The Cancer Professionals Podcast

Learning disabilities and cancer care, talk to me not about me

(Intro music fades in)

Emma (00:10)

How can healthcare professionals ensure people with learning disabilities remain involved in decisions about their cancer care?

Irene (00:16)

Include people, involve people, look them in the eye and ask, what do you need? What can I do to make this better for you? Ask them and ask their family. So don't assume anything. They're the experts.

Emma (00:31)

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

Paul (00:34)

And I'm Paul and I go by He/ Him. Welcome to the Cancer Professionals Podcast, a podcast from Mac Millan In this series we chat to a wide range of guests to share insights, experiences and perspectives on current issues faced by the cancer workforce.

Emma (00:49)

If you enjoy this episode, please subscribe, rate and share with your colleagues and friends. Just a quick reminder about our listener survey. If you haven't had a chance to complete it yet, we'd really love to hear your feedback. It only takes a couple of minutes and you'll find the link in the episode description.

Paul (01:06)

This episode contains conversations about cancer and learning disabilities which you may find upsetting or triggering. Listener discretion is advised.

Emma (01:17)

Hello and welcome to the Cancer Professionals podcast. In today's episode, we'll explore why it's so important to include people with learning disabilities in conversations about cancer treatment and care. People with learning disabilities often face inequalities in cancer care and are excluded from decisions around their own health. We'll discuss the impact of being left out of these conversations and how healthcare professionals make a difference by listening, adapting their

communication and ensuring people are fully involved in discussions and decisions about their care.

We're delighted to be joined by two guests who bring such valuable insight and experience to this discussion. Amanda Cresswell and Irene Tuffrey-Winje. So if we could start with you introducing yourselves and what brings you to the conversation today.

Amanda, shall we start with you?

Amanda (02:08)

My name is Amanda Crosswell, I'm a researcher and I have a learning disability and I work at Kingston University. And I have experience of having cancer.

Irene (02:23)

And my name is Irene. I'm Irene Tuffrey-Winje. I am a nurse by background. I've worked in a hospice for about eight years in London. I've also lived and worked with people with a learning disability before that for a number of years. But for the past 25 years now, I have done research around cancer, end of life care, and people with a learning disability.

And it might be interesting to know that you and I met because you, Amanda, were a participant in my first study, which was on what is it like to have cancer if you have a learning disability. And it had 13 people in that study. 11 of whom died, you were one of the survivors and you were so passionate about needing to help doctors and nurses know and understand more that I thought actually I need to employ you to be my research assistant. So we've been working together as you say for quite a long time on various studies around end of life care. We work at Kingston University in the KIND research group. That's an acronym and it stands for Kingston University Intellectual disability research.

Emma (03:34)

Thank you both so much. We are really grateful to have you both join us and share your experiences, your knowledge and your insight So, Irene from your experience and from the evidence available.

What do we know about the scale or the impact of cancer for people with learning disabilities, either through their own diagnosis or from that of a family member?

Irene (03:59)

Yeah, that's a good question. And actually, when I think back, this is probably why I first got involved with doing research and projects like this, because it's quite a hidden issue. People, when I worked in the hospice, I was there for eight years. I had one person with a learning disability in that time on the ward who had cancer. That doesn't mean that there aren't more. And so it's people really weren't accessing services in those days. So the annual LeDeR report came out that stands for Learning from the Lives and Deaths of People with a Learning Disability. It's a national program that reviews the deaths of people with a learning disability.

So this review had well over 3,000 deaths and they found that deaths from cancer was about 16%. So that's lower than the general population. But that is partly because people with a learning disability die a lot younger than the general population, about 19 years younger on average. You know, cancer often is more sort of common in older age. And the profile of cancer is also slightly different. So for example, there are a lot more deaths from bowel cancer. And again, these happen at a younger age. So we're really sort of thinking we should know that and start maybe entering people into screening programs earlier. So that's that. But of course, people who are families, who have somebody in their family with cancer, that is huge, you know, because it's a common diagnosis and lots of people have experience. So we've done studies around that, haven't we? Talking to people with a learning disability who have families and what it's like for them, what their needs are. And in fact, you Amanda have experience of both those things. Right, of having cancer and having a family member, isn't it?

Amanda (05:41)

Yes.

Irene (05:42)

Do you want to say a little bit more about that?

Amanda (05:43)

My mum died of a brain tumour. But nobody in my family told me that my mum was very, very ill. She didn't tell me at all. And I found out from my auntie and my mum was in hospital for long time but she came out of hospital and she actually died at home. I actually found her.

Irene (06:06)

You were quite young weren't you?

Amanda (06:08)

Yeah I was just 14 years old when my mum died. She was only 52.

Emma (06:12)

Oh my goodness, Amanda.

Amanda (06:14)

Because the cancer has spread all over her body.

Irene (06:17)

And I do remember, Amanda, because as I said, you were in my study on what is it like to have cancer, and you were telling me a lot of things that were difficult because you've had cancer and all the treatments and the diagnosis. You told me about other things in your life that have been really difficult. And you said without hesitation that my and mom didn't tell me that she had cancer. And I always remember that because that is really what led us then to doing studies on you know, how do we talk to people with a learning disability about cancer? How do we include people? You were one of the very few people in my study with these 13 people who were told that you had cancer. Most people didn't know. I mean, that's now 15, 20 years ago, but I think things change very slowly, you know. So it's an important issue is how, it's a hidden thing for people themselves, but also for the rest of society, the issues around cancer and learning disability.

