

This is an excerpt from a book by Dr Kathryn Mannix, who is an experienced palliative care doctor. The book is called, 'With the End in Mind', and this excerpt is from the part in her book, where the leader of the hospice (who speaks both English and French) takes the time to explain to an 80 year old survivor of the French Resistance what the normal process of dying looks like.

It is the best explanation I have read, and from my own experience of being around people in the final months of life it is very true.

### **From around page 17 to page 22 of 'With the end in mind' by Dr Kathryn Mannix**

And yet, Sabine is keeping a secret. She, who wears her Resistance Medal and who withstood the terror of the war, is afraid. She knows that widespread bowel cancer has reached her liver and is killing her. She maintains her self-possession when she allows the nurses to manage her colostomy bag. She is graceful when they wheel her to the bathroom and assist her to shower or bathe. But she is afraid that, one day, she may discover that she has pain beyond her ability to endure, and that her courage will fail her. If that should happen, she believes (with a faith based on 1930s French Catholicism mixed with superstition and dread) she will lose her dignity: she will die in agony. Worse: her loss of courage at the end will prevent her forever from re-joining her beloved husband in the heaven she so devoutly believes in. 'I will not be worthy,' she sighs. 'I do not have the courage that I may require.'

Sabine confesses this deep-seated fear while a nurse is drying those silver tresses after a shower. The nurse and Sabine are looking at each other indirectly, via the mirror. In some way, that dissociation of eye contact, that joint labour at the task in hand, enabled this intimate conversation. The nurse was wise; she knew that reassurance would not help Sabine, and that listening, encouraging, allowing the full depth of her despair and fear to be expressed, was a vital gift at that moment.

Once her hair was dressed, her silk scarf in place and Sabine indicated that the audience was over, the nurse asked permission to discuss those important concerns with our leader. Sabine, of course, agreed: in her eyes our leader was almost French. He would understand.

What happened next has lived with me, as if on a cinema reel, for the rest of my career. It formed my future practice; it is writing this book. It has enabled me to watch dying in a way that is informed and prepared; to be calm amidst other people's storms of fear; and to be confident that the more we understand about the way dying proceeds, the better we will manage it. I didn't see it coming, but it changed my life.

Our leader requested that the nurse to whom Sabine had confided her fear should accompany him, and added that I might find the conversation interesting.

I wondered what he was going to say. I anticipated that he would explain about pain management options, to help Sabine be less worried about her pain getting out of control. I wondered why he wanted me to come along, as I felt I was already quite adept at pain management conversations. Ah, the confidence of the inexperienced . .

Sabine was delighted to see him. He greeted her in French, and asked her permission to sit down. She sparkled and patted the bed, indicating where he should sit. The nurse sat in the bedside chair; I grabbed a low stool and squatted down on it, in a position from which I could see Sabine's face. There were French pleasantries, and then our leader came to the point. 'Your nurse told me that you have some worries. I am so glad you told her. Would you like to discuss this with me?' Sabine agreed.

Our leader asked whether she would prefer the conversation to be in English or French. 'En Anglais. Pour les autres,' she replied, indicating us lesser beings with benevolence.

And so he began. 'You have been worrying about what dying will be like, and whether it will be painful for you?' 'Yes,' she replied. I was startled by his direct approach, but Sabine appeared unsurprised. 'And you have been worrying that your courage may fail?' Sabine reached for his hand and grasped it. She swallowed, and croaked, 'Oui.'

'I wonder whether it would help you if I describe what dying will be like,' he said, looking straight into her eyes. 'And I wonder whether you have ever seen anyone die from the illness that you have?' If he describes what? I heard myself shriek in my head. Sabine, focused and thoughtful, reminisced that during the war a young woman had died of gunshot wounds in her family's farmhouse. They had given her drugs that relieved her pain. Soon after, she stopped breathing. Years later, Sabine's beloved husband had died after a heart attack. He collapsed at home and survived to reach hospital. He died the following day, fully aware that death was approaching. 'The priest came. Peter said all the prayers with him. He never looked afraid. He told me goodbye was the wrong word, that this was au revoir. Until we see each other again . . .' Her eyes were brimming, and she blinked her tears onto her cheeks, ignoring them as they ran into her wrinkles.

