



Dying is normal, but there is a good way to do it and a bad way to do it, writes Professor **Bruce Robinson**

Wise words: Professor Bruce Robinson speaks to medical students Monique Dixon, left, Edward Barlow, Daheng Xia and Luke Wheeler at Sir Charles Gairdner Hospital. Picture: Nic Ellis

# The good side of dying

I just want to die now. I am living in hell," said my 50-year-old cancer patient. "I am sorry to hear that," I said. "Are you in pain?" "No," she said "But, my husband is angry all day, because he is stuck in the anger phase of grief, my son couldn't stand it so he moved in with his girlfriend which has made my husband even angrier because he says my son is now living in sin.

"To add to it all, he is angry with my daughter because she drops in each evening on her way home from her hairdressing job but doesn't do anything to help, she just sits on the sofa and talks to me just like she has always done, without

ever mentioning the cancer. "My husband is angry with her because I make her cups of tea and cook her dinner in the same way that I always have and he thinks she should do it. I just want to die now." At the end of this article you will read about an extraordinary event that changed this "living hell" into a happy ending. This discussion about dying well or dying badly is not about euthanasia. It is about how you manage the dying process. As a lung specialist, I have looked after hundreds of patients (lung cancer is the common lethal cancer) and have in the process watched and participated in the "journey to death" of many patients and their

families. This article is for carers and patients alike — it made my typist cry and it might make you cry. Dying is normal, but there is a good way to do it and a bad way to do it. And by good or bad ways of doing it, I am not just talking about the patient but about the family. When the dying process is handled badly, the survivors can be left with a life-long bitterness. You only have to open the daily newspapers to see examples of bitterness that flow on from badly handled death — rage expressed at the hospital, the doctors, the Government or God. But when death is handled well, there is a way in which the surviving family





members often describe a positive effect on them, such that they say, “I am glad we handled it that way”.

This is a reflection of the old but true saying “death handled badly makes people bitter, death handled well makes people better”.

Handling death well starts from the time that the diagnosis is given. This is partly out of the control of the family because it depends a little bit on whether the doctor, or other person giving the news, knows how to do it according to best practice. For the past 23 years, I have been responsible for the Breaking Bad News course at the University of WA Medical School. We teach what is best practice in this area. But not all doctors in WA have undergone this training and some get it wrong. Though every situation is different, the right approach generally involves selecting the right site (a quiet room, turning off a mobile phone or pager etc.), an empathetic style (sitting down, making eye contact, appropriate touch etc.) and the right words (reaching out with words of empathy, not avoiding the use of the word cancer etc.). The success or failure of that emotional and poignant event is not all up to the doctor — it is also determined by the patient and the family. How?

The patient can feel lonely and isolated in the process. In my experience it is vastly better if a trusted and significant family member (or friend) is present at that initial breaking bad news consultation. That is because the patient, once they get the bad news, will have trouble remembering any of the information provided from that moment onwards — the head will be in a spin. It is much more likely that a loved one, if present, will remember the information.

I had to tell one of the young West

Coast Eagles some years ago that he had cancer. He described in a subsequent interview how his head went into a spin — but his partner was there and she was the one who asked me all the key questions.

I was so glad she was there, and so was he. It is too much of a burden on the patient, having received the bad news, to then have to explain it to family members. It is better if a doctor is explaining it so that the patient doesn't feel under pressure to explain a complicated situation to people who are themselves feeling emotional.

It is important to ask the doctor any question that is on your mind.

It is vital that you leave the consultation with clarity. For example if the doctor uses complex words that you don't understand, ask for simple words. Some doctors are afraid of using the word cancer — that word feels a bit like a sledge hammer at times. But it is more important to get it right. I remember hearing about a patient who was told they had a malignancy with metastases to the bones. When they told the doctor they didn't have any questions, he asked, “Are you sure?” “Yes I am sure,” the patient said, “I am just glad I don't have cancer.” You need to be really clear about what is going on. I often draw a picture for the patient and write the words on a sheet of paper to help them and their family understand exactly what I said and what the treatment options and schedules are.

You need to decide whether or not you and your loved ones want to know the prognosis. Not everyone wants to know the prognosis. It is easy to not want to know and to even deny the presence of the cancer. I have to be honest and say that in general it is

best if they do know, not necessarily at the first consultation, but soon thereafter. But the truth about cancer is like a drug — it must be given in the right dose at the right time. Truth can be withheld from a patient but only at their request — and never altered to suit their feelings. I respect the rights of patients to live and die in denial. I just don't ever see it helping much — short term gain for long term loss.

Once the diagnosis has been explained and the treatment commenced, the journey to death continues. This sounds like an awful journey but it can be made better.

First, don't avoid talking about the cancer. Avoidance is a very powerful reaction, either in the patient, or among loved ones or even among medical or nursing staff. It is natural to avoid talking about things that make you feel uncomfortable. Indeed it is often a reflection of love being so afraid that you will say the wrong thing that you say nothing. Love also can create avoidance in other ways.

Because death is about grief, and grief is about loss, and it is difficult to accept that the person is dying, it is easier to offer false hope e.g. “apparently there is a new treatment in Mexico”, “I read about a patient with cancer who was healed by a fruit juice diet”, “I am sure the doctors have it wrong” and a host of other phrases.

Because they are reflections of love, I don't wish to criticise them. However, they often don't help the patient. They provide short-term comfort but in the end increase anxiety and do not help the family

▶ **CONTINUED** P48



This sounds like an awful journey but  
it can be made better.