Emma (07:13)

Absolutely. I think firstly, Amanda, thank you for sharing about that experience of not being told that your mum had a cancer diagnosis, but also the impact that that's had on you in terms of being the person who had found your mum. And I'm so sorry to hear that. And I think it really does highlight, doesn't it, what Irene was saying that actually it is so important because we know that the numbers of people who experience a cancer diagnosis or know someone with a cancer diagnosis is so high and it is about having those open honest conversations and making sure that people understand that.

And it's just bringing me on to another thought about what do we know about the experience of people with learning disabilities across those cancer pathways?

Amanda (08:01)

I mean, I'm quite lucky because I can understand what was going on even though my mum didn't tell me what was going on. But if it's someone who's got very high support needs, they might not understand what's happening to them, where they're going to live, because I didn't know where I was going to live. And I ended up in care.

Irene (08:29)

Yeah. And these are very big and practical questions, isn't it? And that makes it a lot harder if you don't know what's going on. And sometimes people think, it's too upsetting or we can't tell the person because as you say, some people would really struggle to understand what cancer means, et cetera. But what everybody can understand is how your day and your life is different, how it's changing.

And to not acknowledge that difference in what has changed is very hard for people. So I think you could see your mum wasn't. Why do you think she didn't tell you? Because you say you could understand, really, if she had.

Amanda (09:05)

Because she wanted to protect me. And she didn't know what to do. But it would have been good if I had known

Irene (09:13

So it's a big impact, isn't it? Yeah. And that is partly to do not so much with cancer, but the fact that your mum died and therefore you did, you know, that the home situation then changes. We are fans of telling people what's happening, isn't it? And that is very hard. And I can see how that is particularly hard for the families themselves, right? It's

Emma (09:33)

Mm

Irene (09:34)

because they're also struggling and upset, probably. So Yeah, people need a lot of support, but actually not being kept in the dark and you know, there's often a conspiracy of silence where everybody in the family knows what's happening except that person with a learning disability.

But they will, you you will be able to pick up that people are slightly different or slightly, you know, behave differently. And if you do include people, and that includes actually letting people see that you are also upset, you know, that it's not something unique to you, that your feelings are not, you know, are feelings that are shared, then I am always I'm very often surprised by how supportive people with a learning disability can be of others and of the rest of their family. So giving people an opportunity to be involved, also give them an opportunity to care and to be involved in looking after mum or to be involved in supporting others. And that can be a huge comfort, you know. Even if those are practical things, you might not need to say or want to say your mum is going to die,

You can say, mom is very ill, she can't get out of bed, she needs help, would you bring her a cup of tea or, you know, draw her a picture or something. That is comforting and that will help, you know, everybody to be involved in some way and to think back, at least with some comfort that you were able to be there.

Emma (10:59)

Absolutely. And I think that really highlights, it, that it doesn't have to be large or big changes. It can be that involvement in those small practical ways that are familiar and feel comfortable and supportive.

Irene (11:16)

I think one thing to think about is that for all of us, but particularly people with a learning disability, it can be quite hard to imagine the future.

Emma (11:25)

Mm Hm

Irene (11:26)

So what is for many people important is really what is happening today and what is happening now. You know, particularly if you have a severe or a profound learning disability, then your concept of future might not stretch beyond lunchtime. So, you know, really think about what actually is the bad news here and what is changing. But the other thing, I remember a conversation I had with some doctors in a hospice were looking after a mother who was dying of cancer and her son was in his twenties and was autistic and had a learning disability. And they, quite rightly I think, sort of, when she was actively dying, so it was going to be a matter of days, told him, you know, into the hospice saying, your mum is going to die. He got his diary out and he wanted to put in the hour and the time of the death and exactly when and what. And that is hard because of course you don't know that.

So, but giving people some sort of script, I think the thing that I would do there is to say, we don't know when your mum will die, but when she dies, what we will do is the nurse will ring you and you will come into the hospice and you will see your mum and she will be on the bed and she will be dead and you will be able to. So a practical guide of a script of what is happening is very hard, but imagine how hard it is if all that is going to happen without him having expected or anticipated that. So I think the fact that something is hard and upsetting is actually true because it is hard and upsetting.

Emma (12:52)

And we can't avoid that, can we? And, and like

Irene (12:54)

You can't avoid it.

Emma (12:56)

you said, the impact of not knowing can be far greater, especially if people aren't involved and they aren't informed. And you mentioned as well that distinction between someone who may have a high support need and a low support need, and actually adapting that care and your approach to ensure that you're meeting that person's needs and still involving them and making sure they know as much as they're able and are involved as much as they're able. I

Irene (13:24)

Yeah, exactly.

Emma (13:26)

I wondered Amanda, if you're happy to, would you be able to tell us about your own cancer experience

Amanda (13:34)

Yeah, I'm happy to do that. But before we did that,

Emma (13:42)

Mm-hmm.

