

THE INESCAPABLE TRUTH ABOUT DYING IN SCOTLAND

“Assisted dying would bring me peace. It would allow me to live my life to the very end.”

**DIGNITY
IN DYING
SCOTLAND.**

Acknowledgements

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Written by Lloyd Riley and Davina Hehir

Research support from Hannah Easdown and Upeka De Silva

Research interviews by Professor Bronwyn Parry and Sally Eales

Design by Weaseldance Design

Photography by Luke Doyle and Chris Leslie

Legal advice from Paul Mason, Doughty Street Chambers

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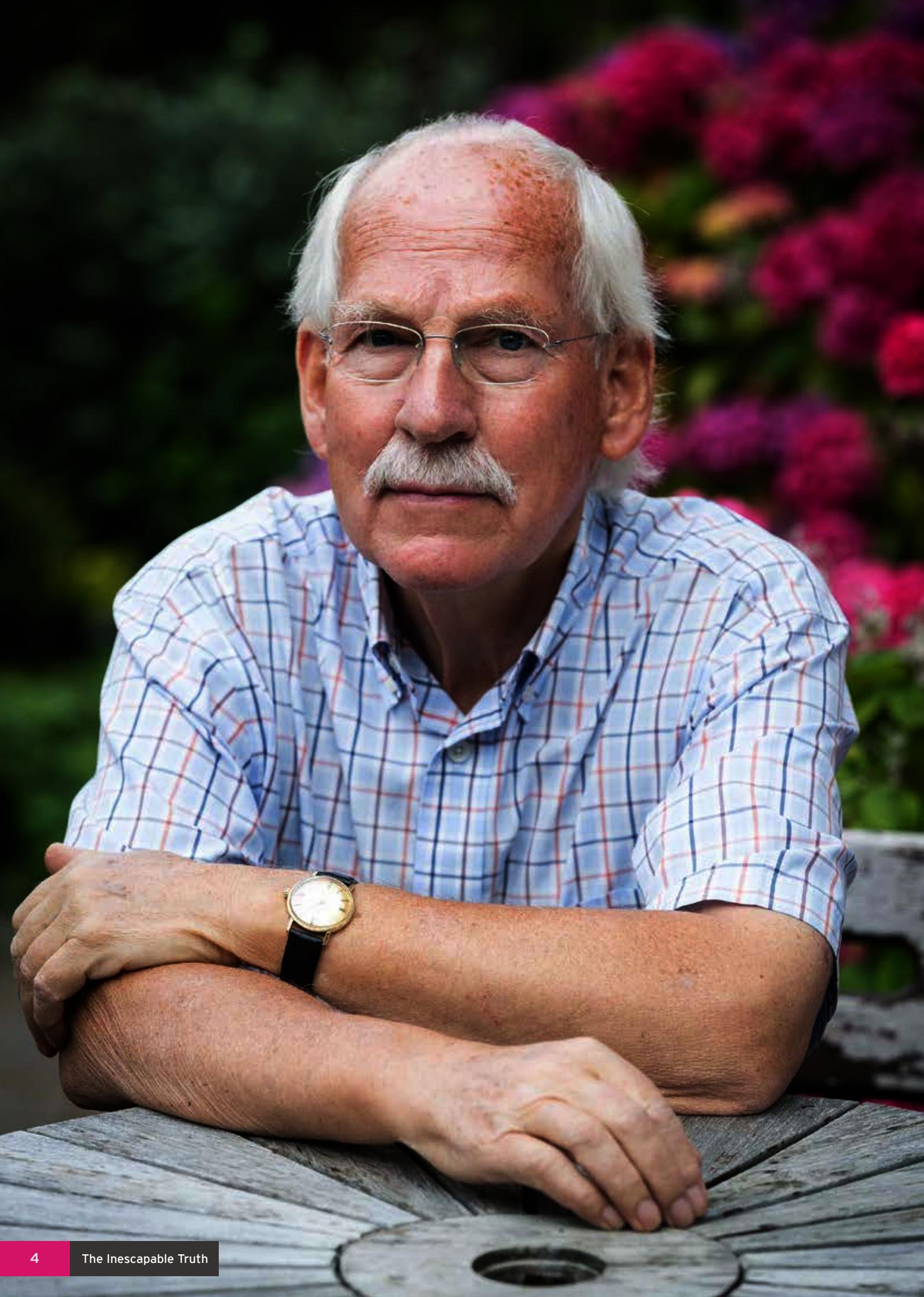
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WARNING

This report contains detailed and graphic accounts of physical and emotional distress that people have experienced at the end of life. A list of organisations that can provide support and information around terminal illnesses, end-of-life care and bereavement can be found on page 91.

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Foreword

“ I have participated in many debates on assisted dying, in public and in private. Invariably, one of the points raised in opposition to law change is that we must do more to develop our palliative care services, the logic being that as the availability of good palliative care increases any need for assisted dying will subside.

My immediate response has always been that of course we must prioritise good care – and indeed experience overseas shows that when assisted dying is legalised palliative care in enriched and prioritised – but that there will always be a small but significant number of people who will suffer even when they have access to the very best palliative care.

When I next speak to someone who thinks that the answer to every person who wants an assisted death is more investment in palliative care, I will show them this report.

I will sit with them as they read it. When they are finished I will ask them to look me in the eye and tell me that they are content with the pain and misery that some dying people in Scotland are being forced to endure every single day.

I will ask them how a compassionate, free-thinking society in the 21st century could expect its citizens to tolerate such agony, rather than find a way to do what other nations have done and implement a law that offers a safeguarded, transparent means of relief from suffering for dying people.

I will ask them to listen carefully to those who have courageously shared their stories on the pages that follow: the compassionate honesty of palliative care professionals who recognise the limitations of their speciality; the trauma of bereaved relatives whose precious memories have been poisoned by the things no son, daughter, mother, father, sister, brother or partner should ever have to witness; and the fear of dying people who simply want the peace of mind that comes through having choice and control at the end of their lives.

This report proves that these are not stories that will dissipate with greater resourcing of palliative care. To put forth that view disregards the voices of the people whose suffering sits beyond the reach of the medical profession.

What must we do to address the needs of those Scots whose suffering could never be relieved by existing palliative care practices? How can we move towards a goal that surely commands a consensus – a society where nobody is forced to endure a painful, undignified, harrowing death against their wishes? The answer is not to dismiss these as fringe cases, divert our attention or find refuge in sophistry that claims that all suffering can be alleviated with good care. We must change the law. We must find a way to provide the safeguarded option of an assisted death. We must do everything we can to provide for all dying people of this country.

Professor Sir Graeme Catto

Former President and Chair of the General Medical Council

Executive summary

This report exposes a truth about dying that is often ignored and sometimes even mistakenly denied: like all areas of medicine, specialist palliative care has its limits.

The nature of these limitations means that, whilst the majority of dying people will have their symptoms managed, a small but significant minority of people will suffer intolerably throughout the final months, weeks and days of their lives.

This is not an argument against specialist palliative care or an effort to diminish the valuable work of those who provide care at the end of life more broadly. On the contrary, campaigners for assisted dying recognise this vital work and support all efforts to improve the quality of care in this country through investment, research and improved access.

However, even if there were universal access to the highest quality care, some people would still have no relief of their pain as they died. This is what is happening to dying people at present. Others suffer with symptoms that they feel rob them of their dignity. What these dying people go through, against their wishes, could be regarded as the collateral damage of maintaining the prohibition of assisted dying.

The experiences shared in this report do not represent the majority but they do reflect the reality of dying for a small but significant group, and they should not be ignored.

The prospect of experiencing such physical or emotional distress causes dying people to fear the future. This fear can be a form of suffering in itself, leading to a reduction in quality of life. In contrast, having the option of an assisted death would be a source of comfort and reassurance to many dying people.

An examination of end-of-life practices reveals the line between the current law and assisted dying is often blurred and this raises ethical questions for healthcare professionals to which there are no clear answers. In this context, assisted dying would not be a substantial departure from what is happening now, but it would provide a safe, transparent and compassionate option for those who wish to control the manner and timing of their deaths.

KEY FINDINGS

1. **At the end of life, some people experience severe pain and other symptoms that result in suffering**

Some dying people experience physical and emotional suffering. Crucially, this suffering occurs even when high-quality specialist palliative care is present, meaning improving the provision of care will not address this problem. Specialists in palliative care and pain management whose interviews are featured in this report confirmed that they see cases where a person's suffering cannot be relieved despite their best efforts.

In research commissioned for this report, the Office of Health Economics concludes that, even if every dying person who needed it had access to the level of care currently provided in hospices, 591 people in Scotland a year would still have no relief of their pain in the final three months of their life. This equates to 11 Scots every week. Evidence suggests the number of people suffering from other symptoms of the dying process is likely to be much higher.

2. Current end-of-life practices are no less ethically complex than assisted dying

The practice of sedating people until death, dying people choosing to stop eating and drinking, and the disputed principle of double effect (where the legal administration of pain relief or sedatives may result in someone's death) raise significant ethical questions for healthcare professionals. Many healthcare professionals do not consider there to be a clear difference between current end-of-life practices like these and assisted dying, while some do not consider these practices to be effective alternatives to the option of assisted dying. What's more, some of these practices leave decision-making in the hands of doctors rather than dying people.

There are cases in the UK where healthcare professionals intentionally end the lives of dying people with compassionate motives, blurring not only the principles of medical ethics but also the boundaries established in criminal law.

Bereaved relatives often do not consider these end-of-life practices to be effective in relieving suffering. They can lead to protracted and painful deaths and can deny people a clear opportunity to say goodbye to their loved ones, which negatively impacts on bereavement. Bereaved relatives who have witnessed a loved one suffering at the end of life can experience symptoms of complex grief and post-traumatic stress.

Current end-of-life practices lack the safeguards, regulation and guidelines that would be present under an assisted dying law.

3. Having the option of assisted dying would lead to an increase in quality of life for dying people

Dying people view the option of assisted dying as a choice that would significantly increase their quality of life. The comfort and reassurance of knowing they would have the means to relieve their suffering and die at a time of their choosing would be considered just as valuable as having access to the best possible palliative care.

In the absence of a safeguarded assisted dying law, dying people live in fear of what their deaths may be like. This is not fear resulting from ignorance; it is often triggered by first-hand experiences, knowledge of the limitations of end-of-life practices and an awareness of the uncertainty that surrounds how their condition may progress.

Some dying people's fear of suffering is so strong that it leads to them attempting to end their life. This can lead to severe distress for everyone involved and the absence of professional assistance means these attempts can fail.

POLLING RESULTS

46% of Scottish healthcare professionals have experience of caring for someone who has suffered at the end of their life despite receiving high quality palliative care.¹

41% of Scots have witnessed a dying family member or friend suffer unbearably towards the end of their life.²

62% of Scottish healthcare professionals believe there are circumstances in the UK in which doctors or nurses have intentionally hastened death as a compassionate response to a patient's request to end their suffering.¹

Only 29% of Scottish healthcare professionals think refusing treatment to bring about death is more ethical than giving people the option of an assisted death.¹

Only 14% of Scottish healthcare professionals think that without an assisted dying law there are sufficient options available to give dying people meaningful control over their deaths.¹

Only 6% of Scots think the laws prohibiting assisted dying are working well.²



RECOMMENDATIONS

In light of the issues highlighted in this report, Dignity in Dying Scotland supports:

- the Scottish Government's commitment to end-of-life care, set out in its Strategic Framework for Action on Palliative and End of Life Care.³
- the vision of the Scottish Partnership for Palliative Care, which seeks to improve people's experiences of declining health, death, dying and bereavement.⁴
- the 2018 amendment to the Social Security (Scotland) Bill which increased access to benefits for people living with a terminal illness and the recommendations of the Our Voice Citizens' Jury on shared decision-making and a personalised approach to health and social care.^{5,6}

However, evidence shows that even if all these things were to be implemented, some dying people would still suffer at the end of their lives. Therefore, we also recommend that:

- all healthcare professionals involved in the provision of end-of-life care are given sufficient training and accurate information around the likelihood of symptoms of suffering associated with the dying process and, where possible, how to manage these symptoms effectively. This should include resources to help healthcare professionals have honest conversations with dying people about the types of symptoms they might experience.
- relevant associations and regulators for healthcare professionals produce up-to-date, national guidance setting out best practice around palliative sedation and the practice of voluntarily stopping eating and drinking. This guidance should be tailored to healthcare professionals and also members of the public, so that dying people and their loved ones have clear and transparent information about what choices are available under the current law and how those choices can be implemented. The guidance should be produced with the input of dying people and bereaved family members and friends who have first-hand experience of these practices. Guidance should reflect current societal attitudes and values, rather than historic norms of medical ethics.
- assisted dying is legalised in Scotland to give terminally ill, mentally competent adults a further option of escaping or avoiding a period of unbearable suffering at the end of lives.

Methodology

INTERVIEWS

The content of this report is based on interviews with people who have been affected by the limits of palliative care. 25 semi-structured interviews were conducted by Bronwyn Parry, Professor of Global Health and Social Medicine at King's College London and her Research Associate Sally Eales.

Interviewees belonged to three groups:

- People living with a terminal illness.
- People who have recently witnessed a loved one with a terminal illness suffer at the end of life.
- Healthcare professionals with experience of caring for people approaching the end of life. This included GPs, palliative care consultants and doctors, palliative care nurses and pain specialists, with a combined 165 years' experience.

A thematic analysis of the interviews was conducted and an extensive review of the literature available on each of the identified themes was carried out.

All interviewees gave their full consent for the content of their interviews to be accessed by Dignity in Dying and used in this report. All the quotes in the report are taken from the interviews, but may have been abridged for concision and clarity. All images used in the report are of people who were interviewed or people whose stories are featured. Some interviewees opted to remain anonymous. Interviewees were from across the UK, including Scotland.

STATISTICS

Dignity in Dying commissioned the Office of Health Economics (OHE) to carry out a review of literature on pain relief at the end of life. The OHE then used the available and most reliable quantitative data to estimate the current extent of unrelieved pain in end-of-life care in the UK. The OHE also extrapolated the data to estimate the frequency of unrelieved pain that would be present even if every dying person who needed it had access to high quality palliative care.

Dignity in Dying commissioned two polls for this report. Polling of a sample of healthcare professionals, weighted to be representative of the NHS workforce, was carried out by YouGov. Polling of a representative sample of the general public was carried out by Populus. Both these polls were conducted in March 2019. Figures quotes in this report are from the Scottish sample of these polls.

REVIEW

This report has been peer-reviewed by a group of palliative care experts who were not amongst the interviewees.



Introduction

“ Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering.

World Health Organisation⁷

THE LIMITS OF PALLIATIVE CARE

The British Medical Association (BMA) states ‘high quality palliative care can effectively alleviate distressing symptoms... for most patients.’⁸

To date, research has not quantified the number of people whose distressing symptoms cannot be alleviated by even the best palliative care. Furthermore, little effort has been made to explore the impact those unrelieved symptoms can have on dying people, their families and the healthcare professionals who care for them.

This report draws on the experiences of bereaved relatives and healthcare professionals who have witnessed extreme suffering at the end of life. It also explores the views of dying people who live with the knowledge of the suffering that may await them.

CURRENT END-OF-LIFE PRACTICE

The withdrawal of life-sustaining treatment, palliative sedation and people being able to choose to stop eating and drinking to hasten their deaths have been put forward as suitable, legal alternatives to assisted dying. This report examines these practices in detail, highlighting their benefits and shortcomings.

Dignity in Dying’s report *The True Cost: How the UK outsources death to Dignitas* uncovered injustices caused by the current law.⁹ The report found that dying people who do not have the money or physical ability to travel overseas, or who lack the support of people willing to break the law, can be denied the peaceful death they seek which often results in people seeking alternative means to end their lives.

This report builds on those findings and examines the suffering experienced by some dying people and the lengths to which they often go to achieve a degree of choice and control at the end of life.

