The Cancer Professionals Podcast

Episode 5 (May 2024) – The Weight of Empathy: Understanding Vicarious Trauma in Cancer Care (Part 1)

(Intro music)

00:00:08 Paul

When so much remains uncertain, how could you approach conversations about the future?

00:00:14 Claire

It's about confidence as well having these conversations. I suppose if you want to think, actually I'd like to start having a conversation with patients about this, start by thinking about yourself first, think about what you would want. If you can think about those things, If you can apply them to yourself first and gain confidence in doing that, then you can start to have a conversation with patients.

00:00:35 Carly

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

00:00:38 Paul

And I'm Paul and I go by he/ him. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, including health and social care professionals, to lift the lid on current issues faced by the cancer workforce.

00:00:56 Paul

This is the first episode in our exciting new collaboration with UKONS, the UK Oncology Nursing Society. UKONS aims to promote excellence in the nursing, management and care of all those directly and indirectly affected by cancer. Going forward, you can expect to hear episodes in partnership with UKONS every other month.

00:01:18 Carly

In this episode, we're joined by Claire Cadwallader, palliative care, clinical nurse Specialist, and Daniel Monnery palliative care consultant. They talked to us about why advance care planning is important, and Claire's award-winning service improvement project.

00:01:34 Paul

So hello, Dan and Claire, and welcome to the Cancer Professionals Podcast.

00:01:38 Paul

It's lovely having you join us today.

00:01:41 Paul

Can we maybe start with you telling us a little bit about yourselves?

00:01:45 Claire

Hello, my name is Claire Cadwallader and I'm a palliative care nurse at Catherines Cancer Centre in Liverpool. But as part of my role, I'm also the lead for advance care planning and Amber in the trust, and have been for the last four years.

00:01:59 Dan

And hi, I'm Dan Monnery. I'm a consultant in palliative care at the Clatterbridge Cancer Centre in Liverpool. I'm also the chair of the National Steering Group for enhanced Supportive Care, which is a subgroup of the UK Association for Supportive Care in cancer.

00:02:14 Paul

So can you start by explaining what advance care planning is? and it's often referred to as ACP. Could you tell us a little bit why it's important?

00:02:25 Dan

Yeah. I mean, I think advance care planning is essentially recording, asking people to think about and record what their preferences would be for the future. Before that time occurs because we've got to anticipate the fact that when people are unwell, possibly with palliative illness. There may come a point where they're not able to participate in decisions and discussions around their care at that time, so it's important that if people do have strong preferences around what care is right or wrong for them, that they have the option to say that in advance so that their wishes are respected.

And I think it's really important because it gives a bit of control back to people. I mean, we work in cancer purely. So actually we see a lot of these situations where a lot of control is taken away from people. You can't control your diagnosis, treatment plans, you know you have limited control over those as well. So one of the things that we can do for people is say, well, actually tell us what's important and we will try and structure the care around you at a time that seems critical for you. So I think it's all about giving people choice and giving people control and I think the importance of introducing it early is so that people have got that time to consider what their wishes and preferences might be and talk to those important to them about those things as well. Because I think if you ask people just on the hop, right, tell us what's important to you, cause you're really poorly now. It's too much people can't, can't think clearly in those situations. So it's important to try and do it as early as possible or at least give people the option of it.

00:03:59 Paul

And Claire, you did mention amber. Could you just explain what that means?

00:04:07 Claire

So Amber Care Bundle was devised by Guys and St Thomas's in London in 2010 and it's a guide to discussing uncertainty when recovery is uncertain in a patient. I think it's really challenging caring for patients, you know, with uncertain outcomes and you know and clinicians recognise that patients are deteriorating, but we're not sometimes very good at communicating that to patients and their loved ones really. So. So if we as clinicians struggle to recognise that then you know patients and their families will kind of just look to us for guidance and if we're just talking about treat and treat and treat the whole time and not explain to people that were worried about them and recognising the uncertainty and then at least at all the all kinds of issues regarding communication issues and you know delayed communication, poor patient experience and family experience and sometimes worse end of life outcomes for patients as well.

So Amber is about uncertain recovery and recognising uncertainty as well, and they're communicating that to the patient and their loved ones so that we can start conversations earlier in the patients journey about where they would want to be if things started to deteriorate, rather than trying to plan in the last of these last hours of life to try and get them home. So it's about open, honest conversations, recognising uncertainty, writing a plan down for it as well for the clinicians, not recognise it at 2:00 AM in the morning as patients deteriorating or we need to get them out or home.

It's about look, we're worried about you. Clear, concise language. We are worried, you know, you are sick enough to die. Really clear language so that we can have those conversations. And there's always a family member in London, Australia, America, there's always somebody miles away and you know, if we don't tell families what we're looking at, then they won't recognise either cause they don't know what they're looking at. Their loved one might have been in hospital two or three times before with an infection and seeing them this way before. But actually, when we're really worried, we need to communicate it and so that's what Amber is about.

00:06:10 Carly

Can I just ask this cause the term Amber is is in all capitals? Is it an acronym or what's behind the name?

00:06:17 Claire

It it is an acronym, AMBER stands for Assessment, Management, best practise, engagement and recovery uncertain. I just say amber equals uncertain recovery really simple.

00:06:32 Paul

That's lovely there. That's really clear. So just thinking about the advance care planning, what are the key components?

