The Cancer Professionals Podcast

More than a diagnosis: Dementia and cancer together

Episode transcript

(Intro music)

Emma (00:10)

What does isolation look like when it's shaped by things others don't understand?

Andy (00:15) (clip from episode)

You can feel very lonely and I've been through that. I felt isolated in an environment where people don't understand why I do certain things, why I feel a certain way,

It can be very, very isolating. I can't imagine what it must be like to be on your own having received a diagnosis. And that's one form of loneliness. But there are lots of others where people just can't interact with you. They can't connect because they don't understand. And that makes you feel very isolated from society, really.

Paul (00:48)

Hello, I'm Paul and my pronouns are he/him

Emma (00:51)

I'm Emma 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 including health and social care professionals to lift the lid on current issues faced by the cancer workforce. This is part one of a two part episode.

Paul (01:10)

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

Emma (01:33)

If you're a Macmillan professional attending the Macmillan Professionals Conference on the 23rd and 24th of April, we'd love you to join us for the Cancer Professionals Podcast live recordings. On day one, we'll be talking about Macmillan membership with Kim Bowles, Claire Taylor and Emma Quintal. you'll be able to pre-submit your questions on sign up for the session.

Paul (01:54)

Day 2 will be joined by the artist behind the Cancer Tapestry, Andrew Crummy, along with Rodney Mountain and Eleanor Ogilvie. You'll be able to see the tapestry live on stage and hear the story behind the artwork and its connection to cancer care.

Emma (02:10)

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

Paul (02:19)

Hello, and welcome to the Cancer Professionals Podcast. Today we're exploring dementia and cancer and the realities of living with both, including the emotional impact and the practical challenges that can shape someone's experience of care. We're really grateful to be joined by three guests with different perspectives. Let's start with some introductions and your connection to this topic. And And Andy, if I may start with you.

Andy (02:44)

Hello, Hello I'm Andy and I'm living with vascular dementia dementia and plus I have two different types of cancer, one of which I've recently just gone through treatment for. My activities now relate around research and lecturing on patientcentred care, dementia, palliative care and also on the newly and introduced allied health professions.

Paul (03:16)

Thank you, Andy, and we look forward to more about your story as we progress through the conversation. And Rachel, if I may come to you next.

Rachel (03:25)

Hi. My name is Rachel and I'm an Academy Lead Admiral Nurse with Dementia UK. Admiral nurses are very similar to Macmillan nurses, but where Macmillan nurses work with families, support families with cancer, cancer, Admiral nurses work with and support families with a diagnosis of dementia. And I lead on professional development, education and support to help families and professionals feel more confidence in their care.

Paul (03:56)

Thank you Rachel and Lorraine.

Lorraine (03:58)

Hi, my name's Lorraine and I work at the Christie Hospital in Manchester, which is a cancer treatment centre. I've been working there for about 14 years now. My role is actually I'm a Macmillan dementia nurse consultant. So I work in a partnership with So I predominantly work with people with both cancer and dementia. And I do lots of things, write the policies etc. work very very closely with patients and carers that are affected by cancer.

Paul (04:31)

Thank you, Lorraine. And again, we look forward to hearing more about the work, some of the work that you've been involved with during during the conversation. So, So Andy, if I can kind of come to you first if you're happy to share, can you perhaps take us back to when you were first diagnosed with the dementia diagnosis?

Andy (04:50)

Well, it was 11 years ago and I had a very early diagnosis, so young onset dementia, but nobody ever really thought it was dementia because I didn't have any problems with my memory. I had a tremor and I'd lost things like my sense of taste and smell and my balance wasn't very good, which I ignored for a while and then friends told me, you need to see your GP about this. I saw my GP. I was admitted to hospital for tests really quickly after that, which was a bit concerning, but they thought that I had Parkinson's disease. So I had all of the relevant tests for Parkinson's. And the good news was I didn't have Parkinson's disease, but the MRI and CT scans noted that I had ~ visible lesions at different parts of my brain, which were being caused by what's called TIAs, transient ischemic attacks. And those showed up, which is why really the diagnosis was early, and ~ I was diagnosed with vascular dementia.

