

THE TRUE COST

How the UK outsources death to Dignitas

**CAMPAIGN FOR
DIGNITY
IN DYING.**

Acknowledgements

Thank you to everyone who shared their story:

Alan, Anne, Carmen, Carol, Caroline, David F, David W, Denise, Dianne, Emil, Ila, James, Julie, K, Lesley, Lloyd, Mick, Sandy and Simon

Research interviews by Professor Bronwyn Parry and Sally Eales

Written by Lloyd Riley and Davina Hehir

Design by Ashley Goldstein (hello@weaseldancedesign.com)

Photography by Alexander Whittle, Luke Doyle, Neil O'Connor and Zach Moss

Legal advice from Julian B. Knowles QC

A digital version of this report can be found at <https://features.dignityindying.org.uk/true-cost-dignitas/>

Contents

Foreword	5
Executive summary	6
Methodology	8
1. Introduction	10
2. Wanting greater choice	12
3. Planning an assisted death	14
4. Involving family and friends	17
5. The threat of prosecution	20
6. Inconsistencies within the medical profession	23
7. The cost of dying overseas	31
8. A logistical challenge	35
9. A cruel trade-off	38
10. Desperate measures	40
11. Painful deaths	45
12. Withdrawing treatment	49
13. The journey to Switzerland	52
14. A peaceful death	56
15. The journey home	60
16. Becoming criminals	63
17. How things could be different	66
Notes	70
Support	71



Foreword

I can't remember the first time I heard the name Dignitas but, like millions of people, what it represents is now well known to me. The vast majority of the British public understand the courage of those seeking a dignified death, and the compassion needed by their loved ones.

The difficulty and expense faced by those desperate people who choose to travel to Switzerland is, however, less well understood. So too is the horror for those who can't get there.

It wasn't long after I was elected as an MP that one of my constituents was assisted to die at Eternal Spirit, another Swiss right-to-die organisation. I only learned of this afterwards when her partner came to see me, passionate in his desire to help others through the practical difficulties of the process. I can only guess how many more constituents may have made that terrible journey, or how many have investigated it but were unable to travel.

Tragically it's also impossible to know how many other dying people in my constituency have taken their own lives at home, traumatically, without the support of their doctors. It is certain that many more have suffered the misery of an agonising and protracted death, as happened to a member of my own family, despite the very best end-of-life care that our country already offers. Nor can we fully understand the distress and sorrow of the many partners who, in the face of their loved ones' torment at the end of life, feel they have no humane option but to accede to the request to help end their suffering.

With no other safe option, many people in this country experience unimaginable suffering at the end of their lives. The findings of this

report are shocking, but they offer only a glimpse of what is a deep well of anguish.

Our outdated laws discriminate between rich and poor, discourage proper conversations between patients and their doctors, criminalise grieving relatives who spend time with their loved ones in their dying moments and oblige people to end their lives before they are ready. Worst of all, while they are predicated on preserving the sanctity of life, they show no mercy to those facing an agonising death, and deny free will to those whose lives and deaths depend upon it.

One day we will look back in disbelief at how long it took Parliament to realise this.

I hope my colleagues will read this report and understand what we, as a society, are turning a blind eye to. Acting in the best interests of our constituents, we must ask whether these terrible experiences can truly be justified by a false dichotomy between dominion over our lives and protection of the vulnerable, a premise long-disproved. With the USA, Canada, Australia and several European countries all having grasped the nettle of assisted dying, our lack of leadership in the face of profound suffering will be a black mark against our humanity in years to come.

The evidence that we need change is overwhelming. It's time that the UK stopped outsourcing its compassion to Switzerland and began listening to dying people who want and need the most basic choice they will ever face.

Kit Malthouse MP

Chair, Choice at the End of Life All-Party Parliamentary Group

Executive summary

In England, Wales and Northern Ireland it is a crime to encourage or assist suicide. This crime carries a maximum penalty of 14 years' imprisonment. If someone provides encouragement or assistance, that is a crime, even if the person ends their life overseas. There is no specific crime of assisting a suicide in Scotland, but it is possible that helping a competent adult to die could lead to a prosecution for culpable homicide.

With end-of-life choice limited under the current law in the UK, many people seek to arrange an assisted death in Switzerland, with organisations such as Dignitas.

This research has uncovered the real experiences of people who have been affected by this issue and explores the reality of the prohibition of assisted dying in the UK.

Dying people are victims of inequity

The current law does not offer dying people meaningful choice at the end of life.

- The average cost of obtaining an assisted death overseas is £10,000. This means that the majority of people in the UK cannot afford to have one.
- The process of arranging an assisted death overseas can be extremely difficult and time consuming.
- The requirement to be physically able to travel to Switzerland to have an assisted death means that people are ending their lives much sooner than they might otherwise choose to.

- Dying people need the help of friends and family to make the arrangements for an assisted death, yet any assistance provided is against the law.
- Dying people who want to exercise choice at the end of life are subjected to a lottery when it comes to the level of cooperation they can expect from healthcare professionals.

For dying people who seek to arrange an assisted death overseas these factors raise anxiety and reduce quality of life. For some, these factors have forced them to endure suffering against their wishes.

Dying people who want an assisted death receive inconsistent care

Without a clear and transparent law on assisted dying, doctors and other healthcare professionals often feel unable to have open and honest end-of-life conversations with dying people.

Guidance from authoritative bodies such as the General Medical Council and British Medical Association is not providing doctors with enough clarity to be able to respond effectively to requests for assistance in obtaining an assisted death overseas.

There is evidence that when a dying person is considering an assisted death overseas, GPs, consultants and palliative care professionals are providing inconsistent support. This ranges from a refusal to discuss the issue to implicit cooperation in the planning process. There is also evidence of healthcare professionals refusing to administer pain medication for fear of breaking the law.

Dying people are reluctant to discuss the possibility of having an assisted death overseas with their care team, either because they do not want to implicate them in a crime or because they fear that a healthcare professional might thwart their plans. Many dying people are therefore being denied the opportunity to discuss their end-of-life preferences, care and treatment options.

The current law is incapable of protecting vulnerable people

Under the current law, if someone were a victim of malicious or coercive behaviour during an assisted death overseas, it would be unlikely to be detected by UK authorities.

Unless someone reports a person considering travelling overseas for an assisted death, or reports a person who is providing assistance to them, there are no legal mechanisms to trigger an upfront investigation. In addition, only a

minority of cases are investigated after the fact. People from the UK who are able to access assisted dying overseas are doing so without any regulation or monitoring in their home country.

The criminalisation of assisted dying in the UK means the process of seeking an assisted death overseas happens behind closed doors. As a consequence, consideration of assisted dying can lead people to investigate more dangerous and traumatic methods to end their lives at home. Many of the interviewees in this report have seen the aftermath of failed suicide attempts.

By discouraging systems that promote open dialogue with dying people about their concerns, the current law drives people who want end-of-life choice to act in secret, where they cannot be protected.

Those who claim the current law is safe have no reliable evidence on which to base their claims.



Methodology

Dignity in Dying commissioned two independent researchers to conduct 19 in-depth qualitative interviews.

Bronwyn Parry, Professor of Global Health and Social Medicine at King's College London and her Research Associate Sally Eales interviewed people from three affected groups:

- People with a terminal illness who are considering an assisted death in Switzerland.
- People who have helped a loved one to have an assisted death in Switzerland.
- People whose loved one considered an assisted death in Switzerland but died in the UK.

Interviewees were drawn from a pool of people who had contacted Dignity in Dying to share their experiences. Dignity in Dying approached people about the research. Then, if the person wanted to find out more, the researchers made contact. The researchers provided Dignity in Dying with full transcripts of the interviews together with a thematic analysis.

The majority of interviewees had experience with the Swiss not-for-profit member society DIGNITAS – To live with dignity – To die with dignity (referred to in this report as Dignitas). A small number of interviewees had experience with the organisation Eternal SPIRIT, also known by the name of its sister organisation Lifecircle (referred to in this report as Eternal Spirit).

All the quotes in the report are taken from the interviews but may be abridged for concision and clarity. All interviewees gave their full consent for the contents of their interviews to be used in the report.

Dignity in Dying carried out secondary research on the financial costs involved in obtaining an assisted death in Switzerland. We also commissioned polling on public attitudes to travelling overseas for an assisted death and analysed the enquiries we receive from people seeking information on how to control their deaths.



1. Introduction

THE CURRENT LAW ON ASSISTED DYING

In England and Wales under the Suicide Act 1961 and in Northern Ireland under the Criminal Justice Act (Northern Ireland) 1966 it is a crime to encourage or assist suicide. This crime carries a maximum penalty of 14 years' imprisonment. If someone provides encouragement or assistance, that is a crime, even if the person ends their life overseas in a country where assisted dying is legal.

Following Debbie Purdy's legal victory in 2009, the then Director of Public Prosecutions (DPP), Keir Starmer, had to clarify what factors are taken into account by the Crown Prosecution Service (CPS) when considering whether a prosecution for encouraging or assisting a suicide is in the public interest.

The guidelines published by Keir Starmer, and updated by the current DPP Alison Saunders in 2014, list 22 factors that will influence the decision.¹ These factors make clear that prosecution is less likely when the person 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.

The DPP's prosecution guidelines apply in England and Wales, and have been replicated by the Public Prosecution Service for Northern Ireland.²

There is no specific crime of assisting a suicide in Scotland, but it is possible that helping a competent adult to die could lead to a prosecution for culpable homicide.

Article 115 of the Swiss Criminal Code says that any person who incites or assists in suicide for selfish motives is liable to a custodial sentence or to a monetary penalty.³ Assistance provided with non-selfish motives is permitted.

Several organisations in Switzerland provide assistance to people to end their own lives, subject to eligibility criteria and regulation. The two

largest of these organisations, EXIT Deutsche Schweiz and EXIT A.D.M.D Suisse romande, are only accessible to Swiss residents. Dignitas, Eternal Spirit and EX International provide assistance to people from outside Switzerland.

With end-of-life choice limited under the current law in the UK, many people seek to arrange an assisted death in Switzerland.

