

CAMPAIGN FOR
DIGNITY
IN DYING.

RE
ME
S
O
RT

LA
S
T

*"He could have had a longer
life and a kinder, safer death."
Anil, campaigning for his dad*

The hidden truth about
how dying people take
their own lives in the UK

CONTENTS

ACKNOWLEDGEMENTS

Dignity in Dying would like to thank the individuals who shared their stories for this report.

Written by:

Lloyd Riley and Davina Hehir

Research support:

Hannah Easdown and Upeka De Silva

Interviews:

Professor Bronwyn Parry and Dr Sally Eales

Photography:

Luke Doyle

Design:

TEMPLO

Legal advice:

Katie Wheatley, Bindmans LLP

Published October 2021

CONTENT WARNING

This report contains accounts of dying people ending their own lives, as well as the emotional distress subsequently experienced by their loved ones.

A list of organisations that can provide support if you have been affected by these issues can be found on page 82.

Foreword	4
Executive summary	6
Methodology	12
Introduction	14
Language	16
Diagnosis	20
Support	24
Planning	30
Dignitas	32
Other means	34
Zoe	38
Attempts	42
Julian	44
Secrecy	46
Barbara	48
Help	51
Susan	54
Crime scenes	57
Joy	60
Grief	63
Data	68
Assisted dying	74
Summary and recommendations ...	80
Resources	82
References	84

It was my experience with my beloved parents that led me to support the legalisation of assisted dying. In 2005 my 80-year-old mother, who had suffered from Parkinson's Disease for a decade, moved into a nursing home because her needs were too complex for my father and me to manage. She had lost all her independence. She found no pleasure in life. She was in great pain. Every day she told me she wanted to die and begged me to help her go. I was powerless. After nearly a year she was unable to swallow and was starving. She resembled a living skeleton. Eventually she died in the early morning just before Christmas. She was alone. My father and I were heartbroken.

Six months later I told my father I would be unable to visit for the weekend. It was my birthday. I was going away. He said he was fine and wished me a jolly time. As I was leaving for the airport and hadn't seen him for nearly a week, I had a call from his neighbour. Dad was desperately ill. Could I come over? He lay thin and weak in his bed. He'd neither eaten nor drunk and had clearly intended to end his own life in my absence.

I persuaded him into hospital. A diagnosis of advanced lung cancer followed and two weeks later he died, holding my hand in the local hospice. In both cases an assisted death at home surrounded by a loving family would have saved so much anguish and desperation for them both and for me.

Neither of my parents had the financial means or indeed the fitness to make the journey to Dignitas in Switzerland and they are not alone. This report tells the stories of the dying people who take their own lives in the absence of a safeguarded assisted dying law, those who feel they have no other option but to turn to rope, oncoming vehicles, shotguns, suffocation, starvation, drowning and overdoses of imported or stockpiled drugs.

Their courageous family members, amidst their grief, are subjected to further punishment in the form of police investigations that prove traumatic, drawn out and entirely without purpose.

The law we have at present is not fair or caring, it is barbaric and it is not fit for purpose.

There is a growing body of literature that tells us the desire to control an impending death is substantially different from what motivates someone to take their life by suicide. We are relying on anachronistic laws and misplaced prevention strategies to cope with a problem that requires a more informed and compassionate approach.

That approach is not out of reach. Our friends in Australia, New Zealand, the USA, Canada and more and more countries across Europe are ahead of us. Dying people fortunate to live in a jurisdiction that has changed the law do not have to live in fear. Their choices are valued and respected. They are not abandoned - like we have inadvertently abandoned our people - to plan a cruel and lonely death. Their families are not left broken and haunted by final images of their loved ones' mutilated bodies. Some things cannot be unseen.

It is no surprise that the public's support for law change is unwavering and that the views of doctors - and their representative bodies - have shifted in recent years.

We can wish it were not true. We can choose to ignore it. We can turn to flawed reasoning to justify it. But when the history books scrutinise how we confronted the question of assisted dying we will no longer be able to claim ignorance of the horrors inflicted by its prohibition.

If you think you oppose assisted dying, all I ask is that you look at this evidence, and then think again.



DAME JENNI MURRAY.

EXECUTIVE SUMMARY.

Banning assisted dying forces many dying people to find alternative ways to control the end of their lives. This results in deaths that are needlessly violent, unsafe and damaging to those who are left behind.

There is an unacceptable degree of inequality built into this status quo. Some dying people are able to plan, arrange and achieve the peaceful death they want, but whether they can do so is largely dependent on their wealth, knowledge, resources and luck. Dying on your own terms in the UK is currently unattainable for many people.

Researching the most effective ways to die, arranging access to methods or sourcing equipment, trying to protect family members from being implicated in a crime, all while experiencing the limitations of a medical profession which has its hands tied by the current law, creates intense anxiety and dramatically reduces dying people's quality of life.

There is inconsistency in how these deaths are investigated. While the law puts police in very difficult positions, their investigations are intrusive and detrimental to how people experience grief. Many of these investigations prove incapable of detecting the true circumstances that surrounded someone's death and, as they happen after the fact, it is impossible for them to offer protections to the individual who has died, calling into question whether they are an effective use of police resources.

There is also inconsistency in how deaths are recorded. Our research has found examples where some deaths may not have been registered accurately. This makes data collection in this area extremely difficult.

Crucially, there is clear evidence that the wish for greater choice at the end of life is different from what motivates a person to die by suicide,

stressing the need for two important issues - assisted dying and suicide prevention - not to be conflated.

More data is needed, but in the UK we now estimate between 300 and 650 dying people end their own lives every year and as many as 6,500 attempt to end their own lives.

While we may never know the true extent of the harm inflicted by the UK's blanket ban on assisted dying, findings from this report can be added to the existing evidence base. In the six years since MPs in Westminster and MSPs in Holyrood last considered assisted dying legislation, Dignity in Dying has shown that every year dozens of UK citizens still travel to Switzerland to die, hundreds end their lives in this country and thousands more suffer against their wishes.



EVERY YEAR IN THE UK...

50

People travel to Switzerland for
an assisted death

300 - 650

Dying people end
their own lives

Total number of dying people directly
affected by the UK's blanket ban on
assisted dying every year: 9,500 - 13,500

3,000 - 6,500

Dying people attempt
to end their own lives

6,400

Dying people who will suffer
pain in the last three months of
life even with access to the best
possible palliative care

RECOMMENDATIONS.

The law must change to allow terminally ill, mentally competent adults the option of an assisted death, subject to robust, upfront safeguards

A change in the law would reduce anxiety, inequalities and unnecessary suffering amongst dying people in the UK. Crucially, it would make society safer, replacing the chaos of the status quo with a law that is open and transparent and has meaningful upfront protections, both for those who would want to explore the option of an assisted death and those who would not. This is in stark contrast to the current law, where investigations tend to take place after someone has died, if they happen at all. Law change would provide an opportunity for robust data collection and regulation, providing a much more accurate picture of the end-of-life choices dying people in the UK wish to exercise.

There must be recognition that assisted dying and suicide are distinct concepts

People who are terminally ill and approaching the end of their lives simply want to control the way they die. Presenting this as 'suicide' is misleading. It does not reflect the academic literature or the views of dying people and their families and leads to a lack of clarity in the assisted dying debate. In line with guidelines from the Samaritans, the phrase 'commit suicide' is inappropriate in any circumstance. As this report shows, many terminally ill people feel driven to end their lives in lonely and violent ways. An assisted dying law would protect these people from those kinds of deaths.

Society must know the true numbers of dying people who end their own lives in the UK

The Office for National Statistics (ONS) is currently researching the rates of deaths recorded as suicides amongst dying people. The ONS should routinely collect and present this data to Parliaments in the UK to inform debates about assisted dying. Those with relevant expertise should work together to explore how further data could be collected. The Coroners' Society of England and Wales should consider ways that it can contribute its expertise and knowledge to societal debates.

Dying people should be able to have open and honest conversations with others about their wish for an assisted death

Those who want to control the manner and timing of their deaths should not have to manage that wish alone out of fear of implicating their loved ones or healthcare professionals in a crime. Organisations that provide care and support to dying people should assess their policies on assisted dying to ensure they are creating space for their members, staff and service users to have conversations about the subject. They should ensure they are proactively promoting a culture of openness and respect for diversity of views around choice at the end of life.

Police forces should review their procedures for responding to deaths where a dying person has ended their own life

Police officers should not be asked to instigate investigations into breaches of the 1961 Suicide Act without sufficient training and support. Grieving relatives should not be subjected to unnecessarily intrusive and insensitive police investigations immediately following the death of their loved one. Police forces should review their existing procedures and learn from previous investigations they have conducted. Organisations responsible for other first responders should also ensure that people have the support they need to respond to and deal with these cases.

The content of this report is based on interviews with people who have been affected by dying people ending their own lives. Bronwyn Parry, Interim Vice President, Vice Principal (Service) and Professor of Global Health and Social Medicine at King's College London, and Dr Sally Eales conducted semi-structured interviews with 14 individuals. These included bereaved family members and clinicians.

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, unless otherwise stated, 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.

Polling figures, unless otherwise stated, are taken from a YouGov poll commissioned by Dignity in Dying. The total sample size was 1,767 adults. Fieldwork was undertaken between 12th - 13th August 2021. The poll was carried out online. Figures have been weighted and are representative of all GB adults (aged 18+).



In September 2015, MPs in Westminster voted down an assisted dying bill which would have legalised assisted dying for terminally ill, mentally competent adults in England and Wales. Earlier that year a similar bill had been rejected by MSPs in Scotland.

This is the third in a series of reports published since 2015 that sheds light on the reality of what is happening under current laws in the UK, demonstrating to parliamentarians why they must look again at this issue with a sense of urgency.

In 2017, we published *The True Cost: How the UK outsources death to Dignitas*.¹ The report found that the law discriminates between those who can afford to access assisted dying overseas and those who cannot. It found that people who die at Dignitas and similar facilities often feel forced to do so prematurely to ensure they are well enough to be able to make the journey. Many doctors, fearful for their careers, shun any attempt to broach the subject while others, in breach of guidance from regulators, are complicit in making arrangements for their patients.

The report found that family and friends, while not prosecuted for the crime of providing compassionate assistance, are forced to act in secrecy and left distraught or fearful by police investigations. When the circumstances of an assisted death overseas are investigated this usually happens long after the person has died and in approximately half of cases there is no investigation at all. This negates claims that the current law is capable of detecting foul play and offering protection to individuals.

In 2019, we published *The Inescapable Truth: How seventeen people a day will suffer as they die*² and an equivalent report in Scotland.³ Interviews with palliative care professionals, dying people and bereaved relatives exposed

the limits of palliative care. Even in hospices, clinicians are sometimes left helpless when confronted with physical, emotional and existential distress that many dying people experience. Analysis by the Office of Health Economics found that even if every dying person in the UK had access to the very best care, 6,394 people every year would experience no relief of their pain in the final three months of life. UK governments could divert their entire healthcare budgets into palliative care provision and there would still be people who suffer against their wishes. It is likely that we will all know someone in our lives who will be unfortunate enough to find themselves in that small but significant group.

The report also exposed the reality of current end-of-life practices. Doctors already make decisions that lead to – or in some cases actively hasten – people's deaths, but these decisions are made with little oversight, regulation or transparency. The status quo appears even more hypocritical and illogical when we learn of the dying people who starve and dehydrate themselves to death with medical support. As a society we tacitly accept acts of self-determination at the end of life as long as they occur out of sight, regardless of how inadequate they may be.

This report examines the third way in which the current law fails dying people. It reveals the stories of those who feel they have no other option but to take matters into their own hands. It explores their motivations and lays bare the repercussions for those who are left behind. It looks at the ways in which the police struggle to enforce the law and examines how we might quantify how many dying people in the UK take their own lives each year.

LANGUAGE.

Language around the assisted dying debate is contested.

The term assisted dying is widely used in academia, the media and draft legislation put before parliaments across the UK in recent years. In 2016, the term assisted dying was added to the Oxford English Dictionary.⁴ Assisted dying has been used as the primary term in briefings produced by the House of Commons Library,⁵ as well as literature from clinical stakeholders such as the British Medical Association⁶ and the Royal College of Nursing.⁷

However, most campaign groups opposed to assisted dying legislation instead favour the term 'assisted suicide', arguing that there is no difference between a dying person who chooses to control the manner and timing of an imminent death and someone who dies by suicide.⁸

In 2015, during Committee Stage of Lord Falconer's Assisted Dying Bill, amendments were tabled by opponents to the Bill which would have inserted the phrases 'assistance with suicide' and 'commit suicide' throughout. This language was rejected by Peers by 179 votes to 107.⁹

It is widely accepted that the term suicide carries social stigma¹⁰ and the idea that a person 'commits' suicide is an outdated reference to when - prior to the 1961 Suicide Act - suicide was a crime that could be committed. The Samaritans advises against the phrase 'commit suicide' for this reason.¹¹ 'Commit suicide' can also refer to the belief that suicide is a religious sin that can be committed, regardless of how it is viewed under the law.

In recent years there has been exploration of the psychological distinctions between a dying person who wants to shorten an imminent and inevitable dying process and traditional understandings of suicide. A piece in the Psychiatric

Times argued that there is a growing body of literature which 'outlines the differences between decisions to decline disease-modifying treatments (or directly hasten one's own death) and the psychopathology associated with suicidal behaviour. The latter may trigger efforts at suicide prevention and intervention, sometimes even against an individual's will.'¹²

The American Association of Suicidology (AAS), a non-profit association dedicated to the understanding and prevention of suicide, has a position statement which outlines how assisted dying, as is legal in numerous States in the USA, 'is distinct from the behavior that has been traditionally and ordinarily described as "suicide," the tragic event our organization works so hard to prevent.'¹³ The statement lists a number of reasons why this is the case, such as:

- The fact that accessing assisted dying means exercising control over a death that is foreseeable within months, which is notably different to sacrificing a substantial number of years of life;
- The view that assisted dying is 'self-preservation' as opposed to 'self-destruction';
- The observed reduction in severity of grief for family members following an assisted death compared to grief following suicide;
- The reality that traditional strategies of preventing suicides are ill-suited to being applied to assisted dying requests.

The AAS believes the phrase '[Physician] assisted suicide' should be deleted from use.

Despite speculative and unevidenced fears of a 'suicide contagion' the idea that the legalisation of assisted dying has led to an increase in suicide rates of non-dying people has been categorically refuted.¹⁴

ASSISTED DYING. NOT SUICIDE.

"My mum wasn't suicidal, the option of living had already been taken away"

In fact, research suggests media reporting of myths around suicide may be associated with an increase in suicide rates.¹⁵ This stresses the importance of accurately describing and reporting deaths where a terminally ill person has ended their own life.

Even in the circumstances explored in this report, where people have ended their own lives without access to legal and safe means of assistance, interviewees were keen to highlight the importance of distinguishing their loved ones' actions from suicide.

She never used the word suicide, just always said, 'Don't worry about me, I'll sort myself out.' I don't think of it as suicide. The coroner said, 'This could be quite difficult for you emotionally because we're going to put suicide on the death certificate.' My sister turned around and said, 'You can put suicide if you want, it means absolutely nothing to us.' In New York, when people jumped out of the Twin Towers, the death certificates didn't say suicide, because if your choice is burning alive or jumping out of a building it isn't suicide, you've made a

choice which way you're going to die. So we always think of it that way. Mum didn't die by suicide, she didn't decide she wanted to get out of life, she decided she wanted to go her way and that's all it was.

Dignity in Dying commissioned a poll for this report to gauge public opinion on the distinction between suicide and a dying person hastening their impending death. The results, illustrated on the next page, suggest there is widespread recognition that these are separate concepts and a clear majority view that assisted dying is an appropriate term to describe the process of a doctor providing life-ending medication to a dying person at their request in order to control the manner and timing of their death.

Dad was always quite insistent on the importance of language and in his notes to me he said that finding the right words to be able to describe what has happened to him was going to be very important. He suggested that instead of the word suicide you say, 'He chose to end his own life'. And that's something that I have stuck with. I've never said Dad committed suicide. And

I think that that difference in the language is everything. It shows you that it's not a crime as suicide used to be, but instead it's a positive choice of change and decision-making rather than a negative act that suicide has a connotation of. It's not a weakness, it's a decision full of power and autonomy, authority, made by someone who has very few of those characteristics left if their body has completely degenerated. It's a show of strength and resilience and power. I feel like it's completely different.

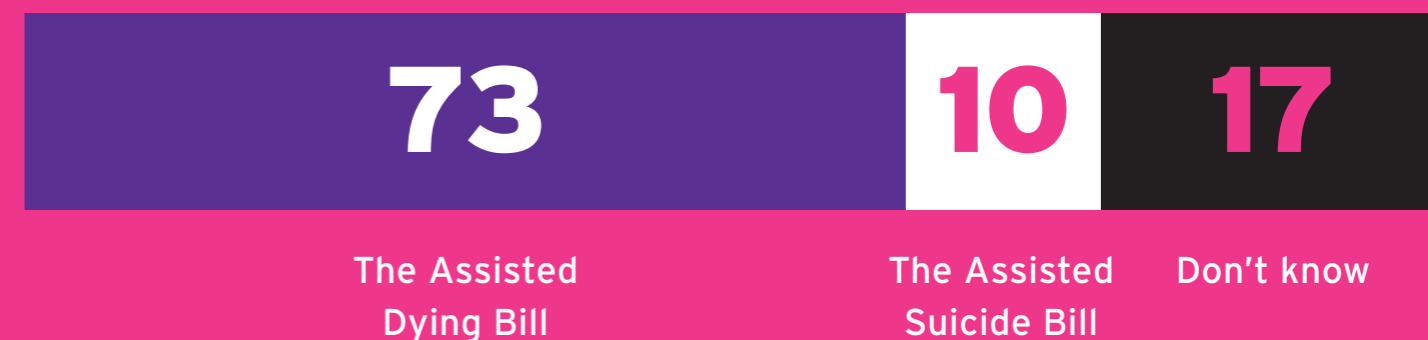
I don't think it's differentiated enough. Mum's death went down as suicide. It shouldn't have, but the coroner had no choice. My mum wasn't suicidal, the option of living had already been taken away.

In order to reflect public and expert opinion and most importantly the views of dying people and their families, Dignity in Dying rejects the term 'assisted suicide' and this report does not refer to dying people controlling the manner and timing of their deaths as having died from suicide.