Paul (06:13)

In terms of what the process was like for you, in terms of getting the diagnosis, was there anything that helped or didn't help that you can tell us about?

Andy (06:27)

Well, unfortunately at that time there was very little post-diagnostic help for people who'd just been diagnosed with dementia. I was basically told I had it and go away. There are lots of questions that are difficult for to answer. For example, dementia, everybody is different, so that doesn't help for a start. So things like a prognosis, or questions about prognosis is a hard one. And of course there are over a hundred different types of dementia, so that doesn't help either. But as those of us with dementia will always say is, when you've met one person with dementia, you've met just one person with dementia, we're all different and we all develop. Our dementia develops in in different ways, not just dependent on the type of dementia that we have. I was devastated by the diagnosis, I have to say. It was the worst day of my life. It was worse than being diagnosed with cancer. There's something about thought when you're diagnosed that I'm losing my mind when you're not.

It's not like that. But of course, my experience of dementia was very limited, limited to my grandmother and two of my dad's sisters. And I only saw them in late stage or was only aware of it in late stage. And I was very young. So I had, if you like, false memories of what it would be like and how quickly it developed, all of which were wrong. I subsequently found once I had had it properly explained to me, things were much different and I must emphasize it is possible to live a good life or a better life with dementia and with the right support. Life is good. Yeah, it's good.

Paul (08:36)

Well, I'm pleased to hear that after and, you know, I'm sorry to kind of hear how, how kind of devastating it was for you at that time. And I wonder if we often default to memory loss when we're talking about dementia. And I wonder if we can maybe bring Lorraine in here. And would you like to maybe tell us a little bit more about dementia?

Lorraine (09:05)

Yeah, of course. I mean, like you say, I think we do usually associate dementia with short term memory particularly, but as the condition progresses, it can affect other cognition as well. So it may affect language, it may affect calculation, it might affect perception, it might affect the way you walk, anything really that can be associated by our cognition. it's not just memory problems, it's other things as well. So yeah, things like speech, perceptions, etc. can be affected and your behaviour perhaps even and sometimes even your mood, you know, so it's not just short term memory. It's a whole host of things that I think people don't really associate with dementia.

if they haven't experienced it themselves really or know anybody with dementia.

Paul (10:01)

And Rachel, could you tell us a little bit more about perhaps what we do and what we don't know about dementia and the scale of people being diagnosed?

Rachel (10:12)

I think Andy and Lorraine have made some really important points there. So we do know that this year or last year, dementia was tipping the one million people being diagnosed in the UK, which means that that actually it's enormous. The number of people living with a dementia diagnosis is huge.

and that dementia is the leading cause of death in England as well. So, you know, when Andy said about the devastation of the diagnosis, I think it's such an important point. We know it research that it's actually the most diagnosis that people can get. And people are actually more frightened of a diagnosis of dementia than cancer or diabetes or heart disease. So yeah, it's something that we need to pay more attention to, I think.

Lorraine (11:09)

I think sometimes we don't really recognise dementia as a life-limiting condition, and it is. And sometimes people aren't aware of that when they first get a diagnosis. So it's so important to, you know, plan for the future, I think that probably needs to be explored more with people when they get a diagnosis in order for them to think about the future and decisions.

Andy (11:34)

And I guess I would like to add just one thing to that, which is all of these things make it obvious that staff in the NHS, all staff, not just those who are dealing with dementia patients, but administrative staff as well, require training in dementia awareness and the problems that that can cause, and the myths and the stigma that are associated with the condition as well.

Emma (12:06)

Thank you all for kind of explaining and setting that scene. And I wondered, Andy, if I might ask, from your perspective, how did living with dementia shape or impact your experience of being diagnosed with cancer?

