**Advance and Future Care Planning for People with Learning Difficulties**

**March 2022**

**Dr Rowena Christmas GP and Safeguarding Lead there for over 20 years and established their Cluster Safeguarding Peer Support group in 2018. Currently Chair of RCGP Cymru Wales. RCGP Safeguarding Lead for Wales since 2019. A Bevan Exemplar for Safeguarding.**

0:01 **Speaker:** Hello. Thank you so much for joining me today. We're doing a webinar looking at advance and care planning for people with learning disabilities. Now I know you all recognise the importance of advance and future care planning for everybody, but I'm hoping by the end of this webinar, you'll see that for this particular group of people it's even more important.

I decided to write this because I've been privileged enough to be looking after a residential home for people with extreme learning disabilities for the last 22 years. It's a tiny care home, only eight people, and I can't tell you the learning that I've gained from things that have gone well and things that haven't gone so well over that time period. And the things I've learnt from the carers there who do a fantastic job, the families of the residents, the multi-disciplinary team, the sort of gang of people helping to care for them, but most importantly, for the patients themselves. It's been so rich and so useful, the learning, that I wanted to share it.

1:14 **Speaker:** One of my advance care planning gurus is Kathryn Mannix. She's a palliative care consultant and an author. She's written two fantastic books that I recommend: ‘With the End in Mind’ and most recently ‘Listening’. And Kathryn said ‘If palliative care can be seen as about living instead of dying, we could transform practice, conversations and the way people live the last part of their lives’. And, you know, a good death is very, very much a part of a good life, and we can really help to get that right in primary care.

1:57 **Speaker:** So I'm afraid people with learning disabilities are some of the most marginalised groups in our society. We've got approximately one and a half million people in the UK with a learning disability, which is an incredibly diverse group of people. But effectively a learning disability is a reduced intellectual ability which can cause problems with everyday tasks. This is a lifelong condition and usually has a significant impact on the person's life. You know it can make shopping and cooking or travelling to new places really difficult. It tends to take people longer to learn and develop new skills, learn how to do things, to understand information and to engage and communicate with people. It's important to note it's not a mental illness, and learning disability is not a learning difficulty, such as dyslexia or dyscalculia. The level of support someone needs is different with every individual. But overall, these are a group of people who find it harder to learn and communicate and understand things.

3:08 **Speaker:** So there are some differences. But the more important thing is that people with learning disabilities want the same thing that everybody else does. They want to have choices about how they live and what they do, as they can very, very often achieve this if they only get the right support. So as I said, they remain one of the most marginalised groups in contemporary society, and that's never more evident than when it comes to death and dying. The sad reality (and this is a whole other topic for debate, really) is that people with learning disability have poorer health than other people, and they're much more likely to die at a younger age. It's one of the reasons we have a local enhanced service to do annual health checks on people with learning disabilities because really end of life care for this population is very inconsistent across the UK, and we really can do better if we think about it.

4:10 **Speaker:** So key issues, the things to hold in mind are that people with a learning disability have far more similarities to the rest of society than differences. But we tend, especially as professionals, to highlight and focus on the differences rather than prioritise the similarities. And this is to our detriment. Now it's true that almost a quarter of health professionals have never attended specific training on meeting the needs of patients with learning disability. I haven't, even though I do a lot of this work. Just as with just about every other sort of health inequality, the Covid pandemic has deepened the barriers to accessing health care, which this population has long, long faced. And this is even more noticeable, these inequalities, when you have somebody from a minority ethnic background who has also got a learning disability; it sort of accentuates everything. Things that were concerns during the pandemic were there was sometimes questionable DNACPR decisions made, especially in the first lockdown. And there was also, as we know, a disproportionately high death rate of people with learning disability during the pandemic. Statistics show that people with learning disabilities from Asian or Asian British backgrounds were eight times more likely to die in early adulthood than people from white British backgrounds.