00:06:41 Claire

So key components of advance care planning and there are loads of books about this, there are loads of podcasts about it, there are lots of web pages about it. But the key component of advance care planning is having a conversation first. So communicating first, then writing down your wishes and preferences. What you want to happen, what you don't want to happen to you, then sharing that with your family. You might not want to discuss ii you don't want to sit down and discuss it and you want to do yourself, tell them it's in the drawer on the left. That's what we know about my father-in-law. Everything we need to know about him is in the drawer on the left.

So communicate where things are and then share it with healthcare professionals too, because again, like Dan said before when you're really unwell, there are things that you forget about what you know, you forget where your keys are in the morning coming out sometime. So when you're unwell, how are you gonna say actually these are my wishes and pull them out of your bag. So it's about sharing that with healthcare professionals your GP, your district nurses, your oncologist, so that we know what you want and and also sharing it with the people who you trust the most at that time to communicate that too. So I always say this, my poor husband. I have a delightful husband he's lovely, but my information if you need anything about me, go to my sister. She'll be calm and concise at that point and my husband's lovely but he's not gonna tell you anything. So find the person that's got the most confidence and that will speak for you on your behalf and that you know that can kind of stand, you know, a bit of emotion as well too at that point. So for me, they're the key components.

Simple language as well and you know, like I said, there's a lot written about advance care planning, but we can make it really hard, but just keep it really simple, some sheets about yourself. I think Dan and I now if we've talked so much together, we we could care for each other quite easily, I think and do very well. But so you know that's what we need to do with the people around us. So keeping it very simple is my motto for Advance care planning.

00:08:46 Paul

And Dan from your point of view, anything you want to add to that?

00:08:50 Dan

I mean, I think, I think Claire's encapsulated it really in its entirety. The one thing I would add perhaps is that it hasn't got to just be your wishes as it relates to healthcare, it can be your wishes as it relates to you know the conversations you want to be included in at the end of your life or not because some people know that their their time is short, but they actually don't want to be involved in those conversations at the very end.

Some people will want to write things down about their preferences with regards to personal care. So Claire was mentioning there that we could very easily care for each other cause we've taught this together so many times. What Claire means is she wants champagne mouth care. So we know that about her. I don't want my feet tucked into the covers. I can't bear it. So it's things like that as well, so knowing things like that and writing them down in advance so that so that people give you the right care at the right time as well.

00:09:44 Paul

And who carries out the advance care planning?

00:09:49 Claire

This is a huge conversation. We have all the time and and it's one of our sort of teaching slides who does this and I've been into so many meetings, it's always somebody else's responsibility. So it'll say oh palliative care should do this, oh the GP should start this conversation or or the oncologist should do it on their first meeting or it's always passed around and actually everybody should have this conversation at any point in a patients journey. And we should all start it really early on and you know, it's our plans in our 20s are different to our 30s or 40s or 50s and we start planning for life back in our 20s with you know once they start taking your pension payment out in your 20s and you protest about it, you think this is ridiculous. But actually I am now looking at that now and I'm very grateful I've done that. But back, you know, 30 years ago, I wasn't at all so we start planning for things in life without realising we're doing that, so we should always have a plan in place and and we just need to kind of normalise this really about, you know, having a will, you know, doing lasting power of attorneys, taking care of our finances and our loved ones, we should have that plan already rather than it being a big rush. So anyone should start this conversation. We're just not very good at having it.

So in our teaching here, which probably get on to a bit later, it's about training everybody to start that conversation and signposting people to where they can get the information that suits them about it. So it shouldn't be left to one group of people. Everyone should have the conversation at any point and when a patient's ready to have it, what we should be doing is planting seeds, letting people know that we're ready to have that conversation when they are and they can come back to us at any point. So that's what we should be doing and then anybody can pick that up.

00:11:37 Carly

I think that's really important for listeners as well because our listeners are health and social care professionals and they're in such a a wide variety of roles. So it's really interesting and perhaps really good to know that no matter who you are, you can have that conversation with the patient.

00:11:58 Claire

And it's about giving people confidence to have that conversation and not be frightened of it. So if, for example, you say oh only GP's can have these conversations, then you know sometimes people will think actually it's it's the GP. It must be a really professional conversation, but it's not. It's talking to a friend over a coffee. It's normalising this as a conversation that you would have with somebody. So it's, it's about you know, arming people and giving them confidence in having a conversation that they would have with their best friend, you know, over a coffee somewhere. And it's all, you know, it doesn't have to be in a formal setting. It can be in the Information Centre, it can be in a day room, it can be in a clinic room or in a garden somewhere. These conversations can take place anywhere and it doesn't have to be clinical at all, so it's just normalising it and keeping it really simple.

00:12:50 Dan

I think the other thing that I would like to add to that is yes, it's everybody's responsibility to start it, but it's also I think everybody's responsibility to progress it. I think there's this perception that it's somebody else's job to go and have this conversation and then it will be done and it'll be over and it'll be written down and recorded. But actually some of these decisions are big, you know and people therefore need a number of conversations with a number of people over time. You wouldn't buy a house on the basis of one chat you'd had with one person on one occasion, would you? You'd go and you'd ask different people's opinions. You'd go and look at the house and look at the options and see what's about and have more conversations and an advance care plan is kind of a bit like that. You've gotta allow people to, you know, take the choices from you, take the information from you and go and see what works for them and speak to different professionals. Speak to different members in their family before, sort of crystallising it down into some kind of plan.