Andy (12:21)

It made it more difficult, I think, to understand and it certainly made my acceptance of the treatment, which the radiotherapy in particular, very difficult, very frightening because of the machinery and the noise that's associated with the treatment. I'm very sensitive to noise, but I must say I was treated at the Velindre Hospital and they were excellent. They knew that I had dementia and they treated me accordingly. I was given additional help, if you like.

Emma (13:04)

And Andy, if you would be happy to, could you share a little bit more about what that support looked like and how that made a positive difference for you during that period of diagnosis and treatment?

Andy (13:18)

Well, I was so traumatised just by the equipment and the room and everything that was going on that after two days you're given a form to fill in to say how you're feeling. And I was scoring myself high on things like agitation and nervousness of the treatment, et cetera, which basically meant within 24 hours, I was being seen by a consultant and she was marvellous. And I had to explain that I wish I'd filled the form in perhaps a few days later because I was beginning to get used to what was going to happen because it's a repetitive treatment. I had 20 doses.

Andy (14:11)

of radiotherapy. So by the time it had finished and and I got the chance to ring the bell on the way out of the hospital, I had a very different feeling to the treatment than when I started. But that talking to people and also talking to other people who were having treatments as well, because we were waiting in

Andy (14:33)

waiting areas together, smaller waiting areas from the main one. You're called down about half an hour before you're due to have your treatment and I think talking to them helped as well.

Emma (14:45)

Thank you for sharing that. And I think it really does demonstrate how that experience through treatment can really vary on that day to day of how you might feel, what may impact your, not only your physical symptoms, but your emotional symptoms. And it's great to hear you had those opportunities to check in and have that support at various points during treatment. And although you said about completing that questionnaire a few days later. It's really good that at that time you were able to really share how you were feeling and for that support to be put into place for you.

Andy (15:19)

when I filled the form in, I will be perfectly honest with you, I was going to abandon the treatment. I thought, can't take this anymore, you know? And it's not significantly bad at all. Unfortunately, I needed just that little bit more coaching, if you like, and explanation, and maybe breaking things down in a different way to someone who perhaps doesn't have.

Andy (15:43)

the co-condition of dementia that goes with the cancer support.

Paul (15:49)

And I was going to ask Andy about that a little bit. Did you feel you had enough support to kind of navigate through that pathway at the time?

Andy (16:02)

I did from the actual cancer center, the hospital. And it was just reassuring to know that Macmillan were there in the background because they contacted me, which was really nice. I'd been referred and also so did the Admiral nurses at Dementia UK. Now, whilst I didn't use the support, it was just so reassuring to know that it was there if I had another crisis. I had someone that was available to help me and just knowing that they're there is so reassuring.

Paul (16:47)

Can I ask... Maybe Rachel, From your experience, what do you maybe wish that cancer teams understood about dementia beyond memory? And it might be from work you and the other admiral nurses do terms of supporting Is there anything that you see often?

Rachel (17:08)

Yeah, think one of the things that I noticed is like predominantly for me, if you think about the sensitivity of the brain as an organ, because it has, because there are changes to the brain, I think it's really, really important to think about the challenges in cognitive functioning in terms of things like decision making, personality, behaviour, physical changes, word finding.

but also depression and anxiety. things like that are actually super important, but also cancer pathways are largely built around cognitive capability and stamina. So you have to have quite a lot of stamina to go through cancer treatment. And I think that it's really important that that's explained and that can be

explained in a way where things are reinforced. So information might be given with additional information and information might be given more than once. You might have people, other people present so that they can reinforce and help somebody to process. Processing is one of the things that's really affected and it would, so for me it would really help.

cancer professionals to understand what's happening within the brain for the person so that we can make sure that they don't kind of feel lost in the system.

Andy (18:40)

It's very difficult for the people that are treating you because because it's a very fine line, isn't it, between being patronising and talking to you like a child and talking to you like a grown-up that needs that extra ~ information or needs to have things explained slowly. So to me, it's not something that comes naturally, which is why I say training is so important.

