

Getting Personal



When patients ask you to help them die

The public, politicians, and legislators debate the morals, ethics, and unintended consequences of assisted dying. But it is clinicians, in the privacy of their consulting room, who face requests to be the person giving that assistance. How do cancer professionals feel about being asked to help someone die, and what do they do? *Cancer World* asked some of our readers. **Simon Crompton** reports on what they said.

“When you see how the patient is suffering, the thought that comes into your head is how to help him or her go, to ease that process. On the other hand, it’s scary to do this according to your morality and the stereotype that physicians can only save a patient’s life. But in the case of dying, this is a matter of the integrity of a patient’s personhood.”

How far would you go to respect a patient’s autonomy? What if they ask you to help them die? It’s a situation that many clinicians have been faced with – but few talk about it in public. All too often physicians, nurses and other health professionals are left to struggle with the dilemma alone, unable to share their thoughts as they try to weigh respect for the patient’s wishes, their own

personal and professional beliefs and abiding by the law.

This year, *Cancer World* asked some of our readers to tell us about their experiences of assisted dying in a confidential survey. Twenty-seven cancer professionals, including the palliative care specialist quoted above, responded. They spoke honestly, on the condition of anonymity.

Ten of them stated that they had been asked by a patient to help them end their life.

Six respondents said that, under the right circumstances, they might help a patient die. Among them was an oncologist from Southern Europe, who told us of his internal battle when a woman of 72 with metastatic breast cancer asked to meet him out of the hospital set-



ting, and then asked him whether he would help her die if she were losing her dignity.

“She wasn’t currently my patient, but she had been my patient during adjuvant treatment and she had come to my clinic for a second opinion about her current treatment plan. She said she wanted to speak to me confidentially, but she didn’t want to talk in the hospital. So I agreed to go out to dinner with her, and she told me the remarkable story of her life. Then she said she knew she was dying, and that she knew things would get worse, and she really didn’t want to be put in the position of losing her dignity. What she was most worried about was not being able to choose any more, once in a hospital situation.

“She said she was sure I could find a way to help her if needed. So I said, ‘You are asking me a lot, and we will do all we can to ensure you are not in pain and won’t lose your dignity.’ So she said, ‘Yes, I know doctors say that to everybody, but when it really happens you must be there.’ So I felt in a bit of a corner, and finally I made a commitment that I would be there.”

Over the coming months, the oncologist kept informed of the patient’s progress as she began palliative treatment

and she phoned him with updates. “And when things got really bad for her, she didn’t ask me anymore,” says the oncologist. “She was well palliated, and she died at home. It’s rare for people to die in peace, without regret. But for her, having a Plan B in place in case everything went wrong, was good.

“To be honest, I don’t know what I’d have done if she had called me one evening and said ‘I’m sick of this, please help me.’ Probably I would have gone to speak with her and looked at the possibilities, maybe discussed it with the supervising physician a little bit. But it was all a bit borderline. I didn’t rule it out, but I didn’t intend to do it. There was a disturbing feeling that I had committed to something that was practically, ethically and legally very difficult. But when I think of it now, I still think I made the right choice at the moment I committed to it. I couldn’t just pass it by.”

“I felt in a bit of a corner, and finally I made a commitment that I would be there”

Getting Personal

Not everyone would have responded in the same way. But the fact is that the issue of assisted dying raises its head regularly enough in the clinic for it to weigh on the conscience of many practitioners for a long time.

Public pressure

There is new pressure to reopen public debate about the role of doctors in helping patients end their lives. In February this year, the *BMJ* (*British Medical Journal*), called for an independent poll of doctors on the issue of assisted dying, asserting that doctors' organisations are out of step with public opinion. The *BMJ* editorial quoted UK and US polls where 80% of the general public expressed support for assisted dying, and surveys showing a growing number of doctors are also in favour.

Yet the most common responses to the *BMJ*'s series of articles on assisted dying was that doctors should not be involved in intentionally bringing about the deaths of others, and that assisted suicide might be open to abuse.

For advocates of health professional involvement in assisted dying, a patient's right to self-determination is paramount.

For opponents, any role in assisting death fundamentally compromises health professionals' responsibility to do everything possible to preserve life and quality of life. Both sides believe fundamentally in maintaining a relationship of trust with dying patients, but take a different stance on how best to preserve it.