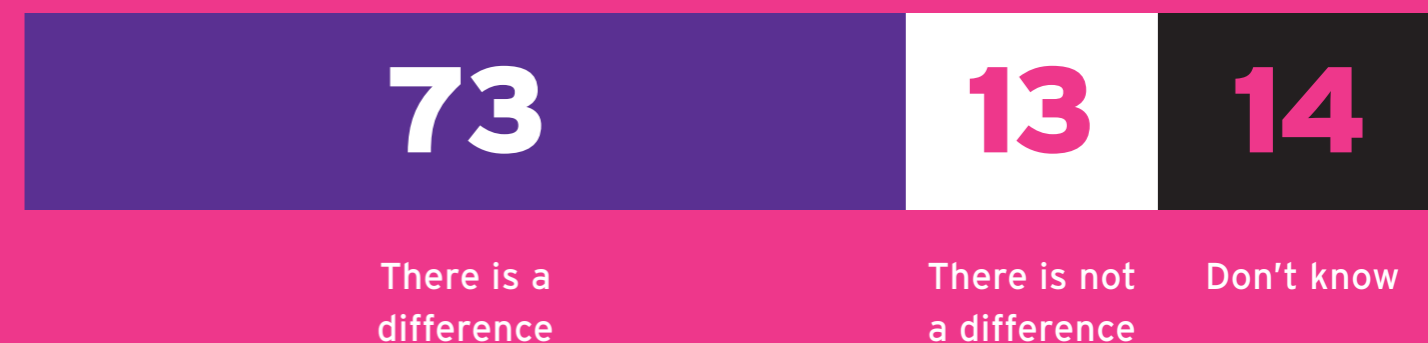
POLLING (%)

Q. A new Bill has been tabled in Parliament that would allow terminally ill adults the option of legally seeking assistance to end their lives. This would mean being provided with life-ending medication, to take themselves, if two doctors were satisfied they met all of the safeguards. They would need to be

of sound mind, be terminally ill and have 6 months or less to live, and a High Court judge would have to be satisfied with their decision. Which one of the following do you think is the most appropriate name for this Bill?



Q. Do you think there is or is not a difference between a terminally ill adult seeking assistance to end their life and suicide?



Q. There is ongoing local and national work to prevent suicide. Do you think this work should or should not include trying to prevent terminally ill people from seeking assistance to end their lives?



In the interviews commissioned for this report, bereaved relatives were keen to share how their loved ones enjoyed and valued their lives.

He worked as a modeller for animation. He worked with Wes Anderson and Aardman. He was the creator of The Pie Machine in Chicken Run. You know, he was totally respected in the trade. The letters and messages that I've had from his colleagues indicate that he was extremely well liked. Very generous in his advice, they regarded him as the 'vade mecum' and the person to go to if they wanted an answer. You can see he was very happy and contented. There was no indication at this particular point in December, when this photograph was taken, that his throat cancer would come back.

She was the only person at Crufts to have won Heelwork to Music, Freestyle and Freestyle International in the same year. She was the first person on Britain's Got Talent with her dancing dog to be in the finals. [Dog barks]. That's our dog, getting excited at the very idea. She had a Master's in music from Oxford and she had a book published. She was just amazing. We met in November 2015 and we were engaged within two weeks. We were married within five months. And the week before the wedding is when she was diagnosed with melanoma. She died three weeks after our first wedding anniversary.

He was very, very charming and kind of magnetic when you spoke to him. He was a difficult man to argue with, not just because of his intelligence but because he was very piercing. He was very convincing and enigmatic. He was the best speech writer and giver I've ever heard. He was very sharp, very witty, very clever. He was slightly impatient and he was stubborn but he was also

incredibly resilient and those personality traits made his ability to deal with MS considerably easier than maybe it would have been for other people. His resilience and just pure strength of mind and character meant that he was able to just get on with the fact that his body was falling apart and not moan about it. He also lived an active life before his body gave up on him. Losing his body and his ability to socialise meant that it was a very difficult process for him psychologically, which he tried to battle as best he could but as the disease got worse that battle got harder.

Her name was Vicky. She was born in 1934. She had a fantastic life which involved going all around the world as a dancer. She was one of the fittest people I ever knew and in her 70s and early 80s she was still walking to the shops, doing her garden and what have you. She died from bone cancer which was secondary to the breast cancer, which I think is quite common. She had the MRI scan in December, it came back three days later to say she was Stage 4. My mother would read up on everything so she knew that bone cancer was a very, very painful way to go. Bones break and they don't re-heal. It's a very, very painful way to go.

None of the interviewees believed that their loved ones wanted to die, in that they did not welcome their terminal diagnosis. Thoughts about hastening their death were in response to facing the reality that there were no curative treatments available to them or that the palliative care that was going to be provided would have side effects that they did not want to endure.

A wish to hasten death is a recognised and common phenomenon in dying people, with studies suggesting it affects between 10% and 40% of people with advanced diseases.¹⁶ The European Association for Palliative

"She decided, really right from the outset, that she wasn't going to let cancer do its worst. She would construct a way to escape"

Care (EAPC) is in the process of producing a white paper on the wish to hasten death.¹⁷ The EAPC recognises that there have been cultural changes in recent years that have prompted diverse responses on an individual and societal level to the wish to hasten death, an acknowledgement of the fact that since the start of the 21st Century assisted dying has been legalised in many countries across Europe.

A 2012 review of relevant literature 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.'¹⁸ Interviewees' recollections of their loved ones' feelings reflected these findings.

I wasn't a fantastic child. At the time I'd actually just stolen her car and she was fuming to say the least. She said, 'Come round and talk to me because we need to discuss this.' My mum was a firecracker and I thought, 'Oh my god.' But she unloaded this bombshell on me, that she'd gone for a screening and they thought that she might have cervical as well as oral cancer. That kind of

took the car thing out of it. That conversation ended.

They wanted to do scans because it was around her voice box. We went to see the surgeon, he did this tube up her nose and down the back of her throat. He couldn't tell us the exact size. He said we won't know until we can have a look, that's when the laryngectomy conversation came up, which was a difficult conversation because she just said, 'No'. She would be left without a voice. She would be breathing from a hole and when it came to eating it would just be gravity, she would no longer be able to swallow. She said, 'No'. She said, 'This is what life has intended for me and I'm not going to...' It's hard to explain, she didn't want to mutilate herself.

It was very painful and it was very difficult to cope with. It affected her mobility and the smell was humiliating. I think the palliative care team with all the will in the world... The dressing needed changing every other day so her whole life had become medicalised. It was really bad. She decided, really right from the

outset, that she wasn't going to let cancer do its worst. She would construct a way to escape. It was a huge comfort to her knowing that if it got really difficult and she could... I don't like using that term, 'commit suicide', it sounds like committing a crime, I prefer to say that she wanted to accelerate the process. That was a comfort to her knowing that if things got too difficult she could escape.

He was diagnosed with motor neurone disease. At that stage he wasn't too bad, he was still getting around fine and still doing the things that he did. He was a keen golfer and a bridge player and loved, absolutely adored, the grandchildren and spent a lot of time with them. He was still doing all the things that he would normally do. But the minute he got diagnosed he did quite a bit of research, that's the sort of person he was. He said, 'I want control of this, I don't want it to have control of me.' And he wanted to know that at a time of his choosing he could bail out.



She didn't fear dying and she was a realist about it, and I'm very similar myself. You want to live as long as you can but you want to live as long as you can being able to do what you can. The healthcare professionals who knew her didn't offer support, but in fairness I'm not going to blame them for that, they didn't have an opportunity to because she was very, very determined and she just said, 'I don't want anything, thanks very much.' That's it. She'd made her mind up. There wasn't anyone going to change it, unless somebody could have turned around and said there's a miracle drug that we'll inject you with and you'll be fine in two weeks' time. That was pretty much the only answer that she would have wanted to hear.

•

The results were secondary pathological fractures. As soon as mum found out about that - that was it. She said, 'I will end it. I'm not going to let this decide.' And I said, 'Mum, I don't want to discuss this with you, I really don't.' I said, 'There's treatments, there's this, there's that, it can't be curable but it's liveable with.' 'Not for me,' she said.

•

He was driven to do it because of no choice, no alternative to a lingering and gradual death, basically by strangulation. That's what he would be dying through. I'd seen his MRI scan myself and as soon as I looked at it I knew it was a death sentence.

Evidence shows that people who receive a life-changing diagnosis are statistically more likely to end their own lives than the general population, with rates of recorded suicides higher in diseases with particularly poor prognosis. Most studies have primarily focused on the risk after a cancer diagnosis,^{19, 20,} ²¹ but one study has examined other chronic and long-term conditions.²²

However, as highlighted by the American Association of Suicidology, traditional suicide prevention strategies seem ill-equipped to address a dying person's wish to control the manner of an impending death.

She had quite a few health problems and chronic pancreatitis, so she couldn't absorb protein properly and chemo wasn't an option. They wanted to put a mask on and do radiotherapy and Mum asked the question, 'What are the side effects?' They're quite bad with radiotherapy anyway, but particularly around your face and neck, they can be really nasty. So she, in her words, said, 'Two fingers to that, I'm not doing that either.' I sat down and I had a big chat with her and I was honest with her because at that point I was starting to grow up. I said, 'I want you to stick around long enough so you can see me getting my act together.'

She was more angry than upset at first, not in a sense of, 'Why has this happened to me?' These things happen and she came to terms with it, she was more angry that these were her options and it was out of her control. I would have been exactly like she was.

We agreed with the speech therapist and surgeon that we would meet somebody who's had this vocal apparatus fitted, so she could see how she'd be living. And although he was a smashing chap, it was still a no. There were lots of weeks of umming and ahing but in the end she did go off and do the surgery. The rest sort of spiralled downhill from there. It wasn't great up to that point but then it just got worse.

There were complications. Her lung collapsed during the surgery so the surgeon had to make the decision that the lung needed to be sorted and to do that he wasn't actually able to fit the speaking apparatus. The next day she was

in intensive care and I drove up. She looked very unwell. She had all these tubes in her because of the lung. As soon as I walked in her eyes lit up and she went to say my name and nothing happened. It was sort of that moment of 'Ahh'. She was very frustrated. The anger you could feel from her from not being able to talk, I can't imagine being trapped in my own head and not being able to express myself. For her that was always very important. She was very much like me, I move my hands a lot and I jig about a lot. She was the same. You might laugh, the only words she could actually say were swear words. We always giggled about it because I said, 'If there's one voice you've been left with then at least it's one where you can tell someone to F off!'

This lump had come so far across her throat there was no swallowing ability left as it had sealed up. If she'd have tried to eat it would have just sat there. So it was quite severe. It would have suffocated her if she'd been breathing normally, that's how it would have killed her. The lump was coming up over her jaw line and it was so big and there were others around it, they were also so big and were starting to have pus coming out of them. So not being able to drive, not being able to work, having all of this and the pressure on her skin, on her joy as well. She was very sad, always sad and crying a lot, like I am now...

While many people attempted to instigate conversations with healthcare professionals about the choices they wanted to make at the end of their lives, it was clear these were not always constructive. This is consistent with studies which show many healthcare professionals, even those working in palliative care, find talking about a person's wish to hasten death uncomfortable.²³ It is also concerning, as research has found proactively discussing a wish to hasten death within the doctor-patient relationship is beneficial²⁴ and open discussion can be an opportunity to explore therapeutic interventions.²⁵

Despite the shortcomings of these conversations, there was understanding amongst healthcare professionals of the reasons why a dying person might be frustrated by the lack of choices available to them.

She just wanted to go at a time of her choosing and she told every medical profession in that six weeks, the cancer people, the oncologists, her own GP. The oncologist said, 'Look, with the right medication we can keep you going for another year or two.' And she said, 'Can't you just give me something to kill me now?' And this oncologist just laughed and said, 'No we can't, we've got to keep you going.' And she said, 'Well, I don't want anything then. I don't want to keep going.'

They knew. They were aware. They knew what his intentions were. They didn't know any of the detail about how or anything like that, but he made it quite clear to them what he intended to do. It's quite interesting, because one of the things he had problems with for a long time was that he couldn't sleep very well, but they never actually prescribed proper sleeping pills for him.

The doctor would just say, 'This is something we can't do. You know,

we understand why you're saying that but we can't, we can't do that.'

I mean they just basically smiled. Not in a nasty way. I'm not being malicious about the GPs at all, but they're basically just trying to say, 'Look, you do realise you're talking to somebody that's sworn an oath to keep people alive?' And she said, 'I do realise that, but what's your personal opinion?' 'Well, I can't give my personal opinion,' they'd say. I think they were trying to say to her, 'If it was my situation I'd probably go the same way as you, but I can't say that.' But they were intimating that. A lot of medical professionals do feel like that.



In 2020, results from the British Medical Association's membership survey on assisted dying - the largest survey of doctors on this issue ever conducted - found that more doctors support a change in the law (50%) than oppose it (39%). When asked to give their reasons for support the most common answers were about the importance of patient choice and the reduction of unnecessary suffering.²⁶ In September 2021, the BMA dropped its opposition to assisted dying and adopted a neutral policy.²⁷

A retired GP who was interviewed suggested that the culture around medicine has changed and whereas once doctors may have assisted people to die outside the law, they

are now much more fearful of the legal consequences.

I think there was a time, in fact I know there was a time, listening to the generation above me, when doctors would aid people without fear of litigation. They would bump up the doses of morphine and diamorphine. This predates syringe drivers. Shipman and the investigation changed everything. It led to a generation of doctors who are frightened to aid people because they fear litigation.

The concept of 'double effect', where a doctor administers medication with the intention to relieve pain, but with the knowledge that it may result in the person's death, is contested. Some argue

that when titrated appropriately opioids and other drugs are not dangerous and do not shorten life.²⁸ Others have tried to defend the principle of double effect from accusations of hypocrisy.²⁹

Nevertheless, 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.³⁰

“She was a private person, she didn’t want her intimate care, intimate hygiene taken care of. This was unthinkable and would have been so destructive to her as a human being”

Having access to and experience of the very best palliative care did not alter people’s views on how they wanted to die on their own terms. Those who ended their own lives did not die ignorant of their palliative care options; they had come to an informed decision that palliative care could not address their needs.

The lymphoedema got worse and eventually she needed to have it drained as it had built up so much in her stomach. And at that point she didn’t want to go to hospital. The doctor was really good and he said, ‘Look I’ll get you into the hospice where it’s a much nicer environment.’ And it was. She had her own room and the doors opened out into the garden at the back, which she loved, and she’d sit outside. Her whole point was that – she was such a bright, intelligent woman – she didn’t want her mind to be befuddled. She wanted a clear head all the time, to know what was going on and she said, ‘I don’t want to be in a coma, taking all these painkillers.’ She wanted to be alert, she wanted to be able to say goodbye to me and know I was there. But that meant that it was really painful. And so one day – she was still in the

hospice – she was really in a bad state. The people at the hospice said, ‘She’s probably not got very long left. She’s probably not got very long left at all now.’ So then she said, ‘Look, it’s time, I want to go home now.’

She was ready to die. She was dignified. She said to me, ‘I’ve had a good life, so I feel I’m not needing to see anything else. I have no grandchildren being born. I have no weddings to go to. I have done my thing and it’s time for me to go.’ She said right at the outset, ‘I don’t want that sort of palliative care because no matter how caring, determined, attentive the palliative care team are...’ It’s incredibly difficult because we talk about dignity and it’s a very unique personal experience, dignity. My mother’s view of dignity, palliative care couldn’t actually give that to her. She was a private person, she didn’t want her intimate care, intimate hygiene taken care of. This was unthinkable and would have been so destructive to her as a human being.

No matter how sweet the palliative care team are and how they smile and tell you it’s going to be okay and they’ve got great drugs, it’s not the way it is, it just doesn’t work like that. And I hate to say that because I really respect the palliative care nurses and what they do and I would want the best palliative care for myself, but I’d also want choices for myself too.

He would have refused palliative care anyway because his attitude, like refusing the chemo, was, ‘What is the point Mum? I’m dying. What is the point of sort of dying two, three, four weeks later than I might if I don’t have any treatment whatsoever?’

We had excellent palliative care from Marie Curie and there is absolutely no contradiction between excellent palliative care and assisted dying, it’s not an issue as far as I can see. We had excellent carers from Marie Curie but at the end of the day it became very, very difficult for my wife to just get the pain controlled. I’ve spoken to a lot of hospice doctors and it is clear that some

of them are willing to actually admit that particular fact, but not all of them are. Some of them wish to continue with that somewhat hypocritical situation where they know one thing and they are saying another.

Early on in my career I thought, like a lot of doctors, that my role was to provide comfort. I hadn’t really come across much death. I’d come across a few deaths in hospital as a junior hospital doctor but I was so busy trying to keep awake, working one in two rotas and I never really thought about these things. But General Practice afforded me the time to see people die slowly over many years and I began to notice that some people’s deaths were not great, especially with the neurodegenerative disorders which were very common in my large practice.

And when I got the job at the end-of-life care unit I realised that there was a significant minority that had utterly wretched deaths. But I was frightened by the law. I felt that I couldn’t really do anything about it and I kept my mouth shut. I didn’t want to cause waves. Gradually I realised that there must be a better way of doing things. I was aware of the legal fudge of the double effect whereby one can give larger doses of opiates, knowing full well that will hasten someone’s death but that isn’t the prime reason for giving it. So I was gradually changing because of what I saw. I saw human beings suffering more and more and I was unable to prevent them from suffering, both physical but also mental anguish, and I realised that some people wished they didn’t have to suffer that. It was often pain and breathlessness and inability to swallow and a gradual increase in the feeling of drowning in your own secretions and all of those things which one could aid to some extent, and some people were very successful, but there were a

minority for whom one could not alleviate pain unless you subjected them to a comatose position which I didn’t think was a particularly good way of dealing with pain.

People were utterly fed up with existing in what one could call God’s antechamber, or maybe the Devil’s antechamber, depending on the life they had. So it wasn’t just physical symptoms, which in some cases one could do very little about, it was the sheer hopelessness of it all.

Interestingly, I could never predict how people would be. Those who started off with great religious faith sometimes seemed to lose it. Those who had no religious faith seemed to grow enormously fatalistic and find strength. It was very much an individual thing that I could never predict until it happened.

A study of the circumstances surrounding the deaths of five cancer patients who ended their own lives while receiving palliative care at home found that all expressed ‘great concern’ about their lack of autonomy.³¹ Research has also found that over two-thirds of palliative care units in the UK have experienced one or more suicide attempts by people within their care,³² despite these units offering the high quality physical, psychological and spiritual support that would normally form a core part of suicide prevention strategies.

PALLIATIVE CARE AND ASSISTED DYING

Dignity in Dying has repeatedly and unequivocally argued for further funding of palliative care services and we believe every dying person should have access to all the care that they require at the end of their lives.³³ This is not an either/or debate and assisted dying is not proposed as an alternative to good palliative care.

The experiences in this report and elsewhere show that without assisted dying legislation, dying people choose to remove themselves from palliative care services in order to exercise control over their deaths. An assisted dying law would therefore allow for greater and more meaningful involvement of palliative care in some people's lives.