You have to appreciate that. And also people that deal with those with dementia, it's late stage or part of the journey, the dementia journey, it's understanding the nonverbal signal that I know I was making and understanding what's causing those like fear, agitation, depression.

Andy (19:30)

So, you know, the non-verbal signals are important too.

(Ad)

Emma (19:36)

This conversation is really bringing to light the complexities faced by people living with cancer alongside another long-term condition like dementia.

Paul (19:44)

Yeah, it's more common than we might think. Around 70 % of people with cancer are also living with at least one other long-term condition, which which really highlights how important it is to take a more holistic approach to care.

Emma (19:57)

And as we've been hearing, dementia can add additional challenges, particularly around decision making and supporting people living with cancer and also those around them.

Paul (20:05)

If this is something you'd like to explore further, there are some really valuable resources available on the Learning Hub.

Emma (20:12)

That includes the Cancer and Other Conditions eLearning course, as well as the Palliative and End of Life Care toolkit, which has guidance on supporting people living with dementia.

Paul (20:21)

Dementia UK also has a range of resources for people living with dementia and the people around them. You You can find all of these via the links in the episode description.

Emma (20:30)

Definitely worth a look. And now let's get back to the conversation.

Emma (20:35)

I think that's such an important point that not only our verbal communication but our body language and how professionals can pick up on that is so important for those key conversations and really exploring how each individual is and what support they need. And I wondered Lorraine if we could explore from your perspective with the work you what can healthcare professionals do to support people living with both dementia and cancer through treatment, through diagnosis, from your insights and experience,

Lorraine (21:10)

I think the main or the most important thing really is honesty and it's honesty about treatments. If somebody's got a dementia and cancer, we never want to say that because you've got a dementia, you can't have treatment. We would never say that. And I think it's about the assessment of that person individually of whether it's going to be appropriate for that person person. And we should always kind of recognise

Lorraine (21:38)

that any treatment quality of life should be the outcome of that treatment. So, you know, if it means that sometimes somebody doesn't get treatment, but they're better with their quality of life not to have treatment to be able to continue to function as they do normally at home and socially like they do, then, you know, if that's what they want and that they feel that's better, we've got to appreciate that. Oncologists, from my experience of working with them for many years, they really want to treat, they want to treat cancer. But sometimes you've got to get them to stand back and think, maybe this treatment, particularly chemotherapy, because that's very toxic and that can exacerbate cognition problems with people with dementia dementia. So So you've got to make them stand back and think sometimes, is this treatment the best option for the person?

Lorraine (22:35)

Is there another treatment maybe they can have instead? Or, you know, is it that they don't have treatment? So, and that involves a lot of discussions and honesty from the start. I I mean, we did a small piece of research at the Christie many years ago about carer and patient experiences of cancer cancer treatments at the Christie, Christie. And, you know, some of the carers said, well, we like honest discussions at the beginning and we want you and the

Rachel (22:54)

Hmm.

Lorraine (23:03)

patients with dementia said we want consultants to talk to us instead of our carers because we are still people we still can you know make our views known and the other one was you you know, that they should involve everybody in the care it's a partnership really so I think the examples that we had with the research were that before you have treatment everybody sits down and discusses

what the treatment is and that for things like head and neck, for example, I always say head and neck because that's quite a big treatment and very complex treatment. So for head and neck, the person's got to have it explained that they've got to wear a mask, have a mask made, it's fixed to the table. They They are then on their own in a room by themselves with somebody outside and they have to stay still for so long while they have the radiotherapy. As they get

Lorraine (23:59)