Amanda (13:42)

The one thing that I was allowed to do was help plan my mum's funeral. And I went to her funeral. It was very upsetting at the time but it helped me to say goodbye to her. I've already planned my own funeral.

Irene (14:09)

That is good and that actually takes us straight to because our latest, one of our most recent research projects was to help support people with a learning disability to think ahead like that isn't it and plan their funerals. We did lots of new resources about funeral planning. Yeah, there's whole videos on YouTube with you telling Amanda, with you talking through your own funeral plans.

Emma (14:30)

And I think that's a real example, Amanda, of being involved in those conversations and being part of that

Amanda (14:33)

Thank you.

Emma (14:38)

planning and sharing what's important to you.

Amanda (14:40)

Yeah.

Emma (14:41)

That's really important.

Irene (14:43)

I'm glad to hear it too, Amanda, because that's a long time ago and it was still then and it's even now some unusual for people with a learning disability to automatically be going to their parents funeral and we still hear stories now of people who are not told that mum or dad has died even years later. They still think that dad seven years ago went on holiday and still hasn't come back.

This is really shocking. I keep thinking this is no longer happening, but there are still stories like that for the best of reasons.

Emma (15:14)

And I know we'll be talking about communication So I wondered Amanda, whether you'd be able to tell us a bit about your cancer diagnosis and what that was like.

Amanda (15:26)

How are we going to start?

Irene (15:28)

How are we going to start? Shall we start by maybe we start by explaining that my very first move away from the hospice, from being a nurse and clinical work, was to do a project at the university to improve cancer services for people with a learning disability. And one of the things we did, and this is 20 years ago now, was to commission a play performed by actors with a learning disability at a theatre company to do a play about cancer. And actually that is before we met you in the research, that is the first time I heard about you, Amanda, because you are one

of the people in that theatre company. And that's how it started because we said to the theatre company, could you help us do a play about cancer? And people weren't keen, were they, in the company?

Amanda (16:13)

No. Because they thought if we did a play about cancer, someone would end up getting cancer. And I said, that's stupid, it doesn't work like that.

Irene (16:24)

So they put on the play with a number of actors, took it around the country for people with a learning disability to watch. You can't put too many messages in one play. So the two messages we put in was, if you feel there's something wrong in your body, then tell someone and

Emma (16:38)

Mm-hmm.

Irene (16:39)

that's because often a cancer diagnosis is made after somebody goes because they feel something is wrong, pain or whatever it is and so that often doesn't happen for people with a learning disability because you need to notice it, and somebody else needs to notice it. So the first message was go to the doctor if something is wrong. The second message was if you don't understand what is happening or what the doctor is saying then ask.

So that was the play, it went around the country and then you were part of an education that would then help do workshops with people with a learning disability afterwards. And then what happened next? Because people said, that's a bit scary. If you do a play about cancer, you'll get cancer. And you told them that was nonsense.

Amanda (17:19)

And then I wasn't feeling very well. And I went to my GP and told him what was wrong. And he didn't do anything. He said, oh there's nothing wrong with you. And I knew there was something seriously wrong with me.

Emma (17:34)

Mm

Irene (17:34)

Because you went back a few times, didn't you? So actually there's something not right.

Amanda (17:38)

Yeah, I knew. I knew there was something seriously wrong.

Irene (17:43)

One of our colleagues said, goodness me, one of the actors has just been diagnosed with cancer.

Emma (17:49)

Mm

Irene (17:49)

And that was our worst fears. But actually, I think you were saying that maybe the cancer, the play about cancer helped save your life because you did then go to the doctor because you realised something was wrong, even though they didn't believe you. So what happened next then? Because in the end, you did go in for treatment.

Amanda (18:05)

Mm I was actually doing, because I was at college and I was doing voluntary work and I actually collapsed while I was doing my voluntary work at the flower shop. then I was taken into hospital. They done some tests, but not straight away. They didn't find... And then I was transferred to a different hospital. And then the consultant told me what was wrong. He says, he told me, you got Non Hodgkin Lymphoma, And he was honest with me.

Irene (18:39)

And you had to ask what it was, wasn't it? Because there was a bit of a jargon there.

Emma (18:42)

Yeah.

Amanda (18:43)

I asked what it was and he said it's cancer My tumor was in right in... was the size of a football. And then he shocked me a bit but he said, he was honest, he said, if it's up to you what you do but if he did shock me you might be shocked. He said, if you don't have chemotherapy or radiotherapy in three days you're going to be dead.

Emma (19:15)

Goodness, Amanda. A very big shock.

Irene (19:18)

That is, and we've told this story, it's interesting, we've told this story many times at conferences to audiences of doctors, nurses, et cetera, and you say that Amanda, your doctor told you it's cancer, if you don't have radiotherapy or chemotherapy, you are going to be dead, right? And you see the audience bristle, you know, there's a people, because it's so blunt, but actually it was that bluntness that helped you make up your mind, isn't it?