Public opinion

Polling commissioned for this report shows that the law in the UK is significantly out of touch with public opinion, echoing the experiences of our interviewees.⁴

Public attitudes towards having an assisted death in Switzerland

- 53% of people would consider having an assisted death in Switzerland if they were terminally ill (see Section 2).
- 66% of people would break the law and help a loved one to have an assisted death in Switzerland (see Section 4).
- 82% of people think that if someone is considering an assisted death in Switzerland they should be able to discuss this option with their doctor. But only 32% of people would be likely to do this themselves (see Section 6).
- Only 25% of people would be able to afford to have an assisted death in Switzerland (see Section 7).
- 77% of people would like assisted dying to be legal in the UK. This level of support has been consistent for over 30 years (see Section 17).⁵

In recent years there has been a consistent rise in the number of people from the UK becoming members of Dignitas.⁶ Between 2012 and 2016, membership in the UK rose 39% from 821 to 1139. This increase is matched by an increase in the number of people from the UK being assisted to die at Dignitas. In 2016, 47 people from the UK died at Dignitas, the equivalent of one person every eight days.⁷

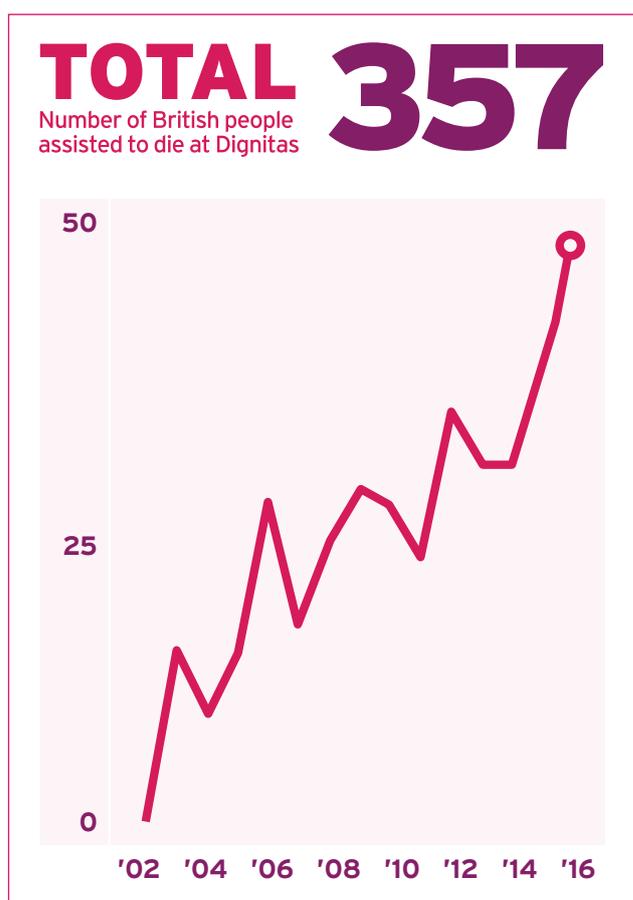


Fig.1 Number of people from the UK dying at Dignitas between 2002 and 2016

But these figures do not tell the whole story. Why do dying people seek an assisted death overseas? What does it take to arrange one? How do doctors in the UK support dying people under the current law? What is an assisted death like? What happens to dying people who cannot arrange their assisted death? How could things be different?

Using the voices of those most affected, this report answers those questions and uncovers the real stories behind the statistics.

2. Wanting greater choice

While some interviewees had a general awareness of organisations in Switzerland that can facilitate an assisted death, it was not until the point of diagnosis that they or their loved one gave serious consideration to this option.

For some this was an immediate response to being told they were terminally ill, for others it was a reaction to a gradual deterioration in condition as their disease progressed.

“We had a meeting in hospital. It was one of those meetings where there were two doctors, consultants, a Macmillan nurse. It was one of the rooms where they have flowers... ‘There’s nothing we can do. It’s wrapped around an artery, and I just couldn’t get it out. It’s going to become quite painful, but we can give you palliative support.’

I came out of this meeting and went online to Dignitas, and got their form, and sent in an application to join them. That was almost immediately. ”

“I was driving back with him from the hospital consultant department with another friend, and then in the car he said ‘I will not see this through. It’s just not what I want. I’ll see how it goes obviously, but at some point, I will carry myself off to Switzerland.’ ”

“He was diagnosed in May 2014 with advanced prostate cancer. It had already spread to his bones, so we knew pretty much at the outset really that there was not a lot that could be done other than to extend his life. Straight away Paul went into overdrive sorting things out, and one of the things that he wanted was to make the choice when he wanted to end his life. So he registered with Dignitas and became a member. ”

“She was diagnosed with supranuclear palsy and she deteriorated from there. She came to my 60th birthday party in the May and over the summer she decided that she wanted to go to Dignitas. We went in the January. By then she was very, very poorly. Walking was difficult, swallowing was difficult, she couldn’t really see. ”

“His progression was fairly rapid. He’d started using a wheelchair, and then summer the following year, he had the peg tube [for feeding], because swallowing had become too dangerous. By that point, he’d virtually lost the ability to speak clearly as well, which was a great sadness, because he had a lovely speaking voice, he liked telling jokes, and more importantly, he liked to sing. He was sitting at his computer, and he showed us a story about Reg Crew, who went to Dignitas. He typed,



‘That’s how I’d like to go when my time comes.’ 》

Despite being clear about wanting the option of an assisted death, dying people made a distinction between a desire for their lives to end and controlling the manner and timing of their inevitable death.

“I was diagnosed with terminal cancer, inoperable. I may go peacefully, but there’s always that chance that I may not. If it gets that bad I want to be able to opt out and not put myself or my family through a horrid, horrid death. 》”

“My opinion is suicide is the choice between living and dying. I don’t have a choice, I’m dying within weeks anyway. 》”

It was important to dying people to acknowledge that wanting the choice of assisted dying stemmed from an acceptance of death, not a fear of it.

“I’m fine, I’m not scared, this is the life that’s been dealt me. We don’t talk about dying enough, we don’t normalise it. I’ve got a grand-daughter, I bought her a book, ‘Cry, Heart, But Never Break,’ and it normalises death. 》”

“I’m not depressed. I don’t want to end my life because I’m depressed with my life. I just don’t want to suffer.”

3. Planning an assisted death



All interviewees were able to get the information they needed to plan an assisted death through the internet. Some used websites and forums that enabled them to talk to others in similar circumstances and learn from people who had been through the process.

There are an average of 14,800 internet searches of “Dignitas” every month from the UK.⁸

Even at this early stage in the process it was clear that planning an assisted death moves people beyond any support legally available in the UK. The planning process becomes isolating, for dying people and for anybody who assists them.

“I just went to the website. And there are videos out there that show you the process from start to end.”

“He looked on the internet for information about it. And then contacted them and they said that he needed to become a member. Which he did, and there was a fee, I think. Then they sent an information pack.”

“I Googled everything, I went on forums.”

“You do all this without any support from any of the care systems. If you were dying here now, there would be a whole care system which is in place through the state and through volunteer organisations as well, that you can refer to. When you do this, you do it completely on your own.”

“He was trawling stuff on the internet, desperate not to get me involved, knowing the implications.”

Many interviewees accessed websites aside from the official websites of Swiss organisations providing assisted dying. One consequence of relying on these “unofficial” websites for researching assisted dying overseas is the unclear, unreliable and often contradictory nature of the information available. One interviewee, acting on information found online, was anxious about the number of journeys he would need to make back and forth to Switzerland prior to his assisted death at Dignitas. This was not based on information from Dignitas and was inconsistent with the testimonies of interviewees who had been through the process, suggesting that this may not necessarily be a requirement.

Another consequence of the law forcing people to seek information about assisted dying online is that this becomes a gateway to information about other methods of taking your own life.

“Because access to the internet and information is so easy now we’d heard of Dignitas over and over. So we knew to just phone but you have to look into it, like anything. There was also another crew, who did an e-book on how to commit suicide.”

Section 10 includes accounts of people who attempted to end their own life in the UK. It is evident that being unable to obtain advice and support through healthcare professionals, charities and campaigning organisations does not deter or prevent people from obtaining the information they need. Current systems are providing inadequate support to dying people during this process.

ENQUIRIES MADE TO DIGNITY IN DYING

Dignity in Dying is a campaigning organisation. We are working to change the law in the UK and are clear that we do not provide information or advice to access assisted dying overseas. Doing so could be interpreted as providing encouragement or assistance to someone to end their life and therefore against the law. Between January 2016 and August 2017, Dignity in Dying received 256 calls, emails and letters from people seeking information on how to end their lives. Many of these contacts raised issues relating to obtaining an assisted death in Switzerland.

The legal implications of helping someone have an assisted death overseas	32%
The practicalities of making an application to Dignitas	30%
How to obtain the drugs used for assisted dying in Switzerland in the UK	17%
The financial cost of having an assisted death overseas	12%
The difficulty of travelling to Switzerland to have an assisted death	8%
Encountering doctors in the UK who disagree with having an assisted death overseas	1%

Fig.2 breakdown of contacts received by Dignity in Dying regarding assisted dying overseas.

Planning an assisted death



Fig.3 A Facebook message received by Dignity in Dying

Dignity in Dying does not provide contact details or signpost to organisations that provide assisted dying, even though this information is already in the public domain. Dignity in Dying does, however:

- discuss and explain the current law in relation to accompanying someone to have an assisted death in Switzerland, if this issue is raised directly;

- listen to individuals who express an intent to hasten their death and explore the reasons why, so that we can signpost to other organisations where appropriate;
- encourage people to speak with a healthcare professional, and organisations that support people to plan ahead for future care, if they want to discuss their care and treatment preferences;
- encourage people to contact disease specific charities to obtain information on disease progression and support services;
- provide details of the Samaritans and other means of listening or counselling support that may be appropriate.

All Dignity in Dying staff members receive specialist training to be able to answer these calls and are given the option of counselling support.



4. Involving family and friends



Due to the logistical, financial and emotional challenges of arranging an assisted death overseas, interviewees said that the involvement of family or friends is inevitable. However, becoming involved is often an incremental process.

Conversations about the possibility of dying overseas often leads to providing help to find information. This, in turn, can lead to actively assisting someone to make the journey to Switzerland.

“I was 24 when he was diagnosed. I was 26 when he died. He approached myself and my sister, and said, ‘Could you look into this?’ So, we did.”

Involving family and friends

“She wasn’t mobile enough at that point in time to get to the post office, or even to get foreign currency, so then you’re automatically seeking your family’s assistance. ”

“Even though I was initially reticent, I think when you watch someone in that situation, who’s been given a very clear terminal diagnosis, who’s in pain throughout, who’s no longer mobile and knows worse is to come, I mean... I think there’s no way you can fail to be persuaded. I was by then firmly on her side, convinced that this was a choice she really had to be entitled to make. I was reluctant to do anything that might force her to have a painful and ugly death, which she was fighting to avoid. ”

“I’ve discussed with all my daughters, we had a little meeting and I said, ‘Look, this is not happening tomorrow or the next day, but it’s there. And this is how I would like to end my days, if I could.’ At the end I might have a problem getting there. But my daughters all want to come with me. ”

“She got the information pack through. There was a big form that came with it. You had to give a lot of information. She couldn’t cope with doing it, she was exhausted and really struggling with breathing, but also mentally she’d just found out she was going to die a really horrible, slow death. I offered. I said to her, ‘Can I help you do it?’ She said, ‘Please, please do, I don’t think I can sort this out on my own.’ ”

“She asked me and a few others to go with her and so that’s what we did. We were all 1960s lefties, we’d always talked about dying. ”

Some family members were initially resistant to the idea of their loved one having an assisted death overseas. Common concerns were in relation to a potential loss of valuable time that might come through ending life prematurely and the emotional impact of returning from Switzerland alone.

Some interviewees said that when their loved one raised the issue of assisted dying, it was the first time they had had to face the fact that they would soon die. So their initial reaction to assisted dying was, in fact, a denial of the reality of the circumstances.