As they have more radiotherapy, they will become probably more tired and their throat will get more sore. So for people that are in quite a moderate stage of dementia or an advanced stage, they sometimes don't recognise that's why their throat is getting sore. For somebody without a dementia, they understand that, but for someone with dementia, they don't recognise it and they get distressed and they get upset upset. So So the next thing that we might do is put something called a nasal gastric tube down the nose into the stomach to feed them if they can't swallow. And another step after that might be that they have a rig, what's called a rig, it's like a tube put in in the stomach which feeds them. And it can be very, very uncomfortable and it can cause infections and it can cause people to be agitated and they might pull it out. So ~ that's quite a big thing to have a rig put in in your stomach. It can be really distressing for people people. And And sometimes it means that they can't live in the community anymore because they haven't got any district nurses that will do the feeding for it. So they have to go into 24 hour care. So what the carers were saying to me was if we'd have had all this information before, say, mum had the treatment, then maybe I would have changed my mind. I wouldn't have wanted her to have treatment because she ended up in a 24-hour care nursing home. Her quality of life was quite poor. Whereas if she'd have gone down the palliative care approach, where she was being supported through her cancer, then that probably would have been the best outcome for her. So I think it's really important that you always discuss first and be very honest about what that treatment can entail in order for everybody to get the true picture. So yeah, can be difficult.

Andy (25:53)

That conversation was had with my mum and she made her own decision. She said, I don't want to have, was only palliative treatment that they could give her, which would have been extremely difficult, i.e. the chemotherapy. She had a oesophageal cancer and she just decided, no, I've had a good life. I'll live it as well as I can without the treatment as long as I can get some appropriate palliative care, i.e. pain relief. She was happy with that and that was her decision and we all supported it as a family.

Lorraine (26:34)

Yeah, I mean, you would never expect, I wouldn't anyway, I would never expect a carer to make a decision for their loved one, their family maker, because number one, they might not understand the treatments available and not know what the side effects and risks are. So they'd be making a decision on not having that information. But But I think, you know, sometimes it can be quite distressing if the kind of outcome is that there isn't going to be treatment. It can be really distressing for that one carer or carers to have to make that decision. So I think it's vital that, you know, we make the decision together, the health professionals, the carers, the person living with dementia, if they can do. So we all make that decision. So there's no guilt involved for carers because they will probably feel guilty anyway, but we don't want to make that guilt any worse. So, you know, I think it's vital that we share that decision making and not just be be left to one person.

Rachel (27:34)

Yeah, just to add to that from my research, being part of the decision was actually the most important thing for the person living with a diagnosis. And it wasn't necessarily, they didn't necessarily need to lead the decision, but they needed to be part of the decision making process. And I think having the right person and or consistent people there to be able to support them in their decision making and having enough time to make a decision. You know, being given space, having a nice calm, quiet environment to be able to make the decision so that they, and being given, like Lorraine was saying, being given all the information, but in kind of bite-sized chunks so that you're actually making the decision in a measured way and with the support of the most appropriate, appropriate people around you, whether that your family, chosen family, care partners, and or your consultants or Macmillan nurses. So I think it's really, really important that people are given the opportunity to participate in the decision, even if they're perceived perhaps to be further on in their dementia trajectory.

Lorraine (28:49)

Yeah, I think

been occasions when we brought people back two or three times, you know, for a discussion because they've really not known what pathway they want to take. So we give them time to think. And, you know, like I say, it can sometimes be three times when they've come back and that final decision has been made. We would never rush anybody into making a decision. You know, it's complex. It takes a lot of time, you know, kind of impacts on your life, your quality and everybody's life. So it's vital to give that time, like you say, Rachel, to people, it really is. And we would always with people with dementia, we always do a mental capacity assessment first to see if they've got the ability to understand the decision and treatments. If they haven't got it, we will always, by law,

Lorraine (29:43)

have to have a meeting to discuss the treatment. So we always do that. And when I first came into this role, not a lot of consultants did that. They didn't understand it. now it's kind of the normal practice now to do that when somebody with dementia comes in or a cognition concern.