GIVING A VOICE

This is not a report about how the majority of people in Scotland will die. Instead, this report gives a voice to the small but significant group of people who die in a manner that they and their families consider unacceptable.

SYMPTOMS



1. Pain

The only thing in her life was pain. It was strong enough to bring her bubbling up from this cocktail of drugs she was being given.

Bereaved daughter

PEOPLE DO EXPERIENCE PAIN AT THE END OF LIFE

Pain can be severe at the end of life, as terminal illnesses can disrupt the body's usual functions. Macmillan Cancer Support suggests around half of people who have cancer will experience some pain,¹⁰ though others have estimated the figure to be much higher.¹¹

Pain can be relieved through simple painkillers such as paracetamol and ibuprofen or opioids such as codeine, morphine and fentanyl. Other drugs such as antidepressants, steroids and psychoactive substances can also be involved in treatment.^{12,13} Non-pharmacological treatments such as talking therapies have been shown to successfully contribute to the management of pain.¹⁴

Studies have shown that having pain controlled is the primary factor associated with having a good death.¹⁵ The BMA's research into public and professional perceptions of end-of-life care found that being in pain at the end of life was a fear of both the public and doctors. Doctors viewed pain as something that could be managed, but acknowledged that it could not be eliminated entirely.¹⁶

In the interviews featured throughout this report, healthcare professionals echoed this view.

“ There are people who are in intractable pain, whose pain we can't deal with adequately and that may be because they really have such complex physical pain issues that we can't find the right combination of drugs or the side-effects are too great.

Palliative care nurse

“ Those last couple of weeks, particularly for people with cancer, can be very awful; some can be fine, but they can be very awful. Pain, difficulty breathing, confusion, incontinence...

GP

“ I remember a patient from a couple of years ago who had very, very severe pain from a cancer that was affecting nerves in his back. He was in exceptionally difficult pain. He was young, he was married and they had a child.

We tried lots of different medications and it was just getting us nowhere. We had gone through all the normal sedation routes and it was just not working.

Palliative care consultant

Dying people described the experience of living with pain and how it made them consider the level of pain they might suffer in the future and whether or not they would find it tolerable.

I know what pain is. Pain where you cannot think about anything else, you're just rocking there thinking, 'Where's a gun? I want to go now.'

I've had that pain and if it was the case that it couldn't be controlled I would want to die. I don't want a life that has that amount of pain, to lose my identity. If I became somebody enveloped by pain, then at that point I don't want life.

Dying person

“ Everything is overlaid with this constant pain. Making decisions when you are being pushed around by pain is not a very comfortable thing. But I've never, even on my lowest days, said, 'I'm sick to death of this, I'm going to end it all.' I'm a terribly optimistic person, so I love my life. I haven't yet got to that pitch, but I can see a time when I might want to make a decision that I wouldn't make today.

Dying person

Bereaved relatives described witnessing their loved ones in pain, even when they had access to specialist palliative care.

“ The blood just wants to defend the body, so he was getting blood clots all over his body and they were exceedingly painful. Sometimes he'd get a blood clot in his leg and his leg would blow up, or his feet. The worst ones were in his penis. They were excruciating because they were massive blood clots building up and there's nothing much you could do. The clots were evil.

Bereaved wife

“ She was very positive, she was very stoic. She had palliative care in the house but then at the end of September she developed gangrene in one of her hands, which they said was due to the cancer and vascular problems. She was in excruciating pain.

Bereaved sister

“ My brother had a brain tumour. In January he was told that he had a few months to live. The brain tumour had multiplied. Nothing anybody could do. He was a young, very fit 50 year old. And basically he couldn't die until every resource of his body was exhausted.

So what happened was that he slowly lost weight, because his body was trying to fight to stay alive. When he finally died, he looked like one of the inmates in Bergen-Belsen. It was horrendous. And I just thought that was just the cruellest death. He was in a lot of pain because of headaches, he was just constantly in pain. He had no choice but to wait until his body had nothing left...

All that suffering, when in late February he could have taken one of those drinks and not had to go through that.

Bereaved sister

One relative said her sister was not aware of how much pain she would be in at the end of her life. She was in a hospice and the palliative care team had told her they would ensure she had a peaceful death.

“ They did tell her that they would manage her pain. They kept saying that she wouldn't be in pain. She was in pain. She was crying and sometimes she was yelping like a dog. She kept saying, 'Nobody told me it would be like this.'

Bereaved sister

COMPLICATIONS OF PAIN MANAGEMENT

Approximately 10% of people have a genetic variation which can lead to complications in how they respond to pain relief medication.^{17,18} This genetic variation can mean pain relief is ineffective or that higher doses are required. Prolonged use of pain relief can also lead to the requirement for higher doses.¹⁹

High doses of pain relief are associated with symptoms such as drowsiness, hallucinations, nausea, vomiting. Constipation is a common and difficult to manage side-effect of pain treatment and this will be explored in more depth in another chapter. These symptoms are shown to reduce quality of life and are often considered intolerable by patients.^{20,21,22}

Two of the problems all the way through were that she was allergic to anti-sickness and anti-pain medication. We tried everything. She was pacing all night, every night, and that was right through to the end.

Bereaved daughter

“ There are cases where some people seem to be immune to painkillers. Some people are allergic to morphine, even the synthetic morphines. Sometimes people just don't feel they ever quite get on top of the pain.

Palliative care nurse



“ Some people are resistant to the drugs and some people do have pain which isn’t amenable to opioid drugs.

GP

“ I think if she had been tolerant of morphine her death would have been more like what they told us in the hospital. It would have been calm, becoming weaker and then unconscious. But she was allergic.

Bereaved daughter

“ One of the things we found was that my mum had a reaction to morphine. That was something that would actually cause some more pain, so that reduced their options.

Bereaved daughter

A fear for some of the dying people interviewed was that they were already on high doses of pain relief medication and their tolerance had increased over time.

“ Tramadol is the only painkiller that has any effect. I’m now taking the maximum dose that I can take.

Dying person

“ I go to secondary breast cancer support groups. There are perhaps a dozen or so of us sat there and we have a consultant come in to talk about pain and what could be done to relieve it. I did a straw poll and said, ‘Is anybody else on morphine?’ Nobody else was and I couldn’t believe it. I was really dumbfounded because I’d been on it right from the start and this level of pain has become normal to me. I thought that other ladies in a similar situation would have pain that needed to be controlled by morphine. But lucky for them they hadn’t.

At the end I don’t think pain relief is going to be enough because I’m on high doses now. I take 46 tablets every day at the moment and I cope, sort of. But if I had more progression in my spine...

Dying person

Many interviewees, including professionals, bereaved relatives and dying people, highlighted the unpleasant side-effects that can result from pain relief medications. As well as physical symptoms, this included the difficult compromise people often have to make in order to preserve their mental clarity, at the cost of sacrificing relief of their pain.

The Scottish Intercollegiate Guidelines Network advises that ‘patients on strong opioids should be assessed regularly for changes in pain relief, side effects and quality of life.’²³

“ A lot of medication has side-effects which will make people drowsy. We always work with patients to identify where the balance lies for them. Almost inevitably there is some degree of compromise with the things that are actually available to anybody to use.

That compromise might extend to someone saying that they would want to be very sleepy and have no pain, as opposed to being more alert and awake and having pain. We can deal with those cases but it does include a necessary compromise.

Palliative care consultant

Some of the painkillers I’m on have made me not quite as sharp mentally as I used to be. I’m still writing, I write plays and novels, and the idea of losing that creative part of myself is just unbearable.

Dying person

“ Most people want to be alert and have quality time to talk to family. What we hear is they don’t want to be drugged up. A few people will say to us, ‘Oh, can you just sedate me? This is horrible. Just sedate me. Give me lots of that stuff.’ But most of the time it’s, ‘No, please don’t make me drowsy. I don’t want to be drowsy.’ A lot of people decline having morphine because they want to keep their faculties and they want to be able to make decisions and talk to their families. But that does have an effect on their pain levels.

Palliative care doctor

We get symptom control right the majority of the time. There are a small number, I think a small percentage, of patients who continue to suffer until they die.

Palliative care doctor

There is widespread agreement that even specialist palliative care cannot relieve all pain all of the time.

In 2004, the Chair of the BMA's Medical Ethics Committee, Dr Michael Wilks, told the Westminster Parliament that 'there are patients for whom even the best palliative care is not dealing with their pain... in spite of excellent palliative care, the position is not necessarily one which those patients regard as beneficial to them.'²⁴

In 2014, Professor Bill Noble, then medical director of Marie Curie, told The Guardian 'If you haven't got complete pain control it isn't necessarily because the doctor doesn't know what he is doing. There are people who never have their pain relieved.'²⁵

Baroness Ilora Finlay, a professor of palliative medicine and co-founder of the organisation Living and Dying Well, acknowledges that palliative care is not a 'panacea.'²⁶

Despite these acknowledgements there have been few attempts to research how many people receiving palliative care do not have their pain relieved and there is no standardised data collection to quantify the problem.

The World Health Organisation (WHO) claims its three-step pain relief 'ladder' for cancer pain relief in adults is 80-90% effective.²⁷ This is backed up by research claiming up to 90% of cancer pain can be adequately treated by pain management guidelines.²⁸

In Australia, the government-funded Palliative Care Outcome Collaboration (PCOC) collects data from over 100 palliative care services across the country. The most recent report showed that in the last few days of life 4.9% of patients experienced severe physical pain.²⁹

The PCOC data was cited in a government inquiry in Victoria, Australia, which was exploring end-of-life choices. The inquiry concluded that the 'prohibition of assisted dying is causing some people great pain and suffering.'³⁰ The report concluded that the government should continue to develop palliative care and legalise assisted dying.

Attempts in the UK to estimate levels of unrelieved pain at the end of life have arrived at similar figures to those found by the WHO and PCOC. The Church of Scotland claims 'in more than 95% of patients' severe pain can be controlled.³¹ One study of palliative care patients found successful pain control with minimal side-effects was achieved in 96% of patients.³² Dame Cicely Saunders, founder of the modern hospice movement, estimated that pain could not be controlled in approximately 2% of hospice patients.³³

46% of Scottish healthcare professionals have experience of caring for someone who has suffered at the end of their life despite receiving high quality palliative care.¹

41% of Scots have witnessed a dying family member or friend who was suffering unbearably towards the end of their life.²

In light of the evidence gap in this area, Dignity in Dying commissioned the Office of Health Economics (OHE) to study existing literature on the levels of unrelieved pain at the end of life. Their findings can be found in figure 1.

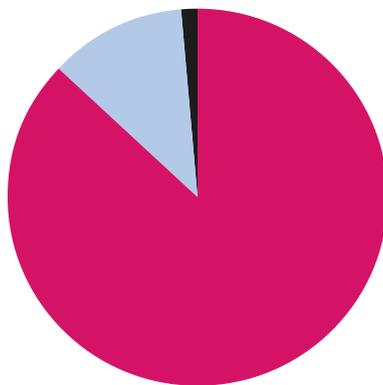
Source of data	Frequency of unrelieved pain
Clinical literature	10 - 15%
Self-reported	30%
Reported by family and carers of hospice patients	13.4%

Fig.1

A more detailed examination of the levels of pain reported by family and carers found that 1.4% of bereaved relatives said their loved one who died in a hospice had no relief of their pain in the last three months of life. A further 12% reported only partial pain relief. These were the most conservative estimates found in the literature.

The OHE extrapolated these figures and concluded that, even if every dying person who needed it had access to high quality, specialist palliative care in Scotland, 591 people a year would still have unrelieved pain in the final three months of their life. The OHE’s report can be found at www.ohe.org.

Figure 2 represents an estimate of the ‘best-case scenario’, where there is universal access to high quality, specialist palliative care in Scotland.



Number of deaths requiring palliative care	42,211
Partial pain relief	5,656
No pain relief	591

Fig.2

Therefore, the figures from the OHE’s research analysis suggest that an estimated 11 Scots a week will experience no relief of their pain as they die, regardless of future investment in or improved access to specialist palliative care.



2. Social, psychological and spiritual pain

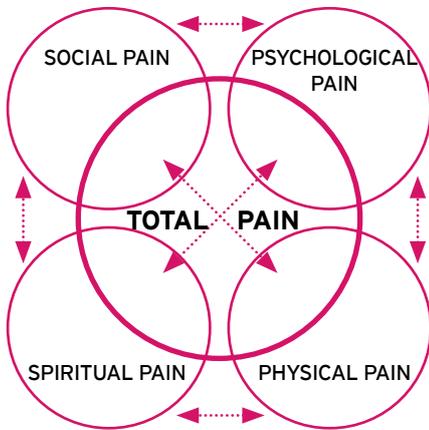


Fig.3

Previous chapters have focussed on physical pain. However, this is only one aspect of what can be called ‘total pain’, a concept developed by pioneers of hospice care. Total pain is illustrated in figure 3.

Experiencing any one aspect of total pain can cause suffering, though people approaching the end of life often experience a combination.³⁴

“ There’s what we call total pain, where you can’t really distinguish the physical from the emotional and spiritual pain, and I think that’s the most difficult thing to deal with and the most distressing for everybody concerned. That doesn’t happen very often, but it does and it’s very, very difficult.

Palliative care nurse

“ Palliative care as a specialty has always been slightly different to many other medical and surgical specialties in that we really have a holistic view of the people that we see. So, as compared to some specialties where the medical input from the doctors is very much problem-based and quite brief, with my line of work I have to take more of a broad view about people’s wellbeing, and that will include their symptom control, social and psychological aspects of their care.

Palliative care consultant

Hospice care is proven to be extremely effective in treating symptoms of total pain.³⁵ Some interviewees praised the effectiveness of the palliative care their loved one received in terms of how it helped alleviate physical symptoms and emotional distress.

“ She was moved to the hospice and she was there for eight weeks in the end. She was put into a lovely room on her own. All the staff there were absolutely amazing and I think she developed some sort of rapport with them that she couldn’t have with us. I wasn’t there at night and because of the bed sores they had to turn her and that was particularly uncomfortable for her, but they dealt with it extremely well.

She was very angry and grumpy as well, so they were dealing with that side of it. She had a counsellor. What went on between her and the counsellor I don’t know, but I think emotionally that did help. Obviously she asked for things that they couldn’t give her like wanting to go home and die. I think they did the best job they could within the constraints of the law.

Bereaved daughter



“ I couldn’t fault the care. Absolutely brilliant, from organising flowers, to doing her hair if she wanted. By their very nature if they’re in palliative care, they’re caring people. She said, ‘Oh, please leave part of my will to the hospice, so they can provide the same level of care for somebody else.’

Bereaved son

However, many interviewees described cases of extreme suffering that could not be relieved by the specialist palliative care delivered in hospices.

“ One of the most distressed patients I have ever seen in my life was a man who had had a penile cancer. His penis had been removed and he was left with a big open hole directly into his bladder.

He was a very gentle person. He was so ashamed and he would cry. He was begging to have his life ended because he just hated it and he had lived for months in that condition. He was begging to have his life ended because it had absolutely no meaning. He was also in pain, but that was not the main thing; it was the utter degradation. I felt so helpless. We could do nothing about that.

Palliative care consultant

Her body was ravaged. It was awful. It was just horrendous. I don’t know what she would have weighed but it was minimal, I would say maybe five stone. She was just skin and bone.

Almost as soon as she entered the hospice, she lost the use of her legs and was bedridden. That distressed her because up until that point she had been reasonably mobile and she could get to the bathroom on her own which was important to her.

Bereaved sister

“ I looked after a man with motor neurone disease who suffered psychologically until the end and there’s only so much you can do. We talked about his suffering. He gave us an impression of his suffering. I feel that we were suffering with him. It was really hard to watch because he wanted to die and he’d ask us, ‘Can you speed this up? Can you give me something?’ He repeatedly asked us if we could do that.

