

**00:00:00**

**Chris Bain:** Thank you. Well good afternoon, everyone. It's good to see so any people here on what I think is going to be a really interesting and important event.

My name is Chris Bain, and I am the Chief Executive of Healthwatch Warwickshire.

This event is about Advance Care Planning. It's a listening and learning event that we're hosting as Healthwatch Warwickshire and presented by our friends and colleagues from Compassion in Dying.

We purpose of this event is to: (as I'm sure you're all aware, is to)

- show you how valuable the advance care planning process can be
- give you more confidence when supporting people to plan ahead for their end of life care.
- explain people's rights to plan for their end of life in line with the Mental Capacity Act 2005.
- show you the tools people can use to communicate their wishes, so that their end-of-life care decisions are heard, understood and respected when it matters most.

To help us in this I'm delighted to welcome Sarah Malik and Jemma Woodley from Compassion in Dying.

Sarah will be presenting, and Sarah is the Senior Information Nurse at Compassion in Dying,

I'm not going to spare her blushes, Sarah has been nominated for the Patient's Choice Award at the Royal College of Nursing Awards 2022, in recognition of her work supporting people to talk, plan, record their wishes and advocate for their loved ones at the end of life. We have a celebrity with us today.

Sarah is a registered nurse with a background in Haematology, Oncology, hospice care and helpline nursing.

Her colleague Jemma will be monitoring the chat and there will be time at the end for Sarah to answer some of your questions.

So, I hope that's all reasonably clear, so now without further ado I'm going to hand over to Sarah.

Sarah, do you want to do your presentation.

**00:02:21**

**Sarah Malik:** Thank you so much Chris for the lovely introduction and thank you all for joining me today.

I'm going to share my screen first of all so let's just make sure that works properly, and that you can all see the first slide.

Does that look ok to you, Chris?

Sorry, yes it does.

Lovely, thank you. Fabulous, so you have done a wonderful introduction, I don't think I need to go through again what I'll be covering today.

**00:02:45**

### **Slide 1: Person-led advance care planning and why it matters**

I really just want to get across why Advance Care Planning is so important and the way it can help you as clinicians and social care professionals to support people to have the end-of-life care that's right for them.

But before I start, what I thought might be quite nice is, and I'm not going to pick on anyone, I'm not going to ask anyone to feed back to me, but I'd quite like you to have a think about this. And just consider this while we go through the session today.

If you were taken into hospital what is the one thing you would like people taking care of you to know, if you couldn't tell them yourself?

Just keep it in the back of your mind, have a think, maybe note it down on a piece of paper, and then as we go through the talk it might be something that you think of throughout.

**00:03:51**

### **Slide 3- who we are and what we do**

So, I'll start with an overview of who we are at Compassion in Dying and the work that we do.

We're a national charity and we help people to plan for the end of life.

How to talk about it, plan for it and then record your wishes.

We really see that as a complete process, we don't focus just on having a conversation, we like to help people with that entire process

And 'Advance care planning' which I will continue to refer back to—is that valuable process that gives people the opportunity to discuss, consider, plan and share their preferences with regards to their treatment and care and allows them to talk about that and to share that whilst they have the

capacity to do so. This includes what medical treatments they might or might not want, and treatments and their goals, and their values.

And whilst we all agree that personalised end of life care is so important, we can't deliver that if we don't have that information.

So, knowing that and supporting people to record what's important to them is that Advance Care Planning process, and that's what we think is so important at Compassion in Dying.

Our vision is a world where people have the end-of-life care that's right for them.

**00:05:12**

**Slide 5 -**

These are the ways we support people at Compassion in Dying.

We're a small team and we have lots of mini teams.

We have a free nurse led information line, I lead on with Jemma actually, and we provide free publications which are RCN indorsed and fantastic, they're written in plain English, and they provide wonderful overviews and insights into this process of Advanced Care Planning and how to support people with that.

We also have this amazing Research and Policy Team who, in addition to this work, work on the Information Line Team as well. That allows them to take what they learn from our callers and the people that get in touch with us and then use that information to contribute to national policy. For example, supporting NICE Guidelines, they submit evidence to Parliament to try and influence change based on what it is that people actually want.

We also are the leading provider of Advanced Decisions, that's a tool I'm going to talk about more later on in the session. We provide these in hard copy form for people who aren't online, people can download the form and people can also create an online tool using the My Decisions website.

