

Mini documentary

Advance Care Planning (ACP)

Amanda Whitehouse, Kerry Thompson, Lisa Rodriguez, Claire wells, Jennifer Bollen:

[MUSIC PLAYING]

AMANDA WHITEHOUSE: So, the advance care plan is a document, a tool, that enables people to think about what they want at the end of life. It offers questions, triggers, and conversations for people to discuss with others that are important to them and then to document what they want.

So, the advance care plan can make a real difference. It can promote independence and control throughout someone's disease process from the beginning right through to the end. And it enables that person to have control of what, where, and how they want their treatments and their care.

KERRY THOMPSON: I do a muscle meeting through Muscular Dystrophy probably every three months. And it was in one of those meetings that Anna brought up the care plan. And it definitely was something that I was interested in just because it takes that pressure off of my husband that if I do end up in hospital and I can't verbally say what I want, instead of my husband worrying about whether or not I'm going to wake up and go what have you done or him having to make a difficult decision that he can't do, it's there. It's all on paper for me to say this is my wishes and this is what I want.

LISA RODRIGUEZ: Well, I'm 50 years old now, finally. And I've got corticobasal degeneration. And the lifespan of that is about six years, maybe seven. Depends what internet site you look at. So, at the end I won't be able to do a lot for myself. I won't be able to feed myself; I won't be able to dress myself or anything at all. So, while I've got the ability, having an advance care plan means that I can have my say and it's not someone else saying - this disease is doing everything to me, and I want the control at the end. I want to be able to have it my way.

CLAIRE WELLS: So back in 2008, mum started having a numb toe in her left foot and put it down to some new heels that she just thought were too tight. And then after a few days and weeks, it still was there and the numbness was kind of creeping up very, very slowly through her foot and her ankle. But yes, I think we probably waited about three or four months for the neurologist appointment. But he sorts of stared his screen for a good long time and it was just quite quiet. And then he said, it's corticobasal degeneration.

I think to be honest, because of the-- more we learned about the condition, the more it really was a necessity to be writing some of these requirements down. You know, it's putting your wishes into place and actually it's making it easier for your family as well so that they don't have to make those difficult decisions. Because if you don't have those conversations, you're not-- you almost live in guilt because you don't know, well, did they want to be resuscitated? So, if you know, then you've got it recorded down. It's signed while someone's got cognition as well, because she's lost her cognition now. So at least she was able to get it recorded.

AMANDA WHITEHOUSE: So, the advance care plan is your voice, is your thoughts on paper. And by bringing it into the hospital or using it at home, any clinician can read through this with you or with your loved ones and identify all of the decisions that you've made along your disease pathway.

So, the questions are very serious, quite intimate, and quite sensitive. They will ask about treatment escalation. If you were offered antibiotics to reverse an infection, would you want to have that in hospital or at home? If your heart stopped, would you want to be resuscitated? We call that do not resuscitate. If you wanted to donate your organs, it talks about organ donation and specifically what organs you would want to donate.

KERRY THOMPSON: I keep mine in a folder in a drawer and there are key people that know where it is. It comes with me if I go to hospital. The paramedics are told if they come in the house that I have this booklet. So, everything is pretty much in a little plastic folder that has things medically for me.

There's everything in there that you need. There's everything in there from what you want as flowers, to who you want to know, to your social media, to who you want to give what to, to what medical you do want and what you don't want. Everything's in there and very clear. That you don't have to fill it all out if you don't want to. You can fill it out as you gradually go on or you can leave it blank. It's entirely up to you.

LISA RODRIGUEZ: It's your plan. It's a working document. So, you can cross through it and do whatever you need to do because it is your document. And it's about that person feeling comfortable in having their say and saying what they want.

AMANDA WHITEHOUSE: Any time is a good time to complete your advance care plan. However, when we're living with something that we know we're not going to get cured from, that we know is degenerative, and there is a possibility that we are going to deteriorate with this disease, that's a really good time to complete your advanced care plan. So, anyone can do an advance care planning. There is criteria that you need to be over 18. So, it's any adult with full capacity, full ability to make decisions and weigh up the risks with those decisions.

JENNIFER BOLLEN: After seeing what has been happening with Claire and her mum, it definitely makes me far more aware of how limited you are in your options if you haven't thought about this well in advance. There is no way 10 years ago we'd have been talking about this stuff. There's no way we'd have thought that this would happen in our lives to people we knew, let alone to the one of us. And I think people need to think about this stuff while they are healthy enough in their mind, in particular, to set in stone what their wishes are.

It's not just a piece of paper. It's life changing. Massively, massively life changing. And for not very much effort at all. And for something that you can-- yeah, it's an organic document-- for something that you can keep updating as your circumstances change and as your perspectives change when you get a bit older. Things that you change your mind about, for not very much effort, you can utterly change an outcome when you're your most vulnerable.

AMANDA WHITEHOUSE: So, the process for filling in the advance care plan is to get the document. So, from your local GP or your local hospital or hospice you'll be able to get the document. You can also download documents from many websites if you search that. And the next step is to think about those questions and to write it down.

And then it's about putting it in a place that is safe and alerting everyone where that safe place is, making sure it's accessible. So if a paramedic were to visit your home and you are unable to state what it is that you wanted or whether you wanted to be admitted to hospital, he or she would be able to read your advance care plan and make those decisions on your behalf.

KERRY THOMPSON: So, it was a good conversation. It wasn't a hard conversation to have. It wasn't a conversation where I'd go, oh my goodness, what am I going to do. I've never thought about this. It was definitely a conversation of oh, OK, I haven't thought about that before but now I am, and it is a good thing to think about.

As much as it's about talking death, it's not as much talking death as it is of keeping your independence. It is a booklet of independence and that's what they need to see it as, is that

these are your choices. These are the choices that you can make and change as the years go on.

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