5:46 **Speaker:** So, people with a learning disability very often have to cope with death, whether it's, you know, of a sibling or a parent or a granny and dying a bereavement without actually being fully informed about what's going on. This may be that their carers or their parents are desperate to protect them from that pain. Maybe their families around them are grieving themselves and don't have the sort of resources that are needed to explain to them. And they often face barriers themselves when they need end of life care and support. But the reality is that people with a learning disability will die on average 25 years younger than the general population. They are three times as likely to die avoidably. You know, for instance, someone with a significant learning disability who has sepsis will often not have any of the red flag symptoms that we're used to looking out for. Recent cases which highlight ongoing institutional discrimination against people with learning disabilities. So a case like Laura Booth, who died tragically in hospital and one of the causes of her death was malnutrition. She just hadn't been fed during her admission.

7:06 **Speaker:** So why are this population challenging for us as health care professionals? I think we know very well that end of life care and support is all about good communication and communication can be harder for this group of people. In addition, they might not recognise a change in their health or in their body; they might not know that a persistent cough is something to go to the doctor about or a mole that's on their bottom, that's changing, is something to raise concerns about. Or they may see the change, but not know that that's relevant. Or they may know that it's a worry, but not be able to articulate that to their carers. They may be able to articulate the concern, but to be too terrified of doing it. Very often, people with learning disabilities have really awful hospital admissions, and they may be more afraid of going back into hospital than of the health concern that they don't want to raise. Carers, as I say, they want to protect them or protect themselves from what's happening. They often have poor access to healthcare, and they can be more difficult to examine or investigate. I had a lady who had post-menopausal bleeding. She was in a wheelchair. It was very difficult for us to get her to an outpatient appointment. She didn't have family who had transport easily, and we went through all of the sort of difficulty of arranging that. And she got to the Gynaecology clinic, and they couldn't get her out of the wheelchair onto the couch because the couch was broken and wouldn't go down, to it to examine her. It just feels harder, often feels much harder, despite everyone's best intentions.

9:00 **Speaker:** So how do we address these challenges? I think it's very, very important for us to inform and support carers to be proactive so that they're alert to spotting and exploring any health related changes. You know, for instance, when I do a learning annual review. I always ask how if it's a female patient, how their breasts are checked? Are they comfortable to have somebody else check when they're washed in the bath? Can they be supported to check themselves? Do you talk about lumps just as you talk about every other aspect of life?

If communication is difficult, then there's really good resources of pictures that can be used to support people and using clear and everyday language can be helpful. There's good evidence that if people are supported with time and energy before a diagnostic procedure, it's much more likely to be successful than if they're just taken to hospital and sort of dropped in front of a CT scanner and expected to lie still for five minutes. Really, really, really important that carers talk openly about all aspects of death and dying while the people they support are well and healthy. It makes it so much easier if they become unwell. Not many people with learning disabilities will have been encouraged to explore sensitive issues such as loss, death or dying as part of their everyday lives. But death is the one thing that we can guarantee in life and just as much for this group of people as for us, and we all need support to be able to cope with it.

10:50 **Speaker:** So the GMC defines advance care planning as a voluntary process, which covers any aspect of future health and social care. It can be verbal or written. It's not legally binding, but it must be considered when acting in the person's best interests, if you're making a best interest decision. It can cover everything. I’ve had advance care plans where we know whether the dog should be in the room. ‘No, don't want the dog in the room, in case he gets upset’. Or, you know, music playing, who they want to come, who they don't want to come. It's a good opportunity to discuss all sorts of different things. The preferred place of care is really, really important. Far more people with learning disability end up dying on an acute hospital ward than the normal population, and that's probably not what they would have wanted if they'd been given the opportunity to discuss it because most people would prefer to die at home. So it creates a record of a patient's wishes and values, preferences and decisions. And that way, the care that is delivered should meet the person's needs and the needs of those who are close to them. It makes everything a lot easier and a lot less likely to result in upset.

12:13 **Speaker:** It's really important because if we get it right, then that person has a good death, which is much better for them, much better for their families and actually much better for the health care professionals supporting them. It's how we empower our patients and especially patients who are less able to express their wishes so that we can give them what they would have wanted.