In jurisdictions that have already changed the law, palliative care has flourished alongside assisted dying. In Oregon, over 90% of people who have an assisted death are enrolled in hospice care.³⁴ Law change has contributed to more open conversations about end-of-life options, more appropriate palliative care training of doctors and increased efforts to reduce barriers to accessing hospice care. Studies have found requests for assisted dying facilitate discussion of other important issues in a person's care and many

doctors report greater confidence and assertiveness in discussing end-of-life issues.^{35, 36, 37, 38} The Oregon Hospice and Palliative Care Association, which initially campaigned against assisted dying legislation, now 'supports the rights of Oregonians to choose or not to choose any and all legal end-of-life options'.³⁹

There has also been a financial impact of assisted dying on palliative care. In Australia, governments in Victoria and Western Australia invested significantly in palliative care services alongside the implementation of assisted dying.^{40, 41}

While Dignity in Dying will continue to demand the very best palliative care across the UK, the reality is that palliative care alone, however well-funded and accessible, cannot always alleviate the suffering of dying people. Assisted dying is necessary as an additional option to sit alongside existing choices that people can already make at the end of their lives. The evidence that suggests assisted dying could be the catalyst for improvements to palliative care illustrates the need to explore how assisted dying legislation and palliative care might be developed concurrently.

The majority of interviewees explained that their loved one's decision to end their own life was not impulsive. This was evident through the conversations they had had with them and also the nature of the plans they had put in place.

He had to know he could die in order to be able to live. And once he had everything in place he relaxed and was able to get on with things and the next year or so were fine. Obviously the disease progressed and he gradually got worse but he still had a quality of life that was acceptable to him.

She began a few months beforehand to make plans. She researched to find out what cocktail would work right.

I was really concerned that if she decided to take that particular action it would cause her more health problems, that she would fail. Because taking your life is challenging. She was in robust health apart from this cancer and I was frightened for her. I was also fully aware of the implications in law. I knew that simply by saying to my Mum, 'I support you, whatever you choose to do I will be there for you. I will hold your hand through this,' I knew that the law is very clear, that to assist you're committing a criminal offence you could go to prison for 14 years. And my mother knew that too. She was worried about us as a family. She made me her Lasting Power of Attorney, we did all the documentation correctly and registered it. She also used the 'Do Not Resuscitate' forms, she insisted that I was with her the whole time that she had the immunotherapy. She said, 'If I have a heart attack,' because it was experimental, 'do not let them resuscitate me, I want to make sure.'

When it came to the end he said, 'Right, that's it, I've had enough, I'm going.' He said, 'I want you to invite the family for Sunday lunch. It'll be the last big one. Put the champagne in the fridge.' I made sure that both my son and my daughter had some time with him on their own so that anything that needed to be said could be said. A few days after that he said, 'It's going to be next Friday.'

In the last two or three weeks before he died we had a carer helping me to look after him, which took a bit of the pressure off me and it gave me more time to sit and talk to him and just be with him and during those... Sorry...

During those last few weeks we had many conversations about the past and he seemed to want to reprise his life and get reassurance that it had been okay and that our marriage was good, which he knew it had been, it didn't need saying, he knew that. I think he needed to know that it was all okay and that he was going to leave us with good memories. He'd asked me to find a particular photograph of my daughter when she was a baby and I couldn't find this bloody photograph that I'd kept. But in the process of looking for it I found other photographs. So I'd come down with just one or two photographs and it would trigger... 'You remember this?' or 'Do you remember that?' And it meant he spent that last couple of weeks reliving lots of good times. Wednesday night to the Thursday morning and the Thursday morning to the Friday morning, which was the day he was going to die, he had the two best nights' sleep he'd had in months. I think it was just that in his mind it was all settled and he was at peace.

While some people wanted to be open about their plans and shared them in order to try and prevent their loved ones being implicated in a criminal act by assisting their death, others felt that hiding the truth was the most effective way to protect their loved ones.

He didn't keep it a secret. There were two reasons for that. One, he was a very upfront sort of guy but I think the other thing was he thought that was a form of protection for me that the more people that knew what he intended the less likelihood the heat would come onto me.

The Friday that she stopped vomiting, and we had got the symptoms under control to a certain extent, at that point my daughter sat down and spoke with her and said goodbye, so it was known that it was going to happen and my husband too told her how much he loved her. We were fully

aware of what was happening. We were totally supportive because we love her and I'm really proud of her. She was a most amazing woman. I remember thinking, 'There she is with terminal cancer, looking into my eyes, dying.' I was a layer of pain for her as well and she wanted to gift a good death, not just for herself but because she loved all of us. I would say I would want a good death as a gift to my family, not as a pressure, not as something that is dark and sinister, but as a gift to them.

He had gallows humour and a dark sort of humour and that definitely became a feature of the way he might talk about death, or anything surrounding that topic. But he was very smart. He knew he didn't want to implicate us. As a result he shielded us from the truth of what was going on in his own mind, that he was going to take his own life.

"We were fully aware of what was happening. We were totally supportive because we love her and I'm really proud of her"

Dying people in the UK can access assisted dying by travelling to facilities in Switzerland such as Dignitas.⁴² This is not illegal itself, but anybody who provides assistance is breaking the law and faces a maximum sentence of 14 years imprisonment. The Director of Public Prosecutions (DPP) has guidelines that make clear that a prosecution for assisting someone to die in England and Wales is less likely when the person who died had reached a voluntary, clear, settled and informed decision to end their life and the person suspected of assisting them was wholly motivated by compassion. Prosecution is more likely if the person did not have mental capacity, or if they were assisted by a healthcare professional responsible for their care, or if the person assisting had malicious motives.⁴³

The DPP's prosecution guidelines apply in England and Wales. They have been replicated by the Public Prosecution Service for Northern Ireland.⁴⁴ There is no specific crime of assisting a suicide in Scotland, but it is possible that helping someone to die could lead to a prosecution for culpable homicide.

In our previous report, The True Cost, we highlighted the distress and anxiety that stems from criminalising acts of compassion. The report also explored other shortcomings in the process of travelling overseas for an assisted death. For example, while 53% of people would consider trying to access assisted dying in Switzerland if they were dying, just 25% would be able to afford the £10,000 - £15,000 cost. Dying in Switzerland also requires people to be well enough to travel, which often results in people dying much sooner than they would if they had the option available to them in the UK.

There are currently over 1,400 UK members of Dignitas and up until December 2020 there have been 475 UK citizens who have

died there.⁴⁵ A majority of these deaths occurred after the DPP's guidelines were published. Since then, the police have referred just 167 cases of assistance to the Crown Prosecution Service for investigation.⁴⁶ This means it is likely that the majority of relevant cases have slipped under the radar of the authorities.

Accessing assisted dying overseas has been made even more difficult by the coronavirus pandemic. Even with confirmation that travelling to Switzerland for an assisted death would not be a breach of lockdown regulations,⁴⁷ making arrangements with such uncertain travel provision has proved an unsurmountable challenge for some. In October 2020, a senior NHS clinician with terminal breast cancer wrote in The Times that the pandemic had caused her to bring forward her plans to travel to Dignitas and she would travel alone in order to protect her family.⁴⁸

It is clear from the interviews for this report that the option of travelling overseas for an assisted death, to facilities such as Dignitas in Switzerland, is not an option for many people.

She was an English woman, she wanted to die on English ground. That was part of the issue for us, on principle, why should you have to do that? The other thing was the timing is quite difficult. She was told she didn't have very long to live and we knew it would take about four months to get all the paperwork to go through. And it was also extremely expensive. My mum didn't have that sort of money, we didn't have that sort of money. And so there were a lot of reasons why we felt that that was not the way we could go forward as a family.

We went through the whole process and became members. We sent medical records, etc., etc. And obviously then you get into

“He'd probably have to die a lot sooner than otherwise would have been necessary had some sort of assisted dying plan been in place here. And that's just so cruel”

this debate about when you go and of course she was keener to go than I was for her to go.

She knew she wasn't going to make it to Switzerland. She said, 'Look, this is a three or four month project and I'm not going to be around in three or four months' time.'

If we'd started the process when we thought about it it would have been too late, she would have been dead before she had got to Dignitas. And also she would have been manifesting some pretty hideous symptoms. You can't necessarily travel when you're that sick.

He looked into going to Dignitas, seriously looked into going to Switzerland, that was an option. But he realised very quickly that if he went down that road he'd probably have to die a lot sooner than otherwise would have been necessary had some sort of assisted dying plan been in place

here. And that's just so cruel.

We looked up Dignitas. Here's the problem, firstly there's money, we didn't have that kind of money, but that wouldn't have stopped me if it had been possible to do. I would have found it, people have found it. But the cruel thing is to go to Dignitas she would have had to go two months beforehand when she was still fit and, in her mind, had a good chance of beating it. So it just doesn't work. If you can't travel when you're on your last legs then, which she couldn't do, then it doesn't work.

I think it's horrendous that people even have to consider going to another country, to a foreign land and dying without their loved ones with them, compounded by the Crown Prosecution Service initiating an investigation and all the rest of it.

She couldn't go to Switzerland, there was no money.

CONTENT WARNING

The following section contains information about some of the ways in which some people have ended their own lives. A list of organisations that can provide support if you have been affected by these issues can be found on page 82.

In his book *Sorrows of a Century: Interpreting suicide in New Zealand, 1900 – 2000*, Dr John Weaver identified what he deemed cases of ‘self-euthanasia’, where a terminally ill person, in the absence of medical assistance, used other means to control the manner and timing of their deaths.⁴⁹ In 2015, Dr Weaver contributed evidence to the legal case of Lecretia Seales, a woman dying of brain cancer, which intended to overturn the ban on assisted dying in New Zealand. In his affidavit he said:

In the course of my research I was struck by the violence and indignity of the methods that were used to affect self-euthanasia... as well as the negative effects on loved ones.

I did not previously have a strong view on physician aid in dying. Having reviewed hundreds of cases of self-euthanasia, my position has changed. I now see medical assistance in helping a competent, terminally ill patient who is experiencing unbearable suffering to die as preferable to the violent, lonely, undignified and distressing alternative of self-euthanasia. The manner in which some individuals chose to end their suffering... was violent and undignified. It could have been nothing less than immediately distressing to that individual and in the long term for family and friends.⁵⁰

A parliamentary inquiry into end-of-life choices conducted in Victoria, Australia, also in 2015, heard evidence from representatives of Victoria’s Coroners Court. The substance of their testimony concerned cases they had recorded

as suicides which involved people who were dying. Coroner John Olle gave detailed testimony outlining case histories (which we do not replicate here). He explained:

What I would like to do is to identify some of the more pertinent details of cases to highlight the absolute determination of these individuals – their desperation, their plight...

After describing the cases of six individuals who ended their own lives in the face of terminal or incurable illness, despite having access to good care and the support of loving family, and the violence of their deaths and the impact on their loved ones, he concluded:

I have other cases still before us. The tally is not ending. It goes on and on.⁵¹

Further comments in the testimony made clear that as judicial officers the coroners were not advocating for or against a specific policy change to respond to these cases, but they felt their work was relevant for parliamentarians to consider when assessing what end-of-life choices people in Victoria should be afforded. They also commented that while they are required to produce recommendations that might lead to suicides being prevented in the future, for some of the cases that involve dying people, ‘it has been very difficult to come up with recommendations or comments that could contribute to their prevention.’

The written submission to the inquiry from the Coroners Court highlighted two key points about the methodologies dying people

used to end their own lives. First, deaths by poisoning were more prevalent in this group than in the Victorian suicide population as a whole. This was thought to reflect the ease of access this cohort has to potent pharmaceutical drugs. This is reflected in the findings from the interviews for this report, where a number of people took an overdose of drugs they had been prescribed. Studies in fact show that drug poisoning is considered an ‘ineffective’ method of suicide⁵² and it is clear from our interviews that people had very different experiences after taking overdoses.

Second, the rate of firearms use amongst dying people in Victoria to end their lives is almost double that which is usually observed in suicides.⁵³ When considered alongside studies of the fatality rate of different suicide methods,⁵⁴ it could be speculated that dying people’s increased likelihood to opt for more violent means of ending their own lives – putting to one side drug poisoning which is explained by ease of access – reflects a level of determination to die that is higher than in the suicide population as a whole. This would be consistent

with a study of cancer patients in England, which found that people who ended their own life following a cancer diagnosis were less likely to display ‘warning signs’ such as self-harming when compared to the general suicide population.⁵⁵

Research for this report has uncovered cases of dying people in the UK who have ended their own lives with overdoses and from a range of highly distressing undignified and violent means.

I have had to think through other options just in case I am unable to get to Switzerland. I have worked out where I could end my life. I have thought about getting drugs. I am not suicidal. If I could choose life over my inevitable fate I would, but I can’t.⁵⁶

The doctor had given her a bottle. She did say, ‘Look, if I ever fancy doing anything I might swig that back.’

My mum was diagnosed with idiopathic pulmonary disease. In December she drank an entire

bottle of medicine and tried to suffocate herself. She survived and the following few weeks were a horrific mix of emotions but most of all I wished she was able to end her life with dignity.⁵⁷

The uncertainty of various methods people used created significant anxiety.

I was having kittens because my concern all the way through had been what if it goes wrong? He never worried about that, he always knew it was going to be alright, but in my mind it was, ‘What if it goes wrong? What if he starts to have seizures or, you know, what am I going to do?’ That was always my worry.

There were always comments like, ‘I should just stand in front of a bus’, which sometimes if you’re going through a stressful situation you say in passing but for her they weren’t just in passing. She was feeling this. It was very real. It was something she wanted to do. She had a wonderful little red sports car that she treated herself to and at least daily she’d say,



'I want to drive this into a wall and be done with it' and then the conversation would turn around, 'but I won't do that because if I survive that then I'm going to be in even more shit than I'm in now.' So she felt trapped.

She started to stockpile any prescription that she had. I had to go to the chemist and collect her medicines for her, she was too ill to do that herself. In all honesty I was quite frightened, but I was just focusing on taking care of her.

When planning their deaths, in particular for those planning an overdose of prescribed medications, it became evident in the interviews that access to professional expertise was a factor in determining whether people's attempts to end their own lives worked as intended or not.

She was aware of the fact that through her professional knowledge, she could buy what she needed and she knew how to store it properly so that she could die at home. It was a privileged situation in that she didn't have to use violent methods like some other people have to.

The eminent surgeon and author Henry Marsh has said he keeps a 'suicide kit' made up of lethal drugs he has acquired in his career, should he ever need to take his own life.⁵⁸ Suicide kits of various descriptions can be bought online, despite sale of these kits being illegal. Their use in the face of no regulation undoubtedly causes significant harm to individuals and their families. There is also evidence in the public domain that Britons are travelling overseas in advance of developing a terminal illness, purchasing drugs that they can use to end their lives and smuggling them back into the UK to use should they need them.⁵⁹

There have been reports that some people choose instead to import

drugs from overseas. In 2016, police broke down the front door of 81-year-old retired Professor Avril Henry after being tipped off by Interpol that imported drugs had been traced to her address, which had flagged her as a suicide risk.⁶⁰ The police confiscated the drugs from Professor Henry but they did not find them all; she took the remaining drugs less than a week later and died.

Dad had to get drugs from the dark web.

The dark web, also known as the dark net, consists of a hidden network of internet sites. It allows people to access and use the internet anonymously and while some people use it for legitimate means it has become renowned for illegal activity, including being somewhere that hosts marketplaces for drugs. These are known as cryptomarkets, as purchases are usually made with cryptocurrencies.

The National Drug and Alcohol Research Centre (NDARC) in Australia monitors listings of drugs on cryptomarkets. The NDARC's data shows numerous listings for drugs that dying people in the UK have been reported to have imported in order to end their own lives, though these listings fluctuate over time.⁶¹ The NDARC is unable to monitor the advertised purposes of the drugs sold or where they are being shipped to, but a study in Australia showed barbiturate-related deaths, for example, have increased in recent years despite a reduction in prescriptions for barbiturates, suggesting cryptomarkets may be playing a key role in their availability.⁶² In this study the researchers found intentional poisoning was the cause of death in over 90% of cases for those over 65, with individuals in this group more likely than others to have severe physical health conditions. The fact that assisted dying legislation had not yet been implemented in any Australian State during the period of time covered by

the study is cited as an explanation for the high number of cases within this demographic.⁶³

Scams and fraud on the dark web have also been uncovered,⁶⁴ which no doubt creates anxiety for dying people who are trying to purchase substances for a specific use at a specific time in a clandestine manner in order to protect their families. This route also exacerbates inequalities given the resources and knowledge needed to navigate the process.⁶⁵

"I AM NOT SUICIDAL. IF I COULD CHOOSE LIFE OVER MY INEVITABLE FATE I WOULD, BUT I CANT"



CAMPAIGN FOR
MY MUM.

ZOE

The first time she tried to end her life it was a beautiful, beautiful sunny afternoon. I didn't know. I was actually in London when she chose to do it. I was at a distance because she was trying to protect us. She waited for everyone to be out of the house. She went into the garden with a picture of her mother and herself a baby.

She'd written some suicide notes. She was very clear that she didn't want to have those symptoms. She wanted to spare herself and she wanted to spare her family from that. She took a bottle of Drambuie - yes, she had some class bless her - and she took all of the sleeping tablets that she had been prescribed. I would have thought that that would have killed an elephant. She took them all. I got a phone call from my husband who said, 'Your mother's lying in a strange position in the garden. There's broken glass. I think she's done something.' I said, 'Just leave it, just leave it, I'll be home shortly.' I drove home, expecting her to have passed away but she was breathing shallowly. I thought, 'This is just a matter of time.'

I felt nervous because I have not done anything to assist her but I'm being passive. I'm not actually trying to save her. I'm just wanting her to be physically comfortable. I put a cushion under her head and then it got later and it started to cool, it was getting dark, and I got more and more anxious about the fact that she was still breathing. I got a mattress and laid her onto the mattress because she was so awkward and it was so without dignity. You can't leave your dying mother outside in the garden on the floor. It's just a really dreadful situation to be in.

We decided that we would call the ambulance because they would have the ability to bring her into the house and she could be comfortable and in private and not in front of the neighbours.

We called an ambulance and I showed them the documents that I had, her Lasting Power of Attorney, the Do Not Resuscitate form. I explained to them that she had cancer, it was incurable and that she wanted to die at home and that was incredibly important to her. I said, 'Please can you bring her inside?' And they didn't quite know what to do. They were extremely polite but they really didn't know what to do because by not acting they might be seen as aiding and abetting suicide and they were frightened about that. I could see they were very concerned.

They called an on-call doctor. They wanted somebody in authority to tell them it was alright. The doctor arrived and he was really not good enough. He said that the Lasting Power of Attorney wasn't viable and the fact

that she had attempted suicide meant it was now a breach of the Mental Health Act if she didn't go to hospital. He spoke to a consultant psychiatrist who also backed him up. They said that she had to go to hospital and I now felt really unheard, I felt she was being unheard.