That’s an example of a person trapped in a body that doesn’t work. He was previously a high functioning chap and he’s lying there knowing he has a small number of weeks left just having to stick it out and that’s suffering that I can empathise with. I imagine if I was in that condition it would be awful. It would be horrible.

Palliative care doctor

“ I remember really vividly a young woman, sat on the edge of her bed, who said, ‘I’m very, very frightened,’ and she died a couple of minutes later.

Palliative care nurse

“ A lot of dying patients are getting admitted to a hospice or a hospital for pain control and put on increasing doses of medications. The outcome is poor quality of life. These patients may not find pain to be the major issue. For them it might be the image they have of themselves, the loss of independence, loss of faculties, becoming somebody who they never were.

Pain specialist

“ Symptoms are much more complicated than people probably think from a lay perspective – they have all sorts of physical and psychological and emotional aspects to them, which you often may not get to the bottom of. Sometimes, from a purely physical point of view, there may not be a medication that will help. I think the narrative is very much that if there is a problem it can always be solved with a medication. And of course that is not always easily done, that is a misrepresentation. That is not the truth.

Palliative care consultant



3. Uncontrollable symptoms

This chapter provides an overview of symptoms that were raised by interviewees in relation to suffering at the end of life.

NAUSEA AND VOMITING

Nausea and vomiting are common symptoms of terminal illnesses.³⁶ Studies suggest around 50% to 60% of people with advanced cancer suffer from nausea and/or vomiting, with people under 65 and women more likely to be affected.³⁷

Nausea and vomiting are also common side-effects of pain relief treatment. Approximately one third of people who are given opioids experience nausea, though this side-effect has been shown to diminish over time.³⁸ In one study, 22% of patients withdrew from opioids because of the severity of side-effects including nausea.³⁹ Nausea and vomiting can be treated with antiemetics, but, as one study in a hospice found, even when guidelines are followed symptoms can persist in some people.⁴⁰

“ I think pain is not necessarily the worst symptom you can have. I think nausea is often worse and is often much harder to deal with. A lady I’m treating has nausea and we’ve been through the medication that we would use for nausea and it is not helping.

Palliative care consultant

“ Nausea and vomiting is usually controllable, but sometimes it isn’t and it’s terrible for people, really terrible. They’re just feeling awful all the time, even if their physical pain may be gone. Of course when you’ve got all those symptoms, I think for a lot of people it’s difficult to distinguish one from the other; they all blur into just feeling awful, really awful.

Palliative care nurse

“ The types of medication for nausea are limited. There are certain ones you can try but it’s not always successful and some come with side-effects.

Palliative care consultant

“ My mum started to feel sick and she was bringing up horrendous black bile. She was throwing up regularly. Even just a sip of water and she was just throwing up and it was projectile, she couldn’t help it. She didn’t know when it was going to happen. I just thought, ‘I wish I could put her out of her misery, put a pillow over her head or something.’ It was awful. They tried nine drugs to try and stop the sickness. One lovely district nurse even came back when she was off duty to try and help.

Bereaved daughter

“ She was desperately thirsty so she would beg for an ice lolly or for some water and then within five minutes she would be violently retching and throwing it up and then she’d say, ‘It doesn’t matter how much I beg, don’t give me any more. I can’t go through that again.’ Of course, within five minutes she would be begging again and that went on for eight weeks. It was awful, absolutely awful. She was allergic to the medication but even if they had been able to give her something she had a complete blockage in the middle, so nothing could go down, there was nowhere for it to go.

Bereaved daughter

“ She was in a lot of pain and discomfort. It was the vomiting and the retching which contributed to it being opposite from calm for her.

Bereaved daughter

“ His body was just slowly shutting down. He was having problems swallowing because whatever it is that’s in the windpipe that controls where the food or air goes wasn’t working as it should. So he was struggling with food and a lot of the time he was being sick because it was going into his lungs rather than going into his oesophagus. I had a phone call from the nursing home, ‘Your dad’s being very sick and it’s brown coloured.’

Bereaved son

BOWEL-RELATED SYMPTOMS

“ We were told that the tumour had spread and there was nothing we could do and she had six to eight weeks to live. I asked, ‘Well ok what can we expect?’ And the consultant apparently is somebody who doesn’t mince his words and he told us exactly what would happen and it was terrible. It was absolutely awful. He said that what would happen was that the tumour would grow and slowly block the bowel. That she would feel very sick and once it had blocked the bowel she would no longer be able to take in any food or drink and she would die.

Bereaved daughter

Constipation can be associated with abdominal and rectal pain, abdominal distension, anorexia, nausea and vomiting, urinary retention, and confusion. In 2008, a pan-European working group of palliative care professionals stated that constipation ‘is one of the most common problems in patients receiving palliative care and can cause extreme suffering and discomfort.’⁴¹ The working group recognised that constipation can significantly reduce quality of life and has been found to rival or exceed pain in terms of the severity of distress it causes to dying people.

Similar to nausea and vomiting, constipation is a common side-effect of pain relief treatment. A review of existing evidence observed that constipation ‘occurs in almost every patient taking opioids and does not lessen with continued use.’⁴²

The treatments available for constipation include laxatives, suppositories and enemas and these are widely regarded as effective.^{43,44} However, there is a consensus that more research on the treatment of constipation is needed.

Treatment can result in diarrhoea, incontinence and the need for rectal care, all of which can have a negative impact on a dying person’s sense of dignity. Therefore, the benefits of treatment have to be balanced against its side-effects.⁴⁵

“ Constipation is a terrible problem, particularly for opiates. It can be a huge problem for people in the last week or so. It’s very difficult nursing people because they find it very difficult, if not impossible, to get out of bed. They’re feeling very uncomfortable and they don’t like the intimacy of trying to take laxatives or being given suppositories or enemas. And then what do you do after that? Do you try and get people out of bed to sit on the toilet? Until you’re doing it you do not realise, and I don’t think the relatives do either, what an awful thing it is. It’s distressing. I think it’s distressing for staff, but of course it’s terribly distressing for the patient.

Palliative care nurse

She had bowel cancer and she basically wanted to be at home so she could just die looking out on her shed and garden with the family around her.

But she had to go into a hospice because of her toilet needs. Her bowel was blocked so she couldn’t pass anything. She’d had trouble passing for a few weeks at home.

Bereaved son

Faecal incontinence is a common symptom of some cancers towards the end of life. It is also a side-effect of treatment for cancers in the abdominal area. One study found nearly half of patients receiving treatment for rectal cancer went on to suffer from incontinence.⁴⁶ These side-effects have been shown to harm people’s physical, psychological, social, and emotional well-being.⁴⁷ However, this does not always lead to an overall reduction in quality of life.⁴⁸

In 2014, clinical ethicist Ann Munro told *The Guardian* that there are symptoms of dying that doctors can do little to alleviate. One woman in her care was passing faeces through her vagina: ‘She said to me, “I don’t want to be here anymore. I want this to stop. What can you do about it?” She found it humiliating and grim and she was going to die.’²⁵

Passing faeces through the vagina occurs when a person has a rectovaginal fistula. The most common cause of these fistulas is childbirth, but they can occur as a result of cancers and radiotherapy treatment.⁴⁹

Munro also said ovarian and bowel cancers can often lead to people vomiting their faeces. Scottish palliative care guidelines acknowledge faecal vomiting as a potential symptom of bowel obstruction.⁵⁰

As part of a public conversation about legalising assisted dying in Australia, Angelique Flowers contacted the then Prime Minister Kevin Rudd to ask why he could not change the law to allow her a ‘peaceful death.’ Angelique was 30 when she was diagnosed with colon cancer and given just months to live. Following her death, her brother Damian said that in the last hour of her life ‘he held a bowl under his sister’s chin as she vomited faecal matter.’⁵¹

“ I have seen people who have got vomiting towards the end of life because they have partial bowel obstruction. They are able to take some sips of water. They are able to take a cup of tea, but an hour later it comes back accompanied by faeces. They are actually vomiting up their faeces.

Palliative care consultant

TERMINAL HAEMORRHAGES

Terminal haemorrhages, also known as catastrophic haemorrhages, are a symptom of some cancers, most commonly in the head and neck, where tumours erode major blood vessels resulting in extensive and rapid blood loss that leads to death.⁵²

Terminal haemorrhages have been described as ‘rare but devastating’ events, primarily because treatment options are limited.⁵³ When a terminal haemorrhage occurs sedatives are administered in an effort to reduce distress for the dying person but research suggests that this practice is largely ineffective because the person is likely to die before the effect of the sedative is felt. It has been proposed that the primary benefit of sedation in these circumstances may be the reassurance it offers to dying people who are at risk of a terminal haemorrhage, even if the palliative care team has doubts over the benefits sedation would offer should a haemorrhage occur.⁵⁴

Guidance for the management of terminal haemorrhages suggests more practical measures to reduce distress for dying people, as well as loved ones and healthcare professionals who are present, such as the use of dark sheets and towels to camouflage the extent of the blood loss.^{55,56} The reported incidence of terminal haemorrhages in patients with advanced cancer is between 3% and 12%. However, the evidence base for these estimates is unreliable, focussing on small-scale studies and expert opinion.⁵⁷

We’ve had people who have bled out suddenly, and you whack them with midazolam and you hope that they don’t know what’s going on. But then they pass away, so you can’t ever ask them.

Palliative care nurse

MALIGNANT FUNGATING WOUNDS

Malignant fungating wounds develop when cancer breaks through the skin. These wounds occur more frequently in breast, head and neck cancers, but can occur in other circumstances. Symptoms include an unpleasant smell, pain, bleeding, itching and leakage. Fungating wounds can sometimes be treated with radiotherapy and chemotherapy, but it is unlikely that they will ever completely heal.⁵⁸

“ One lady had tumours in her abdomen, which were starting to eat their way out of her, actually coming out of her abdomen. The smell was horrific. It was basically dying flesh and she was still with us and her family’s memory of her was her decomposing while she was still alive. And there was nothing we could do to stop it. She went on for about a week and a half like this, literally decomposing from the inside out. She was unconscious and you just have to hope that she wasn’t aware of too much. You just wanted to do something, even if it was just getting rid of the smell for the family, but you couldn’t because it was everywhere.

Palliative care nurse

“ I remember I did a night shift a couple of months ago and we had this woman with the most dreadful wound. I mean it was just horrible. She had a cancer of the vagina and it was fungating. She was perfectly peaceful except when we had to turn her. And we had to turn her. You have to. You can’t just leave people. If somebody needs cleaning up, you’ve got to clean them up. She didn’t have enough sedation. We gave the maximum that the doctors would prescribe. She died fairly soon after, but she was in agony while we were turning her.

Palliative care nurse

The prevalence of malignant fungating wounds is unclear. A survey in the UK in 1992 reported 2,417 new cases per year, with 5% of those cases caused by a primary tumour and 10% caused by metastatic disease.⁵⁹ More recent research estimates that between 5% and 10% of patients with cancer develop a malignant fungating wound, although the true number may be higher as some patients do not present symptoms due to embarrassment.^{60,61,62} In one study, nine people with malignant fungating wounds resulting from breast cancer were interviewed.⁶³ All participants experienced physical pain which impacted on their lives. Some were shown to have experienced deep psychological suffering which stemmed from symptoms such as odour, bleeding, festering, loss of sexual intimacy and loss of control.

In a study of 12 women undergoing treatment in Denmark for progressive breast cancer, just under half reported that their wounds had a negative effect on their femininity.⁶⁴ Participants in another study described their fungating wound as symbolising the end of their life, as many of the elements of their former daily life were replaced by loss of independence, embarrassment, anger, depression and fear.⁶⁵ The odour and appearance of the wound affected the person’s romantic relationships, with the wound acting as a constant reminder to the patient and their spouse of the rapidly progressing terminal illness. One participant stated: ‘I don’t want to die, but this wound looks as if death is more and more near me. I can’t escape.’ The study concluded that while malignant fungating wounds occur infrequently, they are typically described as devastating and overwhelming.

“ I have seen people with open wounds. People with breast cancer where the tumour is eating through the chest wall. They are prisoners in a hospice or a hospital ward.

Palliative care consultant

IMPACT



4. Lack of control

“ Helping people take control at the end of their life should be our goal. Although people can be vulnerable and less resilient as they die, this must not become a reason for not helping people to have control where possible, or at least supporting people to retain as much control as they wish to have.

Ambitions for Palliative and End-of-Life Care: A national framework for local action
2015-2020⁶⁶

A key theme that emerged from the interviews was how the current law denies many dying people the control they have enjoyed throughout their lives.

“ She wanted to be in full control, there was no doubt about that. The hospice staff were wonderful with her. I am not going to lose sight of that because they would kiss her, they would hold her, which was important for her and important for us. But they had to turn her and she would yelp out in pain. She was in a nappy and that would distress her.

I mean she was 66 years of age. She was a business woman. I think she was under the illusion, as we were really, that she would just slip gently away. I always thought that there was some form of medication that would gently help her in her final days of life so that she would have been in a more comfortable state and less aware of her bodily functions and her pain and be able to just leave this world in peace. At the very end she did do that but I mean at the very, very end. She was there for three and a half weeks, which doesn't seem long to many people but it was an incredibly long time, day in day out, 24 hours a day for her. I know we can't necessarily always be in control of how we are going to die, I know that, but actually she should have been more in control of it, shouldn't she?

Bereaved sister

“ Dignity is very much linked to control, I think.

Palliative care nurse

“ I was going in each day with my brother or a lot of the time I'd spend the night there. I'd say to the nurses, 'Is this going to be the day?' and they said, 'Well, no. I don't think so.' And I was sad that my mum wasn't going to die that day, which sounds dark but I know what she wanted. It sounds awful that you're hoping that today is going to be the day that your mum passes away but that's how it was for 11 days. She wanted to be in control, 100%. She was the most strong-minded, clear thinking, lucid person I've ever spoken to. But she wasn't dying in a place or in a manner that she wanted. She had no control.

Bereaved son

“ I have this wish to make everyone say, ‘Oh yeah, that was good. I don’t mind dying if I can die like that.’ When you’re pregnant you want to do the birth quickly, you want to come out of it feeling empowered and I did with the birth of my child. So I’d like to be empowered by how I tackle my death.

Dying person

“ My mother was somebody who was big on control and I think that was the biggest problem for her to overcome. The lack of control, absolutely – not being able to go home, not knowing what was going to happen to her.

Bereaved daughter



5. 'Torture'

A number of interviewees raised the concept of torture, unprompted, and used this term to describe what they had witnessed.

“ There’s a difference between torture and killing somebody with a bullet and, trust me, I want the bullet.

Bereaved daughter

“ I think it’s torture. I really do think it’s torture. We don’t do it to our animals. I’ve never let any of my animals suffer. They’ve been to the vets. They’ve died in my arms with floods of tears on my part. You don’t do it to animals, you’re put in prison for it. But you do it to humans, and that’s not right. It’s the cruellest thing you can do.

Bereaved daughter

“ You feel as if you’re torturing a poor old lady.

Palliative care nurse

“ I use the word torture. I know there was not somebody actually causing the torture but they weren’t removing it, which in itself was torture.

Bereaved daughter

“ The only way I can phrase it is watching her going through torture.

Bereaved daughter

“ The patient should be able to make a choice, understanding their current situation and what the future holds for them. We should respect the patient’s autonomy. Because we don’t have anything better to offer to them we have to stand by and let them suffer. I don’t think that is acceptable. In a civilised society that is not acceptable. It’s torture for the patient, and we are complicit in it by not acting.

Pain specialist

6. KAY'S STORY



Kay shared what it is like to live with a terminal illness. Kay also described her experiences as a nurse working in palliative care and how they have informed how she felt about her own death.

