

Geeta and Sheena **End of life decisions and planning ahead**

Sheena

So at the start. Luckily one of my sisters is a solicitor, so she knew that very early on we should put some legal power of attorneys in place for my mum.

So we sat down and decided who would be best for financial and medical. So we had that in place quite early on, just in case mum lost that ability to communicate or she needed us to sort of step in.

So that was there from the start, and that's only because my sister was obviously very knowledgeable about this. And then after mum's last hospital admission, we'd sort of it was the, mum's specialist that sat us down and went through mum's ReSPECT form with mum. Discuss mum's wishes about palliative care and end of life and where she would like to be, who she would like there.

Also discussed realistic expectations of treatments or resuscitation, whether it's worth it, whether it's futile, the effects that it can have on someone whose condition's like mum prior to any CPR, and then mum was able to sit as difficult as it is, is very, very uncomfortable to discuss.

Mum sat and made her decisions and then she sat the whole family together to explain to the family what her wishes were. So then later down the line, there was no disputes or confrontation, just in case somebody didn't agree with a certain way because it was mum's wishes, mum's choices.

So mum decided that she wants to be at home surrounded by family if possible, only immediate family. So her children, children's partner and her husband and obviously mum's agreed that because of mum's respiratory function at the moment, that CPR is something that is not going to be suitable. or mum's quality of life after wouldn't be the best so we've agreed not to have this.

Geeta

Yeah.

Sheena

Any form of resuscitation. But we did ask for full escalation for any infections. So if mum picks up a chest infection we still want treatment. The reason we've decided for that is because mum has grandchildren.

They carry lots of germs, come with coughs and colds. So we were just worried that if we can just try and treat mum's infection with some antibiotics or some treatment other than CPR, then yeah, great. Yeah, it's a difficult conversation to have.

Actually, earlier on when my sister explained, when we put our legal power of attorneys in place, that the person that's power of attorney for health would obviously be responsible if we if mum didn't have a ReSPECT form in place, that if she was hospitalised, you would make that decision whether she – they can provide full escalation or not.

So I'm one of mum's LPAs for health. And prior to mum being at this stage in her condition, she was admitted into hospital. And I remember thinking in my head, there's no way that I will ever say, "don't resuscitate mum".

And it's crazy because I come from a medical background. I know the effects of CPR on a healthy person and the possible quality of life after, but sometimes you're personally connected.

But as mum's condition's progressed, she needs more respiratory support. I realised that it's obviously not the best thing. I'm able to talk about it now without crying.

Initially I would cry, I'd get very angry. But yeah. It's good to have those things in place.

I kind of feel as well because of the condition and because of the way things are sometimes worded that mum's had no choice with regards to the CPR.

Again, that's me being personally thinking with sort of the emotional head, not the practical head. I feel like she's had no choice but to say, "don't resuscitate" but when I put my practical head on, I do think, well, obviously there's not going to be much point.

She's already needing a lot of support with respiratory functions, but it's difficult. It's really difficult. So we were actually having this discussion as a family yesterday. We're talking about my grandmother who passed away in her 80s.

She had dementia. And when my dad and his siblings were putting in a DNR in place, my dad was really opposed against it and there was no point in CPR on my grandmother and my aunties were like, please explain to your, dad, that this is not the right thing.

And at the time I was like, why can't dad see? Why can't he understand that it's not going to be any benefit? But being in that position myself, I realise how difficult it is just to verbally vocalise it or agree to that.

Or I think because mum had just come out of hospital and was more reliant on her ventilator, and just seeing how much she struggles. Generally, without her NIPPY.

For me that helped me accept it a little bit more. Had we had put it in place earlier on in mum's journey, I think again, I would have been my stubborn self my angry self like I was about mum's RIG.

I would have been totally opposed against it. Me and my sister because we're both mum's LPAs during that first hospital admission, I think another sibling had mentioned shall we put it in place?

And we're both quite similar. Hot headed. We both replied and was like, no, she's not ready for that. She's not at that stage. And I think as the condition's progressing we're at this stage now, I think we're both more accepting of having that in place.

What about you? When did you feel like it was right to have that put in place?

Geeta

It was the, the second hospital...

Sheena

Hospital...

Geeta

Hospital.

Sheena

Because you realise you were struggling more anyway?

Yeah, again, because at the start it was just mum's legs. Everything else was working as it normally should. Everything was functioning well. We thought so I think. Yeah.

But again, it's one of those things where it's a balance because things can change rapidly within a day. So for example, we went on holiday, we took mum. Mum had a bucket list wish we went and did that.

We went, mum wanted to go on a religious pilgrimage. We went to India for a full month. We came back on the flight on the way back. Mum was having cocktails the whole way home.

The very next day when we landed and she was fine. Completely fine, eating everything. The very next day she ended up in hospital. It was quite serious and then we spent eight weeks in hospital.

So if you don't have a DNR in place, things can change rapidly. We've been lucky not to have got to that point, but it doesn't mean everyone's journeys like that.

But yeah, it's finding the balance, the emotional and practical balance for a family and the patient to put that in place. But it is important.

Geeta

When it started. I wasn't scared, I'm still not scared. But it depends on different people, how they deal with it.