My daughter was out in the garden holding her hand. At the centre of all this my mother was dying outside. She hasn't been brought in because it's easier for them to move her out through the garden than to bring her in and then move her again, which really upset me. I said, 'I'm absolutely not letting her go to hospital. This is not what she wanted. This is not what this documentation is telling you. I am her voice now.' The doctor said that if she died that would mean that there would be a police investigation, that there would be an autopsy, that the coroner would be involved. He was threatening.

Then he said he would call the police and I'd never had the police called to my house, never. It's dark outside now and I was just so indignant. I said, 'Yes, please ring the police because they don't just uphold the rights of the NHS, they uphold the rights of my mother, please bring them.' The police came and it was the same story. They didn't know what to do. It really would have been easy for them if I had just said, 'Yeah, take her into hospital.' But because I wasn't prepared to do that they were stuck, not knowing what to do. I said that I wouldn't allow them to take her, 'I know what you're doing is wrong when she wants to die at home. Suicide is not always because of mental health.' She was an intelligent woman who wanted to spare herself, and her family, of the suffering.

We were there until about 3 o'clock in the morning, from about 8/9 o'clock when I called them. They had a conversation with the Accident & Emergency Manager and they said, 'If she has a Lasting Power of Attorney I can't actually do any treatment.' So at 3 o'clock in the morning, sanity prevailed. They brought her inside and they left after taking her suicide notes away, explaining to me that when she did pass away, because it was still expected, I was to call another ambulance and that they would sort out the paperwork. The whole thing was awful and to know that the policemen were going to come back was really difficult.

The next day she woke up and she was devastated. She was really injured. She was really, really poorly. She was in so much physical pain it was unbelievable. I was just beside myself. She could hardly move, all of her joints were inflamed and she was in agony. She couldn't lift her head up off the pillow, she was so sick. It was just horrific. I've never seen my lovely mum in such a terrible state.

I thought, 'Oh my god, there is no escaping this. She's not going to be able to escape. She's going to have to live through this part of her life.'

And the police came back with those suicide notes. She told the police, 'I'm glad you brought them back, because they were difficult to write and I will need them.' And I remember them going, 'Oh my goodness.'

It was a month later that the symptoms really kicked in. If she had died that night it would have been absolutely beautiful and perfect. The photo of her mum nearby, letters to her loved ones, the sun going down in her garden. But she had to live through another month of absolute hell.

“SHE HAD TO LIVE THROUGH ANOTHER MONTH OF ABSOLUTE HELL”



CONTENT WARNING

The following section contains information about some of the ways in which some people have ended their own lives. A list of organisations that can provide support if you have been affected by these issues can be found on page 82.

In our interviews we did not encounter any examples where a dying person attempted to end their life and survived did not try again. The experiences featured in this report all involve people who died at their first attempt or people who tried multiple times to end their own lives. This contributes to our understanding of the differences between dying people ending their own lives and non-dying people who die by suicide.

It is worth noting that the presence of a chronic illness is already considered a risk factor for repeated suicide attempts.⁶⁶ In 2007, a report on the National Suicide Prevention Strategy for England acknowledged the presence of 'painful illnesses' as a factor that increased the likelihood of someone taking their own life.⁶⁷ An audit of suicides in Norfolk, published in 2019, concluded that the issue of assisted dying is 'relevant as a feature of understanding suicide' and cited deaths recorded as suicides over a ten-year period in Norfolk which involved people who had experienced a deterioration in physical health while in their 80s, 90s and even one person who was aged 100.⁶⁸

There were three attempts. Who knows what didn't work and why and what kind of pain and damage that did to his body. Surely we would wish for it to be done safely, around your loved ones and not in such a lonely, lonely and difficult way?

She sent me a message, I still have it on my phone, this was sent on 30th March last year. 'I tried at

the suicide bit.' This was the first I knew about it. 'They think I only survived it because I have been on morphine since 2006. That was my best shot, couldn't even get that right. I will turn down the radiotherapy and hopefully nature will take its course rapidly. Nothing left to say.' I didn't know.

He decided to stop treatment. He came home and it was shortly after that he made his first attempt at taking his life. I was in the kitchen and heard a thump from upstairs. I thought he'd dropped something or he'd tripped, you know, in a weakened state. I got upstairs and there was a lot of blood. He'd cut his throat and wrists. The wrists were superficial, but the one on the neck was more serious. My first thought was that he'd haemorrhaged because that's the progress of this particular form of cancer; it strangles you because the tumour has grown so big or it crushes the carotid.

I immediately called 999, they arrived in droves, including a helicopter that landed in our local park should he need to be taken to the hospital. They stabilised him and then he was taken to the Royal London. He was stitched up and kept in there for about a week. He was moved from the general ward into a psychiatric ward. From that psychiatric ward he was moved into a crisis centre and they really didn't know what to do with him to be quite frank. He had a panic attack there. During that time I saw him twice. I saw him two days before he did take his life.

A couple of policemen knocked

at the door, and I thought, 'Well what are you here for?' having contacted him half an hour or so before. They said, 'We're very sorry but your son's been killed.' One of the side roads to the hospital has a junction with a major road. A witness saw him run into the second lane, where he was hit by an HGV.

Adam explained how his mum tried to end her own life by overdose on a number of occasions.

She sent me this photo one day, it was awful. Her face was much more ballooned than it had ever been before. She couldn't see out of this eye. It was dribbling and that was the point she said, 'It's not fair that I have to live like this.' I went up to see her and she was just lying in bed fast asleep and I woke her up and she was very confused, she said, 'Why am I here?' I said, 'What do you mean?'

And she goes 'I shouldn't be here.' She told me to... She told me to leave her alone. She had taken morphine, quite a lot of it and I got there too late.

I said we need to take you to the hospital. If it hasn't worked now it will. She told me, 'I want you to leave.' She wanted me to leave and she was also very frustrated and upset but mainly peed off that I wouldn't just let her die.

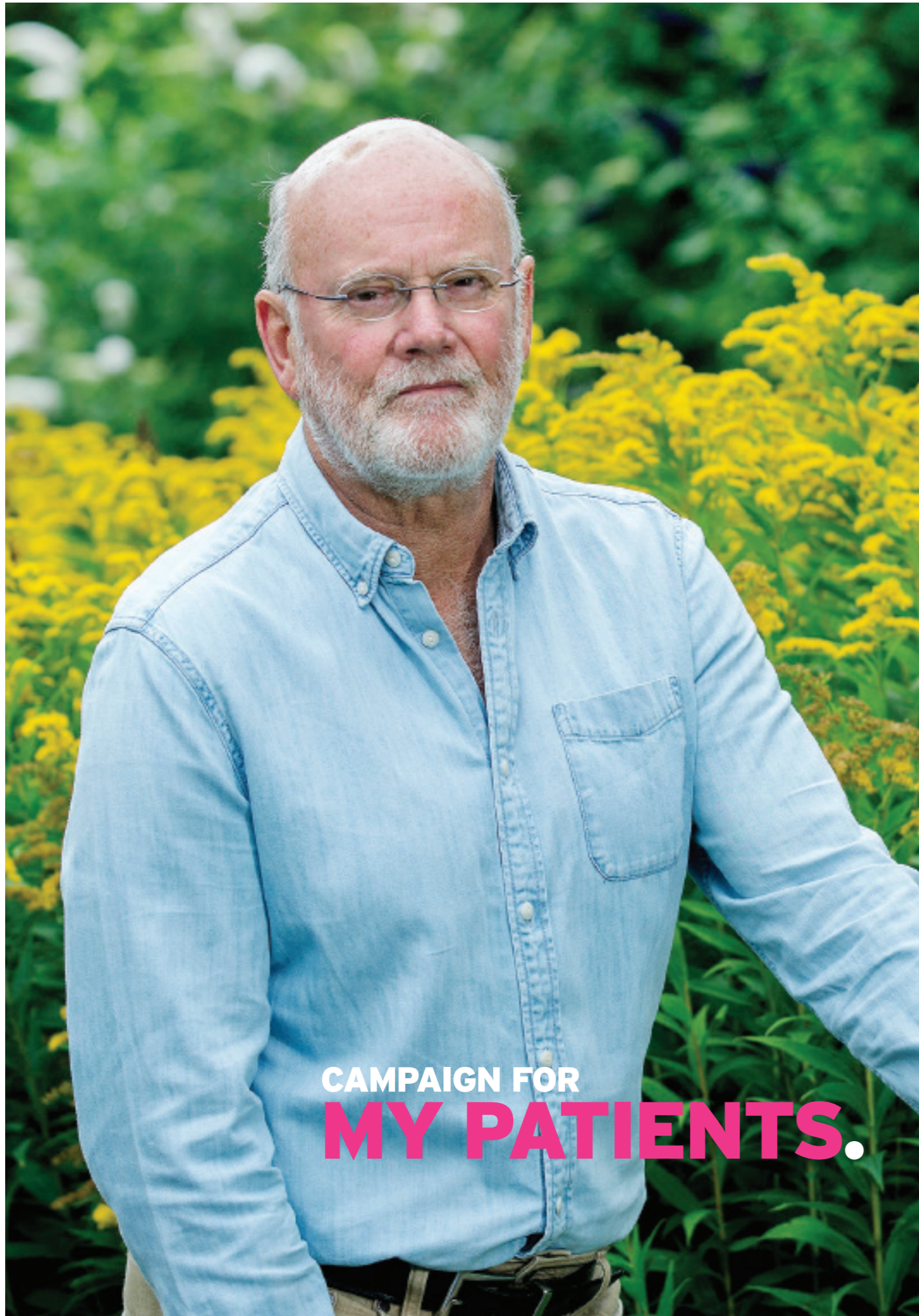
As it got worse and more of these lumps appeared she had to shut her business, she didn't have the strength to dog walk anymore. We had another morphine attempt, but this time she hid the packets and she didn't tell me. It was only about a week later, we were sat having dinner and she said, 'I tried it again and it didn't bloody work.' She was annoyed at the fact that she couldn't kill herself.

Adam's mum did not end her own

life. She died in a hospice. There was a haemorrhage in her throat and she choked on her own blood.

If you could go out in your own way you would, because the way she went out was bloody awful, it really was. And not something she would have been proud of. Her dad went very similar and she always said he would have shot himself if he could. You sit in a room as a husk just slowly ebbing away and that's not really fair in my opinion because that's not how she would have wanted to go. I had taken care of her for so long and I was still able to look after her but there's no life, there's no moving. I went to see her after she had passed, it was just a husk, there was no person left, there was a skeleton with skin and I don't think that's how anyone wants to go.





CAMPAIGN FOR
MY PATIENTS.

JULIAN

I had the privilege of working in General Practice part-time for 32 years, 25 years of which I was looking after an end-of-life facility in the community. I have dozens of accumulated instances of people who would have wished to choose the time and place of their own demise. But a case happened which shook me to the core and I leapt from a position of vacillating and timidity on assisted dying to one of immediately realising that there must be a better way of dealing with some people's deaths.

I knew this late middle-aged woman. She was a lovely lady who came to see me about every two or three months. She was intelligent and she seemed to like me and I liked her. One afternoon an old sea dog came to see me, a leather brown, weather beaten, rather bedraggled fellow. I'd never met him before. I didn't know who he was. He said, 'I've got a swollen leg, what's the problem?' So, unlike some doctors nowadays, and particularly during the pandemic, I was able to examine him. I very quickly came to the conclusion that the swelling in his leg was due to some horrible metastatic disease. He had some hard inguinal lymphadenopathy, massive lymph nodes, in his groin. It was causing one leg to swell three times the size of the other. My brain was working overtime trying to work out what the problem was. I was examining his chest. I noticed a scar and I said, 'What's that?' And he said, 'Ah, I had a skin cancer removed about 20 years ago, I was in the Merchant Navy.' So it became obvious this was a melanoma. He hadn't given it any thought. In those days in the Merchant Navy he spent half his time with his shirt off in the South Pacific. I said, 'I think this may be related.'

I got him seen at the hospital and they found he had metastatic melanoma, not just the groin but just about everywhere. He came to see me about three weeks later after he'd been to the hospital and said, 'What's going to happen to me? Tell me like it is.' I said, 'You're riddled with cancer.' He said, 'Well, what's it going to be like?' I said, 'What do you mean?' 'What's my future like? I know I'm going to die, but how's it going to be?' I said, 'I don't know, but one way could be that your leg will become more swollen. It'll start to weep and the metastasis in your liver will get bigger. You might get some pain.' I painted what I regarded as a realistic prospect of a gradual demise over the next six months. And he thanked me for being honest and said thank you very much and he left.

At some stage I realised he was the husband of the lady who came to see me. A couple of weeks later he came back and he said, 'Look, I've been thinking, can you tell me how to take my own life?' I was worried about someone overhearing. I was worried about

being complicit with his death and being charged with manslaughter and all the rest of it. I said, 'I'm terribly sorry, I want to be able to help you, but I can't.' This was an informed decision he'd come to. He wanted to end his own life in a dignified manner. I think we shook hands and I never saw him again.

A few weeks later after morning surgery I was doing something before going out on my afternoon visits when I heard a bit of a commotion in the waiting area. His wife, uncharacteristically, was almost hysterical and the staff were having a hard job trying to pacify her. I came out and I waved her in. She said she'd been shopping, she'd just come back, her husband's car was parked outside the house, which was odd because he'd gone out for the day. She sensed something terrible. She went into the house. She went to the hall, opened the door into the sitting room and... Sorry...

He'd shot himself.

She had to live with that for the rest of her life, poor lady. Because of my inability, my cowardliness, whatever, to help him. He decided to have the most obscene, cruel, violent death imaginable because he didn't want to have the indignity of suffering any longer for what was likely to be a fairly torrid last few months.

I've had to live with that for the rest of my life too. I felt as though I'd completely let this fellow down and I was directly the cause of his violent death, which will forever be in my memory. And his poor widow... She continued to see me but I think she moved. She had to move, she couldn't live in that house.

From that moment I realised that for a few people, a minority, there had to be an additional way of dealing with their terminal disease.

CONTENT WARNING

The following section contains information about some of the ways in which some people have ended their own lives. A list of organisations that can provide support if you have been affected by these issues can be found on page 82.

A prominent theme in the interviews was loneliness, a feeling that people found difficult to evade as they went through the process of planning their deaths. Many people chose to die alone in order to protect their loved ones. Even for those who did not, the inability to be open and honest about their impending death - with other family members, friends and healthcare professionals - led to a sense of secrecy and dishonesty which negatively impacted their quality of life.

I was on my own here and she just said, 'It's time.' And I said, 'I can't, you can't.' She said, 'Look, I won't tell you when I'm going to do it because that will make it easier on you.' But it didn't. She said, 'I heard you up all night, pacing.' And I said, 'Well, I don't know what I'm going to find, do I?'

She wrote a chain letter to all her friends to say, 'Sorry I couldn't say farewell.'

My sister said, 'She's died. I've got the police here. She's taken an overdose.' One of the things that you always want to do when somebody's terminally ill is be with them when they die.

Dad was forced into a very lonely death and that's something that no family would wish for any of their loved ones. Not only because of the moment itself but also the lead up to it. The fear. The anxiety.

We had the guidelines from the DPP but nobody knew what that would mean, because if you read them correctly then you could say, 'Yeah, of course I'm the person who's going to benefit from her death, I will be inheriting everything.' Who's going to tell me how that is going to be interpreted? And so there was still no clarity on the situation. She was absolutely insistent that I should provide myself with an alibi so I would not be seen to have assisted her. And that, in retrospect, is probably one of the most bitter aspects for me in the whole situation and still upsets me to think about it. On the Sunday afternoon I went to work, I wrote a few emails to make it clear that I was there. I came back and I knew what had happened.

In 2011, Carol Hutchins, who had multiple sclerosis, travelled two miles by herself in her wheelchair and, despite not having use of her lower body, lifted herself over a fence, deliberately fell into a canal and drowned. At her inquest, Carol's father called for a change in the law on assisted dying. 'People say life is precious,' he said, 'But there comes a point when life is not precious and it becomes torture for those that are living. Carol had thought about going to Dignitas in Switzerland but it is very expensive and it puts other people in a difficult position. It showed tremendous courage for her to do what she did all alone'.⁶⁹

In 2012, Dr Jacky Davis's brother Kevin attempted to end his own life after being diagnosed with kidney cancer, which had spread to his lungs and his spine. Kevin's wife found him in a pool of blood, holding

a noose, at the bottom of their staircase. 'If he'd known he could be in control of his end,' Dr Davis has said, 'he wouldn't have done it. He could have been with his friends and family, instead of having a terrible, lonely death.'⁷⁰

In 2019, Paul Blomfield MP spoke in the House of Commons about his father's death.

It is, by a coincidence, the eighth anniversary to the day of my receiving a phone call here in Westminster that my father had been found dead in his garage. The previous night, he had tidied up his belongings, left small piles of money to settle the bills with the

newsagent and others, and written final notes. He had then walked to the garage, connected a hosepipe from his car exhaust into the car, taken an overdose and switched on the engine.

He was not afraid of pain, but he could not face the indignity of a lingering death, and I am sure that he made up his mind to take his life soon after receiving a terminal diagnosis of inoperable lung cancer. But he still died prematurely, and I am sure that what drove him to end his life at that point was the fear that if he did not act when he could and was still able to do so, he would lose the opportunity to act at all. He

could not talk to me or his partner about it, because he would have made us complicit. The current law forced my father into a lonely decision and a lonely death.'⁷¹

"Dad was forced into a very lonely death and that's something that no family would wish for any of their loved ones"



**CAMPAIGN FOR
MY DAD.**

BARBARA

He was called Charles but known to everybody as Charlie. He was 95. About a month before his diagnosis he was cycling 5k. He was out every day. He was doing price comparisons at Sainsbury's and Lidl. He was down at the pub on a Sunday. His knowledge of politics and what's going on in the world was probably better than mine. He was just really alive. Loved his food, very sociable and incredibly active.

He was diagnosed with oesophageal cancer the Christmas of 2015. He said, 'I'm going to have to cut my lunch up in small bits. I'm finding it difficult to swallow.' And I think he had realised there was something going on.

One of the palliative care team said he was a very difficult patient, the most challenging patient they'd ever had. Not because of the illness so much, but he just refused any form of intervention, even if it was to make him more comfortable. They wanted to put a stent in, but I suppose as soon as he was diagnosed he said, 'I've had a good life and I don't want to die not being able to eat.' He loved his food. He had a 'Do Not Resuscitate' in one of those yellow folders. He'd looked it all up without the GP suggesting it to him. He was absolutely determined that he did not want to carry on.

He'd produce a lot of secretions which he was having to cough up and so he was very embarrassed about going out or having people round. His neighbours were knocking on the door at least once a day just to say hello to him. But he wouldn't see them.