**Professor Bruce Robinson**



◀ **FROM P47**

to get on with grieving. Second, having gone ahead and begun to talk, don't continually ask about it — talk about it but also about the children, the news, the football or anything, trying to treat them as normally as possible, without avoiding the issue.

Third, don't avoid visiting them. I often find that when a patient has a diagnosis they will have 20 visitors within the first few days in hospital, yet in the next two months after they leave hospital to go home they have zero visitors. That is understandable because some people feel so uncomfortable, they don't know what to say and as a consequence they "find something else to do". Be willing to spend some time. Usually it is better if it is not a lot of time (if the patient can only handle a five-minute visit, don't say, "I am sorry but I can only stay for an hour").

Fourth, don't just say "if there is anything I can do to help..." but actually take the initiative and do something.

Fifth, thank them for all of the things that they might have done for you in the past, some good times that you have shared together for which you are grateful and their characteristics that you have admired over the years. I have a magical phrase that I use with my patients, a phrase that has helped every single family that I have used it with. This is the phrase: "Plan for the worst but hope for the best." Their doctor may have told them something like, "It could be as short as three months or as long as a year". Planning for the worst means planning for the three months. What does that mean?

It means that I encourage the patients to plan to do within those first three months (when they will be at their fittest) all of the things that they wish to do. For example, going to Paris, seeing Uluru, or whatever. This approach reaches its most poignant

expression when it comes to writing letters or memoirs for their children or grandchildren such as letters for their children to open on their 21st birthday — describing their aspirations for them and how much they love and value them and admire them and believe in them for the future. When they do this, their tears fall on the pages. But if the patient waits until the end of their disease course they are often too tired or affected by painkillers to write such letters. I have seen that happen, avoidance of these hard things, and this is sad because it robs the children of a real gift, the gift of reading those letters in the future.

I sometimes think that avoiding the reality of death is like seeing a black door in the house and walking past it all the time, afraid of going through it, afraid of what is on the other side. If they do get to the point when they are able to put their hand on that black door handle, turn it, open the door and walk through it, to their surprise they can enter a garden. In that garden there is a lot of expressed love, and they notice that the sky is bluer than they have ever noticed before, that the leaves of the trees are greener than they have ever noticed before and that because every day is a gift, they live the rest of their life with gratitude. That is not to say that they don't suffer physically or emotionally in the process, but it is to a large extent the difference between dying badly and dying well.

Recently a patient of mine died having spent six months in complete avoidance. She never talked to her teenage daughters about the fact that she was dying. Although at her funeral someone described this "as showing the kids how brave she was", I thought the opposite. Knowing that you won't be there to see your children grow up, see them graduate, walk them down the aisle and see your grandchildren born, you are able to declare your confidence in them, your hopes and aspirations for them

as people and the gifts that make them special now and which will make their futures special. You can ask them to take any good thing they have learnt from you and "pay it forward" to others, rather than always looking back. That is why dying well "makes people better" — survivors are enriched by the process.

So what happened to the 50-year-old lady with the angry family who was in living hell? Well, by an extraordinary coincidence, I went for a haircut and I sensed that the lady cutting my hair just might be her hairdresser daughter. So I brought it up. She knew who I was but was clearly relieved when I brought it up — that told me immediately she was an avoider. I arranged for the Cancer Council Family Counselling Services to visit them and they all sat around talking about the cancer, overcoming their reluctance, holding hands and crying. I know this because when I went to visit my patient in the hospice, she said to me: "Bruce, great to see you. I don't know what you said to my daughter but everything has been transformed. My husband is no longer angry, my son has moved back home and is helping and my daughter is now happy to talk to me about my cancer. In fact every week she comes in here and does my hair. Thank you so much." It is a clear example of someone who could have died badly and left the family with bitterness but who ended up dying well because they had the courage to talk about it and express their emotions. I would predict that the members of that family would feel that their life was in some curious way enriched by having had that intensely personal and open caring experience as a family at that time.

**Bruce Robinson is Professor of Medicine, School of Medicine and Pharmacology, Sir Charles Gairdner Hospital.**

**More help at [www.cancerwa.asn.au](http://www.cancerwa.asn.au)  
[www.solariscare.org.au/home](http://www.solariscare.org.au/home)  
[www.bruceroobinson.com.au](http://www.bruceroobinson.com.au)**





## **TEN TIPS** IF YOUR LOVED ONE OR FRIEND HAS INCURABLE CANCER



Overcome your avoidance urges – visit the patient and discuss the cancer

Don't feel like you have to say the right things. If you don't know what to say, be honest "I wish I knew what to say". And silence is just fine.

If you find yourself getting teary, don't feel embarrassed. Tears are one of the best expressions of empathy.

Be sensitive to spiritual issues – these are sensitive and often intense at this time.

Avoid unhelpful phrases e.g. "I know how you feel", "move on", "time to pull yourself together", "if only you hadn't smoked" and "it could be worse".

Do specific things to help e.g. shopping, helping with clinic visits, picking up their kids from school, cooking meals.

If you are struggling as a carer be willing to ask for help.

Look after yourself. Take breaks that don't involve discussing your loved one's terminal illness. And don't feel guilty if you do so.

Resist the urge to express your anticipatory grief by giving false hope e.g. "I heard on TV about a new diet that cures cancer", "I am sure the doctors have it wrong" and "just keep a positive mental attitude and you will be healed".

Don't be afraid to get family or grief counselling yourself.