Studies are very clear that this reduces the distress around end of life planning, and it can lead to less aggressive or invasive medical care and a better quality of life near death, with reduced rates of hospital admission that weren't wanted. And people are much more likely to receive care that's aligned to their wishes and dignity. As our Hippocratic Oath says: ‘We first do no harm’. And it's really key at this this stage of a person's life.

13:13 **Speaker:** Unfortunately, though, many of us will recognise that advance and future care planning is not easy. There are a number of barriers often where we're afraid of saying the wrong thing or making things worse. Some people feel embarrassed by this kind of emotional intimacy. Carers will often have a natural and understandable instinct to want to preserve life at all costs, and so they might find it difficult to acknowledge that the person they're caring for may be actually ready to embrace what's happening to them and make it as good as it can be. The person who's dying may be afraid to talk about it because they're still in denial, or they may not trust the healthcare professional. They may be afraid of upsetting their relatives or simply just not having the resources, the sort of background to be able to talk about subjects that are so sensitive.

There are sometimes cultural or religious perceptions around death and dying that can make it more difficult and for us healthcare professionals, it can be a really difficult subject to discuss. It can produce strong and unexpected feelings, which, you know, if you have that, it's really important to try and find a colleague or somebody at home to discuss it with. You know, this is normal, but it's better to talk about it.

Our society is not very good at talking about death. It's traditionally a taboo subject for us. But if we're brutally honest, one of the key reasons this is very difficult for us in primary care is that it takes quite a lot of time. You know, it's very rare that this is a 10 minute consultation. And you know, you think how many other calls we have on our time for, you know, every minute of our general practice day. It's really tricky, isn't it? And you need to make sure you've got private space and you're comfortable to have these discussions.

15:07 **Speaker:** So, yes, everybody in an ideal gold standard world should have an advanced and future care plan in place, regardless of what their illness is. We should be putting this together for everyone who has a life limiting illness. Everyone in their last year of life, although how that's very difficult to predict, isn't it? I've got a patient in a care home who's been on the palliative care register for – well, I think she's into her 11th year now and still going strong. We don't always get this right!

Anyone who wants to have this discussion, we should take the time and have it. And arguably you should say that everyone who's in residential care should have a plan in place because they're frail by definition. And quite a few of my patients in this category have an advance and future care plan that says, ‘I'd prefer to discuss this at the time’. This is fine, but just that sort of initial touching of it is helpful when things become more difficult. And worth in your practices, having a think about who's in danger of slipping through the net. And I would say quite probably that your person with significant learning disabilities, who's 55 years old, is one of those people.

16:29 **Speaker:** When is the right time? As early as possible. Bear in mind, of course, these are difficult and sensitive conversations. Don't rush in. Don't think, ‘Right! That's on my list. I've got to talk to Mrs. Jones today. I've got to get that crossed off’. You know, find out what the patient's expectations and values are. If it doesn't feel comfortable, change tack. Move on to something else. But start early. I think that's a good, good rule.

It's a good opportunity when there's been a change in their condition, you know, sudden fall in their EGFR or a hospital admission, or they've had a fall. Better done earlier before there's a crisis. And for the for the patient and for their families, clarity from us is really helpful.

Give people time. You don't have to do it in one conversation. You don't have to cover everything straightaway, especially if you've done this early. There’s time to address this.

17:33 **Speaker:** This is a picture of me with my lovely Dad who had Parkinson's disease very early. And as you can see here, he's got a cracking black eye. And when he came back from hospital, having had that fall and luckily, he hadn't broken anything, he said to me, ‘Oh God, I never want to go back to that hospital again’. Poor Dad had had a really long time on a trolley. It was ages before he was seen. Nobody's fault. It's very tough going into the Emergency Department. And I seized that moment really because my Dad would never want to upset me. He'd never acknowledged before that he was pretty fed up and his quality of life was a bit grim. And using that cue that he'd given me enabled me and then his doctor, to find out that he really had had enough. He didn't want to go back to hospital anymore. He wanted to prioritise dignity and quality of life and being kept comfortable. And you know, that was a really great opportunity for us to find out exactly what he wanted, rather than what he felt he should be saying for all the people around him who loved him.