All of the support we provide and the documentation we provide is done so for free.

That's another really important component of what we do, we don't like to have any financial barriers with the support we provide.

And lastly, we also have a Community Outreach Team, because it's important we engage with smaller communities and diverse communities and have a broad understanding of the sorts of things that are important to people when they're planning ahead for the end of life.

I thought it would be helpful to you to have an insight into why people contact us and the sorts of things they want when they're thinking about planning ahead. I say planning ahead, that's the process of thinking about what it is they do and do not want, when they start to think about Advance Care Planning

So the themes that tend to arise, fall into two clear categories.

The first (on the left) is the sorts of people who just want to get planning in place so they might be getting older. They have strong feelings about what treatment and care they do and do not want.

A lot of people are actually triggered by a bad experience, if they've seen a relative or a loved one have a bad end of life experience and they want to avoid that for themselves.

That's quite a frequent reason for people getting in touch actually.

A lot of people also want protection from CPR.

CPR is an end of life treatment, an emergency treatment, but a lot of people have a concept of, they maybe don't think of other end of life treatments or life prolonging treatments, this is a thing most people think of and for a lot of people who get in touch it scares them and they want to know how to protect themselves from being given it inappropriately.

People also want help with understanding the different options available, because there are a lot of options of both person lead Advance Care Planning tools and clinician lead tools.

Whilst it's brilliant that we have so many options to enable people to document in a way that's right for them, there's not a huge amount of support for understanding and navigating those tools.

We spend a lot of time just discussing all of those options and helping people to work out what would work for them and what's the right tool for them.

And then on the right-hand side we have the different sort of calls we get, so people who need support at that moment, there's a situation happening now.

Perhaps they have a loved one dying at home and there's not the support in place and they don't know what to do.

They might be struggling to have the loved ones wishes respected so perhaps it's to do with best interest decision making or they might be a health and wealth fare attorney who's not being appropriately involved in the decision making.

These are things that come up fairly frequently and we help them, we support them to advocate for their loved ones.

We talk through the best interest decision making process, what best practice looks like in order to influence and encourage better decision making.

We also support people who are maybe having a conflict situation with clinicians where they don't feel their preferences are being respected.

And lastly people can be quite upset on discharge they found a DNACPR form on their record or their loved one's record and they had no idea it existed.

Now this is something as a clinician, I can understand how this happens. It's usually down to people being too busy and worried about having a conversation. What I have, with my position at Compassion in Dying, is a luxury when you come from clinical practice, I have lots of time comparatively.

I'll take this opportunity to talk through perhaps what the loved one is ill with, why perhaps the clinician completed that DNACPR form.

It doesn't mean that person's being written off. It's usually the right decision from what I can glean, from a third-party situation. It's just that it hasn't been particularly well communicated, for one reason or another.

Giving the people time to talk through that is often very valuable and helps them to understand the situation a little better.

**00:11:02**

### **Slide 7 – what we have learned about advance care planning**

So, I've talked about who we are at Compassion in Dying and what I'd like to cover next is what we have learned about the advance care planning process based on what people tell us.

So, it's really important to us that we use our platform at Compassion in Dying just to communicate what people are telling us, this isn't me giving you my opinion, this is what we learn from the people we support

And what we are very acutely aware of is that there is a disconnect between what people want at the end of life and what they have done to prepare for it.

As well as talking to people on our information service and the calls and enquiries we receive, we also poll people. We do polling to get a deeper insight into what is important to people

Some of our recent polling showed us that:

76% have strong wishes regarding the end of life treatment and care they receive and only 10% want doctors to make the final decisions about their treatment.

However, only 7% of people had gone on to communicate these wishes in advance.

Which is a really important disconnect to be aware of and something to try and unpick and consider carefully as to why that might be.

I think my last bullet point goes some way towards explaining that.

48% wrongly believe that they have the legal right to make treatment decisions on behalf of their loved ones, if their loved ones were to lose the capacity to make those decisions for themselves.

That's quite a broadly held opinion that we're coming across all the time.

So, that myth of what 'next of kin' actually means.

I think that's a really important take-away from today. If you come across people who say 'it's ok my wife knows what it is I do and do not want.'

