**Safeguarding: The Role of Primary Care in Advance Care Planning**

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0:01 **Chair**: Good afternoon and welcome to the next in our safeguarding series on the role of primary care in advance care planning. I'd like to welcome back a speaker who has been leading on our safeguarding series, Dr Rowena Christmas, and ask her to take it away yet again.

0:25 **Speaker**: Thank you, Nicola. So, thank you very much for coming to listen to this talk about advanced care planning from a sort of primary care perspective. I don't know how many of you came or listened to Mark Taubert's really excellent webinar a couple of months ago about DNACPR? I listened to that thinking I might have to take quite a bit out of this talk out because I didn't want to duplicate anything. But actually, I ended up not taking anything out. And I guess that just demonstrates just the breadth of this topic and that it really is quite important in primary care.

1:05 **Speaker**: So, Stewart Alsop said ‘A dying man needs to die, as a sleepy man needs to sleep and there comes a time when it's wrong, as well as useless, to resist’. And I think we always know in NCQs in medical exams that you never tick the always box. But actually, that is the one absolute thing we can guarantee all of us and all of our patients are going to die in the end. And it's important that we face up to that and help them to do the same.

I don't know if any of you have read Kathryn Mannix’s book ‘With the End in Mind’? Kathryn Mannix is a palliative care consultant. It's the most beautiful book that she wrote. I read it after I think I've been in practise for 20 years and done an awful lot of end-of-life care. But it changed my practise. It changed how I talked to patients and their families about it, and I'd really recommend that. But Catherine said: ‘If palliative care was seen as about living, we could transform practise, conversations and the way people live the last part of their lives’.

And for me and a lot of people that I speak to, a lot of other GPs, this is probably one of the most rewarding parts of our job.

2:19 **Speaker**: So, over the next 30 minutes, I'm going to talk about:

* What advanced and future care planning is
* Why it is quite difficult at times and why it's so important
* When the right time is to bring these conversations up
* Which patients need one
* Some strategies for how to start the conversation
* Once again, we'll look at the Mental Capacity Act, because this is really important to make sure we get this right and
* We finish off with some useful signposting resources.

2:54 **Speaker**: So, the GMC defines advanced care planning as a voluntary process that covers any aspect of future health and social care. And it can be verbal or written. It's not legally binding, but it's very important that we take it into account when we're acting in a person's best interests of making decisions on their behalf. So, if someone has told you before they lost capacity that they absolutely didn't want to go in the hospital again, they really have had enough, and you're seeing them when they don't have capacity with a potentially reversible cause of their deterioration and you really want to get them into hospital, you need to have a pretty good justification for overriding their decision that they clearly told you beforehand.

3:42 **Speaker**: So, it's the process of discussing the type of treatment and care that a patient would and importantly would not wish to receive in the event that they lose capacity to decide or they they're not able to express their own preference. So, it might be talking about where they want to be looked after e.g. at home or if they would prefer to be in a hospice or, you know, they do want to be in hospital if there's any chance at all. It might cover who they want to be involved with decision making on their behalf. It might be to say they want their pets in the room or that they don't want their grandchildren around them. It covers whatever the patient wants it to cover, really. So, in that way, you're creating a record of a patient's wishes and values, preferences and decisions to make sure that the care is planned and delivered in a way that meets their needs. It keeps them in control when they're sort of losing control. It keeps them dignified and evolves and meets the needs of those close to them.

4:45 **Speaker:** I had a patient who allowed me to share this with you. She came with her advance care plan, a really one organised one, and she said that she'd done it as the final gift that she could give to her girls. She knew how distressed they'd be when she was dying, and she didn't want them to have the burden of having to make difficult decisions about her when she wasn't able to speak for herself. So, she gave me the information and she'd given the information to them as well to say exactly what she did and didn't want. So, it's a very caring thing to do.

So why is it so important? Having an advance and future care plan is all about ensuring that people receive good care and ultimately experience a good death because a good death is very much part of having lived a good life. It's our means of empowering patients so that when they're not able to express their wishes, we already know what they want us to do for them. And countless studies have shown time and again that this reduces the stress around end-of-life planning for patients and for their families. It just makes everything easier.

Advance care planning can lead to less aggressive or invasive medical care, can lead to better quality of life nearer to death, reduced rates of hospital admission and it helps to make sure people receive care that's aligned to their wishes and dignity. So, it goes back to Hippocrates, is what we're all trying to achieve all the time.