“ I’ve been diagnosed with lupus, which shouldn’t normally be terminal. You can usually live a normal life. But unfortunately, I also have mast cell activation syndrome, which is MCAS for short. MCAS tends to have different triggers, and my triggers are medication, predominantly painkillers and antibiotics. And that rules out any treatment for lupus.

So the lupus has gone untreated for the last 17 years, and now it’s attacking my internal organs. I have a fistula between my bladder and bowel. I constantly get air in my bladder and it means I’ve got e-Coli in my bladder all the time. The prognosis is that I can’t have surgery. I can’t have any treatment, so they expect me to pass from urosepsis.

I’m a wound care nurse and I spent my life helping people recover from traumatic amputations due to sepsis. So, unfortunately, I’m well aware of what my end of life might be, and it will be horrendous. In that regard, it’s not so much what I’ll be going through. It’s the fact that my loved ones will have to endure what is in front of them. In sepsis your tissue starts to die off. They try to save your life by amputating the limbs, and then the blood poisoning continues and it eventually gets to your internal organs. Unfortunately it is associated with horrendous blackening of the limbs and smell, and it’s going to be very difficult for my loved ones to watch that.

“ My husband is aware. My daughters are 33 and 30 and both of them say, ‘Oh, you’ll never die. You’re not palliative.’ I am very concerned that not only will they have to cope with the loss of their mother, but they’ll have to cope with a traumatic experience that none of them deserve.

You do think of suicide. I suppose that hovers in your conscience, on your shoulder, because human nature is to keep fighting in the hope of some miracle. I’ve thought about Dignitas. I can’t afford it. I’ve made that decision. I want to be able to leave any of the assets I’ve got to my daughters.

Quite a few years ago, I was involved in introducing an end-of-life pathway into hospitals. At that point it was only available in hospices. I would sit down with patients and say, ‘There’s nothing more the doctors can do and they expect you to pass away in the next two or three days.’ I was as blunt as that, to give them the opportunity to make their choices.

We would take them off all non-essential medication. We’d make sure they were still drinking, that they got their fluids. If they could manage to eat, there was something there for them to eat. They had their family around them. If the patient had indicated that they didn’t really want to be conscious at the moment of death we would ask them for the password and, if they gave the password, we’d up the midazolam to sedate them. I saw some of the most beautiful, beautiful deaths I could ever imagine.

I’ve walked towards patients with a syringe that a doctor has just prescribed. Two nurses have jointly drawn up the drugs and checked the patient’s ID etc. before administering the prescription that they’ve just been told to give the patient. But sometimes, within 10 or 15 minutes, the patient’s gone. They just peacefully slip away and stop breathing. I won’t be awarded that courtesy.

I’ve fought to make sure my patients died a very peaceful death, surrounded by people they loved. I am going to be denied the very same that I believed in.

I can’t take hydrazine and I can’t take diamorphine. I will be in terrible pain. If you give me one dose of pain relief, I will go into anaphylactic shock and if they ventilate me that will make it even worse. It could go on for a couple of weeks and it will become extremely distressing for my family. Imagine your mother is dying and you can’t go anywhere near there because of the smell.

That’s why I’ve thought about suicide, because number one, as a human being I don’t want to suffer, and, number two, it’s about my family. I’ll recognise and sense it’s starting. The first sign is I won’t pass urine for 24 hours and I’ll start to feel unwell. And at that point I would have a choice: the choice is to dial the ambulance and go in, and the other choice is to go to bed, get my husband to hold me and... I have enough insulin in this house to...

But it’s not something that I want to do. It’s not something that I’ve got planned to do. It’s not something that I’m definitely going to do. It’s just something that’s there. I don’t want to use it. I want to live my life as much as I can, and as fully as I can, to the last. But when it comes to the end of my life, it will not be nice. It will be anything but. I know too much.

“ If assisted dying was available to me right at this minute it would bring me peace. It would allow me to live my life to the very end knowing that, when the end comes, I don't have to suffer, knowing it won't traumatise my daughters for the rest of their lives, or my husband. My way of expressing it is that he's not my first love, but he will be my last. It will traumatise him. It's what it's going to do to your family. If assisted dying could finally be recognised and it was sanctioned, it could give people like me peace of mind.

I pray to God that they actually look at the problem. We all have to die. For some of us, it'll be traumatic and some of us will get ill and for some it'll be instant. I would just like people to realise what it's like to face that without having any control.



7. EMMA'S STORY



Emma shared her experiences of witnessing the deaths of her mum and her nan.

“ My mum had a lot of health issues all her life. I’m 30 now. When I was about seven she was diagnosed with a rare blood disorder. It was something like only two in one million people get it. They said most people with her condition usually live about 25 years after diagnosis. So we always knew that her lifespan would be limited.

In around 2011 she went into hospital. She’d had a blood clot in her liver and she had an associated liver disorder. You have an increased risk of getting it when you have a blood disorder. She was in a specialist unit in Leeds where they fitted a shunt in her liver and then thereafter they provided her with a fortnightly infusion of ecluzimad, a drug which helped manage her condition much better. It meant she had a better quality of life and that all went quite well for probably about four years.

Then she developed myelodysplasia, basically a leukaemia. As a result of that she started chemotherapy which then meant she had no immune system whatsoever. She did not go out because she did not want to contract infection. She didn’t see people. But obviously there is only so much you can wrap yourself up in a bubble and protect yourself from germs, so she did get an infection.

“ She went into hospital and we found out she had what they call necrotising fasciitis. It’s bacteria that eats your skin, eats away at your fat. If you’ve got it in a foot or an arm or something they can just amputate. But she had it in her bum and her middle area and there was nothing they could do. That was when we knew that she was terminally ill.

She had probably been in hospital a few days and I’d been to visit her. Then on the Friday I got a phone call from the doctor telling me to come in, so I knew it wasn’t good. They said she had 24 hours to live. She didn’t. She lived for 11 days.

After a few days the palliative care team came around and they were really good. They would come around daily. She had her own room which was nice, we had some element of privacy.

She was put on diamorphine and first of all it was injections as needed and then she eventually went on to a syringe driver. But we didn’t know that there were side-effects to the drugs. So at times she got anxious, distressed and confused. I was in hospital with her. I was there 24/7 and she would wake up at 3 o’clock in the morning and think there was a white rabbit in the corner of the room. All I could do was reassure her, get rid of the rabbit or whatever... For me, for both of us, that was quite frightening.

She was in a huge amount of pain because she had flesh-eating bacteria eating away at her skin. When she first went into hospital she used a bed pan and I could help her with that. But as things deteriorated she just had pads and she needed turning so they could change the pads. Some of the nurses insisted on cleaning her quite thoroughly.

She would groan in pain and I would just say to them, ‘You don’t need to do that.’ And they said, ‘Well we have to clean her thoroughly.’ ‘No, you don’t. She’s been given 24 hours to live, I don’t think she really cares. Anything that is minimally invasive and pain-free is better.’ So I always helped with that and I basically tried to instruct the carers and the nursing staff. A lot of them were good and we did it together.

Mum said to them one day, ‘Why is it going on so long? I’m still in pain.’ They gave her an increased dose and I went down to meet a friend in the canteen for a cup of coffee. When I came back she was asleep, essentially she was sedated. I’d just been out for a coffee and I didn’t know that was going to happen.

She wasn’t having such a high amount in her syringe driver. It was additional top-ups that put her to sleep. So she did open her eyes but she was under so much pain relief that that was the only movement she had, her eyes. She couldn’t do anything else. I just saw fear in her eyes and I pressed the buzzer and asked for more because I knew she was in pain.

She wanted it to be over and I didn’t want her to be there not being able to move and still in pain. From that point she was essentially sedated because I just continued to ask for more pain relief and they complied.

I was there for 11 days, so I saw everything. At the very end she was sedated. But before that she wasn’t comfortable. She was in agony. She was afraid. She was in pain for most of the time.

“ My nan was diagnosed with kidney cancer in July last year. She was managing at home. She had a nurse from the surgery that would come in and give her pain relief. Her neighbours would pop in and see her and get her any bits from the shop. She didn't have care workers, nothing like that. She just tried to manage the pain.

But she was getting a lot of sickness. I kept saying to her, 'Do you need me to come home? I will come and live with you. It's not a problem.' She was a very strong woman and she said 'No, no, nothing you can do. All I need is a little bit of pain relief and that's it.'

We didn't know how her cancer would progress, but then at the end of October she had a fall and she had a urinary tract infection, which was what caused her to go into hospital. In hospital she just deteriorated really rapidly and I think her cancer was a lot more advanced than she had let on to me.

She was transferred to the local hospice. The hospice staff, they were exceptional and I can't fault any of the care that she had. It's probably the best care I've ever seen and I've worked for six years as a social worker. They were brilliant. The nurses were so responsive. They'd come immediately. They'd give her more pain relief if she needed it. The volunteers were making her tea or bringing flowers around. Everyone was so nice and they made it as comfortable as you could possibly hope for.

But she still experienced the negative side-effects of pain relief, the anxiety, the distress, the confusion. So sometimes she would sit there and she'd be wrapping her call bell lead around her arm and trying to rip her tissue boxes apart and she'd say, 'I feel like a confused, flopping donkey, what day is it? What time is it?' and that was just as a result of the side-effects of the pain relief. She didn't feel herself. That was not how she wanted to be and she would just sit there and say 'Well I want it to be over now, why am I still going on like this?'

In the end they increased the pain relief and she was sedated and she probably lasted about three days under sedation and then she died.

During that time, she probably came out of the sedation. I was with her the last 24 hours and I'd been up watching TV and about 7 o'clock in the morning I started noticing her grimacing and frowning as if she was in pain. So I asked for more pain relief and then she appeared more relaxed after that. So there were moments where I think she was in pain, but because people were there to keep an eye on her and to look out for those signs we could ask for more. I suppose not everyone has that so, if that goes unnoticed, people will essentially be sedated and in pain.

My mum and my nan were very strong, independent people who wanted to live life to the full. But if you're not getting anything out of life, and your life is over, why go on? Why suffer? Why be in pain?

I think you make an assumption that we live in a world that now places importance on human rights and you don't really consider that we could allow someone to suffer like that. You just assume there's a way that they manage it.

“ Both of them would have wanted an assisted death. It would have been much nicer if they could have ended it at a point where they felt enough is enough, when there was still a little bit of them left, with people around them to have a laugh and to end on a positive. I can see a point for both of them where it went from being in some level of pain but still able to talk and still laugh occasionally, to a point where that completely shifted, where it was no longer tolerable.

Both of them were begging me to do something. My mum wanted to die and so did my nan. She said to her friend, ‘Can you help me?’ But her friend couldn’t do anything. I couldn’t do anything. I was filled with intense anger and complete helplessness. All I could think was, ‘Why is no one able to help end this suffering?’ Then you feel awful for feeling relieved when they die and then you feel awful for the next year because you have nightmares about how you saw them die.



8. Grief

“ How people die remains in the memories of those who live on.

Dame Cicely Saunders, founder of the modern hospice movement⁶⁷

Complex grief is a term used to describe grief that is distinct from bereavement-related loss. It can be used to predict long-term health problems and a reduced quality of life.^{68,69}

Research has suggested that the likelihood of complex grief increases when deaths have been traumatic and its symptoms can be similar to those of post-traumatic stress disorder.⁷⁰ One study found an increased occurrence of complex grief when relatives are denied an opportunity to say goodbye to their loved ones.⁷¹

Many of the interviewees featured in this report displayed symptoms of complex grief. Interviewees attributed their own depression, anxiety, panic attacks, social isolation, nightmares, feelings of guilt and fear about their own deaths to the manner in which they saw their loved one die.

“ It was absolute hell. Absolute hell. I don't think I'll ever get over it. To watch somebody suffering and be absolutely helpless... You obviously want to go and be supportive but there is nothing you can do. You're absolutely helpless and it was horrendous. Completely horrendous. Everything from the lack of dignity to the pain to the lack of control. I feel awful that that was the way she went. I know there's no nice way to go, but it was long and drawn out.

Bereaved daughter

“ When she left us it was like I'd won the lottery. That sounds blinking awful but that's how we both felt, me and my other sister, because we wanted her out of this misery that she was in. I have told my husband and my sons how strongly I feel, how I wouldn't want that. I've got a different view on hospices in general. I am still volunteering in my local one but I am about to speak to one of the doctors about this because of how I'm feeling. I wouldn't want that kind of death for myself and I don't think anybody would.

Bereaved sister

“ I feel like I live with it constantly. There isn't a day that goes past where I don't think about it and get upset by it to be honest and I would have thought... I mean I'm better than I was... I wasn't able to talk about it until now. I feel guilty for how she suffered.

Bereaved daughter

“ I still have nightmares about it. This sounds really weak and stupid but it really has affected my mental health. I’m on antidepressants and I’m under the mental health team.

Five months after my mother died I was diagnosed with ovarian cancer as well. I decided that I wasn’t going to have treatment. I was going to go to Dignitas but a consultant who understood what I’d been through said, ‘Let us operate. We are not 100% certain. It’s very small. What I’m going to do is take out your ovaries anyway so you cannot get ovarian cancer, to set your mind at rest.’ It turned out it wasn’t ovarian cancer. It was a particularly nasty cyst. But I had already decided then that I was going to either go to Dignitas or end my own life so that I had control. I cannot go through what she went through. I just cannot. If I think about it I am so scared.

Bereaved daughter



“ I nursed my own mother. She had a syringe driver. She called it George Clooney because she said it was the only time she was ever going to be in bed with him! It took five days. Eventually she developed kidney failure and heart failure and she died in my dad’s arms. She had a blood clot in the chest, a pulmonary embolism, and it took about 20 minutes, and I was absolutely traumatised.

I remember having to go to bereavement counselling. I was a nurse for over 25 years and I nursed all these people right through to their last breaths. But when it came to my mum, I couldn’t help and I had to watch her going through a pulmonary embolism. When you die of a pulmonary embolism it takes 20 to 30 minutes to travel through the lungs and reach the heart. That 20 to 30 minutes was very traumatic to watch. It’s the after-effects of what’s going to happen to you. How is my death going to affect my daughters?

Dying person

“ I’ve ended up with quite a lot of anxiety after it all. I think when you’re a carer of a family member with a disease affecting a loved one like that, you don’t really experience emotions during the time because your focus is on that person. It’s only afterwards that you start to feel the effects. It’s made me withdraw into myself. I don’t really see my friends very often now. I’ve had to start medication. I actually went to Greece a couple of months ago, and I ended up having a panic attack and booked a flight back the next day. I’ve realised a lot of it is to do with the whole shock of everything. I think it’s just the horror of it, and I think it’s because she died in such a horrible way. Those episodes when she was crying and wailing over the six weeks when she was coming out of sedation. There’s nothing we could do about it.

Bereaved daughter

An assisted death would’ve given her a much better ending. She’d have ended her life as she lived it, with her being in control. I wouldn’t have been as angry as I have been for the last three years.

We laugh and celebrate my mum and all the things she did, as you do with somebody that you’ve loved. She was just short of her 80th birthday and for the best part of 80 years she lived her life as she wanted but the last 22 days she didn’t and you never get that back.

Bereaved son

CURRENT PRACTICE



9. Hastening death

It is common for people approaching the end of life to want to hasten their deaths. A comprehensive systematic review published in 2012 found that the wish to hasten death in people with an incurable illness was associated with physical, psychological or spiritual suffering, loss of self, fear or a desire to live but ‘not in this way.’ It also reflects the search for a means to end suffering and exercise control over life.⁷²

A 2014 Freedom of Information request to Directors of Public Health found that approximately 7% of deaths recorded as suicides in England involve people who are terminally ill.⁷³ Applying this figure to Scotland suggests over 50 dying people are ending their own lives every year. The World Health Organisation estimates that for each adult who dies from suicide there may be up to 20 others attempting suicide.⁷⁴

Bereaved relatives shared the different ways in which their loved ones had considered ending their lives.

