The Cancer Professionals Podcast

More than a diagnosis: Dementia and cancer together (Part 2)

Episode transcript

(Intro music)

Paul (00:09)

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

Emma (00:12)

And I'm Emma and I go by she her. Welcome back to part two where we continue our conversation with Andy, Rachel and Lorraine about living with dementia and cancer.

Emma (00:23)

In part one we talked about Andy's lived experience and how living with both dementia and cancer shapes treatments, decisions and everyday life. We also discussed the importance of person-centred care and how cancer pathways and care environments can be adapted to better meet the needs of people living with dementia.

Paul (00:41)

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

Emma (01:04)

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 (01:25)

On day 2 we'll 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 (01:42)

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

Paul (01:50)

Lorraine, I wonder if you could talk to us a little bit about how you've adapted, some of the services that you offer for people with dementia.

Lorraine (01:59)

Well, a lot of it is a lot of it's training that I do within the hospital anyway, and that's not kind of e-learning, it's face to face, it's going on the wards, it's role modelling and, you know, working with people to get to understand, you know, people's needs. The other thing that we've just recently brought in is activity coordinator. So his role is about spending time with people.

Lorraine (02:23)

and engaging them in conversations and engaging them with activities that he's learned what they like, you know, so that kind of kind of helps them in reducing their distress. I think one of the proudest things that I've been involved in is like, I work very closely with people with dementia that are having cancer treatment for skin. So with the plastics team. So when I first went to the Christie years ago, people with dementia,

with dementia, it didn't matter what stage they were in, just with dementia, they would either get off the general anaesthetic in which they would then be admitted to a ward, taken out of their own familiar environment, probably develop an acute confusion and could be in for days and days and they could have falls and everything else that you get with hospital admissions sometimes, infections. So they were either offered the general anaesthetic or they would be given no treatment.

Lorraine (03:21)

to remove their melanomas, which is a skin cancer which could spread. So when I first went, just said, is there any chance that we could maybe offer people a local anesthetic instead of general or nothing? And I remember the consultant saying to me, the plastic surgeon, says, oh, well, I'm not sure. What if they get all agitated and distressed? would we do? And I said, well, you're kind of...

not probably going to get that if you can reduce that person's distress. I said, what about if I come in and sit with the person, maybe hold their hand, maybe play music, let's talk to them, find out about them and let's see how it goes. And he did put his trust in me and me, my trust in him it was a two-sided thing. And we did it and it worked great. We did it a few times with someone with dementia. We got them through the treatment by going in with them, playing music. Sometimes they even sing themselves.

I've got a lovely video of somebody singing while they're having the operation. And it just works wonders. And it's now become the normal kind of skin pathway at the Christie that people with the dementia or older people or more vulnerable people or frail people have the local anaesthetic instead of general anaesthetic. Sometimes people do need a general anaesthetic, but if we know they're going to need a general anaesthetic, if they've got dementia and they're going to be admitted to the ward.

Lorraine (04:42)

an email gets pinged to everybody that, you know, maybe we've got to observe them, put them near the nursing station, ensure that they're on a bowel chart, ensure that they're on a pain chart, ensure that they're on a fluid balance chart so that they don't develop a delirium. And like Rachel said, people with dementia are 10 times at risk of developing an acute confusion. So I think things like that, I mean, I've just found out that they're doing a similar thing now with the pathway, at Whythenshaw hospital.

Lorraine (05:11)

what we're doing about local anaesthetic. you know, that's great. And if everybody could maybe listen and learn and, know, just why reinvent the wheel if you can do it, you know, so, so that's the kind of things that I do in the Trust.

Andy (05:27)

Epidurals are a very good example of that, which is a step, just a little step further than a local, isn't it? I had my hip replaced by epidural and they were reluctant to do that because if I had started to panic, what were they going to do? But they actually did it.

Andy (05:48)

What you're describing Lorraine is excellent for people with dementia.

Lorraine (05:53)

Yeah, we do offer sedation sometimes rather than general, but it really has to be assessed because obviously giving sedation to people, where older people and frailer people can have its complications. But, you know, we would always weigh up the risks and the benefits of having the sedation as to whether it's in the best outcome of the person. and we get anaesthetist involved in everybody because we've got to remember that, you know, sometimes people with dementia also have quite a few other comorbidities as well.

So it can make them quite frail and it's those kind of issues we have to look at when we are treating patients. yeah, it does take a lot of assessment and discussion.

Paul (06:37)

And Rachel, are there any examples in the work that you've done in terms of where you've seen adaptions work really well, as Lorraine has just described?