'So let's talk about your illness,' said our leader. 'First of all, let's talk about pain. Has this been a very painful illness so far?' She shakes her head. He takes up her medication chart, and points out to her that she is taking no regular painkillers, only occasional doses of a drug for colicky pain in her abdomen. 'If it hasn't been painful so far, I don't expect it to suddenly change character and become painful in the future. But if it does, you can be sure we will help you to keep any pain bearable. Can you trust us to do that?' 'Yes. I trust you.'

He continues, 'It's a funny thing that, in many different illnesses that cause people to become weaker, their experience towards the end of life is very similar. I have seen this many times. Shall I tell you what we see? If you want me to stop at any point, you just tell me and I will stop.' She nods, holding his gaze.

'Well, the first thing we notice is that people are more tired. Their illness saps their energy. I think you are already noticing that?' Another nod. She takes his hand again. 'As time goes by, people become more tired, more weary. They need to sleep more, to boost their energy levels. Have you noticed that if you have a sleep during the day, you feel less weary for a while when you wake up?' Her posture is changing. She is sitting up straighter. Her eyes are locked on his face. She nods.

'Well, that tells us that you are following the usual pattern. What we expect to happen from now on is that you will just be progressively more tired, and you will need longer sleeps, and spend less time awake.' Job done, I think. She can expect to be sleepy. Let's go . . . But our leader continues talking. 'As time goes by,' he says, 'we find that people begin to spend more time sleeping, and some of that time they are even more deeply asleep, they slip into a coma. I mean that they are unconscious. Do you understand? Shall I say it in French?' 'Non, I understand. Unconscious, coma, oui.' She shakes his hand in hers to affirm her understanding.

'So if people are too deeply unconscious to take their medications for part of the day, we will find a different way to give those drugs, to make sure they remain in comfort. Consoler toujours. Yes?'

He must be about to stop now, I think. I am surprised that he has told her so much. But he continues, his gaze locked onto hers. 'We see people spending more time asleep, and less time awake. Sometimes when they appear to be only asleep, they are actually unconscious, yet when they wake up they tell us they had a good sleep. It seems we don't notice that we become unconscious. And so, at the very end of life, a person is simply unconscious all of the time. And then their breathing starts to change. Sometimes deep and slow, sometimes shallow and faster, and then, very gently, the breathing slows down, and very gently stops. No sudden rush of pain at the end. No feeling of fading away. No panic. Just very, very peaceful . . .' She is leaning towards him. She picks up his hand and draws it to her lips, and very gently kisses it with great reverence.

'The important thing to notice is that it's not the same as falling asleep,' he says. 'In fact, if you are well enough to feel you need a nap, then you are well enough to wake up again afterwards. Becoming unconscious doesn't feel like falling asleep. You won't even notice it happening.' He stops and looks at her. She looks at him. I stare at both of them. I think my mouth might be open, and I may even be leaking from my eyes. There is a long silence. Her shoulders relax and she settles against her pillows. She

closes her eyes and gives a deep, long sigh, then raises his hand, held in both of hers, shakes it like shaking dice, and gazes at him as she says, simply, 'Thank you.' She closes her eyes. We are, it seems, dismissed.

The nurse, our leader and I walk to the office. Our leader says to me, 'That is probably the most helpful gift we can ever give to our patients. Few have seen a death. Most imagine dying to be agonising and undignified. We can help them to know that we do not see that, and that they need not fear that their families will see something terrible. I never get used to having that conversation, even though it always ends by a patient knowing more yet being less afraid.' Then, kindly overlooking my crumpled tissue, he suggests, 'Shall we have a cup of tea?' I escape to brew the tea and wipe my tears.

I begin to reflect on what I have just seen and heard. I know that he has just described, with enormous skill, exactly what we see as people die, yet I had never considered the pattern before. I am amazed that it is possible to share this amount of information with a patient. I review all my ill-conceived beliefs about what people can bear: beliefs that had just scrolled through my startled and increasingly incredulous consciousness throughout that conversation; beliefs that would have prevented me from having the courage to tell Sabine the whole truth. I feel suddenly excited. Is it really within my gift to offer that peace of mind to people at the ends of their lives? This book is about my learning to observe the details of that very pattern our leader explained to Sabine all those years ago. In the next thirty years of clinical practice, I found it to be true and accurate. I have used it, now adapted to my own words and phrases, to comfort many hundreds, perhaps even thousands, of patients in the same way that it brought such comfort to Sabine.