“ He didn’t talk about ending it until he got to about March 2016. He let me know on the iPad, ‘I’ve had enough. I’ve had enough. I want to go.’ So I said, ‘you realise if you want to do this you’ve got to do this through Dignitas, you’ve got to do it yourself, because otherwise I could go to jail for 14 years.’ He started looking into it and I don’t know how far he actually got but he realised he’d left it too late.

He didn’t actually want to do it himself. I know that because he had a very severe nut allergy which would result in full anaphylaxis. He had one or two close points over the years. I’d never had nuts in the house because it just wasn’t safe. But from March there was a jar of nuts in the house. He could have got to it. He could have killed himself by ingesting nuts but he didn’t do it. It’s not a nice death from anaphylaxis but it’s an awful lot quicker than motor neurone disease. What he wanted was for somebody to help him – peacefully.

Bereaved wife

“ She found out about Dignitas but was not well enough to travel. She was very annoyed that she would have to spend the money and travel so far for something that is so simple and should and could easily be available in this country. She was very, very annoyed and ultimately she was like a lot of people, she was too ill to travel. She didn’t want to go before her time but she did look into it in quite a lot of depth. She was in so much pain that it just... it wasn’t viable.

Bereaved son

“ She looked at various options for taking her own life, but it was really too difficult to guarantee that it would work. From what I can gather I think most suicide attempts are unsuccessful. It’s really not an easy thing to do.

Bereaved son

“ I would have helped her get to Dignitas. She said she couldn't face it. She was too ill and she knew how much it cost. She didn't have the money. But, if there had been an alternative whereby she could have sorted everything out and then died without all of the trauma and the pain and suffering and throwing up and everything, I am certain she would have done it.

Bereaved daughter

Dying people said they had given considerable thought to the ways in which they could end their lives.

“ I am not sure Dignitas is for me to be honest. I don't know categorically. I suppose we are in a fortunate position where we could afford to do it if that was the way we wanted to deal with it. I suppose more importantly I don't want to end my life in another country, in unfamiliar surroundings. I would rather be at home or in the local hospice. Also the fact that it is illegal in this country. I know that it is going to be unlikely they would be prosecuted, but I think I would find it very difficult to ask a family member or close friend to actually assist me in the process. I think it is a burden and I would feel uncomfortable, even if somebody said, 'Look, I am happy to do it.' I am not sure I am comfortable with accepting that offer.

Dying person

I would consider going to Switzerland but you have to be fit to travel, so it's likely that you're going to be going months before you would do if you were in the UK.

If I was being really honest I would rather die at home but kind of a do-it-yourself job. Possibly like stockpiling medication. I think that would be the way that I would rather go if it couldn't be above board. But I've lived my whole life openly and honestly and I'd like to die as I live, not with my husband helping me commit suicide.

Dying person

“ It's really important to me that I die in a place that I know and love. We've moved into a house in Wales, which is in the country in a beautiful place. That's the place I'd pick to breathe my last breath. I would feel very unhappy going to Dignitas. I've seen films of people going and I certainly admire them, but I wouldn't go abroad. I think it would be too traumatic for my family. It's not where I want to be. I just want it to be part of my life. I want my death to be another day in my life.

Dying person

Healthcare professionals reported their own experiences of dying people attempting to end their lives.

“ It isn’t possible to relieve all suffering with the current palliative care options that we have. A palliative care consultant I know said that she became a supporter of assisted dying when one of her patients was trying to kill himself by jumping out of a window because he was in so much distress.

GP

Occasionally we have had people going to Dignitas from the hospice. They do it secretly; not with us helping them.

Palliative care nurse

One GP had given thought to how they would end their life if they had a terminal illness and were suffering.

“ I had a lot of building work done and it was a very complicated roof structure and I was worried about squirrels getting up there. So I managed to get a bottle of chloroform from the chemist and I was going to put a trap up there to catch them and I was going to chloroform the squirrels and dispose of them that way. But then the chap who was doing the building was worried about the cats getting up there and so I thought I’d better not.

Anyway, I’ve still got the bottle. I think I could do myself in with chloroform should it come to it.

GP

Research suggests the desire to hasten death is complex and informed by a number of different factors.⁷⁵ A range of studies have found that dying people who report having a wish to hasten death do not see death as an aim in itself, but as a side-effect of pursuing the only available option of escaping suffering.^{76,77} While the literature is clear that many people at the end of life do experience a wish to hasten death, there is no recognised response to these wishes that can be considered universally effective.

A wish for hastened death is treated using the existing tools available to specialist palliative care teams, such as effective symptom management, talking therapies and spiritual care.⁷⁸ However, research has shown that even when these forms of care and support are present a wish to hasten death can persist. For example, a survey of UK doctors found that in 9.8% of deaths studied, respondents reported that their patient had expressed a wish for their life to end. For 74% of these patients the wish was not shown to diminish over time.⁷⁹ In another study, 67% of UK palliative care units surveyed reported one or more suicide attempts by patients within their care.⁸⁰

In 2018, Bobbie Farsides, a professor of clinical and biomedical ethics told the BMJ that she challenges ‘the belief that a wish to die at a particular time and in a particular way can be “cared away,” however great the skill of the professionals and resources committed to end-of-life care.’⁸¹

This view resonates with the story one person shared.

“ I had a gentleman come round because I was adopting his daughter’s pet. His daughter had emigrated and wanted to take the pet with her but couldn’t. Anyway, I said, ‘I just want to make it clear that I’ve got terminal cancer and I don’t want your daughter to see this down the line and think, “I wish I hadn’t given it to her.”’

He went extremely quiet and I could see that he was upset. I just waited for it to come out. He’d lost his wife the year before. She had cervical cancer for nine years. Over that time they did a lot of travelling and she was fairly well to begin with, but she had parts of her stomach taken away and then parts of her oesophagus and she lost her voice box.

In the last six months she couldn’t go upstairs and they converted their lounge into a bedroom. She was incredibly brave and she decided that life was not worth living for her anymore and she took an overdose of morphine. He came downstairs and found her semi-conscious and dialled 999 and she said, ‘Why did you bring me back?’ She hadn’t made it clear. They hadn’t talked about it because I think she knew that he would not want it to happen.

She went from hospital to a hospice. She was in a hospice for six weeks. She had convinced them it wasn’t going to happen again because she was talking to people, getting more support etc. But the first night she was home she did it properly this time, with more morphine.

And he said, ‘30 years of marriage and I couldn’t be there to support her at the end, because of what the law is now.’ He said, ‘I’ve no idea where she got that morphine from. I was glad for her that she was able to go but I wish she hadn’t had to do that.’

He was an intelligent guy, a nice guy, but he had this terrible air of sadness about him.

Dying person

Some people at the end of life choose to hasten their death by voluntarily stopping eating and drinking (VSED). A death by VSED means the person has actively made the decision to refuse food and water, as opposed to somebody who has lost the ability to consume food and water as a consequence of their illness.⁸²

Studies exploring deaths from VSED suggest a range of experiences. Some deaths are reported to be peaceful, with little physical suffering.⁸³ Others feature pain, fatigue and impaired cognitive functioning.⁸⁴ People initiating VSED require the support of healthcare professionals to help manage these symptoms.

While there is legal clarity that people do have the right to refuse food and water even if it brings about their death,⁸⁵ there remains an ethical debate about VSED. In response to the death of Jean Davis, who refused food and water because she feared a drug overdose ‘would not work’, Dr Peter Saunders, former Chief Executive of the Christian Medical Fellowship, said, ‘It is not illegal to starve and dehydrate oneself to death but neither is it right.’⁸⁶

Some claim VSED is a form of suicide and believe a healthcare professional who provides medical support to someone who is in the process of VSED is in fact assisting them in that act. This view suggests that it is inconsistent for legislators and medical professionals to consider VSED a legitimate end-of-life practice while simultaneously opposing legalised assisted dying.⁸⁷

Others argue VSED is a passive form of hastening death distinct from assisted dying and more akin to stopping life-sustaining treatment.⁸⁸ This perspective has been used to justify the view that, while VSED could be considered a form of suicide, it is acceptable for healthcare professionals to provide palliative care to make the person's death more comfortable.^{89,90}

There has been no research looking into the prevalence of VSED in the UK. Unlike other end-of-life practices, there are also no standardised guidelines in the UK for how healthcare professionals should support people who decide to hasten their death via VSED.

Regardless of the ethical debate surrounding the issue, VSED has been called 'an imperfect but useful last resort' when suffering persists despite the best efforts of palliative care and is known to be practised as an alternative to assisted dying.^{91,92,93}

None of the healthcare professionals interviewed considered stopping eating and drinking to be a satisfactory option for dying people.

“ Starving yourself is a very inefficient way to bring about dying because some people have got more reserve than others, and some people who have been well fed up until then with a nasogastric tube and hydration can actually take days if not a few weeks to die. I think in the 21st century, why are we subjecting someone to such a degrading way of dying? I just find it morally absolutely unacceptable and it shocks me that people, palliative care of all specialties, should put that forward as an option.

Palliative care consultant

“ I've got a patient at the moment who talks about stopping eating and drinking. They've explored it out loud. They said, 'Well if I don't eat I'll speed up this process.' Actually, with the medication they're taking as well, that might be pretty unpleasant. They might feel horribly hungry but there's no guarantee actually that it's going to speed things up because the illness is bad enough anyway. That's all very grey. I think it would be awful. I think it feels to me pretty extreme. That would be a marker to me that that person is really suffering.

Palliative care doctor

“ People do choose to refuse food and water. But when people are going to die soon the lack of nutrition or hydration often does not have the effect that people think it is going to have. I remember a patient who could not eat or drink anything with the condition that she had. She was still alive a couple of months after she came in, having had I think the grand total of maybe two litres of fluid in that time.

So I am very cautious about people thinking that if they decide to not eat or drink it is going to help them die more quickly. I don't think it is a particularly effective way of getting the outcome that they want and I think it is problematic if anybody feels forced to take a way that is ineffective. I don't think that is an adequate solution to address the fact that some people will choose to die more quickly than they might otherwise do.

Palliative care consultant

“ There are people who come into the hospice and don't take food or water. I think it's a very bad option because it's not a nice way to do it. I know a friend of a friend who did it. It's a horrible way to die, horrible, and you don't know how long it's going to take. You can survive for several weeks without taking any fluid because you're not doing anything. That's why you survive so long. If people are on hunger strike... it's horrible. There are feelings of thirst and then all your organs break down.

Palliative care nurse



10. AMANDA'S STORY



Amanda's father, Professor Michael Rosen, had Parkinson's disease. Professor Rosen refused food and water towards the end of his life when his condition deteriorated. He was 91.

Professor Rosen was the inaugural President of the College of Anaesthetists. He played a central role in some of the most important developments in anaesthesia in recent history, including the use of suction during surgery and postoperative pain relief.

After realising that patients were better placed than doctors to assess their needs for pain relief, he developed the Cardiff Palliator, a device that for the first time allowed patients themselves to control the administration of morphine.

Following his death in 2018, The Times described Professor Rosen as a 'pioneer' and a colleague told the BMJ that 'he was the most outstanding anaesthetist in the last half of the 20th century.'^{94,95}

Amanda, a doctor herself, described the final weeks of her father's life.

“ He was very clear in his mind what he wanted to do. He was refusing to eat because he knew he wasn't going to be given drugs to die. He knew that he had to stop eating.

It was distressing in the sense that it was clear what he wanted to do. He spoke to the consultant and saw her on several occasions and she said, 'I can't actively help you die; if you are at the point of discomfort I can ease your pain but I can't kill you.' I wanted him to be able to discuss it with the palliative care consultant because I didn't want to influence him and I also wanted him to be able to freely talk about what he was feeling. The consultant gave him some sedation to help him to feel more relaxed. But he had to take it in his own hands – to not take calories in, which is a pretty horrible way of dying.

One day I came in to see him and he said, 'Take me to Zurich' and I said, 'Dad, it's too late, it's too late.' He wanted to end his life. He wanted to be in control. But he was too weak and he was losing control. There's that balance between being weak and having to kill yourself, then being sedated and not being able to have a say in your actions either. There is this interim period where it is actually really terrible.

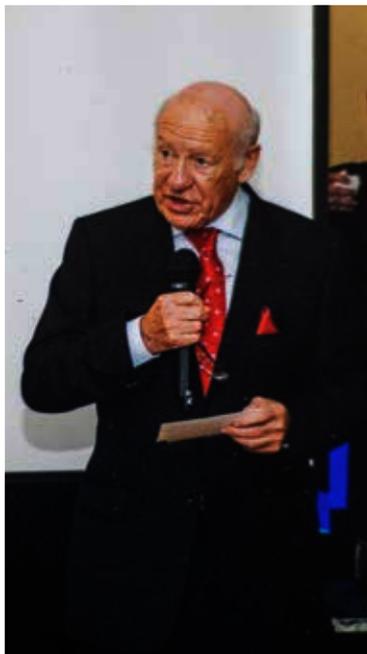
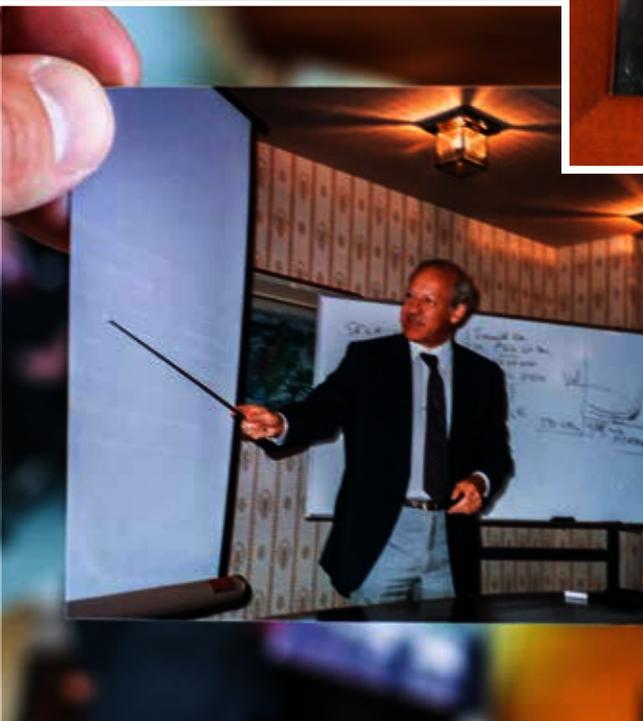
One of the nurses said, 'We need to ask if he wants his food,' and they brought him a tray of a three-course meal at one point, like a pantomime. He had to be the one to say he didn't want any food. He said, 'Please, I don't want any food'. They said, 'We have to offer it to you every time' and he found that irritating. Of course he was hungry and he was being presented with food he didn't want. I think the staff found it incredibly difficult. I think they were worried about being sued.

It was horrible. He was losing weight. He was uncomfortable. He was in the end phase of Parkinson's and he was starving to death but he was still relatively fit. I said, 'Bad news, Dad. All of those times going to the gym are not paying off now.'

It took a lot for him to die. He was in an unconscious state for several days. No fluids, very little urinary output, obviously declining but his heart was pumping away and we said, 'How long can this go on for?' In the end it was a week. I remember saying to the consultant, 'Do you think I will see you again?' and she said, 'Well, possibly.' She was very good. She was very caring. She was trying her best.

I just think it was awful he had to starve to death. He was a very bright, articulate man who knew what he wanted and had had a good life. He was tired and his Parkinson's was getting worse. He would have preferred to have said goodbye in an honourable fashion, in control. I think that is the thing that upset me most of all, he didn't have the opportunity just to say goodbye, which would have been very fitting for him. He would have wanted to share his pearls of wisdom once again and then have a very respectable, clean death.

He was 91. For the majority of his life he was an anaesthetist who rose up to be President of the College of Anaesthetists. He was very focused on pain relief and in the early days was involved in pain relief in pregnancy and also palliative care.



