STORIES FROM THE END OF LIFE
EBONY LEWIS

PODCAST TRANSCRIPT

UNSW Centre for Ideas: Welcome to 10 Minute Genius, an eight-part series created by the UNSW Centre for Ideas, to provide pause and create a space to engage with new ideas from UNSW Sydney's thinkers, dreamers and envelope pushers, as they help to make sense of the relentless information vortex in which we live. In under 10 minutes, lecturer in the School of Population Health at UNSW Sydney Ebony Lewis, will talk to you about how to plan for a good death. Because death and dying is something we should discuss with our loved ones and healthcare team before it's too late.

Ebony Lewis: Did you know that in Australia, seven out of 10 older adults want to die at home rather than in a hospital? And did you know that less than one in five adult Australians have discussed or formalised a document to state what treatments they would want or consider unacceptable in their last days? And would you be surprised to find out that around the world of people over the age of 60, who end up in hospital in the last six months of life, one in three are subjected to treatments that won't make a difference to their survival. And in fact, some of these treatments are potentially harmful? Surprised? I was too. This is 10 Minute Genius, and I'm going to tell you about death and dying well, something we should all talk about a lot more often. As Joan Halifax, author, teacher and civil rights activist says, death happens, it is just death, and how we meet it is up to us.

For the last six years my work has focused on the topic of older people dying of natural causes. You might think this is a strange topic for a talk. Or even that there's not much to say, you might think what's new? Old people just die. There is more to talk about than ever. The past two decades have given us far more choice than we may think on how we die in old age. I want to persuade you that planning for good death is just as important as planning for other life events, such as childbirth and marriage. As a researcher working in the field of end of life, and

as a nurse who has worked in hospitals with elderly patients, and later in the community. I've seen my fair share of deaths. Some have been very peaceful, yet some traumatic filled with suffering for both patient, families and the care team. And they are traumatic, not only because a life was lost, but because it could have ended in a better way. If only we had planned certain aspects.

Many older patients have cared for their own parents in their own homes at the end of life. And they say they wouldn't have it any other way. When I first started hearing these stories, this came as quite a surprise to me, as working in the hospitals for many years, most older people would die there, or in the intensive care or in a nursing home. So this got me thinking, why wasn't I seeing this more? Will this be the case for my older family members? The same for me? The same for our next generation? And if not, why? What has changed? For the first time we're experiencing long life expectancy. Here in Australia, life expectancy at birth is now just above 80 years. This is due to huge improvements in public health, immunisation, and treatments for conditions like cancer. So there is now much more we can do to stave off death. But that also means people are living longer with age associated, irreversible conditions such as heart failure and dementia. By 2050, it is estimated that the proportion of people aged over 65 will double. That means when you look around, one in three people will be older. This is what we call a rapidly aging population. Our lives however, are not just about quantity or longevity, but about quality, too.

Over 70% of Australians want to die outside of an institution. However many deaths still occur in hospital and only around 14% die at home. So why are we not dying in a place in older age like in the good old times my patients remember? We need to reflect. Is doing everything that is medically available for older people dying of natural causes the most appropriate? Is society anticipating immortality and using technology to postpone death? And if we want a peaceful death at the end of our life outside of the hospital, why is this not happening?

As a society we don't often discuss death and dying. Death is confined to institutions instead of homes. It's hidden away and highly medicalized. This conflicts with accepting death as a natural part of life. Physicians are trained to cure and may see death as a failure. Others may not realise for days or weeks that their patient is approaching the end of life. So honest end

of life conversations with patients and their families are delayed. Sometimes end of life care in the home is not always an option due to resources. So hospital is the default. But we have to ask ourselves, are we prolonging life? Or are we just prolonging death? How does the end of life someone has compared to what they hoped for?

One of the biggest drivers to not receiving the end of life we want for ourselves, or our loved ones, or our patients, is we simply don't know what the person would have wanted. What they define as a good death, their goals, their values, and treatment preferences. The good news is, that there are solutions, things we know that we can do to facilitate a good death. Through our research, we've conducted surveys, many interviews with older, terminally ill people and their caregivers, on what is a good death. We found that the majority would prefer to receive higher quality supportive end of life care outside of the hospital, rather than life sustaining treatments to prolong their lives. These people have confirmed that quality of life was the most important factor in end of life decisions. Another important element was having a sense of control, and having their end of life wishes known and adhered to by their doctors and families. We also found that older people today are more willing to discuss their end of life preferences than ever before.

So here are three things you can do to not just live well, but to die well too. Number one, ask yourself the big questions. Two, talk it out. And three, document it. Firstly, here are some of the big questions you should ask yourself. What treatments would I not find acceptable when death was inevitably nearing? What is an acceptable quality of life to me? And what does that look like? Who do I want to have close to me when my time comes? Secondly, talk it out. Discuss this with your loved ones and your healthcare team. Don't assume your doctor knows what you would want for your end of life. The best time to have these important conversations is as early as possible, before we lose the capacity to make decisions for ourselves. And lastly, document it. This can happen in the form of a written advanced care directive. This is a gift to the people who survive us. Our loved ones and healthcare team will have clear instructions on our preferences. And you can update these regularly if your preferences change over time. You can also nominate a surrogate decision maker in case you're unable to speak for yourself in the future. All these actions can benefit you, but also reduce stress, anxiety and depression

in bereaved caregivers and enhance family satisfaction with end of life care for their loved ones.

Not everyone is ready or comfortable to talk about this. But my challenge to you is to bring life back to these discussions, as these are going to be some of the most important conversations that you'll ever have. Death is a natural and inevitable part of life. But a good death is achievable as long as we talk about it and plan ahead.

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