First, do no harm. And I don't know about you, but my worst nightmare really is having a patient who deteriorates, and they're admitted to hospital, especially since COVID they go in on their own. And we know how much pressure the emergency departments are under. So, you know, they're on their own in a trolley in a frantic, busy emergency department. And then, you know, the worst thing is for them to die in that situation. If there's any chance at all, I want the in hospital and I want them treated. But if it's a futile thing, they're much better to die at home with GP care and the district nurses and the St David's nurses and hopefully their family or at the very least the carers that they're familiar with around them. So that's what we're really trying to avoid.

7:13 **Speaker:** As probably any of us have done this know though, advance care planning is not easy. There are so many barriers we might be worried about saying the wrong thing. I mean, I've often thought, oh, gosh, are we there yet? What's he going to think? What was I going to think? If I say that we might be worried that we're going to make matters worse.

Some people some patients feel very embarrassed by this kind of emotional intimacy. Patient’s carers may have, you know, the natural instinct. They just want to preserve life at all costs. There is an awful lot of guilt associated with all this. They may feel that they're letting their loved one down if they start to talk about the end. So, it can feel quite difficult to acknowledge what people want.

For the person who's actually coming towards the end of their life, that they may be in denial. They may not want to accept that. They may be struggling with trust. They may not trust their health care professional. They may not trust their family very well. What I come across an awful lot is that patients are not wanting to upset their relatives, even sort of in the last weeks or days of life, that their aim is to keep everybody happy. They don't want to say anything that would distress anyone. They want to keep the status quo. And an awful lot of people just aren't comfortable talking about this.

It could be cultural or religious perceptions around death and dying that make this a difficult discussion.

Now for us as health care professionals, these discussions can produce strong and sort of unexpected feelings. You know, you suddenly may be transported back three years to when your Mum was dying or when you had that really difficult discussion with Auntie Sue because her husband was in hospital and she wasn't recognising that he was really very ill. So, we are human beings as well as health care professionals, and that can't be taken away from this.

Our society is generally not good at this. I think we're getting better. But traditionally, death has been a taboo subject. And, you know, an awful lot of family members still say don't tell him or he will give up if you tell him that, you know, that there's nothing more could be done. But I found, you know, with careful discussion with the relatives quite often, that the family member that they think wouldn't cope at all is actually quite relieved to sort of have everything out in the open and be able to discuss their concerns and what they want.

The big, big issue with this, of course, is that these conversations take time and time is the one thing in primary care that we are so desperately short of at the moment. So, you might be having this complex discussion when in your head you've got half a dozen other things.

You know, you may have an urgent visit to go on to. You've got 20 messages and things to do. So, time is a big issue. But actually, taking the time to get this right often will save time in the long run.

And you need to make sure that you've got a nice private space to have the discussion, which, again, you know, if you're seeing a patient in a care home there in the sitting room, they need to be hoisted to go to the bedroom. All of that can be quite difficult.

10.37 **Speaker:** Now, who needs an advance care plan?

Fundamentally, we all do. Every person, no matter what's going on, what illness they've got, has the right to good care and a good death. But narrowing it down a bit, I think everybody who has a life limiting illness should be given the option to have this discussion. We're probably much better at doing it with people with cancer. They almost get into a ‘we know where we're going, St David’s nurses are involved. We have these difficult discussions quite early on.

It's more difficult with people with chronic diseases like COPD or heart failure where they tend to be alright, and then they become acutely unwell and then alright again. You know, they're the people that we need to be making sure have also had the opportunity to talk to about this.

People in the last year of their life should have an advanced care plan. Very easy for me to say that. The reality is this is incredibly difficult for us to predict. You know, we laugh every month when we have our palliative care discussions in our practice. We've got a lady who's been on the palliative list for ten years now. She's 102 now. She's still bed bound. She's still very frail, but she's doing quite well. So, we're not good at predicting this. But where was the harm in thinking about this for her ten years ago? It was fine.

And the other thing is, anyone who wants to have this discussion should have it. So, I can think of a woman who's 42. Younger than me. She's a completer finisher type of person and she's told me exactly what she wants, and she feels much better for having that recorded in her medical records.