Amanda (19:44)

Yeah, I had chemotherapy first because I said I don't want to die like my mum, I'm too young to die. I've got a lot of opportunity and I knew that this might sound stupid but I've been put on the earth for a reason and that is to help people do the job and I'm also part of a another study which which I do. Better Care Before Death, which I do online once a month,

Irene (20:16)

Yeah, and that is part of, yeah, that's a current study. We're a big national study funded by the National Institute for Health Research, the NIHR. And it's called the DAPPLE project. It's to look at what are the best models of care

Emma (20:30)

Mm

Irene (20:31)

to support people with a learning disability who are at the end of life. So it's not necessarily just cancer, it's end of life. But yeah, the Better Care Before Death group is our co-production group of about 10 people with a learning disability who meet online, because we're doing a lot of finding out the way I found out from you, in my first study, I went to find out what it was like to have cancer, spending time with people.

The voices of people with a learning disability on their experiences are very rarely heard, so we really want to spend time and listen to them. So we've got four researchers in the DAPPLE project who are at the moment spending time with people who are at the end of life. And the stories come to your group, doesn't it? They come and tell the stories and you help to think about those and you help to lead that group.

Amanda (21:15)

But some of the stories are very upsetting.

Emma (21:19)

Yeah.

Amanda (21:20)

I didn't know this, Irene that people with a language disability could actually have dementia until I started working on the study.

Irene (21:29)

That's interesting and that's important to know, isn't it? Yes, people have, particularly people with Down syndrome, are at very very high risk of getting Alzheimer's disease. That's the most common cause of death of people with Down syndrome who are in their 50s. It's quite early onset Alzheimer's.

But you're right, some of the stories are upsetting. We're hearing lots of good things happening and it was interesting you talking about your experience, Amanda, because you said you first went to one hospital and I remember you telling me that wasn't very good because they didn't

tell you bad things, they didn't support you very well. The difference in the second hospital was the consultant basically telling you what was happening, telling you the truth.

Paul (22:11)

And I'm just wondering, What were your follow up appointments like in terms of, perhaps when you went for treatment.

Amanda (22:19)

I went to the hospital and had chemotherapy because I was an outpatient by then. My cousin was very supportive and because she's a nurse, so she used to come with me and sit with me when I had chemotherapy because I'm terrified of needles.

Irene (22:55)

And that's important isn't it? Even now, many of the people with a learning disability in our group say the same, what you saying, Amanda, is how helpful it is to have somebody with you in hospital who can support you and to have the right support. And that is quite difficult. We're finding that in our current study, the DAPPLE project as well, is that quite often you depend on your support worker, don't you, to come along. And most of the time when you have to go into hospital, they have time or they're available.

But we often find that people don't have the support staff at home. There is no funding really for support staff to support people in hospitals. So it's quite difficult to get the right treatment and the right care. What's it like then, Amanda, what would it be like to be in hospital if you don't have a support worker or a family member with you?

Amanda (23:50)

It's very scary. It is because I was, at the time I was living in, with my carers, but they were allowed to come and visit me every day.

Paul (24:02)

And was that helpful?

Amanda (24:03)

It was helpful, it was, but some of the people on the ward, because when I was in the other hospital, I was, because they didn't know me, I was put on that old people's ward at first. And it was very difficult because there was this one old lady and she didn't think my carers should be visiting me, my family should be visiting me

Irene (24:25)

Well, that is really important to flag up because that happens, you know, people with a learning disability to be able to access care and hospital and treatment need,

Paul (24:34)

Mm-hmm.

Irene (24:35)

and actually that's by law, reasonable adjustments to enable them to access the care. And for you, Amanda, the reasonable adjustment is I need to have my carer with me or my family with me.

Paul (24:46)

Mm-hmm.

Irene (24:47)

And that is true for a lot of people with a learning disability. And we still hear very often that that is not allowed because it's not visiting hours, right?

Paul (24:56)

Mm-hmm.

Irene (24:57)

But actually, it's not a visitor, it's a reasonable adjustment that you allow this. And it's quite shocking that at the moment in our study, we're hearing a lot of stories of people with a learning disability who are not able to get basic nursing care in hospitals, so are not being fed for long, if there is no supporter or carer from their own home with them to help them. But it does mean that if that that is isn't this is a problem right because we hear stories where people say the support workers say he was lucky to come out alive of that hospital because of this. The lack of being helped to just walk to the toilet when you need to walk and therefore losing your mobility.

So it's those quite basic things that actually make things difficult for people. And my conundrum, our conundrum is that families often we hear that they feel quite frightened of having their relative in hospital because what if I'm not there? Really

Emma (25:58)

Mm.

Irene (25:59)

going to be difficult to be there 24 hours a day. And if you rely on support workers or you live in a supported living home where you have staff that is funded by social care funding, they don't often have the resources to ensure that this person can be supported in hospital. But that's a healthcare funding.

And I just want to say, hospital staff often are amazing. Everybody wants to do the best, right? And we have a lot of wonderful, wonderful doctors and nurses who do their absolute best, but people do still fall through the gap. And it's, yeah, sometimes some quite basic things that go wrong. And you, as you can all hear, you all hear, you can speak up for yourself. But

Paul (26:42)

Yeah.

Irene (26:42)

even that is hard in hospital, isn't it? And a

Emma (26:44)

Yeah.