That's an opportunity, right there, to explore a little bit more about what that person wants and what your loved ones are and are not able to do.

I'm going to talk a bit more about that later on, but something really important to look out for when you're supporting people.

I think there are lots of other barriers that stop people from putting planning in place

There are perceived financial barriers. There are people out there who, a lot of people, clinicians actually as well as the general public, who believe that solicitors are required, that there'll be a financial implication to putting planning in place. Any legally binding document makes you think you need to involve a lawyer or solicitors, and that's just not the case.

Again, I am going to be exploring that and talking more about it later on.

Of course, a lot of people just don't think about it and another factor I'm acutely aware of is that lots of people when they get their affairs in order, when they do their planning, they focus on financial planning and post death planning. So, they think about their will, their funeral planning and they think they're sorted.

What people aren't putting enough consideration into, from what I can see, with the people I support, is a potential period where they have a loss of

decision-making capacity, especially when it comes to complex decision making.

So, with dementia as a leading cause of death in this country, that is something we need to pay particular attention to because there are a lot of people who end up needing support with decision making towards the end of life.

That actually could go on for many months or years, not just that final end of life period.

So, these are important things to be thinking about, when you're supporting people.

**00:14:55**

### **Slide 9 – Planning ahead**

When people do get in touch with us their reasons for planning include wanting to be in control of their treatment. A lot of people we speak to, control is a consistent theme running throughout. People want independence, to remain in control and not to be kind of just to be open to the decision making of others.

That is something we should be really conscious of, people like to be in control about their own treatment and care decisions.

A lot of people want to avoid prolonging life when they don't have the quality of life that's important to them. Quality of life is subjective, it's about, we all have a different view of what that is. A lot of people feel that if they lost the ability to make decisions and they were dependent on others in lots of different ways, then they wouldn't want treatment to prolong their life.

So, they want to get in touch and put planning in place to help reduce the potential of that happening.

What we hear from people all the time is that it gives them a peace of mind now, when they get this planning in place, even when they aren't ill, even if they are ill, it gives them so much peace of mind to know that this in place, will be known about and can be followed, if they do then go on to get so unwell that they can't communicate these decisions themselves.

And the benefits of doing this aren't just for the individual who's unwell or who has lost the capacity to make these decisions for themselves.

And having this planning in place allows us to actually deliver person centered care. So, the benefits are not just for the individual.

When it comes to family members, it removes that ambiguity, they know what their loved ones wanted it helps them to honor and advocate for them, depending what the planning that they've got in place is.

I think this is really important as well. A lot of people don't want to be admitted for active treatment when they're very unwell, or in certain situations, and by having certain planning in place, it then reduces unnecessary and unwanted admissions for some people.

And lastly this last bullet point about conflict between clinicians and families. This really strikes a chord with me personally, I used to work in oncology and hematology wards and what I would find so difficult is when different family members would all have different opinions about what it is they thought the person wanted. When you don't know the individual, how on earth you're supposed to navigate that, it's incredibly difficult.

When you've got planning in place that removes that and gives you clarity, it makes everything a lot easier.

I hope that's made it clear, it's not just a process that helps the person themselves but family and the clinicians too.

I have a few quotes from people we have worked with in the community when asked why planning ahead is an important process for them.

I think this really highlights the variation and the diversity of people and how planning ahead can help them to stay at the centre of decisions but also reflect their individuality.

"I don't want an injection that would stop me from saying the Shahada", if you have a religion and it's important to you that you say prayers towards the end of life, perhaps you would want to avoid certain pain relief or sedation, as far as possible, or you'd want that carefully balanced. How would you know that if you hadn't had contact with that person before?

"I'm concerned about not being allowed to die when the time comes. I'm frightened of losing control" That theme of control that comes up for us again and again.

It's so important to us at CID that we use our platform to amplify people's voices. It's far more impactful for me to offer quotes than tell you what I think...

So, in terms of Quality Of Life and personal choice – here are some examples from people that explain why planning ahead is so important to them...



It's important to recognise what the barriers to Planning Ahead are and why these exist. We know it's such an important process, but not enough people are actually engaging with it.

**00:21:06**

### **Slide 12 – common barriers to planning ahead**

An all-too-common barrier is that no one raises the subject Advance Care Planning or asks people what it is they would want towards the end of life. So if you don't know what your options are – it's quite possible that nothing (in terms of planning) is going to happen.