“ He developed patient-controlled analgesia. There was an aphorism he would say to me ‘never accept for people to be in pain.’ That was the irony. His professional life was dedicated to helping others. He had devised something to help others control their pain, yet at the end of life he couldn’t take control.

I remember one day he was getting frailer. He was finding it hard to walk to the toilet and he was using a zimmer frame. I remember him saying, ‘I need to walk up and down the corridor. I need to walk up and down the corridor.’ He was trying to burn calories. He said, ‘It’s not happening fast enough.’

He was a truly honourable, moral man and a reflective and very caring man, not only to his family but to patients throughout his career. He really was hugely respected and I think to lose your dignity... That wasn’t who he was.



11. Withdrawing treatment

Adults who have mental capacity have the right to make decisions about their own treatment and care. People can decide to consent to or refuse treatment, even if doing so may shorten their life.⁹⁶ People choose to refuse medical treatment towards the end of their life for a range of reasons. For example, to spend more time with loved ones at home rather than be in hospital, to avoid the side-effects of treatment in order to maximise quality of life, or to avoid having life artificially prolonged.

An example of how dying people can refuse treatment with the intention to bring about their death is associated with motor neurone disease (MND). People with MND can ask doctors to remove the artificial ventilation that is keeping them alive. This requires the support of healthcare professionals, who can provide sedation when the ventilation is removed to alleviate symptoms of suffocation.

Some dying people would prefer to be able to exercise control through the option of an assisted death rather than by refusing treatment. Noel Conway, a man dying of MND, has said that he would want the option of an assisted death because if he refuses his ventilation the sedatives that will be administered ‘will cause a state of drowsy semi-consciousness until death occurs. This experience may last for a few hours or a few days; no one knows and no one can say how much that will alleviate the sensation of fighting for breath.’⁹⁷

Representatives of the Association for Palliative Medicine have offered a different view. They wrote in *The Times* in response to Noel Conway’s legal challenge to the current law that ‘Mr Conway can die whenever he wishes. He is free to ask his doctors to remove the treatment that is artificially keeping him alive. If he does that, his doctors have a duty of care, using our specialist guidelines, to ensure that he dies peacefully.’⁹⁸

Only 29% of Scottish healthcare professionals think refusing treatment to bring about death is more ethical than giving people the option of an assisted death.¹

“ What came up in the Noel Conway case was somebody who said, ‘Why doesn’t he just remove his ventilation, because then he will die.’ Yes, he could do that. We had a patient at home who wanted to do that. He had motor neurone disease and he asked for the ventilation to be removed. In a sense it was an assisted death, but it was legal.

There’s a very thin dividing line between removing treatment and assisted dying. The intention is the same. You’re responding to a request of somebody who’s asked for it.

The fact it’s possible to do that says to me, ‘Why don’t we just have assisted dying?’

Palliative care nurse

For many terminal illnesses there is no treatment that people could refuse that would enable them to hasten their death. So, whilst someone with an advanced neurological condition who is dependent on ventilation can refuse the ventilation in the knowledge they will then die, a person with terminal cancer would most probably not have a comparable option.

“ Motor neurone disease is one of the few where if you remove the treatment the patient will die. Lots of others, you can remove treatment and you don't know whether they're going to die or not.

Palliative care nurse

When a person with MND asks for their ventilation to be removed, the Association for Palliative Medicine's (APM) specialist guidance states it is the responsibility of doctors to validate the person's decision by ensuring that it is the 'settled view of the patient,' 'that there is no coercion' and that the patient has capacity to make the decision.⁹⁹

However, the inability of doctors to satisfactorily detect and address the possibility of coercion is an argument put forward by some people who oppose a change in the law on assisted dying. For example, in 2015, Dr Kathryn Mannix, a palliative care consultant, wrote in *The Guardian* that doctors see 'occasional loveless families where coercion to "die sooner" would certainly occur should the law allow it.'¹⁰⁰ A few days later, in a debate in the House of Commons, Fiona Bruce MP said that proposed assisted dying legislation did not address how doctors should be satisfied that the person seeking to end their life had a 'settled and voluntary intent' or that there was 'no coercion behind' a request for an assisted death.¹⁰¹ Baroness Ilora Finlay, a former President of the APM, has also questioned how coercion, 'real or perceived', can be detected.¹⁰²

These arguments ignore the possibility that coercion could influence end-of-life decision making under the current law and that doctors have both a responsibility and the guidance to support them to identify it. This is why the APM refers to coercion in its literature around the removal of life-sustaining ventilation.

Safeguards in the APM's guidance are similar to the safeguards that have been proposed in assisted dying legislation in the UK.¹⁰³ They are also similar to the safeguards that exist in assisted dying legislation around the world.¹⁰⁴

In preparation for the implementation of assisted dying in Victoria, Australia, the Department of Health and Human Services published information and training modules to support healthcare professionals to be able to detect possible coercion around decisions relating to assisted dying. The information acknowledged that 'doctors should already be alert to coercion in a range of healthcare decision scenarios.'¹⁰⁵



12. Palliative sedation

Palliative sedation, also known as terminal sedation, therapeutic sedation or continuous deep sedation, is a legal end-of-life practice. Sedatives are used to relieve symptoms of suffering. Sometimes this results in the person becoming temporarily unconscious. At the very end of life somebody may be sedated and never regain consciousness.

The European Association for Palliative Care (EAPC) has published a framework for the use of sedation in palliative care.¹⁰⁶ The framework states that sedation can be used to ‘relieve the burden of otherwise intractable suffering.’

The EAPC framework notes that there is no consensus within palliative care as to the appropriateness of sedation to relieve people from non-physical symptoms such as depression, anxiety or existential distress. There is also a debate around the ethical justification and clinical effectiveness of using sedation to relieve distressing symptoms experienced by people who have chosen to hasten their death by voluntarily stopping eating and drinking.¹⁰⁷ The EAPC framework recognises that palliative sedation can be ‘profoundly distressing to family members’ as they are no longer able to interact with their loved one and the opportunity to say goodbye may be of critical importance.

Dignity in Dying’s view

Palliative sedation is an integral part of good end-of-life care. It can be effective at relieving different forms of suffering and provides many people with relief of their symptoms and a peaceful death. As with all end-of-life practices, it is vital that there is clear communication around the use of palliative sedation and its consequences, not only between dying people and their care team but also with families, friends and carers.

In addition, evidence suggests there are circumstances where some palliative care professionals may be reluctant to instigate or use effective dosages of sedation for fear of being perceived to be hastening a person’s death.¹⁰⁸ It is crucial that education and training focusses on the effective use of palliative sedation so as not to risk dying people and their families suffering unnecessarily.

Paul Chamberlain was diagnosed with motor neurone disease in 2010. In the final years of his life Paul campaigned for assisted dying because he believed the options available to him were not acceptable.¹⁰⁹ Paul knew that he could ask for his artificial ventilation to be withdrawn and that his care team would administer palliative sedation to minimise any distressing symptoms.

Paul died in a hospice in September 2014. While he was denied the assisted death he campaigned for, his family described his death as peaceful and it was made possible by the use of palliative sedation. His son, Andrew, described his dad as ‘one of the lucky ones.’¹¹⁰

Stories such as Paul’s illustrate the value of palliative sedation but existing evidence and findings from interviews with healthcare professionals, bereaved relatives and dying people show that the practice has its limitations. Some dying people may wake unexpectedly from sedation; some may appear to be experiencing pain while not having mobility; some deaths that involve sedation can be prolonged and traumatic; in some cases, even large doses of sedatives do not achieve the intended state of unconsciousness.

These cases highlight the need for other options at the end of life, including the option of assisted dying, to ensure that people do not suffer unnecessarily.

Studies have shown a disconnect between the views of dying people and healthcare professionals in regard to palliative sedation.¹¹¹ Many interviewees, including dying people and healthcare professionals, were unclear as to where the line between palliative sedation and assisted dying or euthanasia is drawn if the sedation results in someone being unconscious up until they die.

However, the concerns of bereaved relatives were more likely to focus on the failure of sedation in giving their loved one a peaceful death and the distress this caused. In a number of cases the use of sedation denied dying people and their family members a clear moment in which to say goodbye to one another and often resulted in a protracted death over a number of days.

“ That is another option to consider if it relieves pain so that I am unaware, but somehow it feels like it is neither one thing nor the other. If you are going to go down that route you are not in any kind of meaningful life, are you? There is no quality there, you are just existing but there is no awareness. It is pain-free but if there is no quality of life there whatsoever.

Dying person

“ It took 22 days for her to die. 11 days pretty much *compos mentis* and then 11 days where they stepped up the medication and she was with it but not with it, *in the worst of both worlds*.

Bereaved son

“ When we went into the hospice we had an initial consultation. The conversation was along the lines of, ‘Towards the end, what do you want? You know, how do you want us to help you?’ It was a kind of unsaid. I took it that they might help her pass on if need be. Over a period of a couple of weeks she went from being lucid to sometimes being lucid in the morning or the afternoon, but the rest of the time being almost unconscious. But her pain was such that quite often it would wake her. You know, from this deep unconsciousness she would moan and writhe.

Bereaved daughter

“ It was really distressing because it was an uphill battle to keep her sedated. What was happening was because the sedation and morphine were put up in increments. So quite often she was coming out of a kind of state of sedation and she was literally howling and crying. It was awful. She did have some very distressing times really, just uncontrollable crying. Of course my dad, bless his heart, was the first one there and he just wanted to try to calm her down and console her. It was just horrible. Sometimes I’d hear her and it was just the most awful sound... All the nurses said, ‘We’ve never seen anybody have so much morphine.’ It was always like her heart was really strong, despite everything else.

Bereaved daughter

“ My brother had cancer and I was with him at the end of life. He was on a very high dose of morphine but he was very agitated. He kept thinking somebody was breaking into the house and that the police were outside. He was very restless and anxious. He had a Macmillan Nurse who came in. She said to his wife, ‘We can give him some sedation, but it will make him sleep most of the time. He’ll just wake up occasionally, but the majority of the time he’ll be asleep and the agitation will go.’ His wife said to me, ‘What do you think?’ It was very hard because he didn’t have the strength to get out of bed but he was trying to get out of bed and look out of the window and he was shouting at people he was seeing in the room and he was very troubled. So we said, ‘Yeah, give him the sedation.’

He was very vocal, my brother. He was quite a character and he never stopped talking. She went to give him the injection and he said, ‘Oh, what are you giving me?’ She said, ‘I’m just going to give you this injection and then it’ll help you to sleep and relax.’ She gave him this injection and he never woke up. He just lay there like a zombie with his eyes still open. We never heard a peep out of him but he had a fear in his eyes. It was like he could hear everything that was going on. That really upset me and his wife. We were very upset about it and we felt guilty because we had agreed for him to have this injection. It was another five days before he died.

Bereaved sister

It has been acknowledged that unresponsiveness and unawareness are two different concepts. A person under sedation may, if they don’t also have appropriate pain relief management alongside the sedation, be experiencing severe pain and be unable to communicate this to those around them.¹¹² Previous chapters have shown that it is not always possible to achieve a satisfactory level of pain relief.

“ He’d intimated that he didn’t want to be here. He said that, but then he had a week in and out of consciousness. He was having episodes, I think that is probably the best way that I can put it. He couldn’t talk so he made noises and he had staring eyes, a very fixed, glazed stare at the ceiling and he went very rigid. Things like that would happen and I don’t know what was going through his mind. I don’t know what he went through. There was no way of him being able to communicate to us what was going on for him at that point. I can’t tell you, it would all be conjecture. It was just a distressing time for both me and my sister. We never left his side that week.

Bereaved son

Research has highlighted variations in the practice of palliative sedation, including in the role the dying person plays in the decision-making process. One recent study investigating the use of palliative sedation in European countries identified a spectrum of practice. At one end (mostly in the UK), doctors discuss the possible use of sedation with the patient, but the doctor makes the final decision over whether or not to use it. At the other end (mostly in Belgium and the Netherlands), the patient initiates the conversation and the doctor’s role is limited to evaluating whether or not appropriate criteria have been met.¹¹³

In the interviews featured in this report, healthcare professionals had differing views on palliative sedation. One palliative care nurse said some of their colleagues are opposed to the practice.

“ Where I work there are some who are very much against palliative sedation. But, if somebody says, and they quite often do, ‘If it gets too uncomfortable and too horrible, I just want to be asleep all the time’, I would say the vast majority of nurses would be very happy with that, and I think in practice a lot of what we do does basically sedate people.

Palliative care nurse

With sedation, it's quite a subtle thing and you can't necessarily achieve it, even if you've got a doctor who's willing to prescribe it.

The main thing is it's a bit hit-and-miss if you're trying to achieve complete sedation for people so that they never do wake up. Most people are going to come in and out of it.

Palliative care nurse

One palliative care consultant was keen to stress that sedation is not always used to deliberately make someone unconscious. Rather, the minimum dose necessary to relieve symptoms is administered and the person may or may not become unconscious as a result of this.

“ We wouldn't jump straight to sedating someone and we wouldn't aim to sedate someone to unconsciousness, unless that is the only way in which we could treat their symptoms. But of course the side-effect of the medication is that the person might be drowsier or they might be sleepier, and so they might be less conscious as a result. I am very clear that I am not going to be aiming to make someone unconscious, but that is something that might happen.

Palliative care consultant

One pain specialist questioned whether or not there could be a better alternative to palliative sedation.

“ In end-of-life care you're going to follow the protocol for controlling pain but, if the patient is ready to die, why do you want to get there at a pedestrian pace? The patient has said goodbye. You don't have to keep them in and out of sleeping for the next two weeks. Why drag the family through that until they no longer remember the patient as the loving father or mother or wife they used to know? We can do better than what is happening at the moment. That's the bottom line.

Pain specialist

Paul was 56 when he was diagnosed with oesophageal cancer. He died eight months later. His wife Ann described his last seven days of life.

“ When somebody’s at the end of life you anticipate their death. You know, my mum’s 88. I’ll be very sad when she dies but she’s 88, it’s natural. Paul and I had been together six years and we were very much in love and we were just starting out. It’s a completely different dynamic, completely different experience. He had been so fit, healthy and body conscious and he lost his sense of self towards the end. He didn’t like looking at himself in the mirror. He lost all dignity. He said he didn’t have any kind of spirituality, because if there were a god why would he do this? When he found happiness for the first time in his life, why would that be ripped away?

We were in a private hospital with this amazing, fantastic, most incredible Macmillan Nurse. She was really exemplary. Paul was never going to be able to come back home so the family came and Paul said to me, ‘Do what you think is right, Ann.’ Because they’d said, ‘Do you want to be conscious over the next few days and kept pain-free or would you like to be sedated?’

I was terrified that he would have one massive bleed and be awake with it. He didn’t know what could have happened. I don’t think he really looked it up and I felt for him it would be better that he was sedated. So I got all his family to go in and be with him so they could speak to him whilst he was completely lucid.

Then the plan was that he would be given morphine and sedation as and when he needed it. But he was incredibly fit so, although he was riddled with cancer, his heart was so strong. He was waking up through the sedation saying he wanted to go home. He tried to get up. He tried to get dressed. He was telling me he was coming home. But of course he couldn’t. He had the strength to wake up but he was still dying.

The family were waiting for his release, for him not to suffer all this anymore. When he was waking up, it was frightening. The whole thing was distressing for everybody, including the nurses and doctors. The nurses came to me and said, ‘This is awful. We are so sorry. It is hideous what he’s going through.’ They were in tears. They were upset about what was going on. There was no quality. It was horrific. All of it. He was a strong man. Paul was the most dignified man you would ever meet and he’d done everything with dignity up until that last week. It’s just barbaric. It’s inhumane. It’s wrong on every level.