So effective communication carried out with compassion and sensitivity, is just fundamental to person-centred advance care planning, and we want to try and create opportunities for these conversations and become comfortable having those discussions.

And because we do this a lot, we're quite familiar with it and it's useful to just step back a little bit and recognise that the patient and their families, they're trying to understand something that's incomprehensible, really. You know, their dad's going to be gone at some point and you're trying to get your head around that. It isn't easy.

19:25 **Speaker:** So, just a bit more on thinking about that. I always try and bring a bit of art into these discussions. Damien Hirst and we all recognise his tiger shark in formaldehyde and that that's called ‘Death is physically impossible to imagine in the minds of the living’. And I think that's true. You know, it's much easier for us, but for our patients, this is just huge; they need a bit of time to get it absolutely right.

19:54 **Speaker:** So how do we open these conversations? A little bit of a time, really. Step back. Make sure you know your patient's medical history, make sure you're familiar with the hospital letters, the last discharge and then find out what the patient understands about their illness and what lies ahead.

Talk about what they want to happen and what they don't want to happen. Listen for cues. As we said before, use the same words the patient uses; mirror them. You know, it's not patronising. It makes them have a more supported and a comfortable conversation. If your patient says, ‘Well, when I pop my clogs, I want to be here, really’ then you can talk about them ‘popping their clogs’. It makes everything a bit more comfortable. Let the patient lead the conversation, you know, go with them.

20:49 **Speaker:** Some good questions. Always open questions help, don't they, in these situations? Who would you want me to contact if you ever became seriously ill? Is there anything that worries you when you think about the future? Is there something on your mind that you want to tell me about? All of these open questions allow the patient to give you more or equally allows them to close the conversation down to if they're just not ready for it. Very, very important, particularly with patients with a learning disability - don't fear tears. This is huge. Dying is very upsetting and crying is a natural and very helpful response to emotionally charged situations. We often fear upsetting our patients with a learning disability. You know, I've had mums criticise me. You know, lovely, feisty, devoted 85 year old mums worried about that their 60 year old son with Down's Syndrome who is clearly in heart failure, and he's cried because I've talked about it. And she felt that was awful. But once we talked it through and explained then she had a good old cry too. And to be honest, I was nearly crying too. It's all very upsetting and it is emotionally charged. She was relieved and we found out, you know, that he wanted to talk to his uncle that he hadn't spoken to for ages. You know, this was the in the pandemic. Communication was difficult and we managed to arrange for the uncle to come and visit him. It was a beautiful visit. It really was. And honestly, it would never have happened if we hadn't had that conversation. And the uncle was glad, and the mum was glad and the person who was dying was very glad, and it really made a difference. So don't be afraid of causing upset. It's upsetting. It's okay, though.

22:44 **Speaker:** Cardiff Postgraduate Palliative Care Programme has a really excellent six point plan worth Googling that and having a look:

1. Comfort is important. I've tried to have these conversations squatting beside a patient's chair to get on their level, so I've got good eye contact. But after about five minutes, my knees were absolutely killing me, and I was focussing more on my knees than on the patients. So, you know, make the effort. Find a chair, find a quiet room, get everybody comfortable physically.
2. Use simple, straightforward language.
3. Use hypothetical questions.
4. Listening is key to this and so is silence.
5. You don't have to panic and fill in a gap. Let that silence sit there for a bit and often the patient will say something that's really important.
6. Reflecting wisdom, supporting them, you know, I often say ‘I'm just so sorry, I can't get you better, but I promise I'll be with you every step of the way. I've got your back. We're going to be in this together’. And honestly, that that makes a big difference to people.
7. If the conversation feels awkward or things are not going anywhere, summarise what's being said and then use that to end things or to steer things forward. But summarising is a really useful plan.