“I think there was a sort of instinctive hesitation on my part to the idea that you could see a loved one end their life in that way. I also was convinced that the chemo and the radio-therapies could buy time.

The oncologist came to visit us, and I think I was expressing my hope that we could still buy some years with the chemo, and she said, ‘Even if the chemo works, you’re talking maybe adding a couple of months.’”

“It wasn’t him having an assisted death that was the problem. It was the thought of having to travel all that way, and then coming back without him. It was a horrible, horrible, horrible, horrible thought. Just not being at home and surrounded by loved ones to support you.”

“My brother still lives in Poland and there are a lot of people there that are extremely Catholic. But he said, ‘Do whatever you want.’ My sister said, ‘Well she’s not gonna die.’ She was in total denial.”

Making the decision to have an assisted death overseas means involving family and friends in what can become a difficult experience. But it also means excluding people from the dying process.

Some interviewees spoke of the distress caused by excluding older relatives, because they would not be able to make the journey to Switzerland.

“His Mum was really not well, so we couldn’t tell her what we were planning. We didn’t want her to have to go through the anguish between us going and it actually happening. Also, not having been before and not knowing exactly what might happen... To have to lie to her, and for him not to be able to say goodbye to her. He did go in and say goodbye to her, but not be able to say goodbye to her properly... It was awful. It was horrible, horrible.”

The stigma of having an assisted death, a consequence of its ambiguous legal status, weighed heavily in the minds of dying people seeking to arrange one in Switzerland. This contrasted with the views of family members and friends, who made repeated references to “bravery” and “courage”.

“Once, I was doing the gardening, which was his passion, so he always oversaw it. We were having a conversation, just general chit chat, then he came up with, ‘Do you think I’m a coward?’ It was horrible – ‘Do you think I’m a coward?’ I think it’s the bravest thing he could have done.”

5. The threat of prosecution



The majority of interviewees were clear that they were willing to break the law. The prohibition of assisted dying in the UK did not and would not have prevented them from helping their loved one to have the death they wanted.

“I knew it was illegal. But there was part of me that was sort of, excuse my language, but fuck you. I had a choice, but she was my mum – I didn’t have a choice.”

“I was the deputy chief executive of a national charity. I wrote to my boss and said, ‘You just need to know that I am going to Dignitas with somebody, and it may have legal implications.’

He wrote back and said, ‘I need to think about whether you can go.’ I wrote back and said, ‘No, I’m not asking you whether I can go. I’m telling you. I am going to support my friend.’”

“Obviously, there’s still a possibility that something could’ve happened to us, we had no assurance that we wouldn’t get prosecuted. But we never even discussed it. We all loved him so much that, if it had been a possibility, I think we would still have done whatever he wanted us to do.”

“Somebody would have had to help her with the paperwork, with the appointments... But I didn’t really care at that point. When it’s the most important person in your life, you don’t really care. I would have done it.”

“She said, ‘Well, I don’t want you being prosecuted. I worry about what will happen afterwards,’ and I was like, ‘Look, I don’t care; if I get prosecuted, that’s fine. I’ll deal with it. I would do anything to help you achieve the death that you want.’”

Relatives of people who considered having an assisted death overseas but ultimately died in the UK said the risk of prosecution was a concern, but they would have still helped their loved one in contravention of the law.

“It crossed my mind. I won’t lie. It did cross my mind, but that isn’t your priority when you see somebody suffering. I’d have risked it, without a doubt.”

“Nope, I wasn’t worried. For the simple reason that I’d do anything for my mum.”

One outcome of the threat of prosecution is the resulting anxiety for dying people, because of how their decisions may negatively impact on their family and friends after their deaths.

“My daughters might get prosecuted. I’m very concerned. How am I to know that they won’t come off the plane at this end and, you know...? They said they don’t care, that they want to do it, they want to be with me... They’re three very strong women.”

“What I said to them is we’ve got to be careful. They said, ‘We wouldn’t let you go on your own.’ I said to them, ‘Look, legally, if you came you could be in trouble.’ ‘Oh blow that’ was their reaction.”

The threat of prosecution resulted in one interviewee being reluctant to seek help in arranging his assisted death overseas.

“I’m not sure how to arrange this in the end, nobody is allowed to help, nobody is allowed to give me advice. I know in the past they haven’t prosecuted people because it’s not in the public interest. But you don’t want to put anybody on the spot in the first place.”

The threat of prosecution

Others said that knowing they were doing something illegal added to the stress of the journey to Switzerland. They were concerned that the authorities could have prevented their loved one from having an assisted death.

“My concern was not about the risk of some kind of personal involvement or incrimination. My concern was really more that someone might try to stop us. My preoccupation at that time was just to make sure she had the choice.”

“The main concern I’d say was that they would go after you, because they might want a test case. It was mainly a Northern Irish thing. I don’t think the system would prosecute you in England, but we wouldn’t have been flying from England, we would have been flying from Northern Ireland.”

“If we’d got back to Luton and there had been a policeman waiting for us then that was fine. But I half expected somebody to meet us on the tarmac in Switzerland and say, ‘No, no, no, no, no, go home. You can’t come in.’ In fact, until the doctor said, ‘I’ll write you the prescription,’ I was on tenterhooks.”



6. Inconsistencies within the medical profession



Organisations in Switzerland that provide assisted dying caution those arranging their assisted death from the UK about revealing their intentions to their doctors, because it could delay obtaining the necessary medical documentation.⁹

Yet despite this advice, the majority of interviewees in our research did describe experiences of raising the issue of seeking an

assisted death with doctors and other healthcare professionals. In most cases it was clear that healthcare professionals were aware of the legal complexity of their role in what their patient was planning to do. However, professional practice in response to this knowledge was inconsistent, ranging from refusing to supply medical reports, to offering advice, to actively participating in making arrangements.

Inconsistencies within the medical profession

Carmen's story illustrates the varying attitudes in response to her mother seeking an assisted death in Switzerland, and the impact this had on her and her family.

“My mum sent me an email saying, ‘Carmen, whatever you do don’t talk to anyone. Don’t tell anyone what we’re doing.’ I said to her, ‘Why, what’s going on?’ She said, ‘I was talking to the lady,’ which was one of the palliative care workers, ‘And they’d told me you mustn’t talk about it.’

It made mum quite worried. It made her feel almost a criminal. I phoned the woman, telling her that I was really angry that she’d given this kind of advice. Apparently they had locked the files so that people couldn’t see what was going on. Mum did tell her GP further down the line because she needed him to sign a letter for the Dignitas forms. He said that he would write the letter, but it wasn’t a conversation that he could have and he couldn’t give advice on it.

My mum had a really amazing relationship with her GP. He came to visit her the week before she was going because he wanted to tell her what an amazing woman she was. You could tell that he would like to have been able to help, but he felt that he wasn’t able to because of the law. There was a lot of shame around it. The fact that doctors didn’t want to talk about it and couldn’t advise on it made me feel like I could get into trouble. ”

Dying people were aware of the lack of clarity in the current law for healthcare professional. Some interviewees limited discussion of their end-of-life preferences with healthcare professionals as a result of this knowledge. In some cases, healthcare professionals discouraged these conversations out of fear.

“As soon as I started saying, ‘Can I have a report of my condition?’ the doctors knew exactly what I was talking about. They’ve never refused, but it’s not forthcoming. ”

“The doctors and palliative care workers want to know how I’m handling things, but they wouldn’t allow me to talk about Dignitas ”

“We were in contact with the GP. We also did have a palliative care worker who came from the local hospice, and we had the oncologist. There were odd occasions when Elaine mentioned to them that she was thinking of

Dignitas. But we never were able to ask for their advice or help. I think it was self-evident at that time that it was very delicate. They were simply polite, but didn't take it any further. 》

“We had to try and get hold of his medical notes but the consultant and the nurse, they were both so scared. It was so obvious they were so scared. 》

In 2015, an independent ‘Review of Choice in End of Life Care’ stressed the importance of an honest and informed dialogue between dying people and their care team.¹⁰ A commitment to support people approaching the end of life to have such a dialogue was the first of six commitments outlined in the Government’s response to this review.¹¹

The fact that healthcare professionals, specifically GPs, consultants and palliative care specialists, are explicitly advising some dying people not to discuss their wishes and preferences for their end of life is a major barrier to the delivery of the Government’s commitments to improving end-of-life care. This evidence is deeply problematic for claims that the current law is working for dying people or those who care for them.

In 2015, a hospice CEO writing anonymously said the assisted dying debate within the hospice sector is “distorted and one-sided” in favour of the current law.¹² The experience below justifies this claim. While professionals may be keen to share their personal views on assisted dying, this does not detract from the reality that some dying people are being denied the one thing that would bring them most comfort.

“My hospice nurse is against assisted dying full stop. She says they can make it peaceful, they can give you anything you want. Whether I want horses running around or I don't know, bagpipes playing. I said I've done all the things I want to do, all I want is a guarantee that I will die peacefully. Without assisted dying, you cannot one hundred percent give me that. 》

“My GP has known me for years, and she isn't against it, she isn't for it. But she said to me, ‘You know you can't talk about this sort of thing, you have to be very careful.’”

Inconsistencies within the medical profession

Julie's husband Paul was diagnosed with prostate and bone cancer in 2014. Paul was denied access to the documents he needed to arrange an assisted death in Switzerland by his GP.

“He did speak to his GP, who he's been with for a very, very, very long time. In the appointment he didn't ask his advice. Paul was very decisive and he'd made up his mind about this, so he went to his doctor and asked for a letter outlining his condition and the prognosis, at which point the doctor said, ‘Look, what's it for?’

Paul said, ‘I'd rather not say,’ and the doctor said, ‘Whatever it is, you can tell me.’ So Paul did and at that point the doctor said, ‘No, I can't give it to you. I need to seek legal advice.’ He spoke to the surgery's lawyers, who said, ‘Under no circumstances give this man a letter.’

He said it went against his oath that he'd taken and he didn't think that he could do it. At first Paul was really angry with him because he felt he'd been coerced into telling him why he wanted the letter and that had literally put a stop to him being able to do what he wanted to do. He knew that nobody was going to give it to him via the GP's surgery so he tried through the hospital consultants.

Then he paid to have his records, but it took ages and ages and ages for him to get them from the hospital, and when they did come, they didn't really outline what he wanted them to outline. So I think at that point he just gave up.

He was getting quite poorly then, so he didn't have the strength to do it. I think he felt from that first hurdle that he fell at, with his GP, that that was pretty much game over, to be honest, because he couldn't get what he wanted.

He was distraught, absolutely distraught because he felt that the decision had been taken out of his hands and he couldn't have the ending that he wanted. To see him so distraught at not being able to do it, that was awful.

Paul made peace with the doctor. I don't know if I would be able to do that. He forgave him. He went back and he said, ‘Look, I don't hold you personally responsible. I understand why you had to do what you did.’ That's the kind of guy he was. He just wanted that choice and he wanted to not be in pain. He was absolutely petrified of being in lots of pain and that was his motivation really for it. He wanted to choose. 》

You can find out what happened to Paul at the end of his life in Section 11.

