living with cancer? Ruth.

Ruth (47:01)

Embellishment of the nursing workforce because I think nurses play a huge part and their contribution is phenomenal and it transforms people's lives but there aren't enough nurses or funding of specialist nurses so that's what I'd like to see.

Liv (47:19)

And Jessie, what change would you like to see?

Jessie (47:21)

My dad died of cancer and he was very very old and quite obviously going to die and I felt a bit sad that in everyone's capacities I felt like he was the bottom of the list because he didn't have much chance of getting better and he was old and all the other bits. So I understand why that happened totally but I feel sad for those people that I don't think they always get the time and care maybe that they need.

Liv (47:48)

Thank you for sharing that and sorry to hear about your dad. Our final question is what would you like listeners to take away from this episode Ruth?

Ruth (47:55)

That they have in the power that lies in their hands the ability to make a change to somebody, to enable them to have a screening that they're entitled to by making really simple adjustments and I'd really like them to think about what they can do to make that happen.

Jessie (48:12)

Yeah, I agree actually. think simple adjustments can have huge results, can't they Ruth? And also, you know, these organisational difficulties that I've spoken about that both autistic, but particularly ADHD people experience in life, it's real. I just want people to realise that. I can't always explain why, but it is real, 100%.

Paul (48:37)

Thank you both so much, Ruth, for your knowledge and expertise on this subject and Jesse for sharing such personal stories of your own experiences. Thank you for joining us.

Ruth (48:46)

Thank you so much.

Jessie (48:48)

Bye.

Outro

Liv (48:58)

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Paul Middleton (49:16)

If you enjoyed this episode, follow us so you don't miss our next conversation. We'll be joined by Jane Ewang, Lead Radiotherapy Clinical Nurse Specialist, and Roy Shufflebotham to talk about radiotherapy, including common side effects and practical ways healthcare professionals can support people before, during, and after radiotherapy treatment.

Liv (49:40)

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Paul Middleton (49:51)

I'm Paul

Liv (49:52)

And I'm Liv and you've been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.