Possibly we should be having this conversation or trying to for all of our patients who are in residential care, who are frail by definition. And so, the key thing for us in our own practices is to think about who's in danger of slipping through the net. And probably, as I say, they are people with chronic illnesses that don't sort of gradually deteriorate like that. So, think about those. Think about people with learning disabilities. They do tend to have a shorter life expectancy. And studies have shown they often do die without it being recognised and possibly miss out on gold standard care as a result of that. So, worth thinking about.

13.01 **Speaker:** When is the right time to have these discussions?

Really it's as early as possible, and that's because these are these are difficult, sensitive conversations and you're not going to necessarily have a complete conversation that finishes everything and answers all the questions first time round. That would be nice for our workload, probably, but it isn't realistic. So, if you go in there early and just plant a seed, patients can go and have discussions if they want to with their families or their friends, loved ones and come back to you. It just opens the door for them to be thinking about it. Don't rush in. We need to find out what people's expectations of what their values are, what their thinking processes are before beforehand.

Important to think about it if there's been a change in condition. So, you know, if someone's been into hospital, maybe we should be thinking about it. If they're EGFR suddenly starts to drop. If they've had a fall. All of those things are sort of good possible cues for us to pick up and have a chat. It's always better to do this early before there's a crisis, when there's a bit of time for a discussion and thought. Us being able to give patients and their families clarity is very helpful. And as I say, go with the individual patient. You don't need to cover everything straight away. It's good for people to have a bit of time to reflect and think about things.

14.36 **Speaker:** This is a picture of my lovely dad. He'd had a fall and a whopping big black eye. He asked me to take a selfie so you could show his brother what he looked like. Now, my dad had Parkinson's disease and he'd had three falls in the previous month. And we thought that was quite a useful opportunity for him to have a conversation with his GP about his state of health. Lots of people, when they have Parkinson's, develop anxiety. My dad had not been like that pre-morbidly, but he just worried very much about being a bother, about being a pain in the neck. And he really appreciated the conversation with his doctor. It turned out that he desperately hated going to hospital. And for him to be told that unless you've broken something, we could try and keep him at home. And managing that home, even if it had a fall, was an enormous relief to him. He thought that was that was a relief for him, but he hasn't like to bring it up himself. So, it's really important to have these conversations.

So effective communication, carried out with compassion and sensitivity, is fundamental to a person-centred advance care planning. And there's nothing that's more important to sort of put the patient at the heart of this. So, we need to try and create opportunities for conversations and for us to become comfortable talking about the subject of dying. The reality is we may have four or five advanced care plans that we need to do in one week. But for the patient and their family, each of these conversations is really, really important and monumental really. The patient and their family are trying to understand something that is incomprehensible. And it's really important that we keep that in mind.

16.30 **Speaker:** You can think about Damien Hirst and his preserved shark, which was titled ‘Death is physically impossible to imagine in the minds of a living’ and I guess us as health care professionals, we are more familiar with it. But it is an extraordinarily hard thing for families to take on. And that's why a bit of time and preparation is really valuable.

16.55 **Speaker:** So how do we open up these conversations?

I think the first thing is to prepare ourselves for the specific patient. Step back, think about the big picture. We need good background information so we can find out what the patient understands about their illness and what lies ahead. And then we're in a good position to correct any misunderstandings if there are any. Now, let's again, sometimes easier said than done. I've had, especially in the last year, lots of admissions to the care home that we look after. And of course the patient comes straight from hospital, not necessarily with an awful lot of information about them. Sometimes a patient can't remember, and it can be a bit confusing. Are they palliative or sort of end of life here or are we definitely admitting them if they deteriorate? And although, again, time is tricky, it really is worth investing the time, phoning the ward if you haven’t got information or trying to get the information from the patient or phoning a family member if they don't know. Find out what's going on as well as you possibly can.