For some, the law is unbreachable. For others it seemed a lesser consideration than the autonomy of the patient. Everyone cared deeply

Overarching everything is the law, which provides a different framework from country to country. In the Netherlands, Belgium and Luxembourg, the law allows physicians to administer lethal substances under specific circumstances. In Switzerland a doctor may assist in a suicide, for example by providing drugs. Everywhere else in Europe it is illegal for health professionals to help people die, although there is provision for 'passive

euthanasia' – disconnecting a feeding tube, for example – in many countries.

For some who responded to our survey, the law is unbreachable. For others, it seemed a lesser consideration than the autonomy of the patient. Most of the responses reflected a sense of internal conflict. Everyone who responded cared deeply.

The options

"There are so many stories that I could share with you," said a cancer nurse from Southern Europe. "But basically all relate to the inability to adequately control the pain and the suffering of patients who are in the terminal phase. Of all the situations that I have witnessed, cases of dyspnoea were the ones that cost me the most. Is it really so difficult to provide a dignified death?"

Is it inevitable that clinicians should be put in such difficult situations? The survey responses, and the experiences recounted, suggest that health service excellence might largely prevent the issue of assisted dying arising – certainly for cancer patients. Two areas stand out as being particularly important: timely and empathetic communication and excellent palliative care services.

A clinical oncologist from Western Europe recalled how a patient with metastatic breast cancer, referred to him for palliative radiotherapy, had sat down in a consultation and stated very firmly that she expected him to respect her wish for assisted suicide or euthanasia if and when she had had enough. "I was slightly surprised she used this as her introduction at the start of the consultation, but we discussed her feelings, how the law would consider such actions as criminal, and in addition how I did not support assisted suicide or euthanasia. And then I said, we'll note that and can talk about it in due course. But I want to talk about your symptoms now. Eventually, we were able to talk about how her fairly stable metastatic breast cancer required a short course of palliative radiotherapy, which she agreed to."

Her symptoms were controlled and the clinical oncologist continued to see the patient regularly for three more years. She died from her progressive disease under the care of her medical oncologist in a hospice. "I always reassured her we would do all we could to control symptoms of both her disease and her treatments. She never repeated her request for assistance to die. Palliative care did what we assured her it would."

The clinical oncologist thinks that having time to talk to her about what could be done to keep her free of pain and

What else respondents said

“A physician became my patient when he was diagnosed with cholangiocarcinoma. He asked for my help in terminating his life and, in fact, unsuccessfully attempted suicide on his own. After that we had several long conversations about the options. He died a few months later, naturally, with the services of a hospice.”

“I would not help a patient die, but I completely understand the suffering and I would do my very best to help with the pain to the best of my knowledge and my competence. I would try to help my patient have an ‘easy’ passing.”

“In patients with clear disease awareness, I usually explain the possibility of controlling symptoms for as long as possible. When symptoms become uncontrollable I propose sedation.”

“A friend of mine, a physician herself, who died of breast cancer, asked me to support her to keep control over her life by helping her to finish it when she decided to end her life.”

“One of my patients, a 65-year-old gentleman with pancreatic cancer, didn’t want to try second-line chemotherapy. Although he was comfortable in hospital, he asked me to help him die sooner, but I refused. He was transferred to a palliative care unit where he died one month later. Was this ‘more time waiting for death’ worthy of him?”

symptoms, and to keep her life as normal as possible, was crucial. “We have to be honest that palliative care cannot stop every symptom. And we also have to say that the situation may be different in cancer, where loss of independence and dignity is probably less of an issue than degenerative neurological problems, or respiratory conditions such as COPD.

“But having said that, I do think communicating and listening to what the person has to say are incredibly important – and that’s what palliative care specialists are brilliant at. Unfortunately, that kind of attention is lacking in a lot of situations in any health service.”

In some Eastern European countries, palliative care is not well developed – and this presents major problems for cancer clinicians. One palliative care specialist from the region remembers how, five years ago, a terminally ill patient asked her to help him die. “He impressed me greatly, and he was suffering pain very very badly. As a human being, I understood his desire to escape. But I said I couldn’t do this: it is against my humanity, against my religion, my profession.”

With no morphine available, the man died in pain. “It was a very sad situation,” she said. Palliative care has only been pioneered in her country in the past ten years, and it was only recently officially accepted as a speciality. “There was nothing I could do for him five years ago, but now there is morphine available I could control his pain. With good symptom control, we don’t postpone death and we

don’t hasten death – we make someone’s life easier. That is the extent of our responsibility. Once you have palliative care, assisted dying becomes less of an issue. If they are not in pain, the issue is less likely to be one that the patient considers.”