Norfolk's palliative care is amazing. Everybody was roped in but he didn't want to know. We had a dietician, we'd got all these people coming in and he just said, 'I know you're trying to help me but I don't want your help. There's nothing you can do to help me.' He was very polite but that was it. It was pride. Until the very last couple of months he'd be sitting there with his shirt and tie and his sports jacket on. He was a very proud man.

He was given a pressure sore cushion because he'd lost so much weight and then I spoke with the GP. He told me that Dad was still refusing any palliative intervention so we managed to get him to see the palliative care consultant at the local hospice. She was just absolutely delightful. She had a long chat with him and it was going okay and then she said, 'Is there anything we can do to help you?' He said, 'All you could do doctor is put an injection in my hand and finish me off. I know you can't do that but that's all I want.' She handled it well. I thought, 'Wow, so she's been in those situations before.'

He started getting incredibly frustrated because he couldn't ride his bike. He couldn't bear to watch television because of all the food adverts and the cooking programmes. But he loved sport and was still watching football. He was attempting to drink soup after blending it but most of it he was regurgitating and it was unpleasant for him. By then he was just expressing the fact that he'd had a great life. He'd married my mum, the love of his life, and she died. He missed eating proper food. He couldn't get to the shops. He said, 'Everybody wants to help me, but there's nothing anyone can do.' He was never unpleasant, he said, 'I know these people are trying to help me, they're lovely people, there's just nothing anybody can do to help me.'

It didn't even cross my mind he was going to take his own life. It didn't cross my mind for one minute. I knew he was saying all this but I never thought he could do that. So on reflection you must think I was a bit daft but it just didn't enter my mind.

In October, Dad rang me and he said he didn't think he could manage to bath or shower himself. Bearing in mind he'd been having a daily bath all by himself up until now, I think it gives you some idea of his character. But he was so weak and frightened of falling. With some difficulty I managed to ask him to give me permission to ring up a care agency to go in to help him bathe. He was incredibly reluctant and I went round to discuss that with him and he had this really nasty incident of faecal incontinence when I was there and that devastated him. It devastated him. He was devastated at the loss of control.

I rang him up on a Saturday and he told me he had watched the England versus Scotland football match. On the Sunday, I called him and there was no reply. I tried him three or four times. My last attempt was at 15.22, I know that because it was in the coroner's records.

Then I rang his neighbour - he'd got some fabulous neighbours - and I said, 'Would you mind just popping round and knocking on the window?' He said okay and I spoke to his wife and had a chat. He came back and he was almost hysterical. He said 'Oh my god. I've got to call the police.' He put the phone down but then rang back immediately, 'He's left a note on the front door.'

The note said Call the police. I've taken my own life. I'm in the garage. Do not come in.

And of course he got the other neighbour and they did go in and I don't think they've ever got over it. He'd hanged himself.

He'd obviously thought it all out. He'd done all his washing. It was heart-breaking, the police said they'd never seen a house in such good shape for somebody that age. I think he'd got it planned out about three weeks before. I think when he had that faecal incontinence. I think he decided that's it, I've got no control in my life.

I went to see the GP and I said to him, 'Why do you think he took that particular way out?' And he said, 'To be perfectly honest, he wouldn't have been able to swallow any drugs and what he had wouldn't have been enough. He obviously wanted to do it. It wasn't just a cry for help.'

It sounds awful, but I wanted to know what time he'd done it. It probably doesn't matter, but I needed to know. They had reckoned it was probably early afternoon. So he must have woken up that morning,

put his clean jim-jams on, done his washing. What must he have been going through? He'd done the washing up. I mean, I don't think anybody should have to go through that. They shouldn't have to do it.

I found myself going into the garage and working out where he'd done it, which rafter it had been from. You know, you do that. And looking at the steps he must have used. I had this morbid need to see him because when the undertaker said, 'Do you want to see him?' I said, 'No.' But then I was having awful dreams of going in and seeing his face and just imagining him. I regretted not seeing him and not saying goodbye, that's why I got the full post-mortem report.

It's the impact... You just think poor guy, to have to go through that, to have to do that. And then the knock-on effects... The people he would not have wanted to hurt.



DEE

When people died with other people around them it led to a range of experiences. Some people found this positive because their loved ones' plans unfolded as anticipated. For others there were complications that resulted in distress. What was clear for all is that being forced to arrange the logistics of dying without professional support was a major problem.

When Friday came along he had his plan in place. I said, 'Are you absolutely sure this is it? Because whatever you want, we can achieve, we can carry on, don't worry about it.' He said, 'Now is the time.'

He went into his room and he said, 'I need some time on my own. I've got one or two things to arrange.' I got rid of the carer. I got rid of the gardener. I was quite calm at that stage, I was ok. I had a long, long time to think about this and my main concern was that it was ok for him. He was a news freak; we bought newspapers from all over the world in languages neither of us understood. It's a Glaswegian thing apparently. He came out and said, 'I want to watch the news.' This was the 1 o'clock news and after it was over he said, 'Right, it's time.'

He had a chair which was in our sort of kitchen/breakfast room. It was his favourite room in the house. I got him to his chair and organised what he had to take. There was a photo screen there and he had photographs of the children. He wanted some music on and he wanted a whisky. It was quite funny actually because I went into the cupboard and got a glass and poured some whisky into this glass and he said, 'No, that glass is too heavy.' Because he was having trouble moving and he didn't want me to feed it to him. I scabbled around in the cupboard, weighing the glasses in my hand, and I picked up one and I thought, 'Oh that'll do.' Low and behold it was a Partick Thistle

Football Club glass and of course he was a Partick Thistle supporter all his life.

And so he had his last whisky out of the Partick Thistle glass and he took what he had to take and we just sat and chatted, very quietly, about when we first met. He said, 'What did you think that night when you first met me?' And I said, 'Well I fell for you.' And I said, 'What did you think?' He said, 'I thought you were very beautiful and I still do.' And those were the last things we said...

I said to him 'Are you feeling ok? How are you doing?' And it was at that point that he started to go and it was just like he fell asleep. He just went to sleep and his breathing got shallower and shallower and that was it. It was very peaceful. It was as he wanted it. He didn't suffer in any way, for which I'm eternally grateful. It was a good way to go. It was a good way to go and it was how he wanted to go.

It was a beautiful day. She was in the garden on the little patio in the corner of the garden, in this flower garden that she'd made. She took all the medicine she'd saved. We had both imagined in a couple of hours she'd fall asleep and then that'd be it, a beautiful, lovely death. But it didn't work as expected, so instead of being a big hit and putting her to sleep straightaway it was coming out in dribs and drabs. She did fall asleep but then she was still alive six or seven hours later.

It started to rain and so I had to try and get her inside, which I did. Probably about eight hours later she suddenly sat up and said, 'Get it off me'. And then she laid back down again quickly. So I don't know how conscious she was and I think she could hear things because I played the music that she loved and I think she smiled.



Her breathing got worse and worse and she started to go into Cheyne-Stokes breathing and one of her eyes was open. I just don't know what she was aware of or not. It took 15 hours before she finally died.

I came into the front room and he was still conscious, but it was immediately clear he'd taken something. I obviously panicked and didn't know what to do. He was still vaguely lucid and just said, 'Don't worry, this is what I want.' I'm almost certain he expected whatever he'd taken, which we later found out were prescription drugs from the dark web, to kick in sooner and for him to have already gone by the time I got home. I didn't know what to do so I looked at his note which said, 'I've taken this. In the event I'm discovered before I've passed on, I do not want to be resuscitated.' It was clear, the note was crystal clear: I want to go, I've had enough, I don't want to carry on living.

Whatever you do, whoever it is that finds this let me go. As his son, as someone who knew that this was on his mind at some level for many years, I decided to follow his wishes.

He'd already asked his friend and his brother to come round at a certain time. So he'd been planning this group of people to come and find him. Again, that didn't happen, he was still conscious but he slipped into unconsciousness about 10 or 15 minutes after they arrived. We were all running around. Panic. We didn't know what to do. We didn't call the police. We didn't call the ambulance or anything. It was crystal clear he wanted to go.

Eventually after several hours of being sat there just drifting between breathing patterns, I couldn't really stand it anymore. I couldn't bear the idea that my sister wasn't there. I just said, 'I know he doesn't want me to call her but I'm going to call her.' So I

called her and told her to get into a cab and she came over and we sat with him.

We were faced with a really horrible problem with nobody to turn to. We knew that we wanted to follow his wishes but we didn't know how. I remember it was hours and I was thinking it's almost now equally nightmarish, because if he dies that's a nightmare, if he doesn't die that's a nightmare and how do we ensure the least amount of pain? I didn't even know if he was in pain and who do we ask?

When we're at home we feel like children. So we just felt like kids not knowing where the grownups were and so all we could do was sit with Dad and wait for the morning. We eventually get in touch with our family GP who came and told us she'd have to call an ambulance. We did tell her there's this note, he wants to go and she was aware of his condition, but she said she's bound by all sorts of legal things. An ambulance arrived. They

stormed through - what had felt like quite a peaceful place - like a thunder cloud and dragged him off his chair by his legs. That's a visual memory that I have. And they immediately tried to resuscitate him. We then panicked. Obviously they don't send their best guys for something like that, it was the same when the police showed up, they were not their best guys. Eventually somebody senior does show up and they have more of an understanding of the situation. But at the time their job is to preserve life. I understand that.

We very, very, very luckily had scrupulously organised the Power of Attorney form that Dad had made us sign. They really wanted it, I had no idea, I just signed it and thought god knows where that is. But luckily it had been filed and put somewhere important.

We had power over the decision of what to do in the event that he was unable to make a decision himself and they kept asking for this DNR. I said, 'It doesn't matter, this is the form. It's a legal document that tells you I am able to make this decision on his behalf.' We were cowards when they came in but when we saw that there was a prospect of him being kept alive we both got angry and went, 'Don't you fucking dare.'

Our GP must have been in the room. I was crying and saying 'No' but even our GP said, 'You've got to let them, you've got to let them do this because there're legal implications if you get anywhere near this situation.' So we just had to stay in the kitchen and we couldn't even say no. There was a legal implication to what was happening and not a medical implication. 100%.

So they came and tried to use those things, I don't know what they are called, and it was at that point that Dad did die.

I think it was that shock that tipped him over the edge.

She probably immediately lost consciousness but the body keeps on going. I was confronted by her completely unconscious. It hadn't worked and so I phoned the ambulance.

My wife had left notices to say she will sue anyone trying to revive her or resuscitate her or take her to the hospital if they were successful. The ambulance service had never seen a case like this and didn't know what to do. So they were here for four hours trying to find out from their superiors, 'What the hell do we do here? We have a person who we could take to the hospital but we have these notes.' After about an hour they said, 'Do you want us to respect her wish?' I said, 'Yes, of course.' And so then they waited for a doctor to come and she was very sympathetic to the situation. I explained what had happened and she said, 'You think she's taken enough?' And I said, 'I think so.' She monitored the situation for about an hour and said her heart is getting weaker and everything's slowly shutting down.

In the meantime the police had been warned and I got a fairly sympathetic person from the CID who came in and said, 'Ok, what's happened, is she dead?' I said, 'No.' He said as soon as she's dead let me know, because until there was a declaration of death by the doctor it was not his situation. My wife lasted until about 5 o'clock at night.

She said to me, 'I've done it.' And I said, 'Oh mum, no.' And she said, 'I won't hate you if you call the ambulance. But you know that I'll never get another chance.' I said, 'I know...' So I never called them. I felt really backed into a corner and this is what it does to you, it completely backs you into a corner

where you make decisions that you wouldn't normally make. I suppose the only comfort I have is the fact that I knew she didn't suffer.

When she started getting a really bad headache and started vomiting I knew that the brain metastases were now beginning to kick in and I knew this was the end of her life, that it was going to end very shortly. I say shortly. You know, one day is a long time when you're in pain and vomiting. One night it was the first time in about five days she was no longer vomiting and feeling sick. She was able to take medication including a painkiller to stop the head pains that she was getting. And it was at that point she said to me, 'I'm going to keep the medicine down now, it's time for me to leave.'

I had total reassurances from her that this was what she wanted, and I reassured her that she was not to worry about me and I was big enough to look after myself afterwards and that I would make sure everything was okay and she was not to worry about repercussions. And then that evening she escaped.



CAMPAIGN FOR
MY HUSBAND

SUSAN

I sat with him for a little while. I wanted to just have a few minutes with him. And then I thought, 'Well, I'm going to have to do something now, I can't just do nothing.' I wasn't quite sure what to do to be honest, I hadn't thought about that. So I rang the doctor's surgery, and said, 'My husband has just died.' 'Oh right, okay, somebody will be with you soon.'

Very shortly thereafter there was a ring at the front door. I went to the door expecting to see the GP but it was the police. I said, you know, 'He's dead.' And she said, 'There's somebody else in the house.' I was on my own. 'There's somebody else in the house.' 'No there isn't,' I said, 'But you're welcome to look around.' She didn't go upstairs. She just said she could hear something. I said, 'I'm here. The cat's here, and that's it.'

She was quite antsy. I was upset, obviously I was upset. Then the doorbell went again and it was a paramedic. She was different. She was sweet and she took me into the other room, put her arm round me and said, 'I can see what's happened here. I know exactly what's happened.' She made me a cup of tea, bless her. Meanwhile I made some phone calls. I contacted my son and I contacted my son-in-law to tell my daughter.

The next people to arrive were the police, en masse. They started to bark questions at me. The GP did turn up eventually and said he'd been in touch with the coroner and it all sort of kicked off from there.

He had left a file for the police and in that file he had put a letter that he had written. That's what he wanted time for that morning, he'd written a letter and quoted the newspaper headlines so they knew it was written that day. He left two voice tapes, one for the police and one for the family. And so I said to the police, 'There's a file for you.' I made sure they realised that was there. They stomped around and two plain clothed policemen questioned me. I didn't hide anything, I just told them what happened. They didn't take his body away until about 8 o'clock in the evening.

The following week I had a phone call from the police saying that the case had been passed to the Serious Crime Squad. I contacted my daughter and said, 'Do you think I need legal representation?' She said, 'Oh no, no Mum, it'll be fine.' Then about 10 minutes later she rang me back again and said maybe we should get somebody.

The Friday, exactly a week after my husband had died, I was at home on my own, just watching telly having a cup of tea, not exactly happy but I was okay at the time. My telephone rang and it was the police. They said, 'We're outside your gate, can we come in?' I said, 'Well, why do you want to come in?' 'We want to talk

to you.' I let them in and they showed me ID and I took them into the sitting room. There was this silence and I thought, 'Oh god, what's going on.' One of them looked around and said, 'Beautiful house you've got here.' I said, 'My husband worked bloody hard to get us this far, from the slums of Glasgow, we both did.' I put him in his place because it was like they expected me to be having a knees up and swigging champagne. They didn't stay too long and off they went.

Then I got a phone call saying that I was going to be arrested. My lawyer, Ian, dealt with the police. He rang me up and said, 'Look, they do want to arrest you, but I've managed to get a deal. If you allow them to search the house they won't arrest you, they'll just interview you, under caution.' So I didn't really want them searching the house, but it's better than being arrested, and having that on record, so obviously I had to agree to it. I thought, 'I don't know what they're going to be looking for, because I'd had 10 days to get rid of anything.'

They'd already taken his computer but they never did search the house, they never came to my house again. But I was interviewed under caution for about six hours. I had to go to Farnham. The lawyer came with me and I told them the story that I've told you. By the time the interview had come to an end I think they knew, but it's a process they had to go through.

Ian was brilliant. He kept me calm through the interview. If I had not had him beside me it would have been a lot harder, it would have been a lot more difficult. This is a point I'd like to make, I was in a position to be able to pay for that. Many people wouldn't be and I don't think that's fair.

He died on 30th October. I wasn't able to have the funeral until December because they wouldn't release the body. I was able to have the funeral thanks to a lovely vicar. Obviously it was a dilemma for her but she was great and she was able to do it, she felt she was able to do it. It wasn't until end of April, beginning of May, that I was actually told that I wasn't going to be prosecuted. So I had it hanging over me a long time. That was hard because you're grieving, you've been through a hellish time, you know? And you've got that hanging over you. Are they going to prosecute me? Am I going to go to prison? What's going to happen?

Eventually I had a letter, after the lawyer kept chasing it up, to say that whilst there was sufficient evidence to prosecute they didn't feel it was in the public interest to do so. That was what the letter said. And then of course we had to wait because Ian said, 'It's not over yet, we've still got the inquest.' The coroner

obviously had made up his mind before the inquest what the outcome was going to be. It was more or less a formality and they recorded a narrative verdict: he took his own life whilst suffering from motor neurone disease. It was the kindest way they could do it. That was a year after he died.



CRIME SCENES.

In all countries in the UK the police are expected to attend all incidents of sudden or unexpected deaths that occur outside of a medical setting. In England, Wales and Northern Ireland, when somebody ends their own life a coroner will hold an inquest. In Scotland, deaths by intentional self-harm must be reported to and investigated by the Procurator Fiscal.

In 2012 the Association of Chief Police Officers, now the National Police Chiefs' Council (NPCC), issued guidelines on dealing with cases of assisting or encouraging suicide.⁷² It is clear from our interviews that some police officers were uncomfortable investigating possible cases of assistance in line with the NPCC guidance, though many interviewees were sympathetic to the plight of the police in these circumstances. For others the police appeared to have acted in a way that lacked sensitivity. Undoubtedly, there is dramatic inconsistency in the way these deaths are investigated.

I again phoned up the doctor and I said, 'Look you have to inform the police now that my wife has died.' But he didn't do that. Then in the morning I started to phone some family and friends to say what had happened. Nobody was particularly surprised, it was clear that this was going to happen. But no police came. The district nurse who was looking after the morphine pumps came in the morning and I explained things to her. She was very upset. My wife was a charmer, a very friendly and nice person. I said, 'Can you inform the police because I'm surprised that they're not here.' And so she did and then the police came. He was a very young sergeant and he said, 'This is a scene of crime. I want you to leave the house.' I said, 'No way. I've been here for eight hours, you think that if I wanted to I have not been able to not clean anything up? This is a nonsense right?' He said, 'Well, then I declare the bedroom as a scene of crime.'

I phoned my sister-in-law who came over from England. She wasn't allowed in the house. She wasn't allowed to see me. She had to stay in a coffee shop around the area. Two friends came to give their last respects. But the police confiscated her computer, so I had no more addresses or access to her emails and friends. I couldn't let anybody know which was really... The sergeant said, 'Do you know what she's taken?' I said, 'Yeah, there is the pot.' We had been careful to make sure that she took the pills herself and that only her fingerprints were on the pot.

The experience of this grief is then augmented being treated like a semi-criminal by the police. Not that I'm particularly fussed about it, I'm resilient enough to say, 'Okay, do as you like.' But she had it well organised, so I could prove that I was away. If there's anything in terms of guilt, what is still inducing the biggest guilt in me is that I did go away.