Rachel (06:50)

Yeah, so some of the really interesting things I've seen have been in different kinds of environments, for example, within care homes or in the community. So really thinking about how to create space, I guess, for people to be able to make a difference. But within the hospital environment, for example,

there's things like personalising radiotherapy masks so that things don't feel quite so frightening. I think Andy, earlier you spoke really eloquently about how your fear and anxiety had quite a big impact on what you were experiencing and what that meant for you kind of moving forward with your pathway and with your journey and almost to the point where you were thinking I might

I might have to walk away from doing this. So creating something that is really useful for somebody. And I think it's really important what you said as well, Andy, about if you've met one person with dementia, you've met one person with dementia. So So what we really have to think about is that stopping this kind of unilateral decision making and unilateral kind of pathways

and really thinking about how can we tailor each individual experience to the individual and try and create something that's meaningful to them. So for example, playing music through through headphones during, ~ it might be through an MRI scan, for example, or just finding ways that really represent that individual's experience.

And it might be using art, it might be using a whole range of different things, but something that actually makes the experience more personal to them and then makes them, puts them in a position where they feel like they can choose to continue

Lorraine (08:50)

We're very lucky at the Christie because we have a really big complementary therapy team. So they are really good at kind of working if people are a bit distressed or a bit agitated and can do like exercises with them. And this can include people with dementia, you know, they can follow exercises. have little stretchy men that you pull and they stretch and it like stress toys. They use those for people, you know, that might be a little bit agitated. So I think it's about

It's about thinking about things like that, isn't it? You know, that can complement not just your own role, but other roles as well. So I know like with supportive Sorry, care, but we call it supportive care. So I did a lot of work with them when I first went to the Christie on pain, because, you know, the pain tools that they were using were like, can you say from one to 10?

what your pain level is, or is it a smiley face or is it a happy face? And people didn't understand that. So So it was about working with them to kind of understand tools that are observational tools rather than what people can say. So the one that we particularly use at the Christie is one called the pain add tool, which is about like looking at the person and seeing if they're agitated, looking at the signs, are they rocking backwards and forwards? Are they vocalizing? Are they walking up and down?

Lorraine (10:13)

So we would use things like that. So it's working with those other teams to try and improve care for that person.

Rachel (10:21)

Yeah, definitely. I think using tools like that, that actually look further than just verbalising something so that you're actually looking at people's levels levels of distress, for example, that's just super important for people that perhaps don't feel capable of verbalizing right now. And in terms of other complementary therapies, something that we use a lot now increasingly in dementia care is ~ something called Namaste Care which is very much about ~ supporting people for example using things like reflexology or different scents, different sounds and massage a whole different range of things that actually create a much more useful experience and it does help with pain. know that actually if we think of, you know, the Dame Cicely total pain model, if we think about that and how how, you know, looking at somebody's spirituality changes how they experience pain, not just physical pain, but also social pain, psychological pain.

So we need to kind of think more broadly when we're thinking about about a person living with a diagnosis of dementia and kind of creating something that's much more individualized and personalized, which is what you were saying earlier, Andy.

Emma (11:49)

And those are all such important factors of actually personalising and tailoring care and support to each individual and the importance as well of collaborating with those services.

Lorraine (12:00)

I think also the assessments, because everybody is so different. We know that everybody's got their own individual needs, their own individual person, their own individual personalities. And I think before we do any treatments, it's not just looking at the medical, physical issues, it's about the social issues as well. So if we tend to get people that live a lot on their own, you know, so we've got to kind of take into consideration, you know, will they understand if they get ill?

who to ring or would they be able to do that? Would they be able to say, they're having radiotherapy down below, if it's gynae, are they able to keep themselves clean? So do they understand the implications of treatment? Are they going to remember to come every day for radiotherapy? Because if they don't, then that defeats the object. So we've got to look at all those things before we even kind of think about treatment sometimes.

Particularly if somebody's a bit distressed as well, we would often trial them first if they were having radiotherapy. We might get them to go and lie down on the couch, go out of the room and see how they react to that. Can they keep still or are they agitated? If they become very agitated, then we would probably say maybe radiotherapy isn't the best option for them. So it's about looking at everybody's individual needs because no two people are the same.

It's very different living on your own than maybe living with someone who is caring for you, you know, and can support you that much more.

Andy (13:34)

I've done two studies that have looked at loneliness and I've also been to the House of Lords when they had a minister in the Lords who was responsible for loneliness, that was Baroness Barran, and gave evidence to to her and had to explain that loneliness isn't just about living on your own. can actually live in a house of multiple occupation, and I mean with lots of your family around you.