You want to talk to the patient about what they want to happen and importantly what they don't want to happen. Listen for cues. So you know, even if you're not planning to have an advance care plan conversation that day, if they say ‘Oh, gosh, I never want to go back to that hospital again, it was a nightmare’ - that's of too golden an opportunity to not seize. And sometimes that is exactly what they mean. And then sometimes you ask them a little bit more, you know, ‘So gosh, what you're saying is if you had an infection and I was giving you antibiotics, but you started to be sick and you couldn't keep the antibiotics down, you wouldn't want to go to hospital at that point to have them intravenously?’ And they might say ‘No, I definitely don’t’. Or they might say, ‘Well, what would happen then? I wouldn't get better, would I?’ And you say, ‘No, you might not. You know, perhaps at that point you'll be looking at us, keeping you comfortable here’. And they might say, ‘Well, no, no, no, gosh, if I if I wasn't going to get better, of course I'll go in if I needed to. I just meant it hypothetically. So, you know, explore what they mean. And often they do mean it, but sometimes they don't. And you can’t always call it without having a more in-depth conversation.

Use the same words the patient uses and let them lead the conversation.

19.30 **Speaker:** Good questions that might be helpful. Always ask open questions.

Who would you like me to contact if you were to become seriously ill? This will often trigger a discussion about that I'm worried that they might become seriously ill again.

When you think of the future, what do you hope for? What can I do to help you at the moment? You just look a bit thoughtful. Is there something on your mind you want to tell me about? And all of these sort of open conversations, open questions offer the opportunity either for the patient to talk more or if they want you to, to close the conversation down. And our job is to listen to both of those things. Don't be afraid of tears. You know, crying is quite a natural response to these very, very emotionally charged conversations. And, you know, it's good for us to have a cry. You know, if you're sitting by your patient, you give them a give them a tissue, you give them a squeeze on the hand that's you know, that's helpful for everybody. It's all right.

20.38 **Speaker:** So, this is really useful. The Cardiff Postgraduate Palliative Care Programme, 6 Point Plan. Good alliteration there. The first thing we need when we're talking to our patients about their advanced care plan is comfort. Comfort for the patient physically, but also emotionally, that they don't feel they're being overheard, that, you know, they can hear you OK. Also comfort for us as health care professionals. I've tried to do this, squatting down beside a patient and then, you know, my knees have cramped up and I'm really uncomfortable that you can't do a good job in that situation. So, drag yourself over footstool or something like that so that you're comfortable, as well as the patient.

Use nice, simple, straightforward language. Use the words the patient uses. You know, if he says pops his clogs, you say pops his clogs. It keeps it all understandable and friendly.

Hypothetical questions work well. So, have you thought about having to go back into hospital again?

Listening. We've got 2 ears and 1 mouth - that sort of thing is never more important than here.

And silence - don't rush to fill gaps, non-verbal ways to show we're listening, you know, a nod, a squeeze of a hand, a sort of thoughtful smile, all of that. And let them take their time,

Reflection and acknowledgement. You know, ‘I'm saying I'm just so sorry. I can't make this better. I wish I could, but I can't. But what I can promise you is that I'm here. I've got your back. I'm not going anywhere. And we're in this together to the end’. And that can make an enormous difference to patients feeling that confidence with you. If it feels tricky, if everything dries up, then summarise what you've what's been discussed already. Tie it up with a little summary and either end it there or it can help steer the conversation forward.

22.40 **Speaker:** The difficulties that are associated with this are, and this is a really tricky one, can individuals accurately predict their wishes for the future? And actually, evidence suggests there's substantial instability in what people choose over time. I've seen this with my grandmother. She was, you know, as a younger woman, emphatic that she did not want to be a burden to any of us. You know, so soon as I'm a nuisance, put me in a home. I never want to be a bother. And as she got older and more frail, she actually did become really quite needy and certainly still had capacity at that point. And by the time she developed dementia, when she was very elderly, she was very needy indeed. And I'll reassure you that we definitely didn't listen to her earlier wishes. We did look after her very well, I hope. But people's minds do change.

There's a variety of culturally specific beliefs about advance care planning and religious views may influence people. And that's really important for us to be sensitive to.

This one is quite tricky - coercion, particularly when there's financial issues involved. It can be really difficult for us to judge family dynamics. You know, does that daughter really have her Mum's best interests at heart or is she just, you know, thinking about a way to pay off her mortgage so she can leave her husband? You know, we can't always know these things, and it's important to just keep that in the back of our minds.

And a particular concern is that some people suspect that advanced and future care planning may be used as a means to reduce health care costs. I'm sure a lot of us can remember the awful, awful sort of press over the Liverpool Care Plan Pathway. And it's absolutely essential that we make sure that everyone understands that that is not what this is about.