Emma (30:03)

I think you've all really shown the importance of that shared decision making really involving somebody in those decisions in those conversations about what matters to them what's important to them whether that's proceeding with treatment or maybe treatment isn't the right option and it's about quality of life and ensuring somebody has the appropriate and the right support not just for them but for their families and their carers and those important to them

We've talked about being part of those conversations, being really involved in that shared decision making and if I might ask and if you're happy to talk about this, I wondered whether we could talk about what was that experience like for you? Did you feel part of that conversation about treatment options and did you feel well informed and supported to understand all of those side effects of treatment to know the impact of you and to be really involved in that conversation and that decision making.

Rachel (31:04)

Thank

Andy (31:06)

I did actually. I think when you're dealing with cancer rather than dementia, I think the doctors find it a little bit easier to talk about that issue. And the recent treatment that I've had has been for prostate cancer, which is becoming more well-known, not prevalent, but more well-known because of, you know, well-known people talking about their diagnosis. And they talked to me at length about the treatment options that I could have, which were obviously the radiotherapy, hormone therapy, and also talked to me about the new robot therapy, which they have locally, which is an operation that's done by robot which baffles baffles me clearly there are surgeons present and you are you have an anaesthetist present as well but they were both explained to me and I was able to make an informed choice I have to say I asked both my consultant and my GP what would they do if they were me and what a terrible question to ask either of them. I thought they're going to tell me, well, I can't make that decision for you. But they did. They were really, really honest with me and said that they would opt for the radiotherapy, ~ both actually in a different environment actually said that. So they were much more helpful than I had expected them to be. And it really helped.

I think cancer support is vital and it's probably much better at the moment than dementia support. If you've got the two together, it's very, very hard for the carers and also ~ the physicians that you're involved with as well.

Lorraine (33:09)

Sometimes as well you have policies in hospitals which can be quite difficult when you're caring for people with dementia. an example would be protected meal times, then people can't go and assess someone or do any work with them while that patient's eating the meal. But But for people with dementia, then sometimes that's not an option, protected meal time, we have open visiting for them.

And if their family or their loved one wants to come and feed them, we would encourage that if they want to, because sometimes they enjoy the respite of not visiting sometimes. So yeah, having open visiting that that person can come any time of day, because obviously that patient with dementia is in an unfamiliar environment. They can get a little bit distressed, a little bit agitated. So to have someone with them that's familiar, can help not only them, but also help the staff on the ward. even though it's not about the staff, it's about the patient, you know, that having that open visiting is vital, you know, that they can come any time and you don't come because it's protected. You know, I do think things like that are important in relation to the culture of organisations.

Andy (34:28)

Familiar faces make you feel safe ~ in a hospital environment. I have to say, there are 11 machines where I went to have my treatment and I had mine with the same team every time. So they were familiar faces. That wasn't the same for everybody, but I don't know, they did that for me and that helped enormously just to see that smile as I was going into the treatment room and being put into the position that I needed to be to have the therapy that helped as well.

Emma (35:06)

I think, like you said, those to have that consistency, have that support is so key and so important. Rachel, if I could ask, are there themes that you hear at Dementia UK as admiral nurses, hear from people who are experiencing living with dementia and cancer about support in hospitals, about what makes that positive difference?

Rachel (35:35)

Yeah, think ~ so consistent staff definitely makes a difference. Quiet, you know, quieter environments where possible. Not always a side room, interestingly, I think sometimes a side room can feel really isolating. And I think staff think that perhaps it will be useful to put somebody in a side room because it's quiet, but it's not always the best way. Lots of hospitals are starting to get Admiral Nurses now, so the Admiral Nurses will support the staff on the ward to actually understand what's happening for the person. We have to be really mindful that, I spoke earlier about the brain becoming more sensitive due to the dementia and we know that ~ delirium is huge. You're 10 times more likely to experience delirium.