Irene (26:44)

lot of people can't speak up for themselves.

Amanda (26:47)

Because the last time I was in hospital, was an emergency. I felt really unwell. I thought it was my appendix, but it was actually my gallbladder. I had to my gallbladder removed and not having the right support in hospital because they didn't understand and they sent me home the next day and they didn't do the operation.

Irene (27:10)

And that's a risk, isn't it? That if you are not able to to say that you're in pain or that it's not right and that you're not right. Often people get sent home and actually when they shouldn't,

Emma (27:21)

Mm.

Irene (27:22)

So there are risk factors and not being able to communicate easily what is wrong or that you're not quite right. And also I suppose often hospitals staff, if they don't know you and you are coming in and you're not feeling well and you're not doing well and they don't know what your baseline is, this is particularly true for people with profound disabilities who may need round the clock care all their lives, then it's easy to people are not really understood as having a very good quality of life at their baseline, which is a life that needs a lot of help and care, but it's a good quality of life. so often hospital staff make assumptions about people's quality of life. That we may think this person can't cope or it might be kind to not treat and sometimes these reasons are true and they are right, sometimes it is the right choice not to treat, where you might treat somebody without a learning disability, sometimes somebody really wouldn't be able to cope with it, but that needs to be a best interest decision if the person can't decide for themselves that and not based on assumptions. So often hear that people have to fight, families and carers have to fight for getting the right cancer treatments.

Paul (28:34)

Yeah. And, and it sounds like Amanda, you've had your fair share of, of hospital stays And, and I know we talked a little bit about some of the, practical ways that the staff have tried to help And I wonder if I can just bring us on to maybe talk a little bit about the the levels of communication, because we've talked a little bit about how the doctor is very blunt with you. And I wonder how, Amanda, for you, if you are there in the hospital, how can the professionals talk to you in a way that helps you understand, and maybe what kind of words could they be using to help you?

Amanda (29:21)

I've got a hospital passport yeah it's got everything on it that has my cerebral palsy, what I need help with

Paul(29:33)

Okay.

Amanda (29:34)

and stuff like this but sometimes... I know not everybody can read it, but I get frustrated because when I do go to hospital with my carer or go to the doctors, they look at my carer and they don't talk to me. And my carer says, no, talk to Amanda. If there's something she doesn't understand, I will take over, but she's your patient.

And that really annoys me.

Paul (30:07)

And how do they react to that then when that happens? Do this start talking to you?

Amanda (30:13)

Yes, they start talking to me, but if it's in jargon, I say, I don't understand this please explain in a different way.

Paul (30:24)

And what kind of, are there any examples of what professionals could do to make it easy for you to understand at those appointments or to help you feel safer at those appointments?

Amanda (30:40)

So for me, I have to go somewhere quiet because I'm very nervous and anxious when I have an operation. So what the hospital does now with permission, My carers are allowed to come with me into the anaesthetic room until I fall asleep. And that really makes me nice and calm and relaxed. And even have my carers sleep overnight before I have the operation, just knowing that there's somebody there.

Irene (31:23)

The hospital passport is something that many, many people with a learning disability and also actually more and more other groups of people have and it's an easy read document with simple words, simple pictures that tell hospital staff the important things that you need to know about somebody. How do I communicate? Who are the important people?

So that we talked about reasonable adjustments, which is small changes and not difficult one, but small changes as hospital can make. And I think the best thing staff can do is to ask, to ask the person and to ask the person, their carer or their family, what can we do to make things easier for you? Because for you, it is having your carer with me. That might not be true for everyone. For some people, it is I'm really scared of white coats, so please don't wear a white coat. Or for some people, is I need a quiet room.

And the other thing I would say when you talked about talk to me not to the person. Of course, Amanda, there are also many people who don't understand any of the words a doctor will say. But I would still look at that person when I'm talking. Making sure with your body language that they are the people that you are thinking about. And then I might say, Amanda, is it okay if I'm just going to tell your carer about this because it's important that they know.

Right, involve people even if you have a conversation with the family or with the carer. You know, you'd always keep them central. And I would look back at them. And these are very simple sort of tips, but you know, if you have a complicated conversation with a carer around the bed I would look back at the person Just repeating the words that makes clear that they're talking about you,

Paul (33:04)

And Irene from, from kind of your experience, perhaps, you know, when, professionals have got to deliver some bad news and, you know, we've had some different examples here, you know, what kind of approach from your experience could perhaps professionals use to, help this along. And you've mentioned kind of, you know, that interaction, but anything else?

Irene (33:28)

I think there are a couple of things to think about. One is to really think what is the bad news actually? And is this really bad news for this person? Right? So if it's somebody with for you, Amanda, saying you've got cancer and if you don't have the treatment, you'll be dead. That was quite bad news and you could understand it because you know what cancer is. Right?

If you don't know what cancer is and you don't know what that means, then saying you've got cancer might not be bad news, right? The bad news might be, you know, you've got to go in for treatment and you'll miss your lunch or you can't see, you know, EastEnders tonight because that might be the bad news. So think about what is the bad news, right? And how much do you actually really need to know at this point to cope with it? And then the other thing I would say is to try and get an understanding of what this person knows and understand about the situation. So I would probably actually talk to family and carers about that, just to see how you can approach that with the person.