Blurring lines

But overlaying many of the comments returned by clinicians who responded to the survey is an awareness of past abuses of the power of life and death by doctors, and the blurriness of lines when it comes to reducing suffering and indignity without hastening death.

A surgeon from Eastern Europe commented that the legitimate question of whether doctors should be involved in assisted dying was unfortunately overshadowed by the

“Communicating and listening to what the person has to say are incredibly important... Unfortunately that kind of attention is often lacking”

Getting Personal

past: “We remember the awful history of euthanasia in the 1940s,” he said, referring to the organised murder of people under the name of euthanasia around the time of the second world war. “But it should be discussed again really seriously. Putting myself into a dying patient’s shoes, I would not want my suffering prolonged. The life of a human is his life, and it is for him to decide.”

“I would not want my suffering prolonged. The life of a human is his life, and it is for him to decide”

A doctor from Western Europe, who opposes medical involvement in assisted dying, said baldly: “The trouble is I don’t always trust my profession.” Before the development of palliative care and the hospice movement, he said, doctors regularly repressed dying patients’ respiration with opioids

so that they ‘slipped away’. But he said that recent cases of patients allegedly having their lives unnecessarily shortened with diamorphine – for example, at Gosport War Memorial Hospital in the UK – only emphasises how easily a sense of trust between doctors and patients can be jeopardised once they see ‘helping people slip away’ become part of their role.

A Southern European doctor said that once there was public debate about medical practice at end of life to uphold patient autonomy and minimise suffering, a ‘slippery slope’ was exposed. “Some situations are easy because, if you have a terminally ill patient in pain, there is really no issue in taking the morphine up and up. It’s kind of implicit when you’ve discussed things with the patient and relatives, and controlling pain is the priority. But things get more difficult when there is not serious pain, and when the patient is just very clear about what they want.”

Responses to the survey demonstrate that theoretical debates about health professionals’ involvement in assisted dying have a concrete reality in the clinic. Clinicians are faced with dilemmas that cause them much private soul searching and there are no easy answers – either in public debate or in the face-to-face immediacy of clinical situations. But sadly health professionals usually face assisted dying dilemmas alone and unsupported, worried about the consequences to their patients, themselves, and their profession, if they start sharing the burden. Somehow, that needs to change.

Trust can be jeopardised once doctors see ‘helping people slip away’ as part of their role

The Southern European physician who promised to help the 72-year-old breast cancer patient looks back on the episode and believes there’s only one thing he’d do differently today. “I wouldn’t be alone in the situation – I wouldn’t have a private agreement with a patient. I think the implications are so big that I would seek help from someone else, and maybe just say to the patient: ‘I’m on your side, but maybe if we got someone else involved, it might help us sort it out.’ We take responsibility for other important medical decisions, but we share them with colleagues or teams before making them, and that helps a lot with the burden of responsibility. Discussing, understanding, sharing is important.”

To comment on or share this article go to bit.ly/CW83-AssistedDying

The survey

Cancer World used SurveyMonkey to email the survey to more than 7000 *Cancer World* readers working in a broad range of capacities.

We said we would like to hear from people who had faced requests from patients to help them die. We were interested in exploring the dilemmas clinicians face when their patients ask them: “If and when I decide I don’t want to carry on, and I want help to die, will you help me?” We said we would like to know the background to the request (the situation of the patient), how they (the physician) responded, how they reached their decision on how to respond, what happened in practice, and how they felt in retrospect about the way they had handled their patient’s request.

We promised to preserve anonymity.

We received 27 substantive responses from people working across 10 European countries, in roles ranging from medical/clinical/haemato-oncologist, radiation oncologist and surgeon, to palliative care specialist, cancer nurse, clinical pharmacologist and GP.

This article is based on those responses, together with interviews with some of the respondents.

The findings are interesting because they throw a light on how cancer professionals view their own role and responsibilities, how they weigh up the dilemma and what they actually do when a patient asks for help with dying. However, they should not be taken as representative of opinion among European cancer professionals, as the sample was small and there are many reasons why survey recipients who have been in this situation may have chosen not to record what transpired. We would like to thank everyone who did respond for sharing their personal stories.