I turned up and she was lying upstairs. I asked the police if I could just go up and give her a kiss which I did and then they turned round and said, 'You know we're going to have to investigate this.'

I had the interview at St. Albans Police Station. The sergeant was absolutely fantastic. He just said, 'I can understand exactly what's happened here.' That was on Saturday night, I was at home on Monday when the same sergeant came to my house, 40 miles away. He said, 'Look I do have to tell you this, you've committed a crime. You've aided a suicide which is a criminal offence because you sent off for forms to Dignitas, your mother didn't, so you've aided her in being able to do that, even though we appreciate she couldn't have done it herself.'

He said that a few years ago this would have been a problem but Keir Starmer had brought in

guidelines that said the crime is one part of it and the public interest is another. So he said, 'The crime will go through the process, I can't see any chance that we will be prosecuting you for emailing the Dignitas forms for your terminally ill mother.' Which is exactly what happened, but it still had to be investigated. He said, 'Look I'm really sorry about this, I don't think there's any foul play here at all but I've got to take your phone.' So he took my mobile off me, which I got back 24 hours later.

Within about half an hour of the paramedics being there and telling us that he's passed on, and us getting to the bottom of the Power of Attorney forms, some coppers showed up. They were bobbies on the beat and are trained to treat every situation with suspicion, a major problem in the Metropolitan Police as a whole but definitely evident here. When they walked in they were not really able to read the room and the atmosphere. We were told to stay in the kitchen, the living room where Dad had been was the crime scene.

Within 15 or 20 minutes more coppers showed up. The neighbour told me that at one point there were five police cars on the street. The neighbours had no idea what was going on and they were frantically phoning Dad because there was such a scene, they blocked the whole road, the school buses couldn't get through because there were all these police cars on the road. It sounded like a kind of murder scene or something. It's like, why aren't you people out doing something else?

Anyway, eventually some senior detectives turned up, relieved the bobbies on the beat of their duty. These detectives sat with us in the kitchen and explained that they'd got a message from higher up that they needed to scrutinise these events more closely than they were comfortable with, that they

wanted to search the house, look in his drawers, check where he'd obtained these drugs from. I gave him his note and I said, 'Look, he's ordered them online.'

Adding another layer of complexity to this is that his carer was a guy from Romania and he was living with us at the time. He would have been at home during the hours where Dad would have taken the drugs. So, you know, two relatively well spoken middle class North London kids are not going to be the target of their suspicions when they walked in the room, they were going after the guy that was a little bit more vulnerable. So the carer was hovering around, panicking, worried because the guy he was supposed to be caring for has died. I mean, poor guy. Anyway, they told him that he needed to come down to the station to make a statement. They confiscated our phones. They confiscated Dad's phone, his iPad, his iMac and told us that they understood we needed to get in touch with people to tell them Dad had died, but they would try and return the phones to us as soon as possible.

When those initial police people came in they clearly had absolutely zero training of what to do in an event like this. Their level of tact was severely lacking and it was very much a grey area. It's not like we were suddenly being treated like criminals, but what was happening was a lot of chaps outside on our front garden, a lot of whispering. They had to take all these photographs of Dad and the room and taking your phones in a moment of grief is not practical. When they took our phones they said they were asking permission to download photos, internet history, messaging and call history and I said, 'Well what happens if we say no?' And they said, 'Then we will have to wonder why you're saying no to something like that.'

He died in the February and it was November when I asked, 'Can we have his computer and his iPad back please, surely you've got what you need. 'Oh yes, sorry.' And one of the coppers came round and gave them to us.

When my mother had died, the police became involved because it was a sudden death at home. If you die at home without being seen by a doctor it has to go to the coroner. And my mum died in my house so the police had to be called and any witnesses had to be interviewed. Then of course they felt that it could be assisted.

I didn't assist, I just didn't stand in her way. I didn't prevent it. So I didn't do an action that aided her. The ambulance called the police and then - I'm not joking - three marked police cars and two detectives were there. We were interviewed and all our phones were taken, they kept my phone for about four days.

The investigation by the police went on about 12 weeks, it was quite a long time. The police asked me about the bottle of medicine. I said, 'Of course I left it with her, it's prescribed to her, I'm not taking it away, it's not my legal duty to remove her medicine.'

After the investigation nothing happened. That was it, end of.

I didn't call the police. I didn't call the authorities or the doctor or anybody that evening. I chose to call them in the morning. I called an ambulance. It was Saturday morning and her doctor's surgery was shut so I assumed that under those circumstances you call an ambulance. They came and I didn't hide the fact that she'd ended her own life. It was the way it was. They called the police. The police came and they interviewed me for about four hours. They wanted to know absolutely

everything. They went through all her things. They went into her room. They went through all her personal belongings. I showed them the suicide notes. They took everything, all her pills, all of her note pads that she had written down her paracetamol and her painkiller regimes on. They took everything away. They also took her away to the coroner. We'd chosen a funeral director but obviously now she had to go to the coroner because there had to be an inquest. I had to sign a witness statement. It was like it was a crime scene. I was terrified. I was

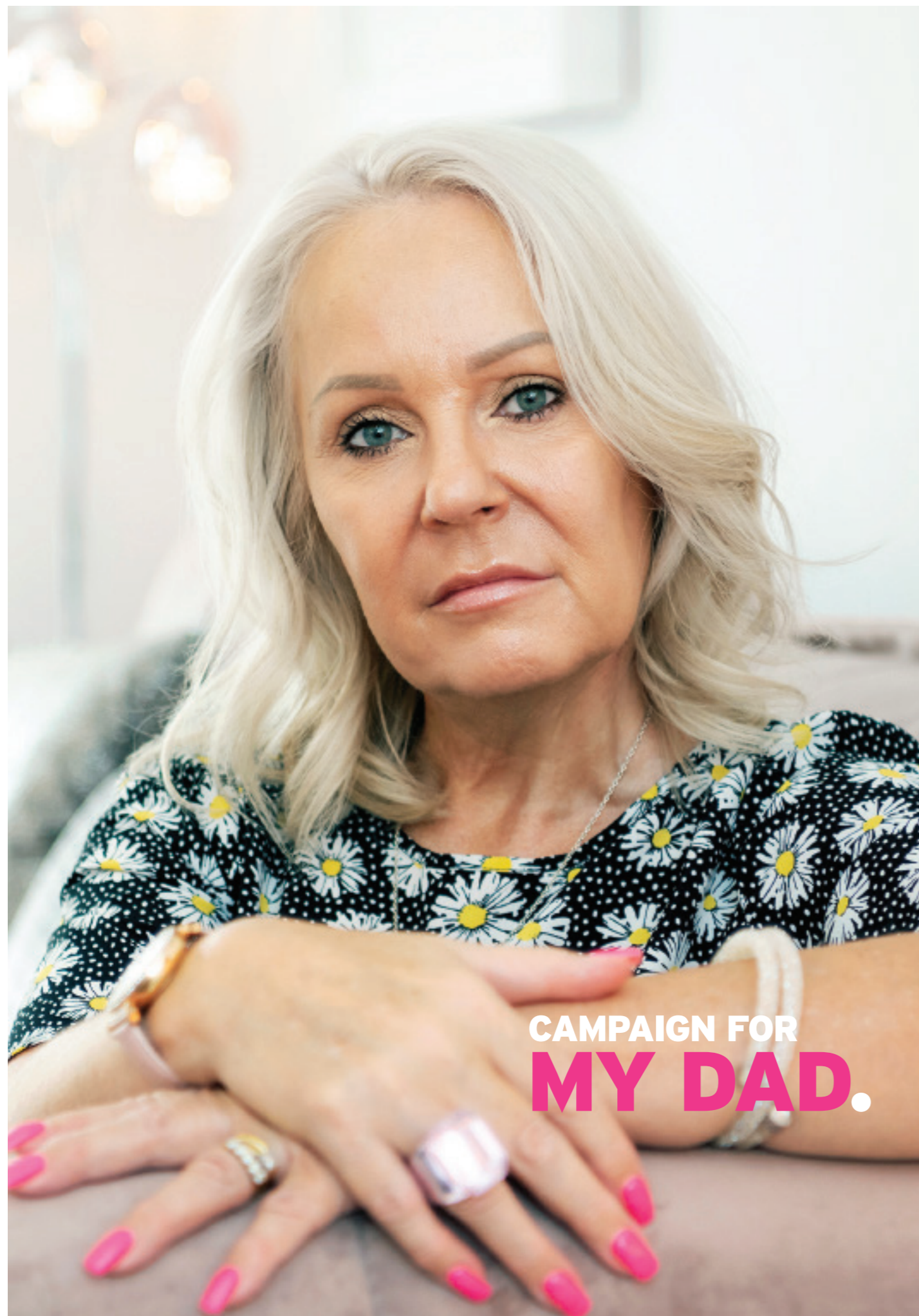
really frightened and I remember feeling so tired. I just wanted them to go away.

I was really upset that they would give my mother an autopsy, now they were going to just disrespect her body in death and I felt so hurt and so abused by the system at that point. I felt she'd been abused by the system. When my father died I was able to go and see him at the chapel of rest. It impacted me on so many levels that we couldn't get her back. We weren't given a proper death certificate. Of course there's the stigma attached

to suicide, and there is one attached, which has to change, these attitudes have to change. That's on her death certificate, suicide, which I feel really is not fair.

I didn't know if they were going to come back and want more information or if they'd call me to the police station. It's a broken law. It is a broken law and I somehow got myself right in the mess of it. For six months we waited and it was just horrible. I felt so ill at the end of it and my family, we were all really quite ill.





CAMPAIGN FOR
MY DAD.

JOY

In February 2018, Dennis Eccleston died after taking an overdose of pain medication. He was helped by his wife, Mavis, who also tried to end her own life. Mavis survived and was then charged with murder and manslaughter. In September 2019, Mavis was found not guilty. Their daughter Joy described her dad's death and how the aftermath impacted her family.

Dad was an old-fashioned, hardy, honest man. He started off as a coalminer when he was 14 with his Dad and his brothers then he ended up becoming the overman of the pits. He was 80 when he was diagnosed with bowel cancer.

As far as he was concerned he'd had a good life. He'd walked us down the aisle, watched us have kids, we were all settled and he was happy with his lot. He said, 'I've seen enough people die of cancer. I don't want to be in a hospice. I don't want people coming in and messing with me.'

They'd arranged it. My brother was the one that was going to find them and my dad had even turned to my brother and said, 'If we're still alive when you get here you just put a pillow over our heads.'

I didn't know when it was going to happen. I was just hoping that he was going to go in his sleep. Had it not been for that morning when Mum woke up and heard him crying - she said he sounded like a wounded animal - I don't think that the events would have taken place the way that they did.

He was out of his recliner on the floor, crying in pain. His dressing gown was open and she saw these two great big massive growths that she hadn't seen before. She had to get on her hands and knees and he held onto her back and they both crawled into the bathroom to clean him up. They got him back to the chair and he messed himself again.

He broke down and said, 'Mavis, please don't call the ambulance.' He was just begging her and she just turned around and said, 'Okay Dennis, we'll do it. But you're going to have to tell me what to do.'

What we didn't know is he'd been stockpiling tablets. Mum had been saying to my brother that they're just not working but she didn't know that he wasn't taking them. She crushed them and mixed it so they could drink it. My dad said, 'Hold your nose because it's going to taste really bitter.'

My mum wrapped dad up because she didn't want him to get cold. She kissed him on the forehead and said, 'Goodnight, god bless darling.' And he said, 'Goodnight, god bless. I love you.' And then the next thing that she remembers is waking up in the hospital.

When we got to the hospital the doctor told us that Mum will pull through but Dad... Obviously with his cancer... It was a 60 year romance and they'd tried to end their lives together. They were so, so lovely at the hospital. They put the beds together so they could be together. Mum was telling us about their first date and my dad had a tear just trickle down his face. And he just passed. And it was so lovely and just as a family, I don't know if you can call his passing beautiful but he wasn't in pain.

The nurse came and sat on the bed and she put her hand on Mum's back and was rubbing Mum's back and she said, 'You see Mavis, you've murdered your husband and you're going to go to prison for a very, very long time.'

They were plainclothed detectives and you could see that they didn't want to do it. I was pleading with them and they were looking at me saying, 'We know, Joy, we know.' The police lady looked as though she'd got tears in her eyes when she was trying to prise me and my mum apart. I was begging them, 'Please don't take her. Please don't take her. She's 80. She's got a heart problem. She's not going to survive this. I've just lost my dad. Please don't take her.' She was in her slippers, nightie and dressing gown and they took her away in the back of a police car.

She was in the police cell for 30 hours and they wouldn't let her use the private toilet, they were making her use the toilet in the cell.

There was the four of us and she was like, 'Oh, you're all together?' She hadn't got a clue and we just said, 'Mum you're going to have to sit down.' And then my brother broke it to her that she was going to get charged with murder. And even then I don't think she understood the severity of it. I don't think she realised that she was going to go to prison if she was found guilty.

We were all brought up never to tell lies, and I've been the same with my kids, and I remember saying to my mum and my brother, 'Just tell the truth, we'll just tell the

truth. Because if we just tell the truth the jury will see we're telling the truth and what kind of family we are.'

The jury came in, and the Judge said, 'Foreman have you got a verdict?' 'Yes.' And he said, 'On murder?' he literally puffed his chest out and he bellowed:

'Not guilty.'

'On manslaughter?'

'Not guilty.'

We were trying to keep it together and hold our sobs in. We were just hugging each other and kissing each other and we were thanking god.

I thought that once the court case was over we would go back to normal and everything would be as it was

and we would just be a happy family again and it didn't. I went into a very, very, very dark place, very dark place. The doctor said to me that there's two modes, fight and flight and through all of the case I was literally in fight mode, really, really passionate, really powerful, really fighting for my mum's life and then once it was over my body was like no, you literally cannot do that anymore. All of this stress and strain for 18 months.

I just feel as though I've had something taken away from me because I wasn't allowed to grieve and the grief has never come. When we talk about Dad now it's always talking about good times and the happy times and smiley times. I've missed that process where talking about Dad gives me that heartache because I didn't have a chance to do that because whenever we spoke about Dad we spoke about the court case.



GRIEF

There is much to differentiate the deaths of the people featured in this report from cases of suicide, yet one aspect where similarities remain is the immediate impact on those who are bereaved. This might be due to the fact that some interviewees discovered their loved one's body, were denied an opportunity to have an open conversation with their loved one about their feelings and intentions or live with regret at the manner in which their loved one died.

People who have lost a loved one to suicide are at higher risk of developing major depression and post-traumatic stress disorder, and social stigma can impede access to support.⁷³ Bereavement by suicide is a risk factor for suicide attempts in young adults.⁷⁴ A UK study examining bereavement following the death of an older person by suicide found nearly half reported difficulties in dealing with coroners and also identified increased rates of stigmatisation, shame and a sense of rejection.⁷⁵

These effects were compounded for some interviewees in this report because they also witnessed their loved ones suffering prior to their death and/or feared the potential legal implications following their loved one's death, for them and for other people they knew, including the possibility of prosecution and imprisonment.

These negative outcomes contrast with what we know about bereavement in countries where some form of assistance to die is legal. A study of family caregivers of people who had accessed assisted dying in Canada found they overwhelmingly viewed the quality of their loved one's death more favourably than the one they anticipated by 'natural causes', namely because of the prevention of unnecessary suffering.⁷⁶ A study in Oregon found that requesting an assisted death did not have a negative effect on surviving family members. In fact it was associated

with greater acceptance of death and bereaved family members were more likely to believe that their loved one's choices were honoured and less likely to have regrets about how their loved one died.⁷⁷ A 2019 systematic review of literature found those bereaved following an assisted death in different jurisdictions had similar or lower scores on measures of disordered grief, mental health, and post-traumatic stress compared with those who died 'naturally.'⁷⁸

Interviewees described many symptoms of complex grief, a term that is used to describe grief that is distinct from bereavement-related loss and is a predictor of long-term functional impairments.⁷⁹

I have nightmares about it all the time.

I had her best friend with me who is a palliative care nurse. She actually took two months off work because it had traumatised her so much.

The last vision of your parent... All the horrible things that can go on when somebody dies... That's not how you want to remember somebody.

We didn't say goodbyes in the way that we wanted. Well, no that's not true, well it's half true. We said our goodbyes and if she had passed away peacefully it would have been a hundred times better for her and me. You know, for her to know that I was there and holding her hand. She was meant to just go to sleep and that was it, and not be distressed, and I will never know how or where she was. Her one fear was that we'd get it all wrong and she was really worried about that.

Well I'd woken up every morning for three years feeling sick because my husband had motor

neurone disease. He was going to die. It was all pretty grim. So you cope with that, you get through that and then you think when he's gone all I want to do is curl up in a ball and cry. But you can't because you've got to hang on some more. You've got to get through this next bit and you're waking up every morning feeling sick in the stomach because, 'Oh god, what's going to happen? Am I going to be prosecuted?'

So it makes it hard to grieve and it makes life very difficult. It makes it hard to even start to try and move on. I was lucky, I have lots of friends and people around me who would listen to me have a moan or whatever, but you can't wear your heart on your sleeve too much, people don't want to know. I was trying to keep cheerful, trying to keep going but all the time it's hanging over you like heavy towels. That, alongside the grief was difficult. It was difficult.

I was really quite frightened that I would end up being prosecuted for assisting. I was frightened of that. And I was so indignant about it. I just didn't want my family to suffer anymore. I wanted us to be able to get on and grieve my mum. That process of grieving and getting

past the loss and being able to think about her in a positive way... No, it kept the wound right open. I would say it's made me have a very different attitude towards the authorities. I'm not as confident in law anymore and I'm not as confident in the medical profession. It's left me quite damaged in that way, definitely.

I never thought how painful it would be to not be there. So I'd say that's one of the most painful things, why didn't we just get that last chance to have that meal on Sunday night?

A couple of months after she passed away I had had enough and I tried to end my life. I don't remember too much about it. I just couldn't understand, if that makes sense? I didn't want to carry on. If she'd gone off how she wanted and I knew that, I would have been happier I think, you know?

I'm a functioning alcoholic now. I will always wonder what she went through. If she didn't know what was going on and she just fell asleep and she wasn't aware of it then I don't care what I went through, that's the thing. I used to

have this common condition where you're lying in bed and you don't quite wake up but you can't move and you feel like you can't move and it's a frightening and terrifying thing. Now if she had that, and 15 hours of it, trying to breathe, gasping for her last breath. It's a horrible, horrible thought and I feel guilty, I feel terribly, terribly guilty for not getting it right.

Your Dad's just taken his own life in a manner that was particularly harrowing on every single level and all you need someone to do is to make that process slightly easier. And the truth is that the police inquiry and the way it was handled from a sensitivity perspective made the entire process considerably harder.