24:15 **Speaker:** Difficulties that are associated with advance and future care planning is we're not really sure how well individuals can predict their wishes for the future. And there is evidence that suggests that there can be significant instability in people's choices over time. Now, an advance care plan is not set in stone, and certainly with the pandemic, I've had people or their families changing the plans, every six months. You know in the first lockdown definitely didn't want to go to hospital under any circumstances. Later that summer, they said: Well, perhaps we would now and then boom. The second wave comes in and they say: ‘No, please look after me at home’. It's fine. It's a dynamic document. You know, we should be looking at this every 12 month and checking and confirming. Nothing is fixed. There may be culturally specific ways that advance care plans all are influenced and we need to be respectful and mindful of that. A really tricky one for us is health care professionals, but we've got to think about the fact there could be coercion, especially when there's financial issues. You know, living in a care home is incredibly expensive. So if there's any concerns about family dynamics, then don't carry those yourself. Talk to social services. Get an independent advocate for your patient if you're worried. Advance care planning should never, ever be used to reduce health care costs. I haven't come across any situation where it is, but the newspapers might feel that that's a concern, so we need to be mindful of that as well.

26:02 **Speaker:** So mental capacity is of key importance when we manage patients. For an advance care plan, a patient needs to have capacity, which of course, is governed by the Mental Capacity Act. If a patient doesn't have capacity, then management is decided by a best interest’s decision. People who don't have capacity - and this may be some of our patients with significant learning disability - still have wishes and desires. And it's really, really important for us to find out what those are. Talk to their carers, talk to their family and friends. Mental capacity is decision and time specific. People can make some decisions. Most people know whether they want a cup of tea or not but may not be able to make more complex decisions. And it can fluctuate over time. So get your patient in their best position, not when they are on antibiotics for a urinary tract infection or if they've just had a disagreement with their colleague. Find the best time to talk to them.

27:11 **Speaker:** The functional test of capacity is that your patient needs to be able to understand the relevant information, and that includes the nature of the decision, the reason why the decision is important, the effect of deciding one way or the other or the impact of making no decision at all. They've got to be able to retain the information long enough to make a decision. They've got to be able to weigh it up and then communicate the decision back to you either way.

27:44 **Speaker:** If you decide that the patient doesn't have capacity and you need to make a ‘best interests decision’ for them, it sounds absolutely crazily obvious to say that you need to carry out make that decision on behalf of them, in the way that best serves their best interests. That's not always the case. So really important not to listen to the sort of very anxious upset relative or the care home manager. Your role is as the patient's advocate in this situation. Try to identify everything that they would take into account if they were making the decision themselves. Do everything you possibly can to enable them to take part in the decision and always choose the least restrictive option.

28:33 **Speaker:** The aims of advance care planning are to empower and enable the family and the patient to discuss the plan, if at all possible. We want to try and increase what we call ‘realistic hope and resilience’. We want to reduce the potential for confusion, for ambiguity and conflict that can arise between staff and family members. And I definitely find good communication really can defuse tensions when they arise.

We always need time for these decisions and recognise for everybody that while decisions made as part of an advance and future care plan may have the potential to result in a person's death, advance care planning will enable the person to balance the benefits of potentially invasive and distressing interventions that may prolong their life with their desire for a good, peaceful or dignified death. So it will never hasten death. But it may allow for a more natural death without life prolonging treatments. And to explain that to family and to the patient is really important.

29:44 **Speaker:** So key components we're looking for all for everyone to have an awareness and an acceptance of impending death. It’s so important to treat our patients as individuals with dignity and respect. We want them always to be without pain or any other symptoms that I find discussing the 4 injectables that we prescribe and how they work, quite reassuring rather than too much information. Family members often find that very reassuring to know. Giving patients the time and the ability to settle their worldly affairs is really important, whether they're sort of a member of Mensa or whether they've got significant learning disabilities. I've seen this really, really been important for everyone in between. And it gives them the chance to make preparations and plan for the death that they would choose.