The tragedy of Paul's story is magnified when it is compared to the experiences of other interviewees. For some, healthcare professionals played a key role in facilitating an assisted death overseas. Others, despite encountering fear and reluctance, managed to find a way to get what they needed by relying on the covert cooperation of people working in GP practices.

“Her doctor’s surgery couldn’t have been better. They actually allowed me to fax her medical notes to Dignitas from their office. They were fantastic, absolutely brilliant. They made no charge and they let me sit in the office and fax everything from there. I was surprised they allowed me to do it. ”

“There’s waves and waves of professionals being obstructive. The hospital wouldn’t give anything without going through ethics committees. It was absolutely ridiculous. All right, maybe they have to go through that, I don’t know, but that would be months... In the end, Bob’s GP had to surrender some partial notes. ”

We are often told that a “postcode lottery” exists in palliative care.¹³ Our research found that dying people experience a lottery of very different responses when they tell a doctor they are contemplating an assisted death overseas. Inconsistent practice means that choice at the end of life is a possibility for some dying people but not for others.



“In the end, we managed to get medical notes from the doctor, but that was through the back door, because we happened to know somebody in the doctor’s surgery. ”

Inconsistencies within the medical profession

GUIDANCE FOR DOCTORS

Examining available guidance on this issue explains why there is such uncertainty and fear in the medical profession. The General Medical Council (GMC) encourages doctors to listen to and discuss patient requests for assisted dying.¹⁴ It also says that providing access to a patient's medical records in accordance the Data Protection Act 1998 will not normally give rise to a question of impaired fitness to practice.¹⁵

However, many interviewees said that they or their loved one required more than medical records and often needed a medical report from their doctor outlining their diagnosis and prognosis. On this issue, the GMC says “writing reports knowing, or having reasonable suspicion, that the reports will be used to enable the person to obtain encouragement or assistance in committing suicide” may raise a question of impaired fitness to practice.¹⁶

The Royal College of General Practitioners (RCGP) and the Royal College of Physicians (RCP) have no guidance for their members on what to do if a patient asks for a report to enable them to have an assisted death overseas. Nor on what to do if such a patient asks for their medical records.

However, the British Medical Association (BMA) is explicit in its advice to members, who are told “not to offer, or to agree to provide medical reports if they are aware that they will be used to obtain assisted suicide, as this could be seen as facilitating that process”.¹⁷

Our research shows that the guidance available to doctors is not adhered to in some cases. Where it is adhered to rigidly, the doctor-patient relationship can suffer.

The RCGP, RCP and the BMA are opposed to a change in the law on assisted dying.

Interviewees were aware of the difficult position that doctors are in under the current law, yet many felt that representative bodies such as the BMA were at least partially responsible for this.

“Since it happened we’ve talked to doctors, and lots of them hide behind

their profession – ‘This is really difficult for us because of what might happen to us,’ and I do understand that, but I just think the BMA need to come out and say, ‘You know, there are times when this is a really good idea.’”

“With my doctor, I wasn’t sure what his reaction would be. He certainly wasn’t disapproving, he wasn’t approving. He was neutral. I wish there was somebody that was medical that you could talk to and explain, and just... I just wish there were people you could talk to... It would be nice if there was a change in attitude by the medical profession and the BMA. ”

“The more doctors I talk to, the more I realise many of them actually would like to see something put in place, but they don’t feel they can talk about it. They don’t speak out for assisted dying because they just feel they’ll be beaten down if they do. ”

“I don’t think any medical professional would have said, ‘What you want to do is wrong.’ His GP addressed a BMA meeting two months after John died, and said that through knowing John he had changed his mind about assisted dying. He said he felt now that the law should be changed. ”

There was a stark contrast between how interviewees experienced communication with doctors in the UK compared to doctors in Switzerland performing assessments for Dignitas and Eternal Spirit.

“You have to see the doctor twice. The guy who we saw was so lovely. He chatted to him as if he was a person as opposed to an illness. He asked him, ‘Is this really what you want? You realise what’s going to happen?’ He talked us through what would happen, he said, ‘At any point you can change your mind, it’s no problem.’

The loveliest thing he said to him was, ‘My belief is always that I need, being a doctor, to treat people and make them well and repair and wherever possible sustain life. But sometimes, the kindest thing I can do is to give people the dignity that they’ve had in life.’ I thought, hallelujah, somebody who understands. ”





7. The cost of dying overseas

The cost of an assisted death in Switzerland is, for many, prohibitively expensive. Based on our calculations it costs anywhere between £6,500 to over £15,000 to have an assisted death in Zurich, where Dignitas is based. The average cost for those interviewed was approximately £10,000.

Some costs highlight inequity in themselves. For example, it is generally cheaper to fly to Basel (where Eternal Spirit is based) and Zurich from south east England than from the rest of England and Scotland. There are no direct flights from Wales or Northern Ireland. Also, wheelchair accessible taxis are difficult to arrange in advance in Switzerland and can be expensive.

Other costs might be surprising. For example, many interviewees booked a return ticket for the

dying person, to ensure they knew they had the option to change their minds if they wanted to and to reduce the chance of suspicion by authorities.

It is worth noting that Zurich is the most expensive city in Europe to live and the 3rd most expensive in the world.¹⁸ The costs incurred in Zurich can escalate quickly. One interviewee said that the “final meal” was over £900 for four people.

Dignitas and Eternal Spirit are both not-for-profit organisations. The fees charged cover the costs of providing an assisted death and the running of their organisations. But the fees charged can vary depending the service required. For example, opting to have a funeral in Switzerland incurs a higher fee.¹⁹

	Lower estimate	Upper estimate
Transport		
Flights	£300	£1,100
Taxis	£350	£450
Stay in Zurich		
Accommodation	£250	£3,500
Food and drink	£100	£1,800
Dignitas fees	£5,663	£8,495
Total	£6,663	£15,345

Fig.4 A breakdown of costs to have an assisted death at Dignitas²⁰

The cost of dying overseas



The cost of obtaining an assisted death in Switzerland denies the option to the majority of people in the UK. A 2017 report by The Money Charity showed that 68% of people in the UK have less than £10,000 in savings.²¹ According to NMG Consulting and the Bank of England approximately 80% of private renters and 87% of social renters have less than £10,000 in savings.²²

One interviewee, Emil, said his mother chose not to have an assisted death in Switzerland because

of the cost. However, as her disease progressed she changed her mind and regretted her decision.

“She was one of those old school parents who needs to make sure that her kids are sorted so every single penny she had she would give to us. So when she asked, ‘How much does it cost?’ and I said, ‘Oh it’s about 10 grand, with the travelling and everything.’ She said, ‘Oh no no no they’re gonna keep me fine with morphine, as long as they keep me on morphine it’s fine.’ And I know why she said it, it was because of the 10 grand.

When things were going downhill she couldn’t cope with the deterioration. That’s when she said, ‘Yes I would like it now.’ But it was just too late then. ”

You can find out exactly what happened to Emil’s mother in Section 11.

Dignitas’ articles of association make provision for reduction or even complete exemption from having to pay fees for members in “modest economic circumstances”.²³ However, this would not apply to the cost of travel and accommodation and would add to the already significant task of procuring and presenting paperwork, as one interviewee highlighted.

“I started applying for a concession. Some of it we did get. We had to start means testing, bank statements to show we weren’t just trying it on. ”

TRYING TO FUNDRAISE FOR AN ASSISTED DEATH

In 2015, the efforts of two sisters to raise money for their mother, who had motor neurone disease, to be able to go to Switzerland for an assisted death was reported in the press. The organisation Care Not Killing notified police of the women's attempts to raise funds through a ticketed party they had advertised in their local area.²⁴ Alistair Thompson, a spokesperson for Care Not Killing, said at the time that he expected "the police to investigate and report their findings to the Crown Prosecution Service for them to make a decision whether to prosecute".

The daughters were warned by police not to seek to raise funds for the trip as it would leave them susceptible to prosecution. Their mother was able to have an assisted death after being notified by Dignitas of the possibility of a reduced fee and after obtaining financial support from an anonymous source. But her daughters told reporters they "would stay out of Britain for a while" in order to be able to grieve.

This case highlights another inequity in the law. People who can afford an assisted death overseas can make the arrangements behind closed doors and the police are unlikely to be made aware of their plans. Yet those who cannot afford it face additional hurdles because attempts to raise funds leave them more open to investigation and potential prosecution.

Despite the cost of an assisted death being a significant issue in debates about the current law, for the majority of interviewees in our research it did not impact on their decision to seek an assisted death overseas. Many said how they felt privileged to be able to afford to make the arrangements, acknowledging that it was not an opportunity that every dying person has available to them.

"We were very lucky. 》

"He was very conscious that he was in a privileged position. He felt, 'I can do this, but this is a right that everyone should have. 》

"When I started researching this on the net, there were a lot of people that just simply didn't have the money to go. They want to go, but they don't have the money. It's so sad, I stopped going on the net because it became very depressing. 》

"My heart breaks for people who can't afford it. It really does. Because I know what the alternative might have to be. I'm sorry but those people in the Houses of Parliament, they've just got no idea. None whatsoever."

The cost of dying overseas

This does not mean that money was no object. All interviewees felt limited in how many people would be able to go with them due to the significant increase in travel, accommodation and living expenses that each extra person results in. This meant that dying people and those accompanying them were denied the support that a larger network of people would offer.

Also, one interviewee who is terminally ill said that the cost of an assisted death in Switzerland meant that he was having to save money that he would otherwise choose to spend. This is having a negative impact on his quality of life.

ESCALATING COSTS

While the average cost to have an assisted death in Switzerland is approximately £10,000, this figure can rise significantly under certain circumstances. David, whose wife Elaine, was unable to travel to Switzerland on a commercial airline due to her condition, explained how the cost of her assisted death increased.

“Literally, it was in the few days before we went that I thought, ‘This just isn’t going to work.’ And I started looking around the web for alternatives, and I found an air ambulance, based in Zurich. I spoke to them, and arranged for them to fly into Biggin Hill, in Kent. That required a local private ambulance to take us to Biggin Hill, and then a private ambulance from the airport in Zurich to the hotel.

The other thing was the hotel. Again, quite difficult to find hotels with facilities and space for stretchers and wheelchairs and this sort of thing. So we had to take a suite and then another double room double room for my two sons, we were there for about five days, with meals and so on.

Even the Dignitas fees themselves are quite significant. With the current exchange rate that would be around £8,000. So if you put all of that together, the whole lot, back at that time it cost £18,166. Nowadays, that would be more than £30,000.”

8. A logistical challenge



The logistical hurdles that need to be overcome to arrange an assisted death means only some people are capable of doing it. Interviewees recognised that obtaining paperwork and navigating bureaucratic systems requires knowledge and skills that favour the “sharp-elbowed” middle-class. Yet as we have seen in previous sections, there is no support available for people who might be struggling with the process.

“I’m good at filling out forms, I’m well educated. I can find what I need and I’m good at doing stuff, I’m a get-up-and-go-er. A lot of people don’t have all of those skills.”

