

THINKING AHEAD ABOUT END OF LIFE CARE

When a loved one is at their end-of-life, it comes with some very important considerations



We all want to live well, but what about dying well too?

It's perhaps not something we think about too often, but when elderly parents, terminally-ill relatives or other loved ones are approaching the end of life, it can quickly become a pressing consideration.

Difficult Decisions

It's certainly not an easy subject to talk about but being prepared can mean that a loved one's thoughts and wishes can be honoured with regard to their care in the final stage of their life. As well as giving them some control and peace of mind, it can also help you and other family members should you need to make difficult decisions.

Often these conversations are triggered by the realisation that a relative is at 'end of life.' This term is used when their medical condition has progressed to the point where no further treatment can cure it and they are perhaps just months or even weeks from dying. Treatment then turns towards end-of-life care, with an emphasis on ensuring comfort and wellbeing for that remaining time. This can be a huge shock for everyone, especially when hopes and expectations have previously been pinned on recovery.

Understanding and Acceptance

As the son of an elderly, frail parent with ongoing heart and kidney failure, I know all about two of his existing decisions about his future medical treatment. One is a [DNAR](#) (Do Not Attempt Resuscitation) Order; the other is that his defibrillator (in his [ICD](#)) is switched off. These decisions I have come to understand and accept: my father knows he is heading toward the end of his life and doesn't want to extend it any longer than necessary.

Palliative Care

I was with him recently as he was released from hospital after another emergency admission. Dad was clear that he had no further wish to be hospitalised in any future emergency. At discharge, the medics confirmed that there was no further treatment they would offer: he'd not be a candidate for surgery or dialysis. His ongoing care would now be facilitated in the community via [palliative care](#). There would be visits from district nurses, heart failure nurses, phlebotomists, and contact made with the local hospice, as well as ongoing liaison with the GP and input from the cardiologists.

Well, that's what he said at the time. More on that below...

Advanced Decisions...

In an ideal world, choices and decisions are written down in an Advanced Decision (also known as a Living Will). As long as an adult has mental capacity, no solicitor is needed and it will be legally binding. It states what treatment they are happy to accept - and not accept - and also the circumstances in which they would want to refuse treatment, even if that refusal puts their life at risk or shortens it.

I understand this. You can't ask someone to keep subjecting themselves to hospital admissions, invasive treatments, noisy wards, risk of infection and delirium, loss of privacy and dignity, and in many cases declining physical and/or mental capacity, just because you'd like to see them live for the longest possible time. An Advanced Decision puts the person concerned in control. Despite his firm views, not all my siblings felt happy that he should sign such a document, and I didn't want to insist he did it either. Not wanting to upset anyone, and perhaps not wanting to finally sign away his own demise, he has - to date - chosen not to complete such a document.

...and Advance Statements

Where we have made progress is with an Advance Statement. This is a document that can cover any aspect of your future health or social care, including where you would like to be cared for at the end of their life, e.g. at home or at a hospice, rather than a hospital. It also can capture thoughts on religious or spiritual beliefs to be reflected in your care, as well as other personal and practical issues. It's not a legally binding document but can help with planning ahead. Guided by Dad, and discussed with various medics, we've got a clear idea on these subjects - and it's certainly been less dramatic and traumatic to talk about than an Advanced Decision.

Changing his Mind

However, things remain precariously balanced around our personal situation with Dad, his ongoing treatment and any end-of-life care. We have done what we think we can in terms of Advanced Care planning, but it has not been straightforward or a linear process.

For one thing, his health goes up and down. Mostly down if I am honest - but then he also keeps changing his mind. On becoming ill he has twice agreed to be re-admitted to hospital, to having invasive treatments and antibiotics. Although he is not jumping for joy about having survived to date, he seems glad to have pulled through.

On We Go

So on we go with our endless conversations and scenario planning. At some point, of course, things will happen: things will change, things won't continue as the status quo or thereabouts.

Until then we are just doing the best we can, and trying to act - with my father - in his best interests and hoping that, whatever does play out, the right decisions are made at the right time.

Dad's lived a good life, and I hope he can live a good death too, with his wellbeing always at the forefront of everyone's minds.