Andy (13:59)

because of the condition that you have and the fact that they don't understand what's wrong with you.

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, which is why it's good to be able to talk to other people, if you like, that are experiencing the same as me and can't say the same.

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 (14:48)

some people might say, I'm not trained in dementia. That's not my area. what would you say to those people and what practical tips could people take away from some of this?

Andy (15:07)

Well, I would tell people first of all when they said that to me that if you're not, you should be. Which is rather blunt. I know that that's how I would feel. I think, you know, it's extremely important because if you think that how many people have got dementia and Lorraine mentioned and Rachel have talked about comorbidities, most people that are on a ward aren't there for their dementia.

They're there for some other condition. So you can say that probably two thirds of the patients that are on a particular ward will have dementia in addition to what they're being treated for. I have the same experience myself following a fall. So, you know, that's why it's important because statistically,

It's probably the most relevant point in person-centered care because it's not something that's a rare thing. It's something which is extremely common, which is why dementia awareness and some form of dementia training is important for everyone. I really say everyone. I even mean that

the administrators at the desk who've got to deal with somebody who's got out of bed and they're confused and want to know if they can go for a walk or something like that, you know, when they're not allowed to. And you've got to explain why and do it sensitively. And they're the first person that's available to them. So you don't call the person that's the dementia specialist. Everybody should have

dementia awareness, it's probably of the most important of training that people should have, regardless of their speciality, simply because of the statistics of the condition. It's incurable.

So you've got another veneer of help that's needed in that whole patient centered care experience.

(Ad)

Emma (17:15)

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

Paul (17:23)

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 (17:36)

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 (17:45)

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

Emma (17:51)

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 (18:00)

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 (18:10)

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

Lorraine (18:14)

I've got three sayings, think the first one is always see someone as an individual, you know, you never get two people the same.

Second one would be, if you don't understand dementia, you can't care for a person with dementia. And I think the third thing is, if you get it right for people with dementia, you get it right for everybody. those were kind of my three little sayings. So, so yeah.

Andy (18:31)

Yeah.

Paul (18:37)

Rachel, anything you wanted to add to that and in terms of anything practical?

Rachel (18:42)

Yeah, so really simple practical things are, know, if you can do a pre-visit or pre-empt a discussion, that's always a really good thing to do. Lorraine mentioned earlier about like, can the person go and, for example, go and lay on the bed? But But just anything that you can do to prepare is a really useful thing to do. Really simple things like don't walk and talk at the same time.

quite often professionals will walk down the corridor and talk to you at the same time that you're walking. That actually takes a huge amount of cognitive effort to listen and walk at the same time. So actually walk, sit down, then talk, or talk, then walk. These are really small, simple things. Speak at just a slightly slower cadence, just ever so slightly slower than you would normally.

Rachel (19:39)

and always, if you can back up what you've said with additional support. So for example, it might be, here's some information for you, giving the person information and then perhaps giving them a leaflet as well. But just giving someone a leaflet is hugely overwhelming and just giving the person information is hugely overwhelming. Being able to do both of those things alongside one another.

~ If you can find the right person to either deliver information or be with the person to support them whilst they're having that new information is really helpful too because they become a partner in that care.

Emma (20:23)

There's been so many tips and practical advice for our listeners to take away from the episode so far. And I wondered if Andy, I could ask as well from experiences, what would you hope for the future for people living with dementia and cancer?

Andy (20:40)

Well, my dream is that everybody is trained in dementia awareness and everybody sees the importance of it. People just think you go into the medical medical profession because you're a compassionate, caring person. And that's true. You shouldn't go into it if you're not. they need to understand that their skills are not just clinical.

you know, that's just a part of what they're there to do. And I really want to see, ~ and it's already being introduced, patient-centered care being a crucial and fundamental part of the training for whatever part of the medical profession you are in. ~ And...

I'd like to see more follow-up, more resources, I think is really important, which is why I guess I lobby as much as possible the politicians simply because we have to make them aware of dementia and how common dementia is and the specific needs of dementia so that they will understand why we are asking for more funding.

Andy (21:59)

for research probably, but particularly for care. People don't necessarily see dementia research as something which is as glamorous as the research for cancer, which I'm pleased to say is well advanced now, and also for heart disease.

Andy (22:22)

So dementia has been like the poor relation and I'd like to see that change. I would like to see everyone recognising that this is a national emergency. It's the major cause of death and it needs to be treated accordingly.