24.40 **Speaker:** So, the Mental Capacity Act is really key. If a patient has lost capacity, then they're not able to make an advance care plan. We want to try and get that done before that happens. If patients lack capacity, then the management is decided by a best interest decision. But please, it's really important we all remember that patients who lack capacity still have wishes and we can try and find out what they are. Mental capacity is time and decision specific. So, you know, don't see someone when they're in the throes of a urinary tract infection and say they've got no capacity. Treat the infection, come back, try again. And sometimes people can make some decisions and not others and it can fluctuate. So, you know, do your best to find out what they would have wanted.

25.31 **Speaker:** The Functional Test of Capacity when you're carrying out an advance care plan, is that your patient needs to understand the relevant information and that includes the nature of the decision. The reason why the decision is needed. What the sort of effects of deciding one way or the other are, and I guess that's a good one is ‘Do you want to go into hospital if you're not able to keep down fluids, you're not able to keep down antibiotics?’ The impact if they make no decision at all. They need to be able to retain the information long enough to make a decision and they need to weigh up all the information and then communicate their decision either way. So, after discussion I’ll ask them if they can summarise it back to me or ask them if they'll tell me what they'll tell their daughter or their husband about it, as a sort of way of trying to assess whether they do understand.

26.36 **Speaker:** And a Best Interests Checklist is where somebody lacks capacity and you make a decision in a ‘best interests’ way, you really do need to make sure that make the decision they would have made if they were able to for themselves. Try and identify all the things that you should take into account. Talk to as many people as you can. Family or friends must be consulted, if at all possible, and again, do everything possible to enable the person to take part in the discussion. You know, don't talk to them when they they've got a reversible infection. Don't talk to them if they have just had a big argument with the person sitting next to in the sitting room in the care home. Consider all the relevant circumstances around this and always, always think of the least restrictive option for what you're doing.

27.33 **Speaker:** So, our aims when we're advanced care planning, is to empower and enable the patient and their family to discuss the plan if possible. We want to increase their realistic hope of what's going on for them and increase their resilience. This will reduce the potential for confusion and ambiguity and conflict that can arise amongst staff or family members and the patient. Clarity makes everything a lot more straightforward, and it allows for more time for people to make these informed decisions.

While decisions made as part of an advance care plan may have the potential to result in a person's death, the discussion enables the person to balance the benefit of potentially invasive and distressing interventions that may prolong their life with their desire for a good, peaceful or dignified death. And there's no right or wrong answer. It's just about taking the decision away from the health care professional and trying to put it back in the court of the patient and their family. It is really important to emphasise that an advanced care plan will never hasten death. Rather, it can at times allow for natural death without life prolonging treatments.

So this is a really a good book that I read recently, a novel about the brilliant music from the 80s and 90s, about the importance of formative friendships, loyalty and about death? It's about a man in his early 40s who's got an incurable oesophageal cancer, and he and his friend are kind of having an informal discussion about his advance care plan, what he wants to happen in the last months of his life. And his friend quoted from Shakespeare's ‘Anthony and Cleopatra’. He said, ‘Tully, let's make death proud to take you’. And you know what, while that's not going to be right for everybody. it's a great book to sort of open the possibilities of what these discussions can be about. It's a good book as well.

29.44 **Speaker:** So, the key components of advance care planning are to gain an awareness and an acceptance of impending death. For the patient to be treated as an individual with dignity and respect. We are almost certainly aiming for them to be without pain and other symptoms. And it gives us the opportunity to talk about how we can achieve that. Giving people the time and the ability to settle their worldly affairs so that they have peace of mind. And they can preparations and planning for a death that they would choose and in some cases for what they believe comes afterwards.

30.24 **Speaker:** So we want to think about who the best person to have this discussion with is, no, it doesn't have to be the GP. It doesn't have to be the most senior staff member in the care home. You know, it might be their hairdresser. It might be the health care assistant that always gives them a wash in the morning. It's for us to empower everybody to know that this information is really important for them, with consent, to feed it back to the people that can write it down and make sure that everybody who needs to know does know.

This is not a once only event, it can be reviewed and revised at any time, and certainly I've had a lot of changes in advance care plans from people in the first wave of COVID, who would contact me and say, ‘Look, whatever happens, I do not want to go into hospital’. And then we came through to the summer last year and I get on the phone again. And they are saying ‘You know, the advance care plan we sorted out well it doesn't look quite so bad now. Can we scratch that *never want to go to the hospital again* and we'll consider it at the time?’ And that's absolutely what it's all about. That's fine.