I suppose the important thing for us was to grieve and to be allowed to grieve. To still not have his personal possessions for many months after hinders the grieving process, for them to be interviewing us 40 hours later hinders the grieving process. For them to not get in touch with us to let us know that this is no longer ongoing, that we have some closure on how he died, that hinders the grieving process. So we're left all at sea because of this.



It still makes me angry because I know that the sense of touch is the last sense to go and it's still upsetting for me that I was not able to provide that sort of last sense. That's still a hard issue for me to deal with. We didn't know how the DPP guidelines would be applied, so we didn't take any risk in the situation. Then the whole thing unfolded with the police which made it impossible for me to have that emotional support from my family on the first day.

It's affected everyone who knew him. When they found out what had happened they were absolutely shocked. I constantly think about him. Because he had to choose this way, we are going to have to live with this for the rest of our lives and there will be situations where we'll be reminded of what happened. It fades but nevertheless it's still there in your mind and something will trigger it. And the HGV driver... We had a family liaison officer who was extremely good. I said to him, 'Please, please tell the driver that we feel really, really very bad

about this. He should not have been drawn into this and it should never have occurred.'

While research on the impact of witnessing a stranger end their life is scarce, qualitative studies have found negative effects, including post-traumatic stress disorder, flashbacks and physical reactions such as sweating, nausea and trouble breathing when people are reminded of the event.⁸⁰ Support resources for third party witnesses of suicide describe it as a life-changing event with shock, nightmares, difficulty sleeping, flashbacks, substance abuse, irritability, guilt and anxiety as common reactions.⁸¹

When they rang the police up, they sent out a first responder. Because it was in a fairly small village about 10 miles outside Norwich, they haven't got an ambulance guy in a rapid response vehicle. The first responder is a volunteer in the community; he was the local biology teacher at the High School. He had to cut him down.

The thing that would have upset Dad no end is to think that that's who found him. That would have

horrified him. If it had been the police I still would have felt awful, don't get me wrong, but they weren't a professional, they're not used to that sort of thing. There is survivor's guilt because of the fact that I didn't have to find him.

In the parliamentary inquiry in Victoria, Australia, the Acting Commander of the police, Rod Wilson, said that he was regularly briefed about cases where dying people had ended their own lives and explained the difficulty for first responders in handling those cases:

I think that the police who attend these events, like ambulance officers and others – our police are only fairly junior and inexperienced and quite young – and I think the impact of dealing with the deceased persons at those horrific scenes, and also having to prepare inquest briefs for the coroner and taking statements from family members who are clearly desperate and frustrated with the system, I would just like to say that that does have some impact on our frontline police officers.⁸²

“If she'd gone off how she wanted and I knew that, I would have been happier I think, you know?”

SHOCK
SHOCK
SHOCK
SHOCK
SHOCK
SHOCK.

GRIFE
GRIFE
GRIFE
GRIFE
GRIFE
GRIFE.

Existing research suggests between 5% and 10% of deaths registered as suicides in the UK involve somebody with a terminal illness, which equates to between 300 and 650 dying people ending their own lives every year. These figures suggest as many as 6,500 more dying people attempt to end their own lives.

In 2011, the cross-party think-tank Demos sent a freedom of information request to Primary Care Trusts in England regarding the number of deaths registered as suicides in their area for which there was evidence that the person who died had a physical, chronic or terminal illness, as well as a number of other characteristics such as pain and physical impairment.⁸³ The results showed that 2.1% of recorded suicides had a record of a terminal illness, 10.6% a chronic illness and 8.2% a physical illness. However, Demos warned that this methodology likely resulted in a significant underestimate, given the likelihood of overlap between these groups and problems they uncovered with the way this information was recorded.

Demos also examined 259 suicide verdicts at Norwich District Coroner's Office. They found that in 3.1% of verdicts the person who died had a terminal illness and in 6.9% they had a chronic illness. However, there was again overlap in these groups, for example some people had diagnoses of progressive diseases which would have reached a terminal phase.

In 2014, Dignity in Dying sent a freedom of information request to Directors of Public Health of every local authority in England, which had taken over responsibility from Primary Care Trusts for local suicide audits.⁸⁴ The request mirrored the request previously sent out by Demos. Out of the local authorities that responded only a minority had noted the presence of terminal illnesses as part of their audit process. In total the circumstances of 760 suicides were recorded and

in 7.4% of these the individual who died had a terminal illness.

In 2017, the Public Health and Social Research Unit at West Sussex County Council published an analysis of suicides and likely suicides recorded in West Sussex between 2013 and 2015. For each recorded suicide researchers were typically able to access the coroner's summary sheet; a toxicology report; an autopsy report; a police report of the circumstances of the death; character references from those close to the individual; copies of suicide notes; photos of the scene; relevant physical or mental health service history; and copies of any inquests or investigations into the death.

The researchers found that in 10% of cases individuals were driven to end their own lives by a terminal illness and 'continuing decline in health, where they felt their standard of living had been significantly reduced' and it was believed they 'had chosen to end their life before their health deteriorated further.'⁸⁵

The meticulous nature of the audit conducted in West Sussex shed light on a number of factors that contributed to suicides in the area, many of which would have otherwise gone unacknowledged. While localised, it represents one of the most comprehensive thematic studies of recorded suicides in the UK, though this is not currently a standardised methodology employed by public health teams in other local authorities.

In 2021, the National Statistician, Professor Sir Ian Diamond,

answered a Written Parliamentary Question by Baroness Royall of Blaisdon regarding the number of deaths registered as suicides amongst people who had been diagnosed with a series of serious illnesses.⁸⁶ Sir Ian provided figures that suggested this would encompass as many as 14.2% of suicides, but cautioned that this figure may involve double counting. Sir Ian also said that the Office for National Statistics (ONS) could draw on its extensive data sources to provide more data on the rates of deaths recorded as suicides amongst dying people. This further work was commissioned by the then Secretary of State for Health Matt Hancock and is expected to be published at the end of 2021.

Research for this report has found that deaths where a dying person has ended their own life might not have been recorded as suicides and further investigation by a coroner (or a Procurator Fiscal) has not been triggered. Once again this seriously undermines any claims that the current law is capable of protecting people or examining the exact circumstances of deaths that might have been assisted. Failure to register these types of deaths consistently also means we must question whether existing data in this area underestimates the true extent of the problem.

We then had a long discussion with the coroners, who essentially came to the conclusion that they didn't want to have an investigation. They said, 'Are you happy with that? I know exactly what has happened, so we don't need to have an investigation because that won't bring anything new to light.' I said, 'Fine. It's not necessary for me. It's a waste of everyone's time and it doesn't bring any more clarity to anything.' So there was no inquest.

I phoned up the hospice before she died and said, 'She's changed her breathing, is she going to be

aware?' And the doctor said, 'You know people like that probably aren't.' The doctor and the nurse at the hospice were very good. They said they'd come out, but by the time they came she had died. I don't know if they knew. I wouldn't be surprised if they suspected because she had repeatedly said to them, 'Look, I just want help, let me leave.' And they'd always say, 'We can't do it. Sorry, but we can't.' So I suspect they might have guessed what happened.

In New Zealand, Dr Weaver, who examined 100 years of suicide records, estimated, conservatively, that between 5% and 8% of suicides in the second half of the 20th Century in New Zealand involved people who were experiencing an incurable illness that would result in their death.

Coroners in Australia have contributed data to parliamentary inquiries into end-of-life choices. In Victoria, coroners were able to quantify that 8.3% of suicides they had on record between 2009 and 2013 involved someone with an irreversible decline in physical health.⁸⁷ In Western Australia, coroners reported that in 13.9% of suicides recorded between 2012 and 2017 the person who died had been diagnosed with a terminal or debilitating physical condition prior to their death.⁸⁸ In Queensland, coroners identified 168 cases a year where the person died as a result of intentional self-harm and suffered from a terminal or debilitating physical condition between 2016 and 2017, representing 11.4% of suicides recorded in those years.^{89, 90}

CORONERS

As part of the research for this report Dignity in Dying approached senior coroners in England and Wales with a view to replicate the work of coroners in Australia. Many coroners acknowledged that they have encountered cases where terminally ill people have ended their own lives and they expressed

support for further research to quantify this problem. However, the structures that surround coroners in England and Wales proved a barrier to constructive engagement in debates around end-of-life choice, including the contribution of data.

This is not to say coroners have not publicly commented on these issues. As part of their research conducted in 2011, Demos spoke to 15 serving and recently retired coroners, some of whom wished to remain anonymous, about recorded suicides and specifically those involving people approaching the end of their lives. 'We have inaccurate and misleading statistics,' one said. The majority of coroners said they experienced between one and two cases a year where a dying person had ended their own life. When asked about the possibility of uncovering cases where people have been assisted to die by family or friends, one coroner said, 'There have been many cases where I had suspicions, but I would not see it as my specific job to delve into it. If I had no option then I would, but you might say I didn't want to know.'

In March 2017, a man on the Isle of Wight with motor neurone disease died alone in his car, officially from drug and alcohol intoxication, although he had also tried to suffocate on exhaust fumes. His son had admitted to helping him into the car. At the inquest the assistant coroner told the man's son, 'I express my sympathy and condolences to you, you were in a distressing situation [...] I am sorry you have been placed in the position you find yourself in. You did it out of great love.' Of the father he said, '[motor neurone disease is] an extremely depressing condition not only for the sufferer, but for the family of the sufferer. I'm not in the least bit surprised [he] acted in the way he did.'⁹¹

In November 2020, a farmer from Ulverston with motor neurone disease shot himself in the head with



a homemade gun. At the inquest the coroner said, 'It is hard to criticise him for doing this. I think his motive is quite understandable.'⁹²

There are caveats we need to take into account when assessing these studies. For example, it is likely that all deaths included in the figures will have met the researchers' criteria, but not all deaths that met their criteria will have been included in the figures. Disagreements between researchers as to whether a death met the eligibility criteria will have led to some deaths that were eligible being excluded as a precaution. Additionally, as Demos found, there is evidence of coroners choosing not to include relevant health information on the inquest records and in these circumstances it would not be possible to ascertain that an individual had a terminal illness. We also know that not all relevant cases are recorded as suicides and these will not have been captured by researchers. On the other hand, it is likely that existing estimates include people who were not at the end of life; they

might have been diagnosed with a serious condition that was not terminal. However, in some of those cases the individual involved may have had a condition that would reach a terminal phase at some point in the future.

We estimate that between 5% and 10% of deaths registered as suicides in the UK involve somebody with a terminal illness. This range encompasses figures in existing research while taking into account the caveats outlined above. When we apply this range to the most recent available data of the number of suicides registered in the UK, which includes probable suicides,^{93, 94, 95} it approximately equates to between 300 and 650 dying people ending their own lives every year.

According to the World Health Organisation, for every adult that dies by suicide there are a further 20 who attempt suicide and do not die.⁹⁶ As highlighted earlier in this report, there is some evidence to suggest that dying people who end their own lives opt for methods that

decrease the chances of survival compared to others who attempt suicide. Therefore, we have reduced this ratio to 10 attempts for every dying person who ends their own life. Accordingly, we estimate that as many as 6,500 dying people attempt to end their own life in the UK every year.

Undoubtedly further work can be carried out and we welcome the Office for National Statistics' efforts in this area. We would like to see further data collected and more work done to ensure the accuracy of this data. Nevertheless, we can add these indicative figures to our existing knowledge base about the scale of the impact of the blanket ban on assisted dying.

ESTIMATING THE NUMBER OF DEATHS REGISTERED AS SUICIDES INVOLVING TERMINALLY ILL PEOPLE

Data Source	Location	Date Published	Estimate % of deaths registered as suicides involving people who have been given a serious, life-shortening or terminal diagnosis
Office for National Statistics	England and Wales	2021	14.2%
West Sussex Public Health and Social Research Unit	West Sussex	2017	10%
Dignity in Dying FOI request	England	2014	7.4%
Demos analysis of coroners' records	Norwich	2011	3.1% - 9.7%
Demos FOI request	England	2011	2% - 10%
Coroners Court of Queensland	Australia	2019	11.4%
Coroners Court of Western Australia	Australia	2017	13.9%
Coroners Court of Victoria	Australia	2015	8.3%
Dr John Weaver	New Zealand	2015	5% - 8%

EVERY YEAR IN THE UK...

50

People travel to Switzerland
for an assisted death

300 - 650

Dying people end
their own lives

Total number of dying people directly
affected by the UK's blanket ban on
assisted dying every year: 9,500 - 13,500

3,000 - 6,500

Dying people attempt
to end their own lives

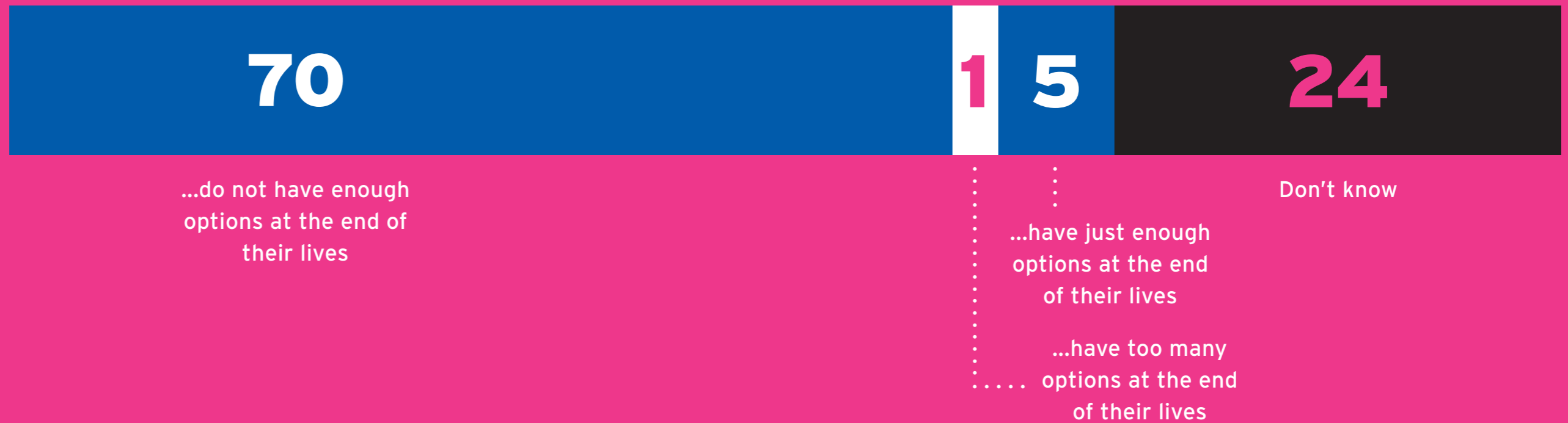
6,400

Dying people who will suffer
pain in the last three months of
life even with access to the best
possible palliative care

POLLING (%)

Polling repeatedly finds that the public overwhelmingly support a change in the law to allow terminally ill, mentally competent adults the option of requesting an assisted death, subject to up-front safeguards.^{97, 98, 99} Polling commissioned for this report found that just 6% of people think the current law provides dying people with enough options at the end of their lives and just 5% of people think maintaining the blanket ban on assisted dying is in the best interests of dying people.

Q. Thinking about existing laws around those who are terminally ill and seeking assistance to end their lives, which of the following comes closest to your view? Under existing laws, terminally ill people...



Q. Which of the following do you think would be better for dying people?



"SHE WOULD HAVE ENJOYED THE SUNRISES AND THE SUNSETS A LOT MORE KNOWING SHE WAS GOING TO HAVE A GOOD DEATH"

Interviewees explained how the deaths of their loved ones would have been different if assisted dying were legal in the UK.

I would have been able to hold her hand and see her away. The fact that she had to do that by herself is still upsetting to me and it's the main reason why I find that the law has to change.

I think he would have felt so relieved if he knew that he was going to have a relatively pleasant death.

The difference with assisted dying would have been night and day. There would have been much more control, there's nothing wrong with wanting a little control of one's life. It would have enabled her to have lived the last part of her life with optimism, with positivity. She would have enjoyed the sunrises and the sunsets a lot more knowing that she was going to have a good death.

There would have been somebody there to be with him, to hold his hand, people that loved him.

It would have made an enormous difference. He wouldn't have had to panic for six months whilst he got everything sorted out. I wouldn't have spent three years thinking, 'What if it goes wrong?'

I wouldn't be having nightmares regularly. I wouldn't have this constant thing that we screwed it up and that she suffered, because I think she might have done and that was the last thing that she wanted.

We would have better memories, rather than our memory of a broken figure on a major road. He could have had an easeful death, one which didn't involve the HGV driver.

She would have gone out happier. That's very important. Because she'd looked after animals for so many years, for her it was almost like a dog had a better option, a better quality of life. And obviously it's different because with a dog you make that decision for them. But I think Mum felt, 'Why can they get a way out?'

I think terminally ill people would live longer and happier lives if they know there could be a point in time that they could say, 'Right, today's the day,' and everyone would get together. There's not the shock, there's none of that. You can't make it a nice experience - when you lose somebody you can't turn that into a nice experience - but you can make it not an awful experience.

If assisted dying were made legal in the UK in all probability he would have had a longer life, not a shorter life, and as his two kids with no mum that was important to us. There was an opportunity in another world where he could have had a longer life and a kinder, safer death.

I guess his death would have been a lot more honest, an experience of honesty and transparency. We would have been able to grieve in a lot less of a cloak and dagger, secret, underhand, dark, depressing way. We would have been much better equipped to handle it when it did eventually come and crucially we would have been able to open up a dialogue with Dad. We would have been able to address his death in a meaningful and honest way.

My MP doesn't have to take this path if she doesn't want to but she has no right to deny my son the right, no right whatsoever. When Mary Whitehouse many years ago was complaining about

television programmes, I always used to say to her in my mind, 'Well you don't have to turn the programme on!'

I think that someone needs to grasp the nettle. We need to move forward, we need to be progressive otherwise we'd still be sending homosexuals to prison, women wouldn't have rights. It takes a bit of bravery and determination.

Thank goodness doctors are moving now from against to neutral and a positive view. I think we have a tendency in this country to treat a medic a bit like lord, what they tell us is true and their opinion is rather more important than mine. It's not. I think we've now gone through that sort of subservient phase and we're now telling the medical profession to do the right thing.

It's going to happen whether it's legal or not, but when it's not it just means people are so much less safe.

Over 200 million people in the world have access to some form of assisted dying. Assisted dying for terminally ill, mentally competent adults was first introduced in Oregon in 1997. That law has since been adopted by ten other states in the USA as well as Washington DC. Many other states are currently debating legislation. Assisted dying is also legal in four states in Australia with legislation being debated in other states and at the federal level. New Zealand has legalised assisted dying after a referendum found two thirds of the population backed Parliament's decision to pass a bill.