And one of the things that's come around recently is this discussion around people ending up in A&E towards the end of their lives and that being because nobody's had an advance care planning conversation with them, I get that a lot. I got a lot of pushback of, oh, could we not have had a could you could you in palliative care not have had an earlier advance care plan with this person. Well, yeah, I can do that. But I'm not the only person doing that. And if you've got somebody who's poorly pitching up in A&E, well, actually there's the role for somebody who works in A&E at that point to progress that a little bit and say, actually, do you realise that you're more unwell now than you were? Have you thought about your options? What conversations have been been had so far? And what information do you want from me as the A&E doctor to be able to progress these kind of conversations? That's where I think the Macmillan campaign for see it. Say it. Share it. If you see a sick person in hospital, tell them. I think you're quite sick and we need to have a think about what we do next and then if they make decisions around advance Care plans, share that with the wider team. Everybody's got a part to play in that whole conversation. And I think that that campaign encapsulates it really nicely because it makes the point that actually it's not just the advance care plan that's needed. It's the continuation of that conversation and bringing that patient into recognition that now is the time to enact that.

00:15:09 Paul

And and do you think or do you see once you've started the conversations that actually patients benefit from starting that conversation and they see the benefits?

00:15:23 Claire

Yeah, we do. We see it a lot. So in our in our first consultation with the patient, we'll speak to them about any plans they've got for the future or if they've ever discussed it with anyone and a few patients to say to us, absolutely not at all. It's not what I want to do. So you let them know that you're here to have that and then that conversation with them when they're ready and then over sort of subsequent consultations. They will start to talk to you about I've had a thought about this or I spoke to my friend about this and they told me this. And actually I've realised that I can't talk to my sister about it cause she just keeps crying and it's ridiculous. So it's about people working out themselves who their support network is over time, who they can talk to and they get things sorted out and then they'll come back and say to us it feels such a relief. Now I've done this. I've once been on my mind. I've wanted to do it for a while and I've never wanted to talk to anybody about it because I was worried about what they what they think about it. And also people worry that people are keeping information from them as well. If they start doing their, you know, their plans for the future so you know, so we see a lot of really positive things come from it and people will get things sorted out, but also they start to communicate with their families and it's about care. You know, we care for our families all the time, and this is just about caring for them in the future as well.

You know, Martin Lewis is one of my sort of favourite people because he can talk about advance care planning, lasting powers of attorneys, wills and things without any healthcare involved at all. No professionals talking. It's purely finance and he comes at it from a really incredible non emotional way and he talks about, you know, the best thing you can do for your families is plan for the future. Because actually, if you're not here, you can't tell them where things are and what to do. So, you know, I think we do see a lot of good come from it when people want to talk and also we we but people when they really don't want to talk, tell us actually I'm. I'm gonna plan nothing at all. This is me. This is my life. I'm not planning anything either. So it can be the other way. People will be really open about that too. And you know in life we're planners, some people are planners and some people aren't. And that's absolutely fine. So we do get that too. And that's really good to know. You're not gonna plan anything well. That's good to know too, because we know what we're dealing with, then aswell.

00:17:40 Carly

I love Martin Lewis. I wasn't expecting him to be mentioned in this podcast, but it's great.

00:17:47 Claire

Martin Lewis did a programme last year on on ITV and our Information Centre actually rang me and said something happened because the next day they saw like a 400% increase in people going into the Information Centre for books on Wills and advance care planning and things and they couldn't understand what had happened and they credited me with that in some teaching. They said oh Claire must have been teaching, but it wasn't. It was Martin Lewis on the telly the night before. So that's why I credit him, because we actually saw in our Information Centre an increase in the demand for information that day.

00:18:19 Carly

Oh wow.

00:18:21 Paul

And obviously, Claire and Dan, you, you've got loads of experience with perhaps starting these kind of conversations and and obviously some of our listeners are might be new healthcare professionals who maybe just starting out. Is there anything that new healthcare professionals maybe need to just start thinking about?

00:18:43 Dan

I I think for new healthcare professionals, I think it's just having the understanding that it is OK for you to start having these conversations. You don't need permission. I think when you're new at something, there's a lot of oh am I allowed to do this and that's certainly been the impression I get from junior doctor colleagues when they start on rotation, you know. They're not having these conversations with patients because they don't know that they're allowed, and it's about saying, actually, no, you're part of this patients care. So you're allowed to ask questions about what they've thought about what they've been told, what they've discussed among their family members, what they're worried about. You can ask all of those questions from that position of innocence.

And therefore make quite good progress with an advance care planning conversation. Because if you're a new person asking innocent questions, you can actually get quite a long way in terms of progressing people's thinking. So I would, I would always encourage new people to feel free to ask all of those questions and if you want to do more advance care planning and if you want to be in a position where you're not only asking questions but being able to sort of feed in some information as part of that conversation, then find your local advance care planning information, find a local lead, find your local palliative care team, find whoever's doing your local intermediate Comm skills training. Upskill yourself in terms of all of those kind of things, because then you can contribute really usefully to those conversations, to the point where you become the person that is providing that continuity. And that's really important.