How often should we review it? Difficult to say. It very much depends on the patient. But certainly, I'll review it annually with my care home patients, for example.

We have got to remember this involves multiple professionals and we in our general practice are closed most of the time. We're closed, I think, 70% of the time. So, it's really key that we record this information so that it can be shared with everybody who needs to know. Having the information is useful, but it's made powerful by sharing it with family members, out of hours, ambulance, secondary care. I had a case not so long ago where a patient with full capacity in a care home had a discussion with me and we got a really nice detailed advance care plan sorted out. It was filed in the right place. I thought we'd done a great job. What I didn't think about was who he was going to tell. I probably just assumed he would talk to his wife about it. As it turned out, he didn't. So fortunately, he had a fantastic out of hours doctor who came to visit him. He had deteriorated significantly. I'd seen him earlier in the week with a chest infection, prescribe some amoxicillin. I had no expectation that he would deteriorate significantly. I hadn't put end of life medication in place or anything. It wasn't on my radar. But he did. And he lost capacity. He couldn't speak and was barely conscious. Now, the out of hours doctor saw him and felt that possibly he should be admitted to hospital to have intravenous antibiotics for his chest infection. But the nurse at the care home showed the advanced care plan we’d developed, which said definitely no hospital under any circumstances. The doctor felt that his wife should be informed appropriately because she felt he may die, and she prescribed and his life medication and everything. Now, his wife was very shocked and thought if he's unwell, he should be in hospital. Now, fortunately, I had written down the patient's actual words for why he didn't want to go to hospital. And his wife recognised that; she heard him say that almost and acknowledged he had said similar things to her. So, she was comfortable with the decision in the end. But possibly if it hadn't been that much detail, he might have gone in. In fact remarkably he had some subcutaneous morphine, but then did very well. And I'm happy to say I saw him this week sat out in the garden feeling fine. He was clear that he was delighted he hadn't been admitted and wouldn't have wanted to, even had he died. And that's a good lesson for me. It was just I couldn't have shared that information with his wife because he had capacity so it wouldn't have been appropriate for confidentiality. But just to remind the patient that it's important that they talk to their loved ones about it.

34.28 **Speaker:** So advanced decisions can be made by someone over 18. Now, this is an advanced decision to refuse treatment, and this has legal power. It must be respected even if other people feel it's not in their best interests. And health professionals will be protected from liability if they stop or withhold treatment because they reasonably believe that an advance decision exists that is valid and applicable. Individuals can obviously cancel this decision at any time. So, these advanced decisions to refuse treatment are a formal decision by a patient with capacity. And it can cover anything really, for example, a specific future treatment like peg feeding or ventilation. And it can be an important part of advance care planning. So long as it is compliant with the Mental Capacity Act, it's legally binding. It can be written or verbal, but if it includes refusal of life sustaining treatment, it must be in writing. It must be signed and witnessed and include the statement ‘even if my life is at risk’.

35.33 **Speaker:** Now, DNACPR forms which we're all very familiar with in Wales, cover decisions specifically just about CPR, not any other life sustaining treatment. If a patient has capacity, then their preference counts significantly. So even if you feel CPR would be futile, if a patient wants it, generally speaking, we will do it because it's just quite a risk to take to not do it. If they lack capacity we really, really want to try and find out what they would have wanted in these circumstances. It can be a ‘best interests’ decision’ that's completed by a responsible clinician. If it's part of an advanced decision to refuse treatment, it's legally binding. But otherwise, this is advisory and clinical judgement takes precedence. And that removes responsibility from the family. The family give us the information. But this isn't their decision. And lots of people find that quite a relief, really, that they're not having to make the call. They're guiding us to make that decision. We know this - do not attempt CPR does not mean do not treat. Lots of family members don't realise that. So, it's really important to clearly point that out. And also make sure that everyone in care homes know that as well, because I think sometimes that message isn't clearly spread.

We know that it's important to talk about the fact that CPR is not like it is on the telly. It's a highly invasive procedure with significant risks and harm associated. And that's why if we feel it would be futile then it's not the right thing to do.