A logistical challenge



“The first thing I’d like to say here is that this is a class thing. I’m middle-class, Bob was a working-class bloke. I know my way around the system, he wasn’t confident, he found it frustrating and instead of getting things done, he just got frustrated and angry with it. I’m afraid you have to smooth your way around, it’s not very pleasant but it has to be done.”

The lack of clarity in the law for healthcare professionals means obtaining medical records and reports can prove challenging. But there are other documents that are also required.

To follow regulations in Switzerland any person that has had an assisted death has to be registered with the local Civil Registry Office. Only this enables that office to register the death and issue an internationally valid death certificate. While Swiss nationals are already registered, foreigners have to be newly registered. This means that in advance of the assisted death individuals must

source birth certificates, marriage certificates, dental records to prove identity, documents which confirm residency and, if necessary, records of divorce or the death certificates of spouses. People are often required to obtain re-issued documents and source documents from overseas if they were born, married or divorced outside the UK. An affidavit from a public notary is sometimes needed and documents may need to be legalised by the Foreign & Commonwealth Office.²⁵

All this happens in the context of communicating back and forth with an organisation that does not speak English as a first language with finite human resources. All interviewees recognised the necessity of the process to allow organisations to comply with regulations in Switzerland. But this did not change the reality that this was an unwanted burden at what is already an incredibly difficult time.

Interviewees commented that, as a consequence of the lack of support available due to the illicit nature of what they were doing, they experienced loneliness during the process of obtaining paperwork. They also spoke of the anxiety caused by not knowing if they would be able to get the necessary documentation before their loved one died.

The most common concern that resulted from this process was the loss of valuable time at the end of life. There was anger and frustration that much of the final months and weeks, that could be spent enjoying life, was spent engaged in bureaucracy.

It was clear that arranging an assisted death had a negative impact on the mental and physical health of those involved. It is telling that this was considered the preferable choice. Having

the control and peace of mind of an assisted death was considered by all interviewees to be worth the pains of making it happen.

“They were always so friendly and so helpful and so informative, but we had loads of hurdles. We had to run around getting birth certificates, marriage certificates, duplicate originals. We had to travel all around because mum and dad got married in South London. Dad was in Essex. We were all over the place getting all of this stuff together. Then, trying to get it to Dignitas. All those things took so, so much time.”

“We had to get her teeth records from the dentist, an X-ray so that the police would be able to identify her body after she was dead. My father died in Israel. All the documentation was in another country but we had to get her marriage certificate, his death certificate, her passport. We had to then reapply for a birth certificate.”

“John found it very frustrating. He found out in January. He applied to become a member in February. He started asking in March for a date for an assisted death. Then they asked for the paperwork, and then he got something wrong or missed something out. It was April before he was in a position to actually ask for a green light.”

“Elaine decided she wanted to go ahead but we ran into an unexpected obstacle. I think they were under pressure in Switzerland, because they obviously had a very limited panel of doctors. They said that the doctor who had to see her when she arrived in Switzerland had to be the same doctor who had approved her file. But he had just gone on vacation, and was going to be away for almost a month.”

“I was very impressed by Dignitas. They’re a very small operation and they operated with integrity. But my wife by then was getting terribly weak, and she was suffering, in pain. She was very scared that time was running out, and that she wouldn’t be able to get to Switzerland. We just had to wait.”

“I’d said to my Mum, ‘Look, whatever happens, whatever you need I’ll help you do it. I’ll help you do this.’ I had taken responsibility. It was awful, because I just wanted to cry. I just wanted to spend time with my Mum, and I wanted to be able to cherish those moments. But I was sitting there writing letters or doing paperwork. Just constantly... I lost my job, because they couldn’t take me being out of the workplace while I was going through this process.”

9. A cruel trade-off

To arrange an assisted death overseas dying people have to negotiate a complex trade-off. Being able to make the journey to Switzerland requires a certain level of health. However, this can create pressure to make the journey before becoming too ill to do so, which in turn often means sacrificing quality time that people could enjoy if they were able to remain in the UK.

For the interviewees that were terminally ill and assessing their options, this trade-off weighed heavily in their minds. For some it proved to be a sacrifice too far, resulting in them giving up on their attempts to have an assisted death.

“It’s going to be a hard decision. It’s going to be hard to say, ‘Right, I’ve got to go now. I’ve got to say it’d be nice to stay longer, but if I stay any longer I could end up not able to make it.’ If it comes to a choice between the two, I’d rather go early than take the risk of leaving it too late. If I could do it here, well, that’d be marvellous. I’d be able to stay longer.”

“You’re cutting your life short. With this going so slowly through me, I could be cutting off a good part of my life. At the same time, you could leave it too late.”

“The best way I could describe that feeling is if you leave it too late, you’re trapped. I want to reach a stage where I say, ‘look, this isn’t an enjoyment any more.’ But there’s no way I’m going to end up trapped.”

“They should allow assisted dying here because to go to Switzerland, I would have to travel while I’m still well enough. I’d be ending my life before I should have to.”

“I feel so strongly about that. If it was available in this country, I could get a few more months with quality of life. Now, you’ve got to end your life early. It’s not practical to say, ‘Oh, let’s go have an extended holiday in Switzerland and then when I come to the end...’ Because you can’t. I want my children with me and they can’t uproot their lives for me for weeks on end.”

For others, reaching the point of not being able to travel was the point at which they realised that an assisted death was unattainable, despite it being something that they still wanted.

“I remember having detailed chats with her, I remember going, ‘Mum, is it something you still want to do? Because I’ll move mountains if that’s what you want to do, I’ll move mountains.’ And I remember her just saying, ‘I think it’s too late now.’”

Many of the interviewees who did make it to Switzerland with their loved one were clear that the decision had led to a loss of time spent together at home.



“If it had been here in our own home, we would have had far more time together. He would not have been so anxious as he was. He was oh so anxious about it all. ”

“The timing is really difficult. If we’d left it very much longer, Bob would have been in too much pain to travel, and I think he knew that, which is why he pushed it forward a bit, because he didn’t have choice. ”

For all interviewees it was self-evident that if assisted dying were legal at home in the UK, this trade-off would not exist. There would be no need to sacrifice quality time to have an assisted death – the death could happen at the point at which the dying process was no longer tolerable.

“I’d rather not go, I’d rather wait that bit longer. Stay here.

*When the time comes,
be able to do it calmly.”*

10. Desperate measures



While the Suicide Act 1961 criminalised assisting a suicide, it decriminalised the act of suicide itself.

A 2014 Freedom of Information request to Directors of Public Health found that approximately 7% of suicides in England involve people who are terminally ill.²⁶ This equates to over 300 suicides every year. The World Health Organisation predicts that for each adult who dies from suicide there may be up to 20 others attempting suicide.²⁷ The exact details of these deaths and the consequences of failed attempts remain unknown, though there is anecdotal

evidence of dying people ending their own lives as a direct consequence of a lack of meaningful end-of-life choice under the current law.²⁸

Our research found that terminally ill people are taking matters into their own hands by attempting to end their lives in unenviable circumstances. Even some of those who had, or were arranging, an assisted death overseas were so clear in their view that their suffering had become unbearable that they attempted to end their life before travelling to Switzerland.

“A day was agreed. He decided he had really had enough of this. We did a video thing for the Coroner. He wrote to me and he wrote to the Coroner, that he had come to this decision himself. I went off into the town, so I wouldn’t be implicated, I was with a friend, I couldn’t tell her but I knew exactly what he was going to do.

We had emotional goodbyes as you can imagine. He went to a local wood because he didn’t want to do it at home. As it happened, it didn’t work out like that because he just wasn’t physically strong enough to be able to do it by then. He’d left it too long.

So, he came back on his mobility scooter and then I came back and you can imagine ... He was absolutely distraught with himself. (A) because he hadn’t managed it and (B) because I was also distraught. ”

“Before she actually started making the arrangements with Dignitas, she tried to kill herself. She took a lot of tablets. The first carer realised what she’d done, she was actually fine with it, and said, ‘You just sleep,’ and let her go. But the second carer that came on duty phoned the ambulance. So, it didn’t get any further than that. I’d actually procured the drugs for her and she did want me

to stay with her while she took them. I wasn’t willing to do that because I felt that that would be a problem. I felt bad that I didn’t want to stay. ”

“He had to set up a separate bank account in his own name. He was looking at purchasing equipment to end his life, and he didn’t want any of that to go through our joint account.”

“I think that’s what people just don’t get... they think, ‘I’m going to be strong, and I’m going to kill myself,’ and they don’t realise how hard it is to kill yourself. So my mother at the very end tried to take sufficient drugs to take her over the edge and she took about half a bottle of morphine and 40 sleeping pills... and 24 hours later she came to. ”

“And then right at the end, when he was beginning to lose function, he tried to hang himself. He had this big garden. He had rigged up this enormous swing for his grandchildren in the back garden and had this sort of long rope. He tried to hang himself on this long rope.

Somebody in the house did see him, not a direct family member, and rushed out. So, I mean, how had he managed

Desperate measures

that...? And then he tried to throw himself out his bedroom window, but he was not really capable of doing that. 》

“We read up on ways on how you could do it yourself. I remember reading something about a woman who wore multiple morphine patches and got in the bath. ‘I couldn’t drown,’ my mum said, ‘I don’t think I could drown.’ 》

In other cases dying people came to the decision that they would not want to end their life because of the potential for, as one interviewee put it, “botched amateurism”. Another factor was the impact that amateur attempts to end life would have on family and friends, particularly when contrasted with the peaceful death that facilities in Switzerland can provide.

“I’ve been on the internet to see what is the easiest way to kill myself. And if you look at all the percentages and the ‘success rate’ and things, and the pain barriers, it’s enough to put you off wanting to do it. I’m a community first responder and I have unfortunately seen the other side of it, it’s been a bit of a traumatic experience – that stops me from taking my motorbike out and riding it into the first tree. 》

“I know there’s a lot of other ways but you could end up in a worse mess. I wouldn’t want to take any chances. For anybody who thinks about me, I don’t want them to think of a suicide like that, I want them to think of me going over to Dignitas – taking that drink, and falling asleep. 》

“I have tried to find ways of having some sort of medication here, when the time comes. I tried the internet and various things, various links. And it looked dubious. And I would have to tell my girls. But, I wouldn’t be sure what I was getting, and if I’d botched it, then there could be trouble. I thought, it’s not worth it. I just want to make it easy for me, and easy for my family. 》

Family members were clear that they would have gone to extreme lengths to help their loved ones to avoid suffering. In addition to providing help to people to end their lives, some interviewees said they would have gone further than this, potentially taking direct action to end the life of their loved one. Such acts are not covered by the Suicide Act 1961 and would be considered murder in the UK. The CPS is clear that prosecution for murder is “almost certainly required”, even if the death was considered a “mercy killing”.²⁹

“I slept overnight in hospital one night on the floor when she’d been rushed in because she was in pain, and I knew that she was going to be sitting in that room by herself, because they’d put her away because she was in such agony, she was making a lot of noise. It was horrific, and I thought I was losing her that night, and she was in such agony, you even contemplate, should I hold a pillow over her face? Is there a camera in this room that would record me holding a pillow over her face to ease her passing? And I didn’t do it, because I’ve got two young kids and you just think, ‘What will happen?’ But the mercy in me wished I could have done it.”