Other types of legislation have been passed in Canada, the Netherlands, Belgium, Luxembourg and Spain and assisted dying remains legal in Switzerland for Swiss and foreign

nationals, though there is no specific legislation in place setting out who is eligible.

Interviewees were aware of the progress that has been happening overseas and in some cases this made their experiences all the more difficult to rationalise.

The Antipodes have actually moved ahead of old Europe in many respects and they see things rather more clearly. Maybe they are uncluttered by establishment and tradition and vested interests. So I think it's a very broadminded and mature thing that the New Zealand public have decided to do.

In places where assisted dying is legal, dying people have explained how knowing they now have the legal option of controlling the manner and timing of their deaths has meant they no longer need to take matters into their own hands in the ways that this report has uncovered.

In 2019, Nia Sims spoke out about how law change in Victoria has allowed her 'to connect in a more meaningful and caring way with my own fragile, crumbling body.' Nia said the law 'freed' her from having to plan how she was going to end her own life, meaning she could 'get on with living.'¹⁰⁰

In 2018, Lois Lynne Sherman died using California's End of Life Option Act. Her children, Heather and Shaun, explained that if the option of assisted dying had not been available to her then 'she would have found another means to end her suffering.' They were grateful that 'it didn't come to that.'

Heather and Shaun have written about how having a transparent choice allowed their mom to die in the manner she wanted. In her final weeks, family and friends were able to visit and say their goodbyes. Her final wish was to be able to die at home surrounded by her four children, which is what happened.

Mom drank the solution of medication and laid down. She was asleep within five minutes. A social worker from the hospice was there to monitor mom and lend support. Mom's partner put on the Rolling Stones, which mom loved. Mom died an hour later to the Rolling Stones' You Can't Always Get What You Want.

"You can't always get what you want

But if you try sometimes, well, you just might find

You get what you need."

Mom got exactly what she needed: peace and an end to her suffering.¹⁰¹



SUMMARY AND RECOMMENDATIONS.

This report has found catastrophic failings in the UK's blanket prohibition on assisted dying.

A lack of meaningful choice is driving dying people towards deaths that are often violent, dangerous and lonely. The difficulty of having honest conversations with healthcare professionals, as well as unequal knowledge and unequal access to expertise of how to die, creates disparities and some people are denied the ability to have the death that they want. The law fails to protect dying people.

The uncertainty that surrounds the planning process and the clandestine nature with which plans have to be put in place creates anxiety for dying people. It also affects family members and friends, who not only have to cope with worries about how their loved one will die, but they can also experience trauma after witnessing their loved one end their own life and must then also confront the problems that occur in the immediate aftermath,

including being the subject of police investigations.

All of this is compounded by knowledge that dying people in other jurisdictions around the world have access to assisted dying, which offers an open and legal process for exercising the choices they wish to make.

While the Office for National Statistics is now investigating this problem, an historic failure in data collection has the problems that dying people face. Based on all the evidence available to us, we now estimate that between 300 and 650 dying people end their own lives in the UK every year, with a further 3,000 to 6,500 making an attempt on their own life.

RECOMMENDATIONS

The law must change to allow terminally ill, mentally competent adults the option of an assisted death, subject to robust, upfront safeguards

A change in the law would reduce anxiety, inequalities and unnecessary suffering amongst dying people in the UK. Crucially, it would make society safer, replacing the chaos of the status quo with a law that is open and transparent and has meaningful upfront protections, both for those who would want to explore the option of an assisted death and those who would not. This is in stark contrast to the current law, where investigations tend to take place after someone has died, if they happen at all. Law change would provide an opportunity for robust data collection and regulation, providing a much more accurate picture of the end-of-life choices dying people in the UK wish to exercise.

There must be recognition that assisted dying and suicide are distinct concepts

People who are terminally ill and approaching the end of their lives simply want to control the way they die. Presenting this as 'suicide' is misleading. It does not reflect the academic literature or the views of dying people and their families and leads to a lack of clarity in the assisted dying debate. In line with guidelines from the Samaritans, the phrase 'commit suicide' is inappropriate in any circumstance. As this report shows, many terminally ill people feel driven to end their lives in lonely and violent ways. An assisted dying law would protect these people from those kinds of deaths.

Society must know the true numbers of dying people who end their own lives in the UK

The Office for National Statistics (ONS) is currently researching the rates of deaths recorded as suicides amongst dying people. The

ONS should routinely collect and present this data to Parliaments in the UK to inform debates about assisted dying. Those with relevant expertise should work together to explore how further data could be collected. The Coroners' Society of England and Wales should consider ways that it can contribute its expertise and knowledge to societal debates.

Dying people should be able to have open and honest conversations with others about their wish for an assisted death

Those who want to control the manner and timing of their deaths should not have to manage that wish alone out of fear of implicating their loved ones or healthcare professionals in a crime. Organisations that provide care and support to dying people should assess their policies on assisted dying to ensure they are creating space for their members, staff and service users to have conversations about the subject. They should ensure they are pro-actively

promoting a culture of openness and respect for diversity of views around choice at the end of life.

Police forces should review their procedures for responding to deaths where a dying person has ended their own life

Police officers should not be asked to instigate investigations into breaches of the 1961 Suicide Act without sufficient training and support. Grieving relatives should not be subjected to unnecessarily intrusive and insensitive police investigations immediately following the death of their loved one. Police forces should review their existing procedures and learn from previous investigations they have conducted. Organisations responsible for other first responders should also ensure that people have the support they need to respond to and deal with these cases.

RESOURCES.

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

COMPASSION IN DYING

0800 999 2434
www.compassionindying.org.uk

CRUSE BEREAVEMENT CARE

0808 808 1677
www.cruse.org.uk

CRUSE BEREAVEMENT CARE SCOTLAND

0845 600 2227
www.crusescotland.org.uk

HOSPICE UK

020 7520 8200
www.hospiceuk.org

MACMILLAN CANCER SUPPORT

0808 808 00 00
www.macmillan.org.uk

MARIE CURIE

0800 090 2309
www.mariecurie.org.uk

MOTOR NEURONE DISEASE ASSOCIATION

01604 250505
www.mndassociation.org

MND SCOTLAND

0141 332 3903
www.mndscotland.org.uk

The following organisations can provide information and support to anyone struggling to cope with suicidal thoughts and mental health.

SAMARITANS (UK)

116 123
www.samaritans.org

LIFELINE (NORTHERN IRELAND)

0808 808 8000
www.lifelinehelpline.info

BREATHING SPACE (SCOTLAND)

0800 83 85 87
www.breathingspace.scot

HAFAL (WALES)

01792 816 600
www.hafal.org

MIND

0300 123 3393
www.mind.org.uk

MIND WISE (NORTHERN IRELAND)

www.mindwisenv.org

RETHINK MENTAL ILLNESS

0808 801 0525
www.rethink.org

SANE

0300 304 7000
www.sane.org.uk

SUPPORT IN MIND (SCOTLAND)

0300 3231545
www.supportinmindscotland.org.uk

REFERENCES

- 1 The True Cost: How the UK outsources death to Dignitas, Dignity in Dying, 2017
- 2 The Inescapable Truth: How seventeen people a day will suffer as they die, Dignity in Dying, 2019
- 3 The Inescapable Truth about Dying in Scotland, Dignity in Dying, 2019
- 4 'The Oxford dictionary's new words are a testament to the fluid beauty of English', The Conversation, 13 July 2016
- 5 The Law on Assisted Dying: Debate pack, House of Commons Library, January 2020
- 6 Press release: BMA publishes results of biggest survey into UK doctors' views on assisted dying to date, British Medical Association, October 2020
- 7 RCN Position statement on assisted dying, Royal College of Nursing, November 2014
- 8 See material from the campaign groups Christian Action Research and Education or Living and Dying Well
- 9 Hansard, HL deb, 16 January 2015, vol. 758, col. 1025
- 10 "Horrorific" level of stigma: biggest barrier to suicide prevention is discrimination', The Guardian, 12 November 2019
- 11 Media Guidelines for Reporting Suicide, The Samaritans, April 2017
- 12 'A New Question in End-of-Life Ethics', Psychiatric Times, 11 June 2021
- 13 Statement of the American Association of Suicidology: "Suicide" is not the same as "Physician aid in dying", American Association of Suicidology, October 2017
- 14 Francis, Netherlands 'suicide contagion' from assisted dying: Theo Boer's smoke and mirrors, Journal of Assisted Dying, April 2019
- 15 Niederkrötenhaller et al., Role of media reports in completed and prevented suicide: Werther v. Papageno effects, British Journal of Psychiatry, May 2010
- 16 Kreimeke et al., The desire to die in palliative care: a sequential mixed methods study to develop a semi-structured clinical approach, BMC Palliative Care, April 2020
- 17 Wish To Hasten Death (WTHD) in Patients with Life-threatening Illnesses: A clinical issue, European Association of Palliative Care, accessed September 2021
- 18 Monforte-Royo et al., What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients, PLoS One, May 2012
- 19 Henson et al, Risk of Suicide After Cancer Diagnosis in England, JAMA Psychiatry, January 2019
- 20 Saad et al, Suicidal death within a year of a cancer diagnosis: A population-based study, Cancer, March 2019
- 21 Zaorsky et al, Suicide among cancer patients, Nature Communications, January 2020
- 22 Karasouli et al, The impact of chronic illness in suicidality: a qualitative exploration, Health Psychology and Behavioral Medicine, January 2014
- 23 Galushko et al., Desire for hastened death: how do professionals in specialized palliative care react?, Psycho-Oncology, May 2015
- 24 Kreimeke et al., 2020
- 25 Rodin et al., The desire for hastened death in patients with metastatic cancer, Journal of Pain and Symptom Management, June 2007
- 26 BMA Survey on Physician-Assisted Dying, Kantar, 2020
- 27 'British Medical Association drops opposition to assisted dying', Sky News, 15 September 2021
- 28 APM position on using sedating medication at the end of life, Association for Palliative Medicine, 2009
- 29 Marker, End-of-Life Decisions and Double Effect, How can this be wrong when it feels so right?, The National Catholic Bioethics Quarterly, Spring 2011
- 30 Seale, Hastening death in end-of-life care: A survey of doctors, Social Science & Medicine, October 2009
- 31 Filiberti, Characteristics of terminal cancer patients who committed suicide during a home palliative care program, Journal of Pain and Symptom Management, July 2001
- 32 Grzybowska and Finlay, The incidence of suicide in palliative care patients, Palliative Medicine, July 1997
- 33 Sarah Wootton and Lloyd Riley, Last Rights: The case for assisted dying, Biteback Publishing, 2020
- 34 Oregon Death with Dignity Act: 2020 Data Summary, Oregon Health Authority, 2021
- 35 Quill, Legal regulation of physician-assisted death—the latest report cards, New England Journal of Medicine, May 2007
- 36 Ganzini et al., Oregon physicians' attitudes about and experiences with end-of-life care since passage of the Oregon Death with Dignity Act, Journal of the American Medical Association, May 2001
- 37 Tolle et al., Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide, Journal of Clinical Ethics, Summer 2004
- 38 Dobscha et al., Oregon physicians' responses to requests for assisted suicide: a qualitative study, Journal of Palliative Medicine, June 2004
- 39 Hospice & Oregon's Death With Dignity Act, Oregon Hospice and Palliative Care Association, accessed September 2021
- 40 'Victorian Government To Invest \$62 Million For Palliative Care and Assisted Dying', HelloCare, 17 November 2017
- 41 Media Statement: Massive boost for palliative care services across Western Australia, Government of Western Australia, October 2019
- 42 The full name of Dignitas is DIGNITAS - To live with dignity - To die with dignity. The organisation considers its approach to end-of-life issues to combine 'palliative care, suicide attempt prevention, advance health care planning and assisted dying.'
- 43 Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, the Director of Public Prosecutions, 2010, updated 2014
- 44 Policy on Prosecuting the Offence of Assisted Suicide, Public Prosecution Service for Northern Ireland, 2010
- 45 Statistics, Dignitas, accessed September 2021
- 46 Latest Assisted Suicide Figures, Crown Prosecution Service, accessed September 2021
- 47 'Covid-19: Assisted dying travel allowed during lockdown, says Hancock', BBC News, 5 November 2020
- 48 'My Dignitas flight to beat lockdown', The Times, 31 October 2020
- 49 John Weaver, Sorrows of a Century: Interpreting Suicide in New Zealand, 1900-2000, McGill-Queen's University Press, 2014
- 50 Affidavit of John Charles Weaver, Seales v Attorney-General, NZHC 1239, 2015
- 51 Parliament of Victoria Inquiry into End of Life Choices Transcript, Witnesses: Ms Caitlin English, Mr John Olle and Dr Jeremy Dwyer, Standing Committee on Legal and Social Issues, 7 October 2015
- 52 Lim et al., Difference in suicide methods used between suicide attempters and suicide completers, International Journal of Mental Health Systems, December 2014
- 53 Expanded and updated data regarding suicide in a context of irreversibly diminished physical health, Victoria 2009-2013, Coroners Court of Victoria, May 2016
- 54 Case Fatality Rates by Suicide Method, 8 U.S. States, 1989-1997, Harvard School of Public Health, accessed September 2021
- 55 Henson et al., Risk of suicide after cancer diagnosis in England, JAMA Psychiatry, January 2019
- 56 From conversations with Dignity in Dying staff, September 2020
- 57 From correspondence with Dignity in Dying staff, April 2018
- 58 'Admissions by Henry Marsh - the bestselling neurosurgeon reveals more', The Guardian, 13 May 2017
- 59 'Euthanasia tourists snap up pet shop drug in Mexico', Reuters, 3 June 2008
- 60 "My body is unserviceable and well past its sell-by date": the last days of Avril Henry'. The Guardian, 9 March 2021
- 61 Trends in the availability and type of drugs sold on the internet via cryptomarkets, National Drug & Alcohol Research Centre, accessed September 2021
- 62 Campbell et al., Trends and characteristics in barbiturate deaths Australia 2000-2019: a national retrospective study, Clinical Toxicology, July 2020
- 63 Campbell et al., Increased barbiturate deaths: an unintended consequence of increased publicity for methods of do-it-yourself euthanasia?, Addiction, August 2021
- 64 'Dark web scammers exploit Covid-19 fear and doubt', BBC News, 19 May 2020
- 65 'Coronavirus is exacerbating inequality, even among drug users as supplies dry up', Independent, 9 May 2020
- 66 Elizabeth Jeglic, Will my patient attempt suicide again?, Current Psychiatry, November 2008
- 67 National Suicide Prevention Strategy for England: Annual report on progress 2006, National Institute for Mental Health in England, April 2007
- 68 Public Health Audit: Suicide in Norfolk, Norfolk Public Health, May 2019
- 69 'MS patient rode wheelchair for two hours to kill herself after sister refused to buy her ticket to euthanasia clinic', Mail Online, 26 February 2012
- 70 'Doctor calls for a change in assisted suicide law after her dying brother took his own life', The Mirror, 20 June 2015
- 71 Hansard, HC Deb, 4 July 2019, vol. 662, cols 1417, 1418
- 72 Guidelines on dealing with cases of encouraging or assisting suicide, Association of Chief Police Officers, October 2012
- 73 Young et al., Suicide bereavement and complicated grief, Dialogues in Clinical Neuroscience, June 2012
- 74 Pitman et al., Bereavement by suicide as a risk factor for suicide attempt: a cross-sectional national UK-wide study of 3432 young bereaved adults, BMJ Open, January 2016
- 75 Harwood et al., The grief experiences and needs of bereaved relatives and friends of older people dying through suicide: a descriptive and case-control study, Journal of Affective Disorders, November 2002
- 76 Goldberg et al., Impact of medical assistance in dying (MAiD) on family caregivers, BMJ Supportive & Palliative Care, March 2019
- 77 Ganzini et al., Mental health outcomes of family members of Oregonians who request physician aid in dying, Journal of Pain and Symptom Management, December 2009
- 78 Andriesson et al., Grief After Euthanasia and Physician-Assisted Suicide, Crisis, July 2020
- 79 Prigerson et al., Inventory of Complicated Grief: a scale to measure maladaptive symptoms of loss, Psychiatry Research, November 1995
- 80 'How a public suicide harms the people who see it', The Atlantic, 25 May 2018
- 81 For people who have witnessed a suicide death, The Connect Program, accessed September 2021

- ⁸² Parliament of Victoria Inquiry into End of Life Choices Transcript, Witnesses: Detective Inspector Mick Hughes and Acting Commander Rod Wilson, Standing Committee on Legal and Social Issues, 7 October 2015
- ⁸³ The Truth About Suicide, Demos, August 2011
- ⁸⁴ A Hidden Problem: Suicide by terminally ill people, Dignity in Dying, October 2014
- ⁸⁵ West Sussex Suicides Audit 2013-2015, Public Health and Social Research Unit, West Sussex County Council, March 2017
- ⁸⁶ Question for Cabinet Office, HL13019, 4 February 2021
- ⁸⁷ Coroners Court of Victoria, 2016
- ⁸⁸ Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia 2012-2017, National Coronial Information System, November 2017
- ⁸⁹ Intentional self-harm deaths of persons with terminal or debilitating physical conditions in Queensland, 2016 - 2017, National Coronial Information System, July 2019
- ⁹⁰ Causes of Death, Australia, 2017, Intentional self-harm, key characteristics, Australia Bureau of Statistics, accessed September 2021
- ⁹¹ 'I cannot live with this illness': Father's final plea to son who was arrested for helping him end his suffering from motor neuron disease', Mail Online, 10 March 2017
- ⁹² 'Farmer from Swarthmoor near Ulverston diagnosed with motor neurone disease shot himself - inquest told', The Westmorland Gazette, 27 November 2020
- ⁹³ Suicides in England and Wales: 2019 Registrations, Office for National Statistics, September 2020
- ⁹⁴ Suicide: Key points, Public Health information for Scotland, August 2021
- ⁹⁵ Suicide Statistics 2019, Northern Ireland Statistics and Research Agency, April 2021
- ⁹⁶ Suicide Data, World Health Organisation, accessed September 2021
- ⁹⁷ Populus, 2019
- ⁹⁸ 'Three in four Britons back assisted dying for terminally ill - poll', The Guardian, 4 August 2021
- ⁹⁹ 'Scots want law changed on assisted dying', The Sunday Times, 13 June 2021
- ¹⁰⁰ 'Victoria's Voluntary Assisted Dying law has changed my life - will it change my death?', Insight, 3 March 2020
- ¹⁰¹ Heather and Shaun, Compassion & Choices, accessed September 2021



CAMPAIGN FOR DIGNITY IN DYING.

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:
dignityindying.org.uk

CONTACT US

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

 020 7479 7730

 info@dignityindying.org.uk

 facebook.com/dignityindying

 [@dignityindying](https://twitter.com/dignityindying)

Dignity in Dying is a not-for-profit membership organisation and a company limited by guarantee no. 4452809

October 2021