Emma (22:38)

you Andy for sharing those those wishes and hopes for the future and the impact that would have on individual experiences and And I wondered whether Lorraine and Rachel whether you also had anything you wanted to share for those wishes and hopes for the future

Rachel (22:56)

you. I think that, I guess, given that I'm an Admiral nurse, one of my wishes would be that everybody could have an Admiral nurse, a specialist dementia nurse, everybody that wants one and needs one, so that there were, at the moment, there's probably 450, 480 Admiral nurses across the whole of the UK.

and ~ I would like to see a time where there's more like 4,000 Admiral nurses, certainly, hopefully, before I retire. I think that would just be fabulous to know that people were able to access an Admiral nurse as and when they need one, just for the support in terms of dementia care, in the same way that they can access a Macmillan nurse, so that an Admiral nurse can be there at their diagnosis.

Andy (23:43)

Yes.

Rachel (23:46)

and through the difficult times and to walk their journey with them in the same way that Macmillan nurses do. So that's one of my hopes. My second hope, I guess, is about research, that there's more research that includes people who have a dual diagnosis of dementia and cancer, because sadly, there's not a... Dementia is often an exclusion criteria for cancer research.

and cancer is often an exclusion criteria for people with a dementia diagnosis. So I think what we end up with then is a paucity of evidence in that specific area where those two intersect. So for me, I would love to see more research that includes people with a dual diagnosis.

Lorraine (24:37)

think for myself it would be education. That education is essential and made essential. At the moment it isn't. There's no policies out there that say that dementia training is essential. Trusts do it, organisations do it, but they don't have to do it if they don't want. It's seen as good practice if they do it, but it's not essential. And for me, it's about making dementia training essential.

Because, like you said, Rachel, dementia is the number one killer, really.

Lorraine (25:08)

And so it should really take priority and I think that education should become essential. think it should be made to be essential for everybody. But depending on what your role is, you know, I mean, you wouldn't be given high level dementia to say maybe a porter that probably doesn't need it as much as say as a matron or as staff nurse. But I think everybody should get it and it should be free.

Andy (25:35)

Yes.

Paul (25:36)

There's some really, really important points that you've all put forward there, I think. And before I move us on to the final part of our podcast today, is there anything else you wanted to say about cancer or dementia or experience? Anything else you want to add? Andy, I'll start with you.

Andy (26:01)

I would say just remember that there are organizations like yourselves that are out there and they're able and willing and kind and compassionate and empathetic enough to help and do what I do. Take, even if you don't use one of them, take

encouragement from the fact that they're there to help. And that's really important that you're able to talk to somebody who immediately will know what you're talking about and understand how you're feeling. I think that's something that I would add.

I often wear my lanyard, which is the sunflower lanyard. can wear the, forget me not if you want to, but the sunflower is obviously, you're not necessarily

not necessarily broadcasting your diagnosis to the world, you're just saying I have a hidden disability. And I've got to say, travelling and shopping, it's actually a blessing because a lot of people understand exactly what they mean. And you don't have to wear a lanyard, you can wear a little bracelet, and there's also a pin. And I've heard lots of mothers in particular saying, well, my son's got autism, a hidden disability.

There's absolutely no way he would wear any of those. Well, what we normally advise is, you wear it. Wear it for them. The child is with you. wear the sunflower. And you'll get the same help and response as someone who's actually wearing it would as well.

Lorraine (27:42)

For me with cancer, ~ it would be there was more voluntary free sitting services out there in the community because I've come across many a time a carer of someone with dementia who's got cancer and they don't want to come for treatment because they've got no one to sit with that person. And you know, when we've explored it, there has been people that will do it, but it costs them something like 50 pounds, 60 pounds for three hours.

Lorraine (28:12)

And people can't keep affording that. You know, I think there doesn't need to be, that needs to be a priority because carers are putting their own health at risk,

Paul (28:21)

Anything you'd like to add, Rachel,

Rachel (28:23)

Yeah, I think for me there's something really important about not making assumptions. Please don't make assumptions that just because someone has a diagnosis of dementia that they are not able to participate in the decisions about their care or their life. Please don't make assumptions that they will behave in a certain way or they will forget things or that they will be a certain way. And if you're not sure about how to work with them best.

ask them, just ask them and if they struggle to answer then quite often they will be good at kind of pointing to their care partner and saying you know can you help me to talk about this particular issue. So the only way we're ever going to get to a point where we're really personalizing care is if we actually talk to the individual and ask them.