00:20:19 Claire

And the other thing I'd add to that is you know it's about confidence as well having these conversations. I suppose you know we have been having the conversations for years, but if you want to think actually I'd like to start having a conversation with patients about this start by thinking about yourself first, think about what you would want. Think about the conversations that you would want to have with people that you would feel comfortable with. And then if you can think about yourself and put yourself in, not into a patient's shoes, but into actually, if I needed to start planning for myself what would I want? What are my wishes? what would I not want to happen to me? Really simple things like, you know, your mouthwash, like your feet tucked in, like a window open. Think about those things and if you can apply them to yourself first and gain confidence in doing that. Then you can start to have a conversation with patients, but if you can't do that with yourself, then you're really gonna struggle having that conversation and you'll block it out of your mind. You'll think this is too hard, but actually start really simply, and then you can be able, you know, then you'll be able to start a conversation, but it takes time and confidence.

And also it's really good to say to people, but I've never had this conversation I don't know what to do. Then people will help and guide you through, you know, so so, you know, be honest about the conversations you've had. And you know, there's lots of things that we all find hard in life, but sharing that thing that we find hard, you know, well, people will help and supporters. So advance care planning can be tricky.

00:21:43 Paul

I love that. Claire. Thank you. That's a great great tip.

Ad - 00:21:47 Suzanne

Hi there, Suzanne here. Before we hear more from Claire and Dan, did you know that the Macmillan Learning Hub has a wide range of free education and training?

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See the episode description for details.

00:22:15 Paul

Can you share any memorable experiences where advance care planning, perhaps made a significant impact for a patient?

00:22:25 Claire

I think it's really tricky because we're a small part of a patients journey and just encouraging people to plan and discuss things with their families. And for me it's the little things when people come back and say, just actually, I've started doing this and I'm feeling much better and I've been able to chat to my daughters about what I want and I've been really frightened. For me, it's those little things rather than, you know, maybe getting someone to America or those big gestures, it's the little things really that we start. We've encouraged somebody to have a conversation with their families that they really wanted to have. For me, that's the the most important thing really.

00:22:59 Dan

No, I don't think there's any specific cases that spring to mind, mainly because we see quite a lot of benefit from these from multiple people. So when you're looking at sort of the outcomes of an advance care plan. Once people have got them and they've shared what their wishes are with you, then the norm is to be able to say to somebody. Well, actually we're in a situation now where in your advance care plan, you've said you don't want to be admitted to hospital. So let's try and arrange a bit more community care so that you can be more holistically cared for in your own home and that then avoids admission to hospital. But that's not a one off case. We see that as quite a routine thing when people engage with the process of when it's done well you know.

And also things like, you know, important milestones of people wanting to get married before they die. For example, you know, these conversations about what's important to you, what are the priorities but sort of fall into this advance care planning conversation. Sometimes things like that will come up where I want to get married to my long term partner or something like that. And it happens because you've had that conversation and therefore it's triggered people into action. So again, it's really lovely when we have somebody who you know in our hospital or as a result of the conversations brings their wedding forward and gets what they want. But again, that's not a, there isn't one specific case that I could say, well, this happened in this case because again, that is, that's almost an anticipated outcome of these kind of conversations because you're bringing people into that realisation that the things that are important to them matter.

But they also they will be more likely to get those things if they if they think about them, share them, talk about them, act on them at an earlier point.

00:24:39 Carly

That's really useful and interesting, and maybe thinking about there might be some patients who think that people might know things about them. But actually, they're making an assumption. And so just having that conversation to be able to spell it out and share it and make sure that people know rather than assuming people know what they want and what they don't want.

So you talked a bit earlier about confidence in having these conversations and I was thinking about it from the perspective of a patient and there might be some examples that you can think of around a patient that might be maybe anxious or resistant to have that conversation for various reasons. What could you as a healthcare professional do about that?

So how could you approach those discussions and help to overcome that resistance that some people might have in talking about this?

00:25:33 Claire

Again, it's about planting seeds because you always presume that a a patient will want to have a conversation with you and you might not be the person that they want to talk to. But you've what you've done is you've planted the seed to say, look, you know, we can have these conversations with you. Here's where you can get some information. There are other people that you can talk to and it might be that they go to say, a Maggie's centre and have a chat with the staff in Maggie's so it might be relationship dependent too. But also you know you can't force people to have conversations that they're not ready to have on that day. We're the the same with anything in our life. You know if you were to ask me what my bank balance is today, I'm not gonna tell you because I've been shopping over the weekend. But if you asked me on Friday, I'd gladly sit down and talk to you about it. So it's about the day and the time. So it might not be the right day or the right time to talk about things to people. And it's appreciating that and not everybody as I said wants to do it at all. You know, it is optional. Advance Care planning is optional. You don't have to do it if you don't want to do it all you have to do is make sure people have had the opportunity to talk to someone about it and know where they can get more information about it. And again that is, you know taking everybody sort of person by person situation by situation but yeah. So for me it's the offer as long as we've made that offer to do it.

00:26:52 Dan

I mean the only thing I perhaps would add is that yes, it's absolutely optional and I make that point to people. If people don't want to do it, they don't have to do it. But I do normalise asking. So my common approach when I meet people for the first time in clinic, is I say to people, well, you know, look, whenever I meet anybody for the first time I always offer to talk about the future, what that might look like, and what your preferences might be. If your health were to deteriorate. Now some people want to do that with me. Some people don't. Some people want to do that today. On our first appointment and some people wanna come back to me in the future with questions. Whichever way you wanna do this or not do it is absolutely fine. But I want you to know that if you want to talk about this then you can talk about it with me and then see what the patient says.