30:43 **Speaker:** Think about who is the best to do this, and it's not always the most senior member of the team. It might be the hairdresser or the person who gives them a bath. Think about how often we should be reviewing this information. So during the pandemic, I was down to six monthly for some people. It can be reviewed and revised at any time. It's very important to recognise that this involves multiple professionals. Years ago, I had a really important significant event where a patient had had a terrible admission, a six week admission. They hadn't enjoyed it and they were back home. Their kidney function was much poorer; they were largely bed bound and discussion partly with the patient as much as was possible, with her mum and with the care home staff we agreed that she was not to be resuscitated and that, if at all possible, we would avoid any further admissions. And I wrote her up for end of life medication just in case. Now that was discussed between those individuals and then about 18 months later, she deteriorated significantly. And I asked the district nurse to come and take some blood tests so we could see what was going on. The district nurse found out that she had a DNACPR certificate, and she felt very upset by this and felt that it was because of the learning disability and wasn't appropriate because she was relatively young, and she spoke to the family and was quite hostile about it. After discussion, it was all resolved. But if only I had just, at the time of that initial conversation 18 months earlier, involved the district nursing team in our thinking and why we'd made that happen, all of that could have been avoided. So communication just works really well.

32:43 **Speaker:** How do we record and share this information. In hours general practice is closed about 65% of the time. So we've got to share this information. Share it with the care home, share it with the family, with the ambulance, with out of hours. Try and get secondary care to be to be aware as well.

33:05 **Speaker:** So the conversation is important, but permission to share it makes it powerful. We are hopefully in the next year or two going to have a digital system for advance and future care planning, which will make this accessible much more easily. But in the meantime, we really need to have robust recording and sharing of information. And that means that our poor patients and their families don't have to keep having these challenging and sensitive conversations and also our professional colleagues. You know, as we say, these are difficult conversations. They take time. If it's already been done and there's all the information makes it much easier for everybody.

33:47 **Speaker:** This is about strengthening teams; sharing the information.

33:56 **Speaker:** So going back specifically to our people with learning disabilities who we are covering. As we've said earlier, this covers a huge spectrum of people with widely varying needs and abilities, but on average these people do die younger. Men will die 13 years younger than average and women will die 20 years earlier. It's a complex area, but carers in these settings may well not be familiar with advance care planning discussions. Whereas carers who live in a residential home where the average age is 80+ are much more familiar. So we need to give these people time and support.

As we've said, end of life period for people with learning disabilities is not always recognised, and that's a tragedy because it might mean that they miss out on gold standard care. You know, our worst nightmare is somebody dying without end of life medication available if they need it. Hospital admissions are often even more challenging for this group of people than for everybody else. And as I said in 2019, 74% of people with learning disability died in hospital, hugely above the national average and quite likely not what they would have chosen if we'd had the opportunity to plan this.

35:21 **Speaker:** So, asking people with learning disabilities themselves what they want. Advance care planning is a useful tool for these people to have control and choice over their lives right to the end. What they are asking for is for these discussions to go at their pace. They want to be supported to make their own choices. They want the process to be adapted to them as individuals. And a message that came over loud and clear time and again is that they want to continue to be supported and plan the life they're still living, rather than focus completely on the fact that they're dying. And really, that's similar to all forms of person centred planning.

36:10 **Speaker:** So to conclude. Generally, as people get older, they welcome these advance care planning conversations. We might find them difficult, but they're usually valuable and important. We need to remember everybody dies. It's the one guarantee, you know, it's the MCQ that you can answer always to. Facilitating how people die is a really important, a really good and satisfying and rewarding part of our job. Good planning helps us to get this right. So take it gently, follow the patient's lead, accept you may well have to come back and discuss it again. Real life is not straightforward, we know this from our jobs. So if we muddle through, do the very best we can. If it feels wrong, don't persevere, come back another day. We'll probably be doing a good enough job. 37:11 **Speaker:** Always happy to be contacted. That is my email address; that is my Twitter handle - if anyone has got any questions about all of this.

But once again, thank you so much for taking the time to join me for what I think is a really, really important issue for our patients. Thank you very much.