

If only I knew...



Suzanne's story

Today, most of us fear dying and death. We don't want to think about it, and we certainly don't want to talk about it. This means when we have to face it, we know nothing. Most of us don't even know where to start. Sometimes we might have questions but we don't know where to get the answers.

If we think about death at all, we might think we want a "good death", we don't want to experience pain or suffer. But we don't think about the systems and resources necessary to make this happen, or about what we need to do ourselves to make our choices a reality.

One resource is palliative care. But most of us don't really know what palliative care is and fear it even more than death itself. We also fear losing control.

Maintaining control

Suzanne Reber has spoken about her experience living with a terminal condition and being referred to palliative care.

"I had a lot of hesitation. I was diagnosed with the cancer five years ago when I was 46. So, it's been a fairly long battle with several operations and the usual up hill and down dale in between.

"When it came to the realisation that outside intervention just wasn't helping anymore, my oncologist wanted to introduce me to the palliative care team and I basically brought out the garlic and the cross, and I said no thankyou very much, not for me.

"My idea was that my life was going to be taken over by these hoards of people rushing into my house, basically taking control of my life.

"For people in my situation, control is the only thing you've got left. You don't have control of the disease, but you do have control over how you intend to live your life until the end.

"It's my life and I didn't want my home invaded and turned into a hospital – to me that was just abhorrent.

"But it isn't like that. If I say don't come, there's no argument. If I say I don't want something, that's okay. It's not foist upon you. It's not this heavy thing – this is what you have to do. You're not being bullied, you're not being controlled. They're there, they quietly let you know they're there, and then it's up to you as to how much or how little you want to use them."

Pain

Aside from fears of losing control, people also fear dying in pain. Palliative care professionals have expertise in pain management. However, despite the expertise available, some people do miss out. Knowing where to go for information and help is a big part in receiving care that meets needs and expectations.

"Once I hit the pain, I knew I needed help – pain management help."

"I had three weeks of bad pain management. I was in this vicious cycle of being very ill, very nauseous, in a very downhill spiral. Terrible side effects because I was on all the wrong medication. I ended up in hospital because I was in such a state. Mentally, it affected me greatly being in pain, you're not normal, you can't enjoy the company of family and friends.

"That's when I met my palliative care doctor, he gave me medications nobody else seemed to be able to put their finger on. Within 48 hours, I was a human being again, a completely different person. It was amazing. He knew his business.

“Pain management gives you an extension of quality of life, of your normal life. It’s not a fix, no-one sells it to you as a permanent cure. All they’re trying to do is control things to make your quality of life as best as possible for as long as it is quality. It’s not we’re going to keep you alive for as long as possible, against the odds, just for the sake of watching you breathe.

“There are very good pain control medicines out there. With time and research it’ll get even better.”

Planning

Planning for the future to ensure we receive the care we want and need when we need it is important. As consumers of the health system, we have choices but we need to make these known.

Having controlled Suzanne’s pain, her doctor started talking about advance care planning.

“He gave me options and asked me what I would like to do. Nothing was foisted upon me like this is what you have to do. The choices were still left in my hands.

“I told him my lines in the sand, what I wanted, I wanted to live but live while I was still me. I had my resuscitation orders and artificial feeding orders and he just looked at me and said ‘I totally agree with you’. I have his assurances that my wishes will be carried out.

“But I have been one of the lucky ones who has actually seen that people can die on their own terms, it puts my mind at rest. When I saw how my Dad passed away, I knew I could wish that on my best friend. There were plans and these were followed – it was the most humane, unstressful way, not just for my Dad but for the family. Peacefully, no drama, no fuss, no histrionics. It wasn’t scary.

“I’ve had five years to think about a plan, so I had a plan. But there would be people who wouldn’t understand what a plan is. I’m the type of person who’ll ask questions, but there are a lot of people who don’t like to do this, who don’t have access to information.

“Sometimes people need someone to open up a conversation that may go over a period of two or three sessions where you first build a rapport and then gently lead them towards information so they can make their choices.

Emotional support

Having someone to talk to for emotional and spiritual support can also be important.

“I’ve thought a lot about dying because my Dad was living with us when he passed. We had a lot in common because we were both facing our mortality. I could talk to him about my fears and he could put things into perspective.

“I once said to him I was afraid of being in a dark box in the ground, and I think that’s obviously a very common thing. He said to me, you’ve got two alternatives. You either believe that there’s a spirit or a consciousness, and that consciousness leaves you when you take your last breath and it goes into a bigger something or other – so it’s not going into the ground. If that’s not what you believe, the other alternative is you’re not alive, there’s no consciousness and you won’t know where you are. So don’t worry either way. I laughed. It really made sense to me.

“Between my Dad’s explanation, and my doctor’s reassurance that my wishes will be carried out, and actually seeing how someone dies, it’s put my mind at rest.

Because we don’t like to talk about dying, death and loss, we often have misconceptions about what help is available and don’t know where to find information.

“There might be other people out there like me who have the wrong opinion about palliative care, and might now give it a second thought, that’s why I want to tell my story.

“I have no regrets. I’m glad I took the path I took, and now I’ve had enough. I’m tired. I’ll stay home for a little longer while I’m still sort of semi-functional, because what I’m doing at home is the same I would be doing in hospital at this stage – so I might as well do it in my home.”

Palliative Care Australia notes the extraordinary generosity of Suzanne Reber and her husband Brook Reber in sharing their experiences with Donna Daniell, CEO of Palliative Care Australia. Suzanne passed away on 23 May 2009, shortly after telling her story.