And sometimes they will sit there and they will do an advance care plan with me in that first consultation and the whole thing takes an hour or they will say thank you very much for letting me know. No thanks. And they either come back and discuss it with me at a future date. Or, as Claire says, they go and speak to somebody else about it or those people don't want to do that and they never do that. And that again is absolutely fine. But they've been offered and that's the important thing. And I think we as an organisation have very much moved in the last five years to a situation where we didn't even offer and now most people are being offered, you know, at those consultations and we record the fact that they're offered. And then we record when they come back and say actually now's the right time for me to have those kind of conversations, certain advance care plan. So the first step in this in embedding advance care planning for us as an organization has been normalising the offer of it.

Is that fair to say, Claire?

00:28:33 Claire

Yeah, that's fair to say. And you know and around those questions that we asked, you know, one of them is what do we need to know about you to care for you best. We want to care for you in the future. So what do we need to know about you in order to care for you? And that's not a threatening question at all because we all want good care and people want to talk about themselves as well.

You know you give them that time and show them that you've got that time to listen to what's most important to them, then they'll tell you and they'll tell you what they're worried about, what they're excited about, you know, whether there's a new baby coming. And then in our head we thinking, when is this new baby coming? What time have we got? So there's little things like that that you then pick up on and run with because there's always a wedding, a baby, somebody in Australia and yeah, there's always things happening and that's life. So it's about, you know simple questions don't make it too hard for yourself.

00:29:28 Carly

So Claire, we know that you have implemented your own service improvement project and it would be really good to hear a bit more about that. So yeah, could you tell us about the project, what it is, how it was set up? Should we start with with, with what it is?

00:29:47 Claire

So in 2020 the trust appointed me as the clinical lead for Amber and Advance Care planning. So the aim was to improve recognising uncertain recovery and also teaching and training around advance care planning. Because, you know, we were doing it but not where we could record it and recognise it. And so that was, that was what was given to me in 2020 alongside the pandemic. When that started as well. At the same time. So we we entered a tricky time, but I was given the most incredible opportunity and the time out of my clinical workload to do this.

So it started with kind of developing digital prompts for our electronic patient records. And so Amber was initially on paper and added into patients notes. So we then developed that into a digital version. And we also put some advance care planning templates as well onto our electronic patient records too. And then we put some prompts into our met calls into our initial annotations on patients as well. And just just so that people could, you know, it would prompt and say, you know, have we considered uncertain recovery? Have we considered advance care planning? So just gentle prompts and then we developed an education package around it and the teaching, the teaching kind of focused on communication importance of recognising uncertain recovery and it was done at that time in really small groups and we kind of did, not quietly, it wasn't like this is what we're going to launch today, but it was done quietly. Small groups where people could feed back their fears and their concerns about their communication skills and things. So the teaching package was developed and delivered face to face, Small groups on ward based teaching sessions and we online sessions as well. And then we also incorporated it into mandatory training in the trust too and into mandated communication skills training course for junior doctors too. So it was in sort of a toolkit communications package as well. And then we developed a did a web page an Intranet web page and an external web page as well with all our teaching on too.

And then we went to trust wide meetings. So there's lots of levels, lots of layers to it, really that I did very slowly sort of over a year and sort of built on it, very quietly built on it. But then slowly we started to see sort of improvement as well. And I also did a baseline audit. So we had figures from 2015 where we previously tried to launch Amber. So we used those figures I audited in 2020 and again in 2022, and I'm about to re-audit again now, so we've slowly seen sort of the from the teaching, to the eproms, to the Internet pages, to me sort of slowly going around the trust, talking to people about it, an improvement in our figures.

00:32:44 Paul

So Dan, what improvement metrics did you see as part of the project?

00:32:50 Dan

So the I suppose the problem that we had to begin with is that the end of life care outcomes for the organisation were not as good as we wanted them to be, so we weren't having conversations early about what people's priorities and preferences were. So our rate of completing advance care planning was practically nothing. We weren't able to achieve people's preferences with regards to preferred place of death, for example. So we had an 8% achievement of patients preferred place of death when they were deteriorating. And also patient and career satisfaction, so, we were doing regular bereavement audits from bereaved relatives about what their experiences had been and their feedback on our care, and the theme that came back was that they had not expected their loved one to die because nobody had had that conversation with them, that it was a possibility. And as a result of the various rounds of implementation that Claire has described, things really, really improved a lot we saw, you know that that figure I gave you 8% achievement of preferred place of death that went up to 80%. You know, the scores that we were getting on our bereavement surveys, all of those scores went up each time they were done every two years and they continue to get better each time they're done as this gets more and more embedded.

I think some of the softer data as well is around sort of satisfaction from our colleagues. So one of the real issues and Claire will hopefully agree with me on this. One of the real issues we had at the beginning of this project was that you'd come in in the morning and you'd find the junior doctor from the night shift in tears in the morning handover. Because they had had to sort out an acute deterioration of a patient who was sick, who was known to be sick, but for whom there had been no conversations or consideration of next steps or any sealings of care implemented. And then that patient had deteriorated in the night and the junior doctor had had to sort it out. And their perception was that they were underprepared and undersupported to be able to do that and that caused a lot of distress. There was a lot of moral injury involved in them being expected to deliver care that didn't quite make sense in the context of people deteriorating with palliative illness when people just hadn't bothered to have a conversation, and that went away. Didn't it, Claire, you know that that coming in in the morning and finding that level of distress on the wards within 12 months that was gone.