37.24 **Speaker:** Now, recording and sharing information is absolutely key. These DNACPR forms and advance care plans need to be accessible. Mark Taubert, who gave the talk a couple of months ago, is working really hard to get a sort of electronic means of this being shared across Wales with all the different in-hours, out-of-hours, secondary care ambulance etc. It would be fantastic to get that done. And I think that is coming.

We really need the family to know what the plan is. As I've said, the conversation is the most important thing. The permission to share it makes it powerful, makes it a useful tool. We need a robust recording and sharing of information because that way you don't have to duplicate these challenging, sensitive and often incredibly time-consuming conversations. If everybody knows, it's there for us all to use.

38.16 **Speaker:** Who needs to know about this?

Well, everybody who's involved in that patient's care needs the information so they can act on the patient's wishes and that strengthens teams. It improves end of life care and it helps families to cope after death, to understand the decisions we’re making. So, the family needs to know. We need to know, out-of-hours need to know, ambulance service needs to know and the secondary care teams need to know. And as much information sharing as possible will really help us.

38.46 **Speaker:** Now, people with dementia are a specific group of people who have lost capacity. And it's really common for people with dementia to become very frail in the late stages of their illness. They often lose their desire to eat and drink. They become very susceptible to infection. Now, as I was sort of describing before with my story about the patient with chest infection, it can be very hard for our colleagues in out-of-hours to make appropriate management decisions about a moribund patient without background information. How are they to know just how poorly this patient is normally? We need to talk to next of kin, try and find out a bit more about them. An advance care plan can be for full active care. That's absolutely fine, but it's just much easier for us all to make decisions when someone's acutely ill, if we know what's already being discussed.

39.43 **Speaker:** Now, people with learning disabilities - this covers a huge spectrum of people, but what a lot of us don't realise is that people with learning disabilities on average, obviously not everybody, but on average die younger. Men with learning disabilities die on average 13 years younger and women 20 years earlier than average. This is a really complex area for us to approach. Carers may not be familiar with advanced care planning discussions, and these people need even more time and support, as do their families. But it's important that we do that because the end-of-life period isn't always well recognised in people with learning disabilities. And so, they can miss out on gold standard care if we'd known what was happening. Hospital admissions for people with learning disabilities can be really, really stressful and challenging and frightening, especially with Covid, you know, people going in on their own without their usual support around them. In 2019, 74% of people with learning disabilities died in hospital, which is well above the national average and isn't necessarily the best place for them to die.

40.56 **Speaker:** So, studies show that advanced care planning is a useful tool for making sure people with learning disabilities, have control and choices over their lives right to the end. People with learning disabilities are said that they do want these discussions, but they want them to go at their pace. They want to be supported to make their own choices. So, try and explain the pros and cons of different choices so that they can understand and decide what's best for them. Adapt this process to the individual and what a lot of them said is most importantly, they want to be supported to plan the life they're still living. So, have this as something that's decided, but also to be supported to get the very most out of life while they can, which, of course, is similar to all forms of person-centred planning.

41.54 **Speaker:** So, to conclude, as people get older, they generally welcome these discussions. They are often relieved if you bring it up and offer them the opportunity to talk about what they want and what they don't want. We for a variety of different reasons, find this harder. But as I said before, everybody dies and facilitating our patients to achieve this in the way they choose is a key and very rewarding part of our job. Good planning helps us to get this right. So, take it gently, follow the patient's lead and accept that you may need to revisit. You know, you may not get all four of your advanced care plans that you want to do this week, done this week. The bottom line is that however many of these talks you attend or how much you read about it, real life isn't always straightforward. And if we muddle through trying to do the very best we can, if it feels wrong, back away, come back another day, we're not going to go far wrong.

So, I am ready for any questions if you've got any.

43.08 **Chair:** Thank you very much, Rowena. If anybody's got any questions can you post them in the comment box, please.

43.12 **Speaker:** If you do have questions, my emails there or Twitter, you can message me on Twitter. I'm very happy to answer any questions you've got or any dilemmas or ethical issues because it's such a complicated area. And I just find it very interesting. I'm always up for a chat.

I’ll talk about some signposting resources that are really good. Again, I'll just give another push for Kathryn Mannix's book ‘With the End in Mind’. It's really readable. It's full of lovely stories about patients. I find narrative medicines a great way to learn and her discussions that she describes having with patients and their families about how things will be at the end, what's likely to happen. I've used that several times now and people always seem to find it very reassuring and comforting to have that idea. I think there are some good resources that you can look at. And this is some more signposting for documents that support us to have these tricky discussions.