We actually polled people who were terminally ill about this and only 16% of them had been asked what they want when their condition progressed. So we clearly have a bit of a problem.

So, when it comes to having conversations about the benefits of Advance Care Planning, at Compassion in Dying we like to try and refer to these as Important Conversations. They're usually referred to as 'difficult conversations', if we re-frame that to Important Conversations I think that offers a more positive approach.

The first thing to say about important conversations is that even if it may be difficult, they are worth having! It does get easier, if you can access training and that gives you confidence, then do it. But the implications of not having these conversations can be so serious.

It may be helpful to know that 87% of people want their health and care professionals to know their preferences (YouGov 2018)

If a healthcare professional were to raise the topic of a DNACPR decision with them, more than three-quarters (77%) of people would either welcome the conversation or be willing to explore the topic even if it worried them (YouGov 2020)

I think that is something to hold onto if you are lacking in confidence in having these conversations with people.

I think it's sometimes hard to know where to start.

**00:24:48**

### **SLIDE 15 – Planning Ahead Cues**

Sometimes it's hard to know where to start.

These are some quite common examples/cues that are opportunities to find out more about what someone does or doesn't want.

If you're too busy – signpost to Compassion in Dying.

If someone requests a DNAR form to be in place, it may be that they have wishes to refuse other treatment, that other life prolonging treatments may just not be right for them.

**00:27:10**

### **Slide 16 – asking open questions**

We are doing people a disservice by focusing ACP process solely on having the conversation – it's an essential part of the process but it's not the whole process. requires documentation so these wishes are known about when needed

Conversations must be documented and shared if they are going to be known about and respected later on.

These are important conversations, and you cannot assume that others have had it.

**00:29:18**

### **Slide 18 & 19- decision making and the Mental Capacity Act (2005)**

So, I've outlined the benefits of ACP for both the individual, their family and the HCP's involved in their care and now I'll look briefly at the Mental Capacity Act.

So again, just a reminder that I am referring to legislation in England and Wales.

We can't question someone's capacity because we don't like their decision.

When decisions do need to be made for somebody in their best interest they should be made with the least restrictive option.

Understanding amongst the general public may not be great, but healthcare professionals need to remind themselves as well. Of how empowering this legislation is and how central it is to decision making, because this isn't happening enough unfortunately.

**00:30:56**

### **Slide 20 – end of life treatment, who decides?**

You do not have the right to demand treatment.

Link to Mental Capacity Act Code of Practice.

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

**00:31:49**

## **Slide 21 – Planning ahead tools**

So, I will now talk you through the Planning Ahead tools people can complete.

These are person-led so you don't need a clinician to be involved in this process.

### Advance Decision to refuse treatment (living will)

(CiD are leading provider)

Mental Capacity Act states that any adult, 18 and above, with the capacity now to make the decision can complete this.

- Free to complete
- Legally binding refusal of treatment

Must be clear and specific as to what is being refused and when that refusal will apply.

When life sustaining treatment is refused, it must be in writing and signed in the presence of a witness.

Use of a solicitor does not make them more valid, complicated language may not make them easier for clinicians to understand.

For refusing treatment, in advance, that is their sole purpose.

You must complete them when you've got capacity.

They then only apply **IF** you go on to lose the capacity.

That's something that gets missed sometimes or isn't fully understood.

People have the right to refuse any medical treatment in an advanced decision and what we typically see included is a refusal of Cardiopulmonary Resuscitation, being on a ventilator, clinically assisted nutrition and hydration, and antibiotics for life threatening infections.

Life sustaining treatments are generally what people want to refuse, if they are very unwell, to avoid them having their life prolonged.

What you can't use an advance decision for is to ask for your life to be ended, people do try, but that is not what these forms are for.

You can't use these forms to refuse the offer of food and drink by mouth.

You can't use these forms to nominate someone to make decisions for you.

You can't use these forms to demand treatment.

You can't refuse basic comfort care.

Nowhere does it say that a person has to prove they have capacity at the time of completing these forms.

Nowhere does it say who the witness has to be, actually a family member can be the witness. I tend to urge people if they can not to use a close family member, because I think it would be questioned in practice, and I feel it's important to prepare people for what happens in practice. But actually, that's not a requirement.