00:35:22 Carly

Wow, that's amazing. I mean, that's such a massive difference, isn't it?

00:35:27 Dan

It was a big culture change and that's the big thing.

00:35:29 Claire

And it's just encouraging people to communicate.

00:35:32 Dan

Yeah, exactly. But the culture of if you're sick, we say so was massive for us because actually that was not in our brand, you know, here we didn't talk about that and therefore we weren't achieving the things that were important. As soon as it became normal to be able to say you are sick, sick enough to die and we may not be able to make it better. That made just a huge difference to the way in which we were then able to move on from that and say, right, so what's important and what do we do and what does everybody who works here need to know about what the plan is next if things get worse. Once we had a plan, once we knew people's preferences and priorities, we could achieve them.

00:36:20 Claire

And then once people saw those conversations happening with patients, it gave them confidence to have that conversation as well. So it kind of slowly starts to move. I think sometimes with change we want it to move really quick, right. Tomorrow we're implementing this and this is what we want to achieve by the end of the week and actually it takes time. It takes years because this is like Dan said a huge cultural change too. And so it's, you know, and it's it's just building on it all the time. Reteaching, re reminding people that actually this is what we do here and and this is what we expect to happen and if we do that then you will initiate change it but it does take time and and I've been given the luxury of time to do that.

00:37:05 Dan

I think that's worth sort of emphasising as well, because it's, you know, that the importance of having a named lead, a named person with that responsibility, but also that oversight of it, to be able to go to the ward and say, look, these are the patients that look sick. Have we had these conversations, are we using the Amber Care bundle? Do you feel prepared to do this? Can I support you? And very much in clinical practise in real time sitting with those staff members and doing that for the early stages of this project has made a huge difference. Having somebody who had that dedicated time to be able to go and show it and then teach it and then observe it and then step back, actually, that's what's made a huge difference here. And it's taking it away from the consultant body, you know, this isn't a consultant delivered quality improvement project. Taking it out of that and saying actually this is Ward based care, this is what's going to happen on the wards. And this is, you know, the standard of care for communication and preparation for uncertainty and Claire is the lead for it. It just worked.

Because the people knew you and you worked at Clatterbridge for a really long time. So people knew that you knew how Clatterbridge worked. They trusted you because you'd see you'd seen it all over the years. And when you came and said it's OK to have this conversation, it's OK for you to say to this patient that they are sick enough to die and that they may not get better.And you, as a person working on the ward, can feel empowered enough to have those conversations without their needing to be a consultant that comes to the ward and says, yes, I agree with you, that made a huge difference.

00:38:42 Claire

Yeah. And it was because I feel because I'd worked here for so long as well, I could stealthily move around the wards and talk to people, people because they were used to seeing me all the time. So it wasn't like heres my new brand, new role that I'm a new person. I was used to being around anyway. And so the people knew me, the consultants knew me the, you know, the nurses knew me as well. So I was able to move around very freely and and have conversations and sit in meetings that people kind of expected me to be there as well. So it worked that way too.

00:39:13 Paul

And it must have been obviously tough for people to change, perhaps their perspective. How did you make the relationship, or how did you build the relationships to make such a big culture change and and you've touched on that a little bit, Claire, when you said, you know, stealthily walking around the wards, anything else you want to add to that?

00:39:36 Claire

I think you know with any change it's tricky. Some people like change, some people don't, a lot of people don't. They feel that it's extra work for them to do. But actually if you go to the people that you know that will support what you're doing and understand what you're doing first. So you go to those people that understand. There's no point in trying to change people's minds about practise that that feel they're doing it anyway, or don't really want to do it. So go for the people that you know that will work with you and work alongside you, and then when you start something and get it moving, it's very hard for people not to kind of jump on board really with something that's already moving. So, know your audience. It's not easy. None of this is easy. There's days where I used to come away and think I don't know what I'm doing today. This isn't going to work. And but then there's other days I used to think oh, goodness me we've done some things today. It's worked, you know. And that's including building, you know, electronic patient records and building websites and doing those things, you know. I'm a nurse I don't do those things, but you learn to do them. And so, you know, you persuade people to to help you and and work with you. So it's just about gently being alongside people. So I would go in and have those conversations that go in alongside people while they started those conversations. So choose the people that are going to support you first. Don't start on the people that are, not that they're not going to support you, but that just like what they're doing ordinarily anyway, that you know, they feel everything's fine. So start with the people that gonna support you first.

00:41:07 Paul

That's great. Some some great kind of advice there, Claire. And where is the project now?

00:41:17 Claire

Yeah, it's just the project still ongoing and always will be ongoing and developing and changing and moving. So it's not that we've done this now and that's it. It has to carry on and we have to keep building on things and moving forward.

00:41:32 Dan

I suppose the one thing that I want to add just to sort of emphasise how successful this has been, is that Claire is now being approached by other organisations to teach them how to do it. So is it four or five other trusts across the country in the last year that have reached out to you, Claire, and said "we see that you've implemented this, we've struggled to implement it. Can you teach us how to do it?"

00:41:53 Carly

Wow, that's amazing.