Having said that, the question I get most often is what if the family doesn't want the person to be told. Because quite often staff are on this page. They really understand and they want to involve. You don't want to tell lies. You want to include people. But you do hear that families are really worried about this and say, you can't tell him. You mustn't tell him. I would then really try and understand from that family what makes them so worried about this, because they may be genuine worries that you really have to understand and try to understand whether they're worry is for themselves about them not coping with this person being having bad news or whether it really is for the person. Because they really are the experts, right? I'm not dismissing people saying you mustn't tell him. Because it may well be that that would become such an obsessive thing. I met somebody who was in the same study actually, but that you were in, Amanda, a woman who was diagnosed with cancer and it was a slow cancer. She lived another five years, but at early stage of those cancers. Her father had died of cancer and it was upsetting and difficult. so she for five years thought that that would be the same. And so we had to say, were going to live with your cancer. You're not dying of the cancer. So understanding what somebody understands is important.

And the other thing I would say is that It is important to understand how families and carers are talking and supporting somebody. Because if you say, I'm all for telling the truth, but we can't tell lies. If somebody says, you know, what's happening, then I think we need to tell them. But if what you're telling them as the nurse or the doctor is the opposite of what the family will say, if you say, actually, no, you're right. It's very, you know, it's very serious. You're not going to be better. You're going to be in bed. If the family then comes and say, you'll fine in no day, no time, you'll be absolutely fine tomorrow, then that is difficult. Who are they going to believe? And remember that breaking bad at the bad news doesn't just land for all of us by the words people tell us, it's often our experiences. You can feel

Paul (36:33)

Hmm.

Irene (36:33)

in your body things are changing. So if what you are experiencing, like I'm getting weaker and weaker, doesn't match what people are telling you, then that is very confusing.

Paul (36:42)

You've both talked about some of the studies and the research and that kind of thing that you've been involved in. And, Irene I wonder if you wanted to talk a little bit about the Victoria and Stuart toolkit,

Amanda (36:56)

So the Victoria and Stuart toolkit, it doesn't mean that you have a box with tools in it, with lots of tools to do different jobs. It means that we've prepared something for not just for people who are dying at the end of their life, it could be for anybody who has a problem.

Irene (37:22)

It's a toolkit to help people plan ahead for the end of life. It's not simply a cancer toolkit because lots of people with cancer like you, Amanda, survive and are living. But we all at some point come to the end of our life. The question I was asked most often is, do you have an easy read or a simple end of life care planning form or leaflet? Which is a simplified form of the questions that are asked in end of life care planning. So where do you want to be looked after? Who do you want to look after you? And do you want to be buried or cremated often in one sentence, in one form?

So we did a project where we, we gathered all the things that were out there and looked with the altogether group, which is a group of people with a learning disability and what worked. And we found that a lot of people when they think end of life planning think funerals. So we made a separate resource for funeral planning to help people think and talk about funerals. We found that actually the gap in the market was to have something that opens up conversations and helps people think about it. Because if you have a form with a box, do you want to be buried or cremated? That is scary because what if you don't know the answer on the box? So we made pictures that this is one of them where we explain, you know, where people can think through, you know, issues that had to do with funerals. And we find that showing these storytelling pictures really does open conversations and people can think about and talk about what they see in the picture.

And then we also, made a toolkit, a resource where we have single image items where people can think through each of these things and what they might want. This one here Amanda says car and if you watched a video on YouTube that you're in Amanda I think you talk about white horses was it? And

Amanda (39:18)

Yeah

Irene(39:19)

and so if you spread all those pictures out on the table, the conversation flows. It's actually quite positive, often experienced for people. And we hear feedback that people are surprised how much they've laughed doing this. We laugh a lot, we cry a lot.

Amanda (39:32)

We do.

Irene (39:34)

So that's that. But the other thing that's really important is then to help think about the end of life, right? The final days, weeks and months. And we found that there sort of talking about, mentioning the D word, death and dying, was a barrier to people because that is quite scary. You know, I mean, the doctor saying you're going to be dead, that was very blunt and important. But asking what do you want when you die is something that often people don't want to go. And what really helps us is to think through, what do we actually need to know? And actually what you need to know is what people want when they're still alive,

So what is it going to be like for you to have a doctor or a nurse in hospital at home, for example? So we again made single image pictures, this one for example, that talks about, This one says nurses in my home. Because that is the practical thing. It's not a question of do you want to be in hospital, yes or no, because the choice might be out of my That's what you said in the study, the choice might be out of my hands. So the question then is, what makes you say, actually we can try this out now Amanda, so you said that you'd rather be at home at the end of life. What makes home so important for you at the end of your life? Why would you want to be at home?