Bereaved wife

There is no official data on how often palliative sedation is used in the UK. In one study, 8,857 randomly sampled doctors were asked about the last death they attended. Palliative sedation was used in 17% of the deaths.¹¹⁴ In another study, 18.7% of doctors surveyed reported the use of continuous deep sedation, that is sedating someone up until the point of death, in the last death they attended. In 12.8% of the reported cases the request came from the dying person.¹¹⁵ Doctors who supported a change in the law on assisted dying, as well as doctors who did not have religious beliefs, were more likely to report using palliative sedation.

13. Double effect

Some doctors believe there is a significant difference between administering medication with the intention of relieving suffering, even if it results in the person dying, and administering medication with the intent to end the person's life. If the administration of medication results in the person's death but the intention was to relieve their symptoms of suffering, then this is viewed as permissible. It is known as the principle or doctrine of double effect.

According to the British Medical Association, the doctrine of double effect has been used to differentiate, legally and ethically, between the legitimate and illegitimate use of strong opioids or sedatives at the end of life.¹¹⁶

Double effect is a contested aspect of end-of-life care. Baroness Ilora Finlay claims 'there is a world of difference' between modern analgesia and assisted dying or euthanasia.¹¹⁷ In 2011, a number of palliative care consultants claimed in the BMJ that 'there are no circumstances in which the prescription of a lethal dose of opioid is necessary to control suffering.'¹¹⁸

The Association for Palliative Medicine states that 'patients may experience distress when symptoms cannot be controlled even after exhaustive attempts with specific interventions. In these circumstances some patients may require sedating medication to diminish awareness of their suffering. Medication used in this way does not shorten life.'¹¹⁹ These claims are backed up by a number of small-scale studies which have observed that palliative sedation does not shorten the lives of people in hospice settings.^{120,121,122}

There is no consensus on the true consequences of sedatives. In 2018, one medical ethicist wrote that 'it is at least biologically plausible that – despite their careful titration – [opioids and sedatives] do in fact hasten or bring about death.' Therefore, the author concluded, we should be 'agnostic' on whether or not the use of these drugs can shorten people's lives.¹²³ Others have taken a stronger view, declaring the principle of double effect to be 'a piece of complete sophistry.'¹²⁴

The European Association for Palliative Care offers a multi-faceted view. Its framework on palliative sedation describes the risk of hastened death as a possible complication of palliative sedation and acknowledges that 'some physicians administer doses of medication, ostensibly to relieve symptoms, but with a covert intention to hasten death.'¹⁰⁶

62% of Scottish healthcare professionals believe there are circumstances in the UK in which doctors or nurses have intentionally hastened death as a compassionate response to a patient's request to end their suffering at the end of life.¹

A 2009 survey of doctors found that 28.9% had made decisions involving providing, withdrawing or withholding treatment that they expected would hasten the death of a person under their care. A further 7.4% reported they had made decisions with, to some degree, the intention to hasten a person's death. These decisions were more likely to be made when responding to a person's request for a hastened death.⁷⁹ Some healthcare professionals discussed the possibility that former colleagues may have actively hastened death.

“ I think in the old days the GP came in and just did it, and I think mostly for very good reasons, and I think people were very grateful for it.

Palliative care nurse

One doctor described a patient who had asked them to end their life.

“ I have been asked to see people out. On one occasion a woman with carcinomas of the ovary had an awful ascites – fluid in the abdomen – and her abdomen had become so distended with liquid. She was in a lot of pain and she was having palliative care but it wasn’t enough. She asked me to put her out of her misery.

GP

The Gosport scandal

In June 2018, an independent panel published a report on practices at the Gosport War Memorial Hospital during the 1990s.¹²⁵

The panel found that 456 lives had been shortened by the prescription of opioid analgesics such as morphine, diamorphine and fentanyl as well as sedatives and other psychoactive drugs. An ‘institutionalised regime’ developed at the hospital, under which lethal doses of these drugs were administered without clinical justification.

The independent panel’s report states that it would be a mistake to view what happened at the hospital in the context of end-of-life care and assisted dying, as the patients involved were admitted for rehabilitation or respite care and not necessarily at the end of their lives.

However, the events at the Gosport War Memorial Hospital do illustrate two relevant facts. Firstly, that opioid medications can be and have been used to shorten people’s lives. And secondly, that safeguards in the current law to protect people from fatal doses of opioid medication can be and have been circumvented.

The disagreement surrounding the doctrine of double effect was reflected in the views of interviewees. Many struggled to see clear ethical differences between some palliative care practices and assisted dying, while others did view them as distinct.

“ We give medicine to treat a symptom, not to hasten the death. But you don’t know, that’s completely unquantifiable. It’s definitely a grey area. It’s blurred for everybody. It’s very difficult to quantify. How do you know how much is too much?

Palliative care doctor

“ You control people’s symptoms right up until the end, and that is a relief for a lot of relatives who are there watching. Sometimes it can be a matter of anxiety because they think, ‘Are you giving them this to finish them off?’ The answer is that you’re giving whatever you’re giving to make them feel comfortable. If that is the dose that finally kills them, then that’s not the intention and that is nature. But the thing you can always say with complete truth is that you never know what degree it’s the drugs and what degree it’s the disease they’re dying of. You can’t know that.

Palliative care nurse

“ We use phenobarbitone as a sedative. It’s actually like a third-line sedation, but the doses we give would not kill someone. The functional distinction between giving someone something that is going to make them unconscious and giving someone something that’s going to kill them is what is legal and what is not.

Palliative care consultant

“ Palliative sedation is where your intention is not to kill someone or stop their life. Your intention is to put them into a state of unconsciousness, from which they are unlikely to recover. Their death will come through the dysfunction of their body, naturally as it were. I think it is a difficult distinction from assisted dying. I mean in terms of legality it is distinct. But actually I think if you are wanting to put an end to someone’s misery like that, then really the best thing is if you can be honest about it and not be trying to do something under another name.

GP

“ My uncle died five months ago and I sat at his bedside, and I held his hand as his wife and his daughter were preparing themselves. He pulled out his nasogastric tube, but he didn’t pull it far enough. He aspirated on the contents of his nasogastric and he died of aspiration pneumonia. In total it took around nine hours and it was horrendous, absolutely horrendous, to watch somebody drowning for nine hours.

They were increasing the dose of the sedation they were giving him. Because I was a nurse I was calculating in my head, and when she came in at 2 o’clock to give him his dose I knew it would be his final dose. And luckily, in ten minutes, he slipped away. And I thought, why couldn’t you have done that five hours ago? Because, if they were seen to have done it too early, then it would be euthanasia. But I do believe that happens every day in a clinical setting.

Dying person

“ I’ve got one patient at the moment. She is dying. I think there is a chance that she will die in the next 24 or 48 hours. When she is awake she is feeling uncomfortable. It is not pain. It is more nausea that is the problem for her. When she is asleep she is more comfortable. She asked me very specifically yesterday if we could do anything to speed up her death, and if she could be drowsier. Of course we can’t do anything to speed up someone’s death, but we will do everything we can to make them comfortable and it may be that that will lead to more drowsiness.

I don’t think the line is that fine. I am not saying that the medications we use are inherently, completely safe. I am just saying that the way in which they are used and increased when someone has a very limited prognosis isn’t very likely at all to hasten their death unintentionally.

Palliative care consultant

“ I think that the line, if there is a line, between assisted dying and palliative sedation is incredibly blurred. I’ve seen reports where a number of doctors say they know it will hasten the patient’s death. They don’t have a problem with that but of course they can’t admit to that because of a fear of a legal backlash. I think we’re almost splitting hairs, for goodness sake. I mean if you’re going to offer palliative sedation not knowing how long it’s going to take the patient to die, why not offer assisted dying? I can see some people’s opinions of where the intent is but we’re really blurring lines when you get to that stage, you really are.

Bereaved son



Dignity in Dying's view

Decisions made in current end-of-life practice lack the safeguards, transparency or monitoring that would be present under an assisted dying law. Therefore, dying people who may wish to have their death hastened face a lottery – they may or may not find themselves under the care of a doctor willing to respect their wishes for such action. Importantly, under the current law, medical decisions that lead to a person's death can be made without explicit input from the dying person. By contrast, an assisted dying law would contain upfront, transparent safeguards to ensure that it would be illegal to proceed with an assisted death unless there was an explicit and documented request from the dying person themselves.



14. SUSAN'S STORY



Susan described the death of her daughter Fiona, who died in a hospice when she was 31.

“ She had a very painful face and the doctor sent her to the dentist. She went backwards and forwards and then she was referred to hospital. She was diagnosed with a rare form of cancer. It was a childhood cancer and it was very unusual for somebody of her age to get it.

First of all they thought it was a brain tumour, but it was actually a tumour in her paranasal sinuses which are under her eye. They wanted to start the treatment the same day. She had a course of three days of chemotherapy and then it was every couple of weeks. It went on and on.

In 2017 she was actually given the all-clear. We were delighted. The tumour was in regression and things were looking up. But unfortunately after a couple of months it reared its ugly head again.

When it grew again it grew on and behind her eye. They wanted to remove her eye but they weren't sure whether taking it out would actually make a difference. She had to make the choice. So she kept her eye and then she had more radiation to her head, which they said was very dangerous because she could lose her short term memory. Then in December 2017 they told us that there was nothing else they could do.

In early January 2018 one of the professors at the hospital said that he thought he could remove the tumour. Again it was her decision, but they thought there was a chance that if they could remove the tumour it might give her more time. She had four operations in quick succession and each time the problem got worse. They removed her eye, but the operations aggravated the tumour and it caused it to spread.

“ She went on a clinical trial but she was so ill. She was in hospital twice with chronic diarrhoea which burned all her bottom. All her insides were painful. She couldn't hold her wee. She started to be in a lot of pain and in April somebody from the local hospice came to see Fiona and he said he could offer her a place in a hospice to try and manage her pain.

Prior to her going into the hospice we decided that we were going to pay for immunotherapy ourselves. The consultant at the hospital agreed it was the only course of action that could stop the progression of the disease, so we were in liaison with a professor in Harley Street. When she said to the hospice consultant that she was in a lot of pain and the consultant said, 'What we can do is we can put you to sleep and then we can wake you up when it's time for you to start your treatment,' I thought that was quite weird.

In the hospice there were 11 individual rooms with a toilet for visitors and two bathrooms. I said, 'Oh it's strange there's only two bathrooms for all the patients.' I didn't realise that all the patients there were comatose. You didn't actually see anybody. Everybody was in bed and the only thing you heard was – it sounds awful – people screaming. In the middle of the night I used to hear people coming to take the bodies away. One weekend there were seven dead in there. It was pretty horrendous but the nurses they were all lovely. They were so nice, so helpful. Fiona was in the dayroom, she was outside in the garden, she had lots of visitors. They made it as jolly as possible.

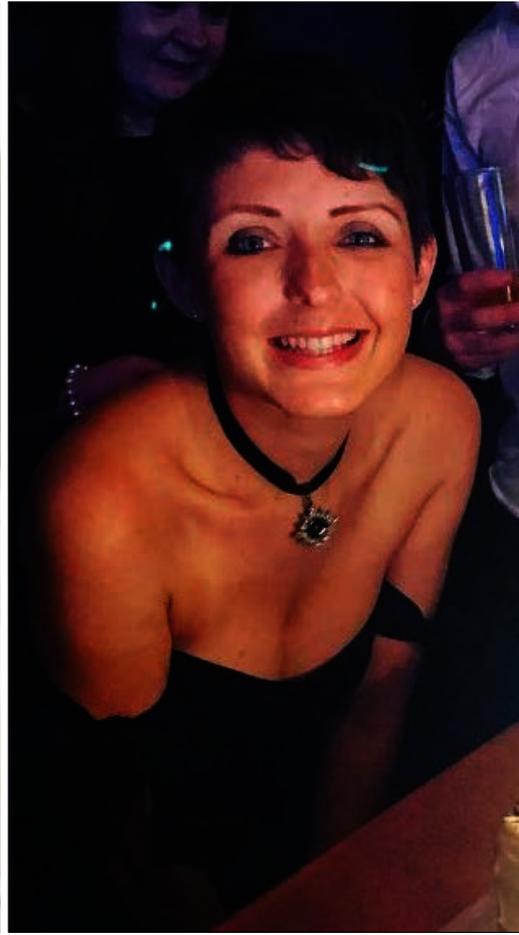
When we were in the hospice I spoke to the consultant and she said to me that Fiona was very, very ill and in her opinion she only had days left to live. The cancer had spread and the tumour was progressing rapidly. The immunotherapy treatment was starting on 27th April, but on 26th we spoke to the professor and the consultant and in both of their opinions it wasn't worth going ahead.

At that point Fiona had been in the hospice nearly three weeks and she was losing all mobility. It got to the stage where she couldn't even lift her hand up and the tumour was starting to actually grow through her nose. She was having trouble breathing. We had a lot of laughs. Her humour and her joy of life – it never, ever diminished. She was in the hospice making funny videos to send to her friends and things. There was never any feeling sorry for herself.

But when we found out on 26th that the treatment wasn't going ahead she said to me, 'Mum, I just want them to put me to sleep. I can't do this anymore.' It was my son's birthday so we decided that we were going to go ahead with the party as usual and have all the friends round and everything.

On 27th the nurses came and gave her sedation and they said, 'What will happen is you'll be sedated and within four hours you'll be asleep and you won't wake up again.' That's what was offered and that's what she wanted to do. I found it strange because I knew there were guidelines that they had stuck to when Fiona was in pain.

There was only a certain amount of pain relief that they were allowed to give her. She was experiencing waves of pain, breakthrough pain, and she was given top-ups. I worked out how many top-ups she had and how much they were allowed to give her the next day.



“ Having the sedation was her decision. It wasn't my decision. I would have hung onto her. The nurse said, 'I will ask you three times if that's what you want to do.' Fiona said, 'No, you know I've thought about it.' She wasn't able to move. She was finding it difficult to swallow, her tongue was swollen and she was finding it difficult to talk. The tumour was growing and she was getting clots at the back of her throat. It was just awful. She was in so much pain and no matter how much pain relief she was getting, it would just exacerbate it. It was always there.

They told us she wouldn't wake up, that she would slip away. My ex-husband came to the hospice and I got the consultant back to say the same thing, because I wanted somebody else to be there to hear it. Do you know what I mean?

On the Friday the consultant came in and she said what did Fiona want to do? Did she want to make a decision before Monday? She said that she wanted it that day. She didn't want to wait for the weekend. We obviously thought that within hours Fiona would be asleep and that would be the end.

I was with her all night. I stayed with her all night. She was still awake. We sat around the bed and put music on but she didn't sleep. She dozed on and off but she was awake more than she was asleep. You could have a conversation with her. She would say that she was thirsty or she wanted a drink.

“ She couldn’t get comfortable and she wanted me to keep moving the bed up and down because she couldn’t move but she just couldn’t get comfortable. So that was the Friday. Saturday she was still awake. Sunday she was awake. Sunday she was actually hungry. She wanted a milkshake and we went out to get her one. She had visitors.

Every day the dosage of ketamine was increasing. The consultant came in and said, ‘Oh Fiona, I can’t believe it. You’re getting serious doses of drugs.’

On the Sunday there was a lovely nurse and she said, ‘Shall we change the bed?’ And I said, ‘Yeah, I’ll help you.’ So we were changing Fiona’s bed and she had fallen asleep for a bit. It was very frightening because every time she did fall asleep we kept thinking, ‘That’s it.’ We had said goodbye and you get upset and then she’d suddenly wake up again, in a horrible way. This happened seven times. We were pleased to see her, but it was like being on a rollercoaster. It was very harrowing. Very harrowing. Your emotions are all over the place.

The nurses were also very, very upset. It was really hard for them. I felt really sorry for them. One of the nurses would often be in tears and she said, ‘There’s nothing else I can give her. I’m not allowed to give her any more. This is as much as I can give her. I can’t take the pain away for her.’