What is it? What's important for you today? What's the most important thing for you today?

Paul (29:24)

think that's such an important thing that, you know, ask them that you said there, Rachel, that that's, you know, it's easy, but it makes a huge difference. And I'm going to move us on to the final part of our conversation today. And I'm going to what would you like our listeners to take away from today's today's conversation? And Rachel, if I can come to you first.

Rachel (29:35)

I think the greatest takeaway that I can offer to people today is please if you need help or support or advice with anything to do with dementia, call the Dementia UK helpline. You will always get a dementia specialist, Admiral Nurse. The telephone number is 0800 888 6678.

or visit our website, And that's for professionals, family members, and people living with a diagnosis of dementia. Anybody is welcome to call and speak to a specialist dementia nurse.

Paul (30:29)

we'll be adding those details into our show notes ~ And Lorraine, may I come to you next? What would you like our listeners to take away from this conversation?

Lorraine (30:39)

Never take no for an answer. You know, because especially in relation to cancer, you know, if you've got dementia and somebody says, no, you can't have treatment. Yes, you can. Why not challenge it? And I know that can be difficult, but you can get advocates, you know, that can come with you to challenge oncologists or GPs if they won't refer to a memory clinic. So I think that is most important for me. think carers are very vulnerable anyway.

you know, because they're in this situation. And I think, you know, they need advocacy sometimes in relation to helping them and support them. So yeah, never take no, just if you can. And I know it's hard because you're already challenging and fighting the system a little bit. But if you can fight it a little bit harder and use Dementia UK.

Macmillan have booklets on dementia and cancer for both carers and for people with dementia. Read them, know, I know sometimes reading isn't always the best but you can give some really good tips with those booklets. So yeah, I think that would be my advice. Stay strong and have your own needs.

Paul (31:46)

Thank you Lorraine.

And Andy, the final word from you, what would you like our listeners to take away from the conversation?

Andy (31:56)

Well, it's really hard to follow Rachel and Lorraine, I have to say, because I agree 120%, maybe 200 % with everything they've said. Dare I say, Dementia UK are respected, I know because of my publications worldwide, Dementia UK are respected across the world for their experience in dealing and nursing people.

~ with dementia. So take away the fact that they're there to help you. Take away the fact that Macmillan are respected for their knowledge of cancer care and that's there for you to utilise. And what I'd like people to take away is probably a conglomerate of all the information that we've been able to discuss today to get rid of some of the myths

that are associated with dementia. There are so many of them out there. And I hope we've managed to dispel some of those. And the fact that, you know, if we don't talk openly about dementia and cancer, then we're asking for people to maybe stigmatize us because they don't understand it.

Andy (33:14)

Lorraine talked about education, Rachel's talked about education, and the only way that you'll ever dispel the myths and the stigma is to educate people as to what it is. I'd like also people to take away the fact that the carers, i.e. the families, are usually unpaid carers, need as much help sometimes, maybe even more.

from the admiral nurses and the dementia care specialists and the cancer care nurses than perhaps the individual does because they go through a different kind of pain, dare I call it, emotion is probably the word I'm looking for. They're going through different emotions. I'd like people to understand that as well.

And I think the one that came out that really stuck in my mind is ask. If there's anything that you're not sure about, ask.

Emma (34:12)

Thank you all so much.

I know there's so much that we've talked about that our listeners will be able to take away with them. And I wanted to thank you all for sharing your experiences, your insights, and it's really emphasised that importance of involving people, inviting people to have those conversations, creating that time and that space to make really informed decisions that are from conversations tailored to that individual, their needs and what matters most to them. Thank you for being part of the Cancer Professionals podcast.

Lorraine (34:45)

Pleasure.

Andy (34:47)

My pleasure too. Yeah.

Rachel (34:48)

Thank so much.

(Outro music)

Emma (34:51)

You've been listening to the Cancer Professionals Podcast, which is brought to you by Macmillan Cancer Support. If you work in health and social care, visit macmillan.org.uk / learning to find out more about our learning hub where you can access free education and training. For links to the resources mentioned, see the episode description.

Paul (35:11)

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll unpack Macmillan's new workforce vision, Macmillan membership. Recorded live at the Macmillan professionals conference at the ICC in Birmingham, we'll be joined by Claire Taylor, MBE, Macmillan's chief nursing officer, Kim Bowles, head of professional engagement and Emma Quintal, senior innovation manager.

Emma (35:36)

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Paul (35:48)

I'm Paul.

Emma (35:49)

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