Amanda (40:52)

Because for me, because I've been in care, and I've moved so many times and now I live on my own with support. I know where everything is, even though I'm partially sighted and sight impaired and Being a home is calming for me

Irene (41:13)

So it's those kinds of conversations. I want to be from where my life is. Home makes me feel safe. You have your DVDs and your radio around. It's calm. the question is, that is great. But if you can't be there, then make sure that that is somewhere else. That wherever you are in the hospital, that that is what you need. But it also has things like, you you had talked about needles. The question for these, there's about 30 odd pictures like this, then you can go through what helps you cope with needles. And it may well be nothing helps you cope with needles and therefore that needs to then inform the choices that people make. Because when you're very ill Amanda, then you might not be in a position to actually say these things. So it's useful to know them beforehand so that the doctor and the nurses and your supporters can think, hang on, she can't say no. But we know that she wants

Paul (42:04)

Hmm.

Irene (42:04)

So the toolkit helps people and helps everybody to think about, and even people with a profound disability, if you can't really even understand pictures, we've heard that support staff and families find going through these pictures and actually thinking about each of these topics for the person was really helpful. We're hoping to do a follow-up study to really see how we can make that work in practice. But those images, those resources are all online, they're free to download and the pictures.

Paul (42:30)

Yeah, they look like really, really useful resources and we'll definitely be including the links to that information within the episode.

Irene (42:40)

Great, and it's www.victoriaandstuart and you'll find the resources there.

Amanda (42:47)

Yeah and you can't miss me because I'm dressed up as the sunflower.

Paul (42:51)

Okay.

Irene (42:52)

and this might be the time to show the sunflower, Amanda, now this, there we go. I feel left out now, I'm going to hold that one up. it's often helpful to make props, this is one that people can hold if they have a feeling. So practical things are helpful. So just coming back to the pictures that we found the toolkit, we stumbled across a thing that we've now included always, is to put a box or a bin on the table to say if you don't want to talk about this, put that picture in the bin.

So people control over it. Because that, you know, many people don't want to talk about it, right? And that is absolutely valid. It helps to understand why. And we find that sometimes when people put the picture in the bin, they tell you more than they would have done without the bin, because they then start to explain why they don't want to talk about it. But it's important to give people control over it and make them choose the picture.

Amanda (43:40)

And the other thing that you should never do is if a person doesn't want to join in straight away, never force them. Let them do

Paul (43:52)

Okay.

Amanda (43:52)

it in their own time. If they want to do it, they will do it. If they don't, they won't.

Emma (43:59)

Those are such great tips and really practical tips that people can take away from the conversation. And I think it shows as well the value of the research you've been doing and how important hearing from those voices of people with learning disabilities really is.

We've talked a bit about this, but in the healthcare system where we know the system can be unfair, where professionals are time stretched, they're time poor, they've got limited capacity, could we talk a little bit more about what professionals could do within their role and workplace to really support conversations and interactions?

Irene (44:36)

Yeah, now that's a very good question. I think the first thing that is helpful is to know that the person has a learning disability. It's not always visible. that is, many hospitals now have a flag for this. So if you can see or you know that somebody has a learning disability, the first thing to do would be to reach out.

And to say, as I said earlier, what can we do to help you for this appointment? Whether it's screening, often people miss out on screening because maybe they don't understand the leaflet or I've heard stories of somebody being sent a bowel screening kit in the post or going for bowel screening. You need to take the medication, the things beforehand to clear your bowel so you

Emma (45:21)

Mm-hmm.

Irene (45:22)

have diarrhoea. People then cancelling their taxi because they have diarrhoea and they think I mustn't go into hospital because I've got diarrhoea. So

Emma (45:29)

Mm

Irene (45:29)

really practically talking people through what needs to happen and ensuring that they understand what the appointment is. It often helps people to note, so maybe to allow people to have a look around the screening room first if it's for a mammogram or whatever it might be. Some hospitals have special clinics for people with a learning disability, so you take a bit more

time, you allow people to look around, all those things are helpful and practical. And as I said earlier, just simply ask. Often people do need more time, additional time, maybe double appointments.

But very often it's simply, I mean, really the person is the expert and their family and their carers, if they can't speak for themselves, you need them on your team. The greatest risk for people with a learning disability dying young, too young, dying prematurely, is families and carers not being listened to and not being included and taken seriously.

Amanda (46:24)

And also for me because I'm sight impaired, When I get a letter and it's too small and I can't read the writing, to have it made bigger, But that's the other thing for me when I get a letter to go to the hospital or the doctors, is...They don't recognise that I've got sight loss.

Irene (46:44)

So it's those things. there are resources out there. I mean, there is Books Beyond Words. They are a series of picture books that you helped create as well, don't you Amanda? With pictures without words. So there are stories and pictures about cancer, about epilepsy, about going into hospital, seeing a doctor, helping people to navigate those things.

Amanda (47:03)

And I actually done the cancer book. I helped to do the cancer book.

Irene (47:08)

The cancer book is called Getting on with Cancer. It's a while ago now since we made that, but it's basically a picture story of a woman being diagnosed with cancer, having chemotherapy, having radiotherapy, and recovering at the end.

Those kind of pictures can really help not everybody, everybody is different, but it often helps people to understand what's happening and to help them talk about what they are worried about or what's happening to them.