It doesn't have to be really recent but I urge people to review and update them every few years, just to avoid them being questioned.

Photocopies of the signed, completed document are just as valid as the original.

**00:36:34**

### **Slide 25 – Differences between ADRT and DNACPR**

The differences are:

- DNAR – Clinician led, only CPR, communication tool only, easily recognisable
- ADRT – Person led, refuse any treatment, legally binding

People often call to say they want a DNAR form. But when we ask for a bit more information, it become clear that they want to refuse more than just CPR, but they think that a DNAR form is a catch all term for refusing life-sustaining treatment.

It's important that if they do want to refuse more than just CPR, that they complete an ADRT and a DNAR form is added to their medical records.

However, some people also want to refuse CPR, but not in all situations. In this case, a DNAR would not be appropriate, but an ADRT would be.

**00:38:12**

### **Slide 26 – Advance Statement**

#### Advance Statement

- Opportunity to document your wishes & values
- Not legally binding, but do have value
- If there is conflict these may be drawn upon as evidence, to get an essence of who the person was

- Can say what you do want and can be helpful for the best interest decision making process
- Support and compliment other documentation

**00:39:39**

### **Slide 27 - Lasting Power of Attorney for health and welfare**

#### Lasting Power of Attorney for health and welfare

Given legal status in the Mental Capacity Act.

This is how you give other people authority to make decisions on your behalf if you no longer can.

The concern about people thinking that next of kin can make decisions for them, if people have a loved one or a relative that they would want to step in as a decision maker on their behalf, if they can no longer make decisions, then this is the form for them.

- Costs £82
- No solicitor required (can choose to use one if you wish)
- Covid delays, Processing delays are significant, this is not a last minute piece of documentation.

Support line at the Office of the public guardian LPA helpline: 0300 456 0300

People can be signposted to Compassion in Dying for assistance.

**00:42:10**

### **Slide 28 - How they work together**

#### **Slide 29 – Summary of tools**

There's no reason why you should only choose one of the documents.

If a power of attorney is unavailable at the crucial time, the other documents can help.

A clear snapshot of how these documents work, whether they're legally binding, and what your responsibilities are as a healthcare professional when you're responding to these documents.

**00:44:35**

### **Slide 31 – Improving the understanding of advance care planning**

It can be difficult if a younger person chooses to do this, but any adult over the age of 18 has a right to. You do need to have the capacity to make the decision now.

Sometimes it can be difficult to support someone's decision and the gut instinct of some is to question someone's capacity when they don't agree.

**00:46:40**

### **Slide 32 - In the absence of advance care planning**

The relatives experience, not only the individuals experience, is not as they would have wished. The relative's experience is often anguished, it impacts their grieving as a result. They can get caught in lengthy complaints processes and they can't move on in the same way.

When you compare that to other situations it's just so different in terms of the grieving process, and so on.

**00:48:25**

### **Slide 33 - Good practices lead to better experiences**

Good practices lead to better experiences for not only the person dying but their family/carers.

What we have also learned from families and carers is that it doesn't take much to get it right and when it goes well the end-of-life experience and bereavement that follows seems to be so much better

I think it's important I include this powerful quote from Rebecca who has beautifully explained how reassuring she finds having ACP in place as well as another from someone who saw the benefit it can have on the end-of-life experience.

**00:50:30**

### **Slide 36 – Get in touch**

**00:56:27**

#### **Robyn Dorling**

My name is Robyn and I am the Central Services Officer for HWW.

Thank you for coming and thank you to Sarah and Jemma for all the work you are doing to support everyone to gain a better understanding of advance care planning.

Please use the feedback form, (the link is in the chat and on the zoom link email I sent you) to let me know what you thought of today's events and if there are any subjects you would be interested in learning about at future events.

I will be emailing you in a few days with a link to the video recording of today's event which you can share with colleagues you think might be interested. I will also be including the person led tools and forms people can use from Compassion in Dying and information from UHCW on what they are doing to support people and their loved ones at the end of their life.

If you would like to be kept informed about any future events, we are running that we think you might be interested in please reply to this email with a quick 'yes' so I have permission to keep your email address and contact you in the future.

So, thank you for coming and thank you to Sarah and Jemma for all the work you are doing to support everyone to gain a better understanding of advance care planning.