if you have dementia, a dementia diagnosis. So having an early awareness of that and being able to tackle that sooner rather than later is really, really important too. I think just having, ~ creating an an environment which feels less overwhelming if possible. Accident and emergency is not a great environment for people with a dementia diagnosis sadly. So where possible, as Lorraine said, having somebody familiar with them and being able to have somebody there kind of consistent is just very, very important for people. And just ways of, for example, signposting things, signage, so people can find things more easily so that they don't feel quite so lost in an unfamiliar environment can be really useful as well. There's also just including the family in important conversations. So all of the conversations that are happening so that the person feels that they have an ability to participate where possible. And we spoke earlier about, you know, giving people time to be able to kind of think as well. And this is really hard for professionals because this is a fast moving, fast paced environment and it's hard for them to be able to do all of these things. But they're really important and actually save time in the long run because it makes the person feel psychologically safe and if they feel safe then they have less needs and their needs are going to be less expressed in terms of ~ either their behaviour or distress. So it's really really important.

Andy (38:18)

I teach the medical students and other medical, the allied health professions, I would tell them exactly what you've just said, Rachel, and they'll say, I haven't got time for that. And I said, no, no, you have. You're creating time for yourself. Please try it. And I call it working smarter rather than harder. I totally agree with what you described.

Lorraine (38:40)

I think sometimes the education just isn't about the nurses or the doctors, it's about the leaders. It's the top management that also need that education because they've got to lead by example. So ward managers have to lead by example. If they aren't dementia kind of trained or aware, then a healthcare assistant sits down, say for example, and has a cup of tea with the person to try and reduce their agitation. And then you get the ward manager saying, what do think you're doing? You've got to go and see that patient down there. Then they have to have that understanding of person-centeredness as well. And I think that's vital. And within any organization, I think that's where your training starts really up there because they can make the differences and they can influence the policies. And for me, that's really, really important.

Rachel (39:33)

Yeah, 100%. I also, I was also going to add that if you can prepare somebody for a conversation, if you can prepare somebody that something's going to happen and give them, because that gives them additional time. So if you say, I will be back in five or 10 minutes and we will, these people will be present and we're going to have this conversation. We're going to be thinking about this.

Quite often we talk about the brain kind of like ~ being a supercomputer. But if you can imagine the brain with dementia, sometimes it's more like a filing cabinet. So the person still has all the information there. They just have to take more time to kind of go and find the important information that they need. So if you can preface a really important conversation and just say, this is what we're going to be talking about.

This is who's going to be present while we're talking about it. And again, like Andy said, it's really, really important that we're not patronising, but it just helps somebody prepare themselves for knowing that this conversation is going to happen and they can prepare themselves. They might want to write a few things down or be able to talk one-to-one with their care partner first.

Paul (40:54)

And some people, might say if the person can answer my questions, they're fine, or they understand what I'm saying, what would you maybe say to those people?

Andy (41:06)

Well, lived experience is, there is no compensation for lived experience as part of the training. And I try and explain to people, we have good days and bad days. There are days when I can't find words. My vocabulary is definitely restricted. I started from a high intelligent quotient.

Lorraine (41:06)

repeat it.

Andy (41:30)

I was 170. So I feel lucky that I came from a high area. Maybe that's helped. That's probably a myth, ~ a total myth, because we know so little about the brain. It's the most complicated organ in the body. And I also think if I look after myself well in terms of my diet, exercise, keep my medication up to date, then I'm helping to keep myself like I am reasonably coherent. But I see the difficulties. People don't realise it's not just that sort of thing. Your social filters go and I've definitely lost some of those, you know, they're important parts of the brain.

Andy (42:20)

Unfortunately, they're the social theatres- filters that can affect behaviour and make you a very difficult person deal with, especially your carers and your loved ones and your family at home, because you're relaxed in your safe in their environment. So you can be yourself.

(Outro music)

Emma (42:42)

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Paul (43:01)

If you enjoyed this episode, follow us so you don't miss part two, where we continue our conversation with Andy, Rachel and Lorraine.

Emma (43:10)

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Paul (43:23)

I'm Paul

Emma (43:24)

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