00:41:55 Dan

But it's. But it's. I think it's really important because again, it builds that that what's the word that culture again of yes, we've learned how to do this. So we will share it and we will support other people to do it. It's not a competition. We're not aiming to say we do this better than everybody else. We're saying we've managed to do this. It's made a difference for us. It might make a difference if you want to have a go at it, and we will tell you what we've learned along the way.

And that was very much what happened for us as well because Guys and St Thomas were very generous with their time with you, weren't they, Claire? You know, because they designed the tool and said to you, well, this was our experience of launching this, you know, this is our advice. It may not work for you. You may have to edit it slightly in the delivery at Clatterbridge and that's what you did. So it's just pass. It's just paying that forward, isn't it?

00:42:44 Claire

Yeah.

00:42:45 Carly

Umm, it's so inspiring to hear about this and I can't even imagine the amount of work that you know you you put in to doing that. It's really amazing. So I'd really like to talk about the award that you won. I mean, it's no surprise that you won the award for oncology nurse of the year at the British Journal of Nursing or BJN. And and I'm actually. Oh, should do a little round of applause.

It's amazing. I mean, it's it, you know, hearing about your project, it it totally makes sense why you would win such an amazing award. And I was firstly interested to hear from your perspective, Dan, why did you think it was important to nominate Claire for this award?

00:43:33 Dan

A number of reasons, I think, because she's because I've seen her work so hard on it. You know, I think it's always. It's always important to recognise when someone's gone above and beyond because she talks about having dedicated time in a job plan to deliver this. And my immediate response to that is, yeah. And the rest because she did quite a lot of work in her own time on top of this, she was having meetings with people travelling around different hospitals to try and find ways of implementing this. This wasn't just leading on an internal project. This was really getting to grips with all of the evidence, all of the models, learning from other people's experience, the teaching, the training, the endless meetings that you had to have, the governance processes, getting people on board to support with building the digital tool. It was massive and she just really, but there could have been days that she could have given up and didn't. So I think that's worth recognising. So that's the first reason. And again the outcomes, the fact that it's made such a difference is certainly worth you know, marking with something and the award is a good way of sort of saying. Yes, this is this is really good on an individual level for Claire, but also a big impact for patients and those important to them If you do something like this. And I think having the presence of that award of being able to say this is what it's for because we did this and it achieved this spreads the word that these kind of interventions and these kind of ideas can make a real difference to patients, such that they win national awards. I think that's really important because I think it encourages people to do the same.

And I think the other thing is I think it's really important to recognise this work with in terms of nominating for awards to try and encourage other people to do similar kind of stuff, because in healthcare there's loads of stuff we see in practise that we would want to improve, you know and and anybody working in their individual area of cancer care will have one or two things immediately spring to mind with things that they want to improve. And I think it's if you send the signal that we encourage you to take up the mantle and make a difference and make a change and fix something that doesn't work and we will support you and celebrate you if you manage to make that work. And that includes recognising through nomination for awards and and similar things like that. I think it just encourages everybody working in the NHS to really try and improve the standards of care around them, and if Claire can do it, and if Claire can pick up on her on a project and really make it work, then actually that's not just restricted to Claire. Lots of people can do that and we can. We can celebrate lots of people. So it was more to try and sort of get that message out there that it makes a difference as well.

00:46:20 Carly

Hmm. Absolutely it does send a a message, doesn't it? About that. Can we talk a bit about the nomination itself, Dan, in terms of how did you go about making that nomination? I'm thinking about perhaps listeners who might be thinking about doing so in the future. Any tips that you might have or any advice if some if someone is thinking about doing it?

00:46:49 Dan

I think the first step is to sort of know what's out there in terms of awards. So British Journal of Nursing obviously has an annual award. There is there are others as well. So knowing what's out there and when they open for applications, I think that's important. And you can register with them so that they sort of send you an e-mail when they're open and then if you've got something that has come to completion or is making good progress at the time that those awards sort of advertise and say were open for applications at this point, then you can put it in. So that's what I did. I I registered with these and when the the BJN emailed and said our awards are now open for these categories, had a look at the categories and I thought well actually, no, Claire's work is is at that point now where it's you know meritorious it will. It's a good application for that for that category and then I just sat and filled it in.

I had all the data I surreptitiously made Claire feed me all of the data that I would need to put in the application. So there are a few emails of "Ohh just remind me what was the the data on that and how many people did we train on that and what was the date that you did this" and you know just asking random questions. So she essentially gave me everything I needed to be able to fill in the form without realising she was giving me everything I needed to fill in the form and then yeah, just wrote it.

00:48:07 Carly

Ohh, so Claire, you didn't know that Dan was making this nomination?

00:48:12 Claire

Oh, no, no, not at all. No. The shortlist was announced and I of course I didn't know this at all. So and then it was we're just about getting ready to go home. This e-mail popped up to say congratulations. You've been nominated for this award. And I was looking at it thinking this is just ridiculous. I thought it was kind of, you know, one of those spam messages to say congratulations you've won a million pounds today. And then I looked it closely and I looked over and I thought ohh he knows about this. This is, this is it's. Yeah, so it was lovely but was surreal at the same time.

00:48:45 Carly

So aside from being surprised, Claire, how was the whole experience? How was winning?