Emma (47:36)

Those are really valuable tips and really valuable resources and we'll include links to those in the episode. And I think it really shows that actually that ask the person, ask their carers, ask the family so that professionals, whether that's in hospital or community, the GP surgery can really understand what support is right for each individual because as you've both so eloquently highlighted, individuals have a different level of need, different information needs and it's really important to make sure that that's tailored for each individual

Irene (48:11)

Yeah. It really is, what is it that helps this person access your service? What blocks this person or stops this person from being able to use your service is a really important question. And if it is because they're frightened of the machine or they're actually frightened of going into hospital at all, I've heard enlightening stories, being people being doctors going out into the car park to do something because the person doesn't want to come in. you know, be creative and think outside the box.

The other thing that's helpful when you think about cancer is often there are different clinicians and different appointments and different departments involved and trying to put all those together on the same day to communicate between professionals and between appointments is also very helpful. Many hospitals have a learning disability liaison nurse and they make a huge difference to people because no nurse, no doctor on any ward, you know can be expected to know everything and all the different ins and outs. The Learning Disability Liaison Nurse can really help you navigate and communicate with families, with people themselves. So contact them as soon as there is a patient or a relative with a learning disability.

Emma (49:25)

I think we've kind of touched on it in sections throughout the conversation, but I wondered really if we could sort of touch on actually, why is it that we know people with learning disabilities have a poorer experience of cancer and cancer treatment?

Irene (49:42)

Yeah, I think there are barriers all along the cancer journey. So the first one is a diagnosis, it's picking up and knowing that some diagnosing the cancer, so people not accessing screening as much as the others. Then you're relying often, as I said, people presenting with symptoms that maybe you can't see from the outside, that might take longer.

But then also, as you were saying, Amanda, with your experience, that if you do go to the doctor or to the GP with symptoms, it often takes longer for them to be taken seriously, I'm not sure that was the case in your situation, but people are more likely to have a wait and see approach rather than immediately referring people for further treatment and for further investigations. So that is a barrier, once you are diagnosed, so it's often quite a late diagnosis, again, then to really sort of thinking about treatment and are people really offered the same treatment as you would if the person didn't have a learning disability. And that is a risk, you know, are you going to offer a 35 year old woman with a learning disability breast cancer treatment, are they offered a reconstruction in the same way as somebody without a learning disability?

Sometimes they're not even offered, and you wouldn't think of not offering any 35 year old woman a reconstruction. If you use something like the clinical frailty scale to assess whether somebody is likely to need you know end of life care, you cannot use that scale with people with a learning disability because many people would score top, you know, that looks like they're dying, but they're not because all their life they needed care and help and can't get out of bed. you know, so think about the treatment and is it equitable? And then of course there's questions around sort of coping with treatment and lots of, that's what we're trying to understand at the moment in the DAPPLE study is sometimes sort of communication between departments goes wrong. People with a learning disability often have multiple multiple long-term health conditions at the end of life. And that can obscure underlying diagnosis.

So diagnostic overshadowing, that's jargon. That means you present with something and the clinician thinks, well, that's because they have a learning disability or that's because she's got cerebral palsy, but actually without looking further. Lots of reasons and altogether, it's a bleak picture. It's improving, but it's really still not good enough.

Paul (52:19)

if I if I bring us to our final question, what would you like listeners to take away from this episode?

Irene (52:28)

So I think if there's one thing that I want people to remember from all the things that I've said, is Include people, involve people, look them in the eye and ask, what do you need? What can I do to make this better for you? Ask them and ask their family. So don't assume anything. They're the experts.

Paul (52:47)

Amanda, what would you like listeners to take away from this episode?

Amanda (52:53)

That professional people listen to us and don't assume just because we've got a learning disability that we can't communicate. It might be difficult, but we're not stupid, we're not idiots. And it's not fair on us, and I'm saying this for everybody who can't speak up for themselves.

Irene (53:18)

And can I just say one more thing which you make me, you may think, so I think the problem is not that people with a learning disability can't communicate, everybody communicates with or without words. The difficulty is that we cannot often understand their communication. So it's not that people need help communicating, we need help in understanding

P**aul (53:38)**

Thank you. I think, you know, really, really powerful messages to end on. So, you know, thank you both so much for joining us today and really for sharing your experiences, your insight and the practical advice that we've discussed. And I think what I'm taking away from this conversation is that inclusion and honesty is really central to good cancer care for people with learning disabilities.

Really putting the person at the centre of their care and involving their family and the carers too. I think the other thing that really speaks out is taking that time to listen, using clear communication, checking understanding and making reasonable adjustments. And all of these things can make a real difference to whether someone feels informed, safe, respected and involved in their own care.

And for our listeners, we hope this episode has offered some practical things you can reflect on and apply in your own role, however small it might be, it can make a big difference. So Amanda and Irene, thank you again

Irene (54:45)

Thank you very much.

(Music fades in)

Paul (54:47)

You've been listening to the Cancer Professionals Podcast, which is brought to you by Macmillan Cancer Support. If you are a health or social care professional working in cancer care, visit membership.macmillan.org.uk to find out more about Macmillan membership, which includes a range of education and training resources and access to our learning hub. For links to the resources mentioned, see the episode description.

Emma (55:11)

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be joined by Kirsty Clutterbuck and Kate Turney to talk about cancer and weight management medications.

Paul (55:21)

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

Emma (55:34)

I'm Emma.

Paul (55:34)

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