“She looked at the other methods but she just said it was so gory. And the thought of us coming in to find her dead, it just didn’t bear thinking about.

But if we didn’t have the money to go to Dignitas I would certainly have been involved in helping my mum. There’s an e-book which gives you instructions. It’s just too horrible to even contemplate, but if mum had said, I would have helped her. I would have done whatever I could have.”

These findings show the failure of the law to provide effective support to dying people, via medical professionals or other sources. When interviewees encountered resistance from doctors to their choice to seek an assisted death overseas (see Section 6), this made them unlikely to return to those professionals to discuss their intentions when they were considering ending their own life in this country.

From this evidence we can conclude that the figures for the number of suicides by terminally ill people each year do not do justice to the extent of the problem. The lack of end-of-life choice under the current law drives dying people to attempt, or consider, ending their lives.





11. Painful deaths

END-OF-LIFE CARE

When someone is approaching the end of their life they should be provided with care to manage the course of the disease and to facilitate as great a quality of life as possible. Palliative care is a part of end-of-life care; its goal is to manage pain and other distressing symptoms through the provision of medical, psychological, social and spiritual care.³⁰

In complex cases specialist palliative care is delivered by expert teams based in hospices and hospitals. These teams can also provide care in day care centres, care homes and in people's homes.³¹

In 2015 the UK was ranked number one in the world in a comprehensive study on the quality and availability of palliative care.³² There are ongoing campaigns to ensure specialist palliative care is available to every person who needs it and that professionals across different care settings have the skills to deliver end-of-life care effectively.

As a result of the UK's commitment to palliative care, and the understanding healthcare professionals have of providing care at the end of life, the majority of people who die in the UK will not suffer pain at the end of their lives.

In our research many interviewees, including those whose loved ones had chosen to have an assisted death in Switzerland, praised the palliative care provided in the UK. Many said that the decision to arrange an assisted death had not come about through poor care or an absence of care.

“We were put in touch with St. Joseph's Hospice in Hackney. And I can't praise those people enough for what they did for us. The nurse that came out to visit him, she was my angel, I absolutely adored the woman.”

But not even those campaigning against a change in the law claim that palliative care is capable of relieving all suffering all the time.³³

There is evidence for this. We know that even in hospices, where we can assume that the standard of palliative care is excellent, approximately 1.4% of bereaved relatives report that their loved one received no effective relief of pain during the last three months of life. A further 12% report their loved one receiving only partial pain relief.³⁴

While these figures represent a minority, they equate to many thousands of people every year experiencing pain at the end of their lives.

The following accounts of dying illustrate the reality for this small minority and the horrific consequences of the limits of palliative care. In all three cases the person who died had either attempted and failed to arrange an assisted death overseas, or had been discouraged from doing so because of the financial and logistical challenges.

Painful deaths

In Section 6, Julie explained how her husband Paul had been denied access to a medical report by his GP. Due to a deterioration in his health it was then too late for him to pursue an assisted death overseas.



“It was exactly what he’d feared. He was absolutely in agony. He really suffered. Really, really suffered.

We had this service called Hospice At Home where the palliative care team were coming in every day. But it still wasn’t enough. It just didn’t work for Paul. I’m sure for other people maybe it would have done, but it didn’t and he was in pain.

He was upset and angry. Paul was never really one to make a fuss, but at the end he really was desperate. I was trying to give him morphine. I gave him so much but it just wasn’t enough. He was in absolute agony.

Then he felt like he couldn’t breathe, so he was gasping for breath. He shot up out of the bed and collapsed. He was frantic.

He shot up out of the bed and collapsed, and that’s when he was gurgling. He was wild eyed and petrified and flailing around, and that’s a horrible memory to have. It was horrific and about the furthest you could get from the nice, peaceful death that he’d wanted for himself.

I remember the palliative care worker holding his hand and saying, ‘Don’t stress,’ because he was so anxious. He was having panic attacks, saying, ‘I’m going to be in so much pain. I’m already in pain and it’s getting worse.’ She was holding his hands, ‘Trust us. We’ll make sure that you’re not in pain.’ And they didn’t deliver on that. At all. He was in a lot of pain and he suffered unnecessarily.”

In Section 7 Emil said that his mother ruled out having an assisted death in Switzerland because of the cost involved.



“She was diagnosed when she was 50. It started off as thyroid cancer then spread. She was extremely brave, extremely brave. She went through so many different horrible treatments.

Medical professionals will say that the care that’s now out there is amazing and it lets you die peacefully and keeps you out of pain. Which in some cases it probably does but not in all cases. Because of the complexity of her illness, my mum was suffering all the way to the end.

It grew into her water works and she couldn’t pee, yet she needed to pee and she had bladder spasms so they were forcefully inserting catheters. And there was me outside the room hearing her

screaming. There was blood everywhere because they didn’t know what else to do. They would try to force it in and then the cancer would either reject it or bypass it so that she would still not be able to pass urine. So she had this urge to go and it just never stopped. That carried on despite medication.

She was in so much distress despite the medication and I was telling the doctors, ‘Can you please increase the morphine?’ And they said, ‘We need to be careful because if we give too much morphine and she passes away it could be looked at as that being the cause of death.’ She was looking at us and saying, ‘Why can I not die? If I had known it was going to be like this I would have gone to Switzerland.’

In the end her symptoms were so distressing they couldn’t manage them so they upped the medication to the point that she was so high. I would say she was clinically dead by then...

My mum didn’t want that suffering and that’s haunting me. It will haunt me to the end of my life.”

Painful deaths

Caroline's mother had a bad death in the UK after considering travelling to Switzerland for an assisted death.



“It was the humiliation towards the end of life for my mother, because she had permanent radiation damage around her bottom from where there’d been tumours and they gave her a massive dose of maximum radiation. Her skin never healed again. So then towards the end when she was incontinent, whenever anything got on that it stung, and she said the drugs that she was on could handle pain, but they didn’t handle stinging pain. She said, ‘I can still feel the stinging, and it’s agony.’ She didn’t want to be there at that point in time, she didn’t want to be in constant stinging pain.”

People don’t get that young bodies don’t die easily. My mum was 64. Your heart is young. Your lungs are young. Your body does not die easily, even at 64. You know, maybe at 89 when you get pneumonia your body dies and gives in a bit more easily, but not at 64.

I think most people believe modern medicine will stop you suffering, whereas in actual fact my mum was crying out for painkillers at the end, and they couldn’t do it because they said if they gave her any more, that would push her over into death, and we were like, ‘Then push her into death, why should she be suffering and in pain? Just give it to her.’

Even Mum was saying, ‘Just give it to me.’ They couldn’t. The medics, they’re very, very wary that if they give you too much, then that will then be cause of death, and that can’t be the cause of death because then they’ll be running into liability issues.”

The suffering of the individuals in these cases could have been prevented if assisted dying were legal in the UK.

12. Withdrawing treatment

Any person over the age of 18 has the right to refuse medical treatment as long as they have capacity to make the decision. This is the case even if that refusal will result in their death.

Some palliative care professionals oppose assisted dying and have said the option to refuse treatment means dying people already have choice at the end of life and therefore a change in the law is unnecessary.³⁵

One interviewee, James, shared the end-of-life experience of his wife Helen, who had motor neurone disease. Helen's story illustrates the blurred lines between seeking an assisted death and refusing treatment and the injustice of this only being an option for some dying people.



James was one of the few interviewees who described an open conversation with a healthcare professional about the possibility of travelling overseas for an assisted death.³⁶ Helen was able to refuse ventilation and this gave her an element of control over the manner and timing of her death. Palliative care workers sedated her through this process, which took three days.

“I had a conversation with the palliative care doctor. She talked through the legality of what she thought I could and couldn't do to help her should she choose to go to Dignitas. You could help plan it. You could help organise it. But you have to maintain a certain level of distance.

She also explained to me that when you have MND, you often end up having to have help breathing – Non-Invasive Positive Pressure Ventilation (NIPPV). And that if you stopped using it you will go unconscious, and you will die. So if Helen ended up using NIPPV, she could choose.

Withdrawing treatment

[...]

One Saturday she woke me at 3:00 in the morning, 'I can't breathe.' We spent a while in A&E. I listened to the doctors talking about her. I just got 'CO₂ 10.6%'. The poor doctor who came up to treat her said, 'How do you feel?' She just simply typed on her iPad 'I want to die,' because she had had enough.

[...]

Her palliative care doctor said, 'Are you really serious about refusing the NIPPV?' Helen goes, 'Yes.' There is a protocol they've got to go through to make sure that she wasn't being pressured. She and Helen had a good long chat. They talked it through. They had something called Hospice at Home. Some people could come on Sunday. Helen could refuse the NIPPV and they would sedate her. 'Then what we normally do is on the Monday, we'll let you come around again and we'll check if you really want to do what you're doing.' Helen goes, 'No. My mind is made up. It doesn't matter what you do. I don't want to live through the end of this disease.'

On Sunday night when the team arrived, I wanted to settle them in. Where is the tea? Where is everything? Because they're going to be up all night. Introducing them to Helen and everything. The one thing I did not do is tell her I love her. I was so focused. That still hurts me. I was so focused on getting everything set up correctly, I forgot to say... I know she knew. Everyone tells me. Everyone tells me that, but I didn't say it.

She died on the Wednesday afternoon, very much what she wanted to do. Could she have lived for another two or three months? Maybe. But it would be miserable. She was one of these people who made her mind up and that was it. She met me on a Monday, by the Wednesday she was telling people that she had met the man she was going to marry. It took me a few months to work this out! That was her personality. If something happens to me, I hope I'm as brave as she was."

For Helen, the withdrawal of life-sustaining treatment was effective, controlled and facilitated the death that she wanted. In cases like this palliative care professionals are able to take precautions to ensure that

the people involved in the process, including healthcare professionals, are protected.

Indeed, to ensure safe practice of withdrawing ventilation when someone has motor neurone disease, guidance from the Association for

Palliative Medicine says that it is the responsibility of doctors to validate the person's decision by ensuring that it is the "settled view of the patient", "that there is no coercion" and that the patient has capacity to make the decision.³⁷

However, in a letter to members of the House of Lords in 2015 regarding the role of doctors in proposed assisted dying legislation, representatives of the Association for Palliative Medicine seemed to provide a contradictory view. They said:

*Doctors' expertise lies in the diagnosis of illness, in estimating the likely course and in managing its effects. Dispassionate consideration of complex issues – such as the settled nature of a request for assisted suicide, the weight of personal or domestic issues that may be influencing the request and the person's capacity to make such a serious and irreversible decision – is the proper province of the Court – and the Court alone.*³⁸

Critics of assisted dying claim that the difference between refusing treatment and assisted dying is the difference between "accepting death and seeking death."³⁹ Helen's experience and her motivations for refusing treatment – a "serious and irreversible decision" – suggest this differentiation is arbitrary and indeterminate. This is especially true given the views Helen expressed at the end of her life echo the views of people who had an assisted death in Switzerland. In fact Helen was considering this option for herself and her palliative care team discussed refusing ventilation as an alternative to arranging an assisted death in Switzerland.