00:48:55 Claire

Umm I get the glare now, because I think that I've just been I've tried to be very British about this of kind of like Ohh, isn't this very lovely. Thank you all very much. And I can kind of hear my mum sort of like thinking now it's very lovely, but don't get too big headed and you know and I because of course you know until you see yourself what you've actually done written down. I don't think you actually realise the journey that you've been on yourself to do something. You just take it for granted that actually, yeah, I've done that and I've plodded along. I don't feel I'm not very good at reflection I think. So you don't don't reflect back on yourself. You do on others, but not on yourself and I think that there's a word that Dan and I have used a lot recently called prideful, you know, so don't get too prideful in yourself. You know, don't you know, don't have this opinion of yourself that's too much, but actually it's taken me a bit of time to go. Actually, this is really good. This is I've, you know. This is a lovely thing to be nominated for. It's a lovely thing to win and actually it's not gonna happen again. And it's only gonna happen now and it's just a really lovely thing. So I'm really proud of it, you know, and I just feel sort of, I'm 54 years old. And if anybody can kind of like, do a project and make change and do those things, then, you know, I just think actually it's lovely to win and encourage other people that you can do this change is possible. You know, you just need a Dan to push you and guide you gently in different ways, you know and I'll be prepared to sort of disagree with him a bit as well along the way and think once going mad here I can't do this but actually then recognise you can do things and and then you can win awards and it's very lovely.

And the other lovely thing about it is is that the feedback and congratulations from people hasn't stopped. I get a message at most weeks and when it when it first was announced that it weren't, you know, colleagues ex colleagues messaged me. My favourite thing was a a patient brought me in 2 lamb chops for my tea in a clinic one day to say congratulations. His wife had told him Claires won an award and you're going to see her. So he brought me two lamb chops and I thought that that was just the best thing ever really so it's just so very nice.

00:51:05 Carly

Absolutely it sounds great and hopefully you know, people listening that, I mean it's it sounds brilliant for me and I don't think you know obviously I can't be nominated for an award, but I'm sure there'll be lots of listeners thinking or to prompt them to either, you know, think about whether they might want to nominate someone in the future or or or get involved in that. So yeah, sounds brilliant. Well done again.

00:51:30 Paul

You're very modest Claire. Really well done on the award.

So, at the end of each episode we've got a feature in which we ask three questions to all of our guests. So perhaps I'll start with you, Claire, with the first question, if you could go back in time, what piece of advice would you give yourself?

00:51:54 Claire

To have some confidence really in your my own ability just, you know, yeah confidence just know that you can do something and think about it and do it and don't overthink it.

00:52:07 Paul

Lovely and Dan?

00:52:10 Dan

I think look for opportunities to make changes. I think that it's one of the things that I've learned is that even if you pick up on small things, you can build ways to improve practice and improve standards in lots of different things in clinical practice. But you have to turn your brain on to notice the things that need improving. And I think until you've actually got to a point where you are actively looking for things and ways to improve, you don't always spot it. So I think the, the advice I would have given to an earlier me would be these are the things that you should be actively looking for day-to-day.

00:52:48 Paul

Brilliant. Thank you. And what change would you like to see to improve the lives of people living with cancer?

00:52:56 Claire

I think that everybody has the same opportunities to access information, to spend time with a clinical specialist nurse , you know, so I'd love lots more clinical nurse specialists really for patient to spend time with.

00:53:12 Dan

For me, I think it's better care navigation. Actually, I think there's a lot of services out there as Claire says, but actually I think what patients get told about and what they get sign posted to is quite a small proportion of what is there to support people. When you think about, you know, the third sector, places like Maggie's, Macmillan. If you think about the the, the, the cancer specific charities that are out there, peer support networks, rehabilitation centres, gyms that are set up to provide cancer, prehab and rehab. There's loads. But most of what's there is not NHS and therefore we don't know about it and we don't sign post people to it and people aren't getting the benefit of everything that's out there to holistically support people through their cancer treatment. So I think we could do more and we could do better at getting together. There are a local understanding of what's out there so that we people can navigate it that bit better and we can sign post people to the whole wealth of the support that's there.

00:54:16 Paul

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

00:54:21 Claire

That change is possible, really. You know, just it just takes time and just see small improvements over time, and we're all capable of implementing change and whether it's advance care planning, uncertain recovery, you know, just have a bit of confidence in yourself and we're all capable of doing it. And and make things simple, we overcomplicate things so much. There's books on everything, but keep it simple and and real as well for yourself.

00:54:55 Dan

And for me it's a similar line is you can do it too. You know the reason we went for the award, the reason we're publicising the fact that Claire's won this award from basing this work is to try and encourage other people in their area of work to really get engaged in quality improvement. It can be achieved and you can be the person in your place of work that drives it and achieve the same kind of outcomes. So everybody can do this.

00:55:19 Paul

Thank you. I love that.

00:55:21 Carly

Yeah, I mean that's a great message to end on. And and I wanna say thank you so much for being part of this podcast. It's been an absolute pleasure and joy to have you both and it's been so great to firstly hear about advance care planning, why it's important, how we can start these conversations early and what difference it does make to people living with cancer and as well as, of course, hearing about the awards and how that works and the importance of those, and I'm sure there's lots of things that the listeners will take away from this and how they can make their own difference and that real, you know, you can do it message. So thank you and thank you so much for coming on the podcast.

00:56:11 Dan

Thank you for having us.

00:56:13 Claire

You're welcome. Thank you.

00:56:15 Paul

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00:56:39 Carly

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00:56:48 Paul

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00:57:01 Paul

I'm Carly.

00:57:03 Paul

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