

# Nobody has ever said to me afterwards,

## 'I wish we'd never talked about dying'

Tackling the subject will lead to a sense of relief, says *Dr Kathryn Mannix*, palliative care consultant

Over a career of 30 years in palliative care, I've worked alongside very sick people at home, in busy hospitals and in hospices. They have inspired me with their courage and their focus of concern: not on themselves, but on their families.

From teenagers to pensioners, most are afraid that their illness and death will cast a shadow over the people they love. Yet so often, they have been utterly unable to discuss this worry with their dearest people.

They've tried. Uncomfortable families deflect them with "Oh, Mum! Don't be maudlin!" or "Can't we discuss something more cheerful?" Behind these deflections there is good intention: "I know you're sick." "I can't bear to lose you." "Let's not talk about it and

sad." It's almost a sensible response, because it protects us from sadness, anxiety and anticipatory grief.

Loss, grief and separation have now been thrust into everyone's attention by the Covid-19 pandemic. Yet death isn't new; it isn't optional; it never was. What is new is that we can't continue deflecting. Being unaccustomed to its everyday possibility, we are shocked, sad and afraid. What if my grandmother, my partner, my child dies? What if it's me?

What I've learnt from around 10,000 families facing death is this: not talking about it doesn't make it go away. Silence forces thoughts about death away, but they bubble and ooze into every aspect of daily life, poisoning precious moments with that gory "what if?" The only way is to turn and face the fear.

Those tender conversations in which families tentatively explore with each other how they would like to be cared for, what treatment options they wouldn't accept, what really matters to them, may begin with halting words and a sense of dread. But what they discover is a freedom, a sense of relief - and

then the universal themes of these conversations emerge: "Do you remember when...?" "I was so grateful that you..." "I'm sorry about..." "Thank you." "I'm sorry." "I forgive you." "I love you. I love you. Never forget how much I love you."

Any of us may be sick with this coronavirus; most of us will get better. Some of us won't. If we are so sick that the doctors ask our families "Would he accept a ventilator?" or "I foresee that a period in ICU may leave her unable to live independently afterwards: would she accept that risk?", will our families know what to say?

Will they know, if we don't make it home, what we would have said had we dared to have that conversation? Talking about dying won't make it happen. Nobody has ever said to me afterwards, "I wish we'd never talked about dying." But I've lost count of those who regret their silence.

*With the End in Mind: How to Live and Die Well* by Kathryn Mannix is free to download in ebook format until April 7 ([harpercollins.co.uk](http://harpercollins.co.uk))

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## 'WHAT IF?' PLANNING

### MAKING DECISIONS ABOUT HOW YOU WOULD LIKE TO BE CARED FOR

**M**aking an advance decision to refuse treatment (ADRT) is one way of ensuring that our decisions about treatment we don't want are respected. It can be as simple as writing a statement and signing it, but it's better to be guided through the process to make sure that the words we use are clear and legally enforceable. For example, if someone writes "I refuse to accept any treatment whatsoever if I am so sick that I could be dying", this would certainly stop doctors using drips, feeding tubes and ventilators, but it also means they would be unable to treat symptoms that might distress us.

Asking experts who

understand the medical as well as the legal aspects is better than asking a lawyer, who may not be able to help you craft the document to fit specific health needs.

During the Covid-19 epidemic, GPs are trying to ensure that every patient's wishes are explored and recorded. This process is called advance care planning (ACP) and is something that was encouraged for anyone with serious health problems long before this pandemic.

Now, it has become even more important to be aware of

Clarity is the key:  
Dr Kathryn Mannix



people's wishes, and GPs may get in touch to discuss "what if..." Many people have already decided that, rather than risk dying in isolation in hospital, they would remain with loved ones at home. Both of those decisions are valid in ACP.

Anyone keen to engage in ACP should contact their GP to arrange a discussion over the phone. Another option is naming specific people who can speak for us if/while we are too unwell to join in healthcare discussions for ourselves.

Without completing and registering a lasting power of attorney (LPA), no one - not even our chosen next-of-kin -

has the right in law to make decisions on our behalf. Parents have this right until their child is 18, but after that, only legally appointed attorneys may do so.

The attorney process can be completed online or you can send for the documents; there is a cooling-off period and some safety checks before the LPA can be registered with the Office of the Public Guardian (for which there is a small fee). It takes at least six weeks, so it's not as rapid as an ADRT.

LPA is the method in England and Wales; it has a different name (but similar status) in Scotland; and there is not yet such a power in Northern Ireland, although change is in progress there.