



FACT SHEET - Article

Dying Well

"I JUST want to die now. I am living in hell," says my 50-year-old cancer patient.

"I am sorry to hear that," I say. "Are you in pain?"

"No, 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 my son is 'living in sin'."

She continues: "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 like I always have and he thinks she should do it. I just want to die now."

An extraordinary event would change this "living hell" into a happy ending, but more on that later.

As a lung specialist, I have looked after hundreds of patients (lung cancer is the most common lethal cancer) and in the process participated in the "journey to death" of many patients.

Dying is normal, but I have learned there is a way to die well and a way to die badly. I am not just talking about the patient, but also about the family. When the dying process is handled badly, the survivors can be left with a lifelong 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.

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But, when death is handled well, surviving family members often describe a positive effect.

Handling death well starts from diagnosis. This is partly out of the control of the family as it depends a little 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 for doctors at the University of Western Australia Medical School. The right approach involves selecting the right site (a quiet room, with mobile and pager turned off), an empathetic style (sitting down, making eye contact, appropriate touch) and the right words (reaching out with words of empathy, not avoiding the use of the word cancer). The success or failure of that event is not all up to the doctor - it is also determined by the patient and the family.

The patient can feel lonely and isolated. 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 on - their head will be in a spin. It is more likely a loved one will retain the information.

Also, it is too much of a burden on the patient, having received the bad news themselves, to then have to explain it to family members.

It is important to ask the doctor any questions that are on your mind. I remember hearing about a patient that 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 decide whether you and your loved one want to know the prognosis. Not everyone does. 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. 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 treatment commenced, the journey to death continues. This sounds like an awful journey, but it can be made better. Here are some of the things I have noted in my practice that have worked well.

First, don't avoid talking about the cancer. Avoidance is a very powerful reaction, in the patient or among loved ones, 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 you will say the wrong thing, you say nothing.

Love can also 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.

"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" ... "Just keep a positive mental attitude and you will be healed".

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 to get on with grieving.

Second, having gone ahead and begun to talk about their cancer, don't continually ask about it - talk about it, but also about the children, the news, the football - treat them as normally as possible without avoiding the issue.

Third, don't avoid visiting. 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 go home they have zero visitors. This is understandable because some people feel so uncomfortable they don't know what to say; 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.

Fourth, don't just say "Is there is anything I can do to help?" Take the initiative and do something, like help with shopping, offer to take them on a visit to the clinic, pick up children from school or relieve the family of the duty of care for a day. You might even want to help them pull together a photo album of memoirs that they wish to have for their children and grandchildren.

Fifth, thank them for all of the things 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 family that I have used it with. "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. I encourage the

patients to plan to do within those first three months (when they will be at their fittest) all of the things they wish to do: going to Paris; seeing Uluru.

This approach reaches its most poignant when it comes to writing letters or memoirs for children or grandchildren; for example, 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 and this is sad because it robs the children of a real gift, the gift of reading those letters in the future.

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 and that, because every day is a gift, they live the rest of their life with gratitude.

That is not to say 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.

So what happened to the 50-year-old woman with the angry family? Well, by an extraordinary coincidence, I went for a haircut and I sensed that the woman cutting my hair just might be her hairdresser daughter.

She knew who I was, but was clearly relieved when I brought it up - that told me she was an avoider. I arranged for the Cancer Council Family Counselling Services to visit the family and they all sat around talking about the cancer, overcoming their reluctance, holding hands and crying.

I know this because when I visited 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. I would predict, although I don't know for sure, that the members of that family would feel their lives were in some curious way enriched by having had that intensely personal and open, caring experience.

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