44.17 **Chair:** We've got a couple of questions come through. So, first from Adam - How is it best to formally record the advance care plan? Is there a template or toolkit available to standardise it?

44.30 **Speaker:** There's not England’s a little bit different. England’s got the respect form, which has got a lot more information than we've got on our DNACPR form. I've got one that I use in my practice, which is about six pages long. And really what I feel we need is about a page or two pages at the most. I suspect as we do more work on this, getting the digital platform sorted out so that we can share this information where it will probably be developing template like the DNACPR form that we can all use. But if you Google advanced care plan, there's a variety of different ones that come up and we just sort of had a look and chose the one that we felt was most appropriate.

45.15 **Chair:** Thank you. Jana has asked - Have you come across advance care planning that's being done in routine situations and with the patient that cease to apply at crisis point in the family?

45.18 **Speaker:** Yes, and that's really difficult, isn't it? It's probably easier when that happens and the GP who's been involved with developing the advance care plan is available to have the discussion with family members. It's much harder when the family don't agree and the person who developed the advance care plan isn't there. And of course, the other thing that happens is advance care plans can get lost. We had a significant event where a bank nurse at the care home just didn't know where the folder was, and the patient was admitted, and she really hadn't wanted to be admitted. So, all of those things, very, very simple. Make sure it's in the nurse’s room with a clear label on it so anyone can spot it. But I think that that situation where a patient loses capacity, they've made their wishes clear, the family member is disagreeing. I don't think the GP will be criticised for going with what the patient has requested. But you do want to have an awful lot of documentation and take your time to talk through with the family member why that decision was made. But really, you want to go with the patient's wishes as priority?

46.52 **Chair:** Thank you, Jennifer asks - Is there any advice on how to handle situations in out-of-hours when no one seems to know what is going on and decisions need to be made quickly?

47.04 **Speaker:** It's so difficult, isn't it? Because if you've got no idea and you can't get hold of a family member and there's no advance care plan and the carers don't know what the patient would want, unfortunately, even if you feel it's the wrong thing, you probably have to take the safest for you option and probably admit the patient unless you're absolutely sure that it's completely futile and that horrible situation where they may die in the ambulance or die as soon as they arrive in the emergency department. And again, it's all down to documentation. If you document why you've made the decision to keep them at home and manage them as a dying patient, document how you've attempted to try and get as much information as you can. You know, you've tried the family member. There's no answer. You've tried to talk to the nursing home staff or neighbours. If you've done your absolute best, I don't think you can be criticised. But I agree, it's very tricky. And it's that litigious worry that means that many, many patients do have an admission to hospital that possibly isn't in their best interests. And I think whilst that's regrettable, it's also very understandable for us as health care professionals to take what can be seen as the safest option for ourselves.

48.26 **Chair:** Jana has come back with a comment saying that while I am all for doing those plans far ahead, I still seems to catch people by surprise unless done when everybody has accepted the death is coming soon. Any comments on that?

48.42 **Speaker:** Yeah, it's difficult, isn't it? I think all of us even in practices where we feel we are really on top of the advance care planning, will still have shocks when they come back at the weekend to think ‘Oh, gosh, I can't believe that happened’. You know, we can only do our best. It's worth thinking in clinical meetings of the slip through the net patients. You know, when you're looking at chronic disease management, patients with chronic pulmonary disease, you're probably seeing them once or twice a year for their medication review to perhaps think about it then, you know, just putting a foot in the door of how they feel about things. So that that's probably our best prompt is if medication reviews because that way, we know what we are talking to them at least every six months or so to that. That's the best thing I can say. But also, we can't get absolutely everything right. We can't always be perfect. So, you know, don't beat yourself up too much. If somebody has deteriorated without an advance care plan in place. We can only do our best.

49.59 **Chair:** That doesn't seem to be anything else coming through, Rowena. So, I'd just like to thank you once again for a fabulous and very comprehensive run through advance care planning. I'm sure we will all be thinking how best to do it now for all our patients. And thank you once again and hope to hear from you sometime soon. Thank you very much.

50.36 **Speaker:** Thank you for coming, everyone.