On the Monday they decided they were going to give her another syringe driver and move it from her arm to her leg. Then her breathing got shallow and shallower. The nurse came in to see her and said, ‘Oh her breathing is really shallow, I think her time’s nearly out.’ About 15 minutes later she died.

It was very distressing for Fiona because she had to keep saying goodbye to everybody. We had to say goodbye to her but she had to keep saying goodbye to all of us and that must have been awful for her. Absolutely dreadful. I wouldn’t wish it on my worst enemy. To see somebody suffer. It was torture. Her illness was traumatic enough and how she coped with it was amazing.

I still feel quite traumatised by her death because I just think that it could have been avoided. I can’t see the difference between giving somebody large amounts of drugs to end their suffering over a period of time or giving them all in one go. It just doesn’t make sense, because the end result’s the same. I just feel that at the end of the day she was let down.

I went to this meeting in London about palliative care. There was a professor at some university who said, ‘What can we do to make people speak about dying, because people don’t broach the subject?’ We were going around the room with people saying what their views were and people said, ‘Oh yeah, I think that when I die I want to be in a middle of a field in a bed looking at the stars.’ And I thought that’s not really reality. I said, ‘Well, we broach it to a certain extent.’ Then I brought up the subject of assisted dying and I was shot down in flames and the professor swiftly moved on.

I feel like Fiona hasn’t got a voice anymore and I’m her voice. I’m the one who can tell her story and bring about change.

REFLECTIONS



15. Opposition to law change

Many interviewees shared their views on why people might oppose assisted dying. A common view was that they must lack understanding of the nature of the suffering people experience at the end of life.

Some felt angry at the prospect of being denied the option of an assisted death.

“ The danger is, at the moment in this country, if you are terminally ill and you want to end your life, you’ve got to arrange it yourself. I think we should respect the fact that people have the right to make their own decisions. Until you’ve experienced it firsthand you don’t know...

Bereaved daughter

“ I would say that everyone makes choices and I don’t think anyone can assume they know what would be best for themselves or someone else until they are in that situation. And it is only a choice. There are a lot of examples where people who have been very openly opposed have actually come to face their end of life and rapidly changed their mind. I think everyone needs to look at this from a point of view of having an open mind and by speaking to people who have experienced this and considering how bad it could actually be for you.

Bereaved daughter

The one thing I would say to anybody that was voting against it is please, please, please do not take that choice away from me. Do not put me through that.

Bereaved daughter

“ What difference does it make to me how anyone else lives their life and, indeed, ends it? It shouldn’t be down to me and it shouldn’t be down to self-appointed moral guardians.

Bereaved son

“ I am really not coping with what happened and I am absolutely terrified. I have actually put the money aside for Dignitas. If I am diagnosed with anything that is life-threatening I’m not going through it. I’m not going through what my mother and brother went through. I have not met anybody who has sat by and seen a loved one suffer who disagrees. The people that say that it’s wrong have never been there.

Bereaved daughter

“ I think people are concerned about safeguards. They’re concerned about whether the law would be abused but actually, whatever their viewpoint is, they need to accept that what’s happening now is not acceptable. Doing nothing is not an option, regardless of whether they think assisted dying is okay or not. Doing nothing is not addressing the suffering that people are facing. Something needs to happen.

Bereaved daughter

Healthcare professionals questioned how people could oppose assisted dying if they had come face to face with the limits of palliative care during their careers.

“ I think it’s arrogance on the part of the palliative care teams, to say that basically they can always sort it out. I think there’s a total arrogance because I’ve seen enough to know that’s not true and they say, ‘Well, the palliative care’s got to be improved then.’ That takes away people’s self-determination and I think there should be a degree of self-determination and choice about one’s end.

GP

“ I don’t think people who don’t think we should change the law have seen some of the things that we’ve seen. They haven’t seen patients suffocating with motor neurone disease. They haven’t seen patients decomposing. They haven’t seen patients who have such a huge facial tumour that their back molar just falls out of their cheek. They haven’t seen these patients and their distress.

I think if these people actually thought about it for themselves they would want to have a comfortable death.

Palliative care nurse



“ I can't quite understand it because the reason I do palliative medicine is to relieve suffering. There's a lot of fear in palliative care about assisted dying and it's not supported by any evidence. I think the medical culture is lagging behind what the public want.

I imagine sometimes it's fear of the unknown and they just can't envisage how it would work but I don't know how they could say that when someone's suffering terribly. I would say, 'Look, can you imagine you were in horrible suffering. You really have a lack of control. You've got symptoms so bad that you can't move your body.' We don't often imagine ourselves in our patients' positions and I think we should. If you do, you would start to think it could be pretty grim and what if we didn't manage to get your suffering under control? What would you think?

Something that we as doctors like is lots of control and lots of knowledge and I think we would struggle to think of a time where we don't have control. We stand at the end of beds and we look on and we know a lot and we can treat a lot, but it's not us. It must be horrible to have such lack of control, such helplessness, being the patient in a terrible situation and suffering.

There's lots of interesting stuff out there about how doctors don't accept certain treatments at the end of life. We make different decisions for ourselves than we do for our patients and if we just thought about that lack of control maybe that would change a lot of doctors' minds.

Palliative care doctor

“ What I always say to people who are against assisted dying is that I'm not for it. I'm for the choice. It's my duty as a nurse to explore those feelings with patients even if I can't do anything about them.

I did speak about assisted dying at a conference once and I got such hostility from people. It was personal. People have very, very strong views. It's possibly a bit like having a very strong political view. You're not prepared to have a discussion where you're trying to find a medium way or some kind of consensus. I think it's very similar to political views or very strong religious views.

Palliative care nurse

“ If we could treat them, if we could make their life better, we wouldn't be having this conversation.

Pain specialist

“ I don't think that there's any doctor I know who has not felt it's barbaric to have to go through the process that we have to now. When you can't relieve suffering, you're basically forcing someone to keep going in a sort of interminable misery.

GP



“ I see a significant number of people who I am sure would find some reassurance if assisted dying was legal. I get enough people asking me about it. I don't know how many of those would actually want to go through with it but I think it would at least be a reassurance for a lot of people. I think that is a decent argument for changing things. Of course the experience of any particular person is going to be their experience and they might find it unbearable and someone else might say, 'Oh that doesn't seem that bad at all.' It is that choice that I don't think that palliative care can necessarily deal with. Because fundamentally, if someone says, 'I know I am going to die. I am not scared of dying. I want to die.' And we are saying, 'Well, we can't do that,' then that is an impasse. We can't solve that problem.

I think the people who are vocally against a change in the law knowingly miss the point. Because fundamentally it comes down to the fact that there is a group of people who will want this, and who will want to have the option of it. So the argument about how you should fund palliative care more. You should. We can treat the vast majority of symptoms, but that's missing the point completely.

Palliative care consultant

16. Assisted dying

Assisted dying is a legal end-of-life option for over 100 million people around the world, including in numerous states in the USA, in Canada and in Victoria, Australia.

In Oregon in 1994, two weeks before a public ballot on a proposed assisted dying law, the Oregon Hospice and Palliative Care Association (OHPCA) formally declared its opposition to assisted dying, fearing the potential for negative consequences of law change.¹²⁶ 20 years after Oregon's law came into force, the same arguments are echoed today in the UK by the Association for Palliative Medicine.¹²⁷

The OHPCA dropped its opposition to assisted dying when it became law and later acknowledged that its fears had not been realised. The law works safely while giving dying people more meaningful end-of-life choices.¹²⁸ The OHPCA now recognises that 'Oregonians need not choose between hospice and physician-aid in dying. Dying Oregonians can choose both from among the options on the end-of-life continuum of care.'¹²⁹

Only 6% of Scots think the UK's laws prohibiting assisted dying are working well.²

Only 14% of Scottish healthcare professionals think that without an assisted dying law there are sufficient options available to give dying people meaningful control over their deaths.¹

“ It's what she wanted, what she would have wanted, without a doubt. It would have happened probably two weeks sooner I would say, if not before. She'd fought long and hard. She never moaned. She never used to talk about pain. She was just a strong girl. She had battled. She was very forward thinking but, towards the end she felt, 'Well it's got me now, so don't let me linger here now. I don't want to linger anymore.' Her fight had gone. She had no more fight in her.

Bereaved sister

“ I think assisted dying would have made it much... I can't really say nicer, but I think it might have been quite a special thing. I think she would have chosen to do it. We would have chosen the right place, the right time, prayed and she would have been there with me and I would have held her and we could have made it something special.

Bereaved daughter

“ I would feel so much safer and more confident if assisted dying were legal. It would be my judgement when I've had enough. It would be wonderful.

Dying person

“ It would have just been pain-free and less traumatic not only for Mum, but for those having to watch her go through that. The only thing I can liken it to is if you were in a room and somebody in that room was causing pain to a child and you could see that happening and you could do nothing about it. You know it’s wrong and every instinct in you wants to ease things for somebody in that situation and you can’t.

Bereaved daughter

I think we just accept the fact as doctors, because we’ve been through it so many times, that it’s all awful. It’s going to be awful, but it doesn’t have to be. There is a better way.

GP

“ If assisted dying were legal it wouldn’t have been protracted. She could have gone very quickly and peacefully. She’d had enough to contend with without having such an awful death and suffering unnecessarily, when we know there are things that they can do to end your life.

Bereaved mother

“ We all talk about people’s rights as patients. Why is it that somebody who is of sound mind, who knows what they’re doing, who’s facing suffering, who knows what their prognosis is – why can’t we give them the autonomy to make a choice? And if they do make that choice, why can’t we make it possible? We are disrespecting their view as an individual and we are actually going against their human rights.

Pain specialist

“ A lot of the people who are against assisted dying say doctors wouldn’t do it. I certainly would, in the right circumstances. If all the legal criteria had been fulfilled and assisted dying were legalised in this country I’d be perfectly prepared to make the concoction for the patient to take themselves. They’d be in their own bed, with any luck. They’d have their family all around them and, instead of going on some wretched plane flight to a foreign country, the medication could be brought round to their own home. It could happen.

GP

“ I suppose in the last 30 years or 40 years there have been massive changes in this country, same-sex marriage for example. When I was growing up the idea that that might change would have been unthinkable, but it has happened and I am delighted that it has. I think the problem with assisted dying is it is not a glamorous subject. But it would give me that comfort of knowing that I would be in control at the end of my life. It would help me deal with things and improve my quality of life now.

Dying person

“ It would be indescribable, the relief that you would feel knowing you had access to that if need be. It would be a massive comfort.

Dying person

“ The radiotherapy has frozen the tumour very successfully for the last six and a half years. Eventually, one day, that will wear off and the tumour will start to grow. They can't give me any more radiotherapy because my spine is already a bit crumbly. When it starts growing it will be aggressive and the spinal cord obviously controls all of your functions.

At the moment I'm continent, I have a sex life, I can walk – pain is my main issue. But once the tumour starts growing, I'm going to have to make some decisions. I suppose it boils down to when I stop being me as I perceive me. That's when I don't want to go on any longer.

Dying person

“ I don't know how things are going to pan out for me. It may be that I just have a relatively short period of illness at the end and that my death is quite comfortable, and that would be fine. But my concern is that it is a prolonged period, possibly painful, possibly where my quality of life decreases and in those circumstances my view is that I should have a choice about how things are brought to an end. It is very much a matter of personal choice but I feel it is something that would give me comfort now and improve my quality of life, knowing that when the time comes it is within my control.

Dying person



17. Summary and recommendations

SUMMARY

This report has highlighted the limits of palliative care and the impact this can have on dying people, their loved ones and healthcare professionals.

A small but significant group of people experience pain at the end of their lives despite receiving the best possible palliative care. Even with universal access to specialist palliative care, 11 Scots a week would have no relief of their pain as they die. Some people experience other unavoidable symptoms of suffering such as severe nausea and vomiting, constipation, faecal vomiting, bowel fistulae, fungating wounds and terminal haemorrhages.

Many dying people fear what they may be forced to endure at the end of their lives and feel they are being denied control over their deaths. These feelings can be forms of suffering in themselves and lead to a reduction in quality of life. Consequently, some dying people explore trying to hasten their deaths. This can be through travelling overseas for an assisted death, ending their lives behind closed doors, or by voluntarily stopping eating and drinking in an attempt to accelerate the dying process. By contrast, simply having the option of having an assisted death would improve many people's quality of life.

When the family and friends of a dying person witness their end-of-life suffering there can be severe consequences for the bereavement process. Caring for someone who is forced to suffer as they die can also have a negative impact on healthcare professionals.

Existing end-of-life practices, such as palliative sedation and the withdrawal of treatment, help many people to have a good death but the ethical distinctions that are often drawn between these practices and assisted dying do not command the support of healthcare professionals or the general public. There are also examples of where these practices prove ineffective and dying people can continue to suffer against their wishes.



RECOMMENDATIONS

In light of the issues highlighted in this report, Dignity in Dying Scotland supports:

- the Scottish Government's commitment to end-of-life care, set out in its Strategic Framework for Action on Palliative and End of Life Care.³
- the vision of the Scottish Partnership for Palliative Care, which seeks to improve people's experiences of declining health, death, dying and bereavement.⁴
- the 2018 amendment to the Social Security (Scotland) Bill which increased access to benefits for people living with a terminal illness and the recommendations of the Our Voice Citizens' Jury on shared decision-making and a personalised approach to health and social care.^{5,6}

However, evidence shows that even if all these things were to be implemented, some dying people would still suffer at the end of their lives. Therefore, we also recommend that:

- all healthcare professionals involved in the provision of end-of-life care are given sufficient training and accurate information around the likelihood of symptoms of suffering associated with the dying process and, where possible, how to manage these symptoms effectively. This should include resources to help healthcare professionals have honest conversations with dying people about the types of symptoms they might experience.
- relevant associations and regulators for healthcare professionals produce up-to-date, national guidance setting out best practice around palliative sedation and the practice of voluntarily stopping eating and drinking. This guidance should be tailored to healthcare professionals and also members of the public, so that dying people and their loved ones have clear and transparent information about what choices are available under the current law and how those choices can be implemented. The guidance should be produced with the input of dying people and bereaved family members and friends who have first-hand experience of these practices. Guidance should reflect current societal attitudes and values, rather than historic norms of medical ethics.
- assisted dying is legalised in Scotland to give terminally ill, mentally competent adults a further option of escaping or avoiding a period of unbearable suffering at the end of lives.



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Support

The following organisations can provide information and support around terminal illnesses, end-of-life care and bereavement.

Bowel Cancer UK
020 7940 1760
www.bowelcanceruk.org.uk

Marie Curie
0800 090 2309
www.mariecurie.org.uk

Brain and Spine Foundation
0808 808 1000
www.brainandspine.org.uk

MND Scotland
0141 332 3903
www.mndscotland.org.uk

Breast Cancer Care
0808 800 6000
www.breastcancercare.org.uk

Oesophageal Patients Association
0121 704 9860
www.opa.org.uk

Compassion in Dying
0800 999 2434
www.compassionindying.org.uk

Ovarian Cancer Action
0300 456 4700
www.ovarian.org.uk

Cruse Bereavement Care Scotland
0845 600 2227
www.crusescotland.org.uk

Samaritans
116 123
jo@samaritans.org
www.samaritans.org

Hospice UK
020 7520 8200
www.hospiceuk.org

Sue Ryder
0808 164 4572
www.sueryder.org

Macmillan Cancer Support
0808 808 00 00
www.macmillan.org.uk

DIGNITY IN DYING SCOTLAND.

We believe that everybody has the right to a good death, including the option of assisted dying for terminally ill, mentally competent adults.

Find out more and get involved at
www.dignityindyingScotland.org.uk

Contact us

Dignity in Dying,
181 Oxford Street,
London,
W1D 2JT

 0141 297 1816

 scotland.campaigns@dignityindying.org.uk

 www.facebook.com/dignityindying

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