The death that results from withdrawing treatment, which can take a number of days

and may require prolonged sedation, is not one that many dying people would want for themselves. Nevertheless, in Helen's experience the process was safe. Therefore it is reasonable to suggest that a similarly safeguarded process for assisted dying would work in practice. It is contradictory to argue that doctors cannot protect dying people under an assisted dying law, whilst simultaneously defending the practice of withdrawing life-sustaining treatment.⁴⁰

While Helen and James were grateful for the peaceful death that palliative care delivered, not everyone who is dying has the opportunity to exercise such control. The three people in Section 11 who suffered at the end of life would not have been able to control their deaths by refusing treatment. This is why James is now campaigning to change the law.



13. The journey to Switzerland



Fig. 5 Journeys made by people having an assisted death and their families

For those able to arrange an assisted death in Switzerland, the final preparations and journey presented conflicting emotions. Many interviewees expressed concerns about the logistics of flying overseas with a dying person and worries that authorities in the UK or Switzerland might prevent the assisted death.

We saw in Section 7 that David and his wife used a private air ambulance to get to Switzerland. Another interviewee helped their friend arrange a private road ambulance to take them to Switzerland, because they feared that flying might “be too obvious”.

“I was very anxious about what it might involve and, in fact, what they did was they transferred him into a special narrow wheelchair and then they hoisted him across from seat to seat to seat... From a logistical point of view, we then had to arrange for a taxi, a wheelchair taxi, to take us from the flat to the airport, because he couldn’t get out of the wheelchair and into a car seat. We had to sort all that out.”

“People don’t understand, when someone has advanced terminal cancer, they become so fragile, and even the local ambulance hitting a bump in the road was an ordeal for her. It became apparent to me that this was going to be a really tough journey at a time when she had no need for a tough journey.”

“They had a private ambulance that took them out to Switzerland. She felt it was too obvious to fly, in a way. She started off by booking the ambulance as a trip to go out and see friends. Then, when she realised that the ambulance crew knew what she was doing and didn’t have an issue with it, it wasn’t really a problem. They knew they were on a one-way trip.”

“In the morning everyone was rushing. As if you’re going on holiday. Everybody rushing to get to the airport. That’s your experience of going to an airport. Then we started to have a bit of a... ‘What if we get stopped?’ My mum’s in a wheelchair. We felt like everybody would know what we were up to. We printed off some tourism guides and all this nonsense. There’s a feeling of shame and guilt, I suppose. I felt a lot of guilt.”

“The airline were fantastic. On the airplane, I was thinking, I wonder if they know. I wonder if they know.”

“My mum fell really ill, she got a terrible migraine which of course was stress-related. Her last night was spent in the room in the dark talking together.”

The journey to Switzerland

As with all steps in the preparation, the law prevents support during this difficult process. One interviewee sought spiritual support from the Anglican Church in Switzerland for his wife, but was denied.

“I had a difficult discussion with the Church. There was a Church of England vicar in Zurich, some sort of Deacon. I phoned him up in advance of our visit, and I said, ‘I’d just like to know, if my wife does need someone to talk to, will you be available when we’re in Zurich?’

And he was very pleasant, but he said, ‘I’ve got to go back to the diocese and take advice.’ I spoke to him a few days later and he said, ‘No, I’m afraid I cannot have any contact or provide any counselling to your wife in advance. However, after the event, if you need any prayers said or whatever, I’d be happy to attend.’ Because of their dogma, they refused to help someone at the most difficult time of their lives, only provide a ritual after. ”

Despite the difficulties of the journey, a number of interviewees said that knowing their loved one was about to be able to exercise the control over their deaths that they wanted made the final days of their life very meaningful.

“He was beaming just because we’d made it there and it was going to happen the next day. We were kind of scared,

sad, but there was relief at the same time because we’d got him to where he wanted to be. We had a meal that night, and laughs. Those kinds of things, a lot of people don’t have them at the end with a relative that suddenly dies. They’re things you can treasure. You can say anything you want to say, if you need to. ”

“They upgraded us to first class, so we went into the first class lounge and we had loads to drink. Patrick loved red wine. The stewardesses obviously knew, so they treated him like a king. ”

“He was still making us laugh. He made us laugh the day before he died. We were on the bridge in Basel just going for the final evening walk. A Jehovah’s Witness came up and pushed a leaflet into his hand, I think it was called ‘Three Questions to Ask God.’ He made a great play of looking at it and studying it and then he got his pen and he wrote on it, ‘Sir, changed my mind.’ He thought this was absolutely hilarious, he was in his wheelchair roaring with laughter in the way that he had always done. ”



14. A peaceful death



In Switzerland, people who have an assisted death must self-administer the life-ending medication. This is usually through drinking a prepared solution. In some cases, for example if due to the person's diagnosis mobility is restricted or swallowing is not possible anymore, drugs can be self-administered intravenously or via a gastric tube. This requires a mechanism to be set up

which ensures the individual has complete control of when the drug is released into their body.

Before self-administering the drug, people have repeated opportunities to change their mind.

“She had all the time in the world, she was encouraged to understand that her options were open, that she didn’t have to go ahead, and that was repeated to her on several occasions.”

The drugs used in assisted deaths in Switzerland suppress the respiratory system. People fall unconscious in a matter of minutes, fall into a deep coma and die. Trained staff supervise every death and tailor preparations for each individual. All interviewees said that the process was peaceful and reflected how their loved one had wanted to die, comparable with falling asleep.

One thing that was notable when compared with deaths that occurred in the UK, even painless ones achieved through sedation, was the moment of lucidity before death. This enabled people to say goodbye to their loved ones.

“She couldn’t swallow but she had to trigger it herself. So they wired her up to a drip and she had this bar in front of her which had a console with a couple of buttons. It was explained what was going to happen, the woman explained it to my mum and to my sister and myself. They offered us a drink, and then said to mum, ‘Are you sure that this is what you want?’”

My mum wanted some music, we had some music on. We said a prayer, and then they said, 'When you're ready press the button.' My mum just, her hand just shot up and she just pressed the button. There was no thinking. No hesitation whatsoever. As much as that hurts me, it clearly was what she really, really wanted.

Within literally 10 seconds her eyes closed, and then she was dead. We were told after that she'd died within four minutes. ”

“It was lovely. It was a beautiful day. We sat out in the garden. We chatted for a while. We did all the forms and they explained what was going to happen, and they said, 'Whenever you're ready tell us.'

The medication was bitter but they brought chocolates and we had sweets. We'd already said I love you. He started to say to them, 'Thank you very much indeed.' And within... It tailed off just like it does on the films with somebody trying and his words were slurred. Within four minutes he was asleep. Asleep. There was nothing unpleasant, there wasn't any twitching, there was no moaning, he didn't wet himself, absolutely nothing. His head went on one side, he went into a deeper, deeper sleep, and it was lovely.

There were dragon flies, there were butterflies, there were fish in the pond, there was everything that Patrick would have wanted, apart from we were in Switzerland and not England, and why? Why? I don't understand it. ”

“She was very concerned with her dignity, with being able to retain her clarity of mind. At home she was very determined not to slide away in some drug-fuelled oblivion; she even cut her medication down when she felt that she was drifting. She was very concerned to retain her clarity of mind; she wanted to pass with her loved ones around her and she had her wish. She was absolutely lucid right to the end, she was making little jokes right to the end. She had her sons there, I was there... She was very sure that that was the way she wanted to go. ”

A peaceful death

Lesley described the death of her brother, John.

“I turned his wheelchair so he was looking out of the window and gave him his organiser. He wrote, amongst other things, ‘It seems a shame to have come to this fine city and such good people just to die.’ But he was so grateful. He wrote that he was so glad there were no more phone calls, no more emails, no more faxes. No more pieces of paper to fill in. It was actually going to happen very soon, and he was grateful. That’s the only word that sums up how he felt. He was simply glad that he was in Switzerland. He was glad that he’d actually be able to take advantage of this opportunity.

We all said goodbye in different ways. I told him I wanted to say something profound, but all I could think of was how much I was going to miss him. I’d wanted to be a poet, all of a sudden, but it didn’t happen. I just felt so sad. Then, when we’d all said our goodbyes, he looked around as if to say, ‘Are you done now? Can we get on with this?’ Erica gave me the syringe. I connected it up, but I didn’t do more than just connect it. This tube, there was a little clip, and when you undo the clip, then you can put the contents of the syringe into your stomach. The clip was done up and the syringe was connected.

John took it back from me. He rested it on his right hand. He pressed on that plunger with such determination, to put this stuff into his belly. There could never, at that point, have been a moment’s doubt that this was where he wanted to be, and what he wanted to be doing. I disconnected the kit, put it back on the table. Then he looked around as if to say, ‘Well, what happens now then?’

In fact, within a couple of minutes, he was starting to fall asleep. His neck was very weak, already, and his head drooped, and his eyes closed, and his breathing slowed. It took about 20 minutes for the medication to actually end his life. Erica came in. She saw me crying and she put a blanket around me. She was so kind.

There was a tiny fly walking across his lips. I brushed it away, and then I realised that he couldn’t feel it. It wasn’t troubling him anymore. Nothing was troubling him anymore. He’d achieved his goal of beating this condition that could so easily have ended his life in his sleep one night, deprived of the opportunity to say goodbye. As it was, I knew that not many minutes earlier, we had said goodbye properly. He’d said goodbye to us, and we’d said goodbye to him, and to this day, that brings me comfort.”

As highlighted in the previous section, the comfort of being able to have an assisted death gave rise to meaningful moments.

“The doctor said to her, ‘Now Mrs Cole...’ and she looked up and could barely open her eyes, but one of the last things she ever said was, ‘It’s Ms’. Of course to a Swiss guy it was meaningless but we thought it was very funny and it was absolutely classic Annie. She was a feminist to the end. ”

“I think he thought, ‘I have choreographed this and I’m happy to go.’ So there’s a wonderful picture of him sort of smiling just as this music is playing. And he’s looking around, and I think he knows that he was absolutely loved by everybody there. And I think he felt very content. He wasn’t anguished and that meant that we were not at that moment anguished. It was very swift. I mean, she said he would lose consciousness in about 30 seconds, which he did, and he would be dead in about three minutes, which he was. It looked to be completely painless and non-traumatic. ”

“The doctor said, ‘Would you like some music?’ He wrote down, very laboriously, ‘Have you got any Led Zeppelin?’ And she said, ‘No.’ I wheeled him over to look at the fairly poor selection of CDs that they did have. His wife said, ‘Oh, look, Cat Stevens. They’ve got a Cat Stevens album. You could have a Morning Has Broken.’

And I said to Simon, ‘No friend of mine is going to die listening to Cat Stevens.’ and then we saw, what we thought was a Rolling Stones greatest hits. So, Simon picks this out and as it’s playing, we’re both looking at each other and then we realised that it’s a karaoke backing track of the Rolling Stones. Simon asked for his pen and paper and he writes something down, incredibly laboriously, and he hands it to the doctor. ‘This music is awful. It makes me want to kill myself.’ She looked rather bemused, the rest of us laughed, he was still making us laugh. ”

15. The journey home



Following an assisted death, Swiss authorities must confirm that there has been no breach of Swiss law. This means that police, a public attorney and an independent doctor inspect the body of the person who has died, review the evidence provided by the organisation and, if necessary, interview the professionals and the loved ones who witnessed the death.

While interviewees acknowledged that Dignitas and Eternal Spirit must allow for these procedures, it was clear that the curtailing of time spent with the body of their loved one, the presence of officials and the implication that their loved one's deathbed had become a suspected crime scene was distressing.

“It’s a terrible shame. Although the event was provided with care and understanding by Dignitas, the reality is that, shortly after, they call the police, and you have literally the police, someone from the local coroner’s office, someone from the local attorney general’s office... you have a whole group of officials, who immediately arrive in the apartment, with your wife still lying there, dead, and your sons in the room, and you’re interviewed.

I don’t disagree with them doing that, you can absolutely see from their point of view, they have to do that for their own

protection. And of course it does illustrate the fact that everything is legitimate, and is properly done. Nevertheless, for the family who go through that, it is not a comfortable experience. ”

“Afterwards, you’re just numb, to be honest. You’re just sitting there. Then all the authorities come in. They nod, and they all speak in a different language. You don’t know what they’re saying. They keep looking over at us, over at dad, and then they ask you to leave the room. ”

The experience of watching a loved one die, in any circumstances, requires time, space and support to process. Many interviewees said that the organisations in Switzerland that facilitated the assisted death of their loved one provided emotional support after the death. But this is the limit of support that was available. Our research found evidence that, while there is comfort in knowing someone has ended their suffering, grief is made more complicated by the death happening in a foreign country.

In addition to this, for some interviewees it was only after the death that the threat of prosecution started to become a concern.

“For me, what I found very, very difficult, which was a big part I suppose of being abroad, was that we were going to leave her there. We were probably

there for about an hour between us, my sister and myself, hugging my mum and crying. Then when we had to leave I had a complete breakdown about it. I felt really bad leaving her there, even though she’s dead. On an emotional level leaving somebody in a foreign country on their own who is the closest person to you, it just felt terrible.

If I’d have gone on my own I wouldn’t have made it home. I would have been on the floor with nobody to help me get me back. ”

“The Dignitas people were very good, but other things like getting a taxi or sorting out the hotel room, you think, ‘I wish they would speak English.’ Okay, I’m in Switzerland, people don’t speak English. I’ve got to learn to listen. Those kind of practical things made the grief much more difficult to deal with in those first couple of days. It felt very unreal, because we were in this strange place. It was very, very strange, the whole experience, because of being in Switzerland. ”

The journey home

“I knew they were going to say, ‘Do you have a fourth person flying with you?’ I just said no. They didn’t question it any further. But you’ve got the empty plane seat where somebody should be.”

“When we were flying back, that was the point at which I thought, ‘Oh, I wonder if there might be somebody waiting for us.’”

If a person dies overseas bringing the body home for burial or cremation in the UK leads to the involvement of a coroner (or medical reviewer in Scotland).^{41,42,43} In the unique circumstances of a person being assisted to die in Switzerland, it is likely that this would lead to a criminal investigation into the actions of those who helped the deceased be assisted to die.

As a result, all interviewees whose loved one had an assisted death said that a cremation took place in Switzerland, with their loved one’s ashes collected at a later date or couriered back to the UK.

“I would love to be able to share this story with him. By the time his urn was delivered, I got a card through saying there was a parcel at the post office. I didn’t give Patrick’s urn a thought. So, poor thing, he got locked in the post office overnight, which he would have thought was hilarious.”

He arrived in a beautiful terracotta urn with a lovely heraldic shield on, which was his thing. He loved them, it would have been absolutely perfect had he realised. So, Patrick is sitting in the summer house, in my garden on the little shelf on top of his lawnmower. He sits there now.”

The reality of having little choice but to have a cremation in Switzerland means that people are denied a traditional funeral service in the UK. This limits the funeral choices available. It can also have severe consequences for people with religious beliefs that forbid cremation, another example of inequity created by the current law.

“My mum was happy to be cremated but we’re Jewish and it goes against the religion. She would have been buried if it had been under normal circumstances. If we’d have been more religious than we are it would have been very, very difficult. Going abroad, having to be cremated, would definitely be a deal breaker for some religious people.”

The difficulty of returning the body of someone who has died at Dignitas to the UK also means that people are unable to donate their body to medical science. This can be upsetting for dying people, as it means they are denied the opportunity to donate their tissue to research aiming to find a future cure or treatment for their condition.

16. Becoming criminals

As outlined in Section 4, our research found that the threat of prosecution for assisting someone to die overseas did not act as an effective deterrent. But it did contribute to a general anxiety for dying individuals and those assisting them.

In our interviews, a small number of people were investigated by the police when they returned to the UK. This resulted in anger at the implication of being involved in a crime.



Alan travelled to Switzerland with his partner Raymond. Alan went public with his story in order to help bring about a change in the law.⁴⁴ He was arrested shortly afterwards.

“The police arrived here on a Tuesday morning at 10 o’clock. Knock knock. Didn’t use the buzzer. Obviously told the concierge, ‘Don’t tell him we’re coming up.’ Four of them. Three men and a woman. I just looked through the spyhole, and I knew exactly who they were.

They didn’t have to spell it out to me. I opened the door and he said, ‘We’re here to speak to you in relation to your partner’s assisted death.’ I said, ‘Oh okay, come in.’ So they came in and said they wanted to question me, take me to the police station, and question me. So I said, ‘If I don’t come with you to the police station, what will you do to me?’ ‘We’ll handcuff you, put you in the car, take you to the nearest station and search your flat.’ I said, ‘Okay. Give me 10 minutes, to have a shower, phone my lawyer. I’ll come with you.’ So that’s what I did.

I felt fucking angry that they were prepared to actually handcuff me but I was thinking to myself then, ‘Maybe I’ll let them do it.’ I didn’t really care, you see, at that point. But I was angry that they even came into my home. I’d done nothing wrong.

So they took me to Shoreditch police station and then they said, ‘There’s a cell over there mister, can you just follow this policeman and he’ll take you in.’ I said, ‘I beg your pardon?’ I said, ‘I’m ready for my lawyer.’ He said, ‘No we have to put you in.’ I said, ‘No. I’m not going in there.’ I said, ‘Just look at me.’

Becoming criminals

So I was kept on bail for 13 months. In the end I got a call from the lawyer saying, 'No charges, Alan.' I said, 'Why?' 'It's on compassionate grounds.' So it's not in the public interest.

I think it's disgusting that people are still visited. They should totally leave them alone, and have some compassion and understanding for what these people are going through. They've already been to Switzerland with their loved ones. It could've been their husband, their wife, their brother, their sister, father, mother, uncle, grandmother. They've suffered enough.

I just wanted it over and done with. I wish they'd done it on March 1st when I came back so I could've been left alone to do what I needed to do... To grieve for Raymond, and I wasn't doing that. Because I was so bloody angry with everybody... I felt that if anyone like myself had been taken to court, no British jury surely to God would have found me guilty of anything other than love."

Years after Alan's arrest, the subject of assisted dying was raised with him during a Disclosure and Barring Service check while applying to work with people living with mental health issues. Despite requests to remove them, Alan's fingerprints and DNA profile are still retained by the police.

"When I came back, I didn't know whether I was supposed to report it. I had no idea. Nobody to ask. Who can you ask? Absolutely zero. Nobody to help you whatsoever in all of this.

The police rang up and said, 'We need to come and interview you.' Two very official, very, very tall, policemen interviewed me very professionally. They came to the conclusion that it wasn't in the public interest to prosecute me. So, end of story.

As I said to them, as I said to other people, what a waste of time. What a waste of police resources. What a waste of money. 》

While the DPP's guidelines suggest compassionate assistance of suicide will not be prosecuted, the policy is clear that the police are responsible for "investigating all cases of encouraging or assisting suicide".⁴⁵

Given the majority of interviewees in our research were not investigated by the police when they returned from Switzerland, we can conclude the law has not been implemented as intended. Since the DPP published the guidelines in 2010, over 250 UK citizens have died at Dignitas alone.⁴⁶ A 2016 Freedom of Information request to police forces and the CPS by The Economist suggests that less than half this number of offences were recorded and investigated.⁴⁷

Our research has uncovered no evidence of coercion or pressure placed upon people assisted to die in Switzerland. Those accompanying them were not motivated by anything other than compassion. It is also clear that Swiss authorities and the organisations that facilitate assisted deaths have their own safeguards in place to protect people.

However, the circumstances of many UK citizens' deaths each year, the people involved and the motivations of those who assisted them to end their lives, remain unknown. Hypothetically, if a vulnerable person were pressured or coerced into an assisted death overseas, UK law has no effective mechanisms to protect that person or detect if a crime has been committed. Those who claim the current law is safe have no reliable evidence on which to base their claims.

Aside from the issue of safety, it is unjust that most relatives are left alone to grieve for their loved ones, while others are subjected to investigations by the police, which can have traumatic and long lasting consequences.

“Were you ever approached by the police?”

“No, nothing at all. Nothing at all.”



“I got a letter from the chief constable of Thames Valley Constabulary saying it had been deemed it wasn't in the public interest to prosecute at that time.

I've looked at those words, '...at that time' and I've thought, 'Oh, they could do it in the future...’”

17. How things could be different



Interviewees wanted to share how things could be different if assisted dying were legal in the UK.

People living with a terminal illness said it would give peace of mind and increase quality of life.

“I’m going to die. I’m not gonna make any miraculous recoveries. If it were legal here it would give me peace of mind. It wouldn’t be rushed. It would be a time and a place of my choosing.”

“Every day I think about dying, every day. I dream about it at night. Knowing I could have an assisted death in this country, I wouldn’t think about it, it would give me just such improved quality of life now.”

“It’s unfair that we have to travel to a foreign country, when we’re at the lowest time of our lives, putting pressure on family.”

“If someone is against, I’d say watch me, watch me with these tumours, come and watch me and tell me that what you’re putting me through is the right thing to do. It’s not.”

People who accompanied someone to Switzerland said that if assisted dying were legal in the UK their loved one would have died with more family and friends around them and with greater support from end-of-life care professionals. They also would not have been subjected to the difficulty and stress of travelling overseas and they would have had more time to spend with their loved ones at the end of their life.

“It was a relief. It was such a relief. The relief of knowing that the end was achievable. Had he had that relief four years previously, knowing it was legal in this country, our life could have been a dream, even terminally ill. We could have done so much more.”

“We had no idea just how horrific the feelings and the emotions would be. We were then in the hotel room just absolutely in tears. No support. If it was legal in the UK, you’d have some

kind of counsellor or somebody who's got experience, who knows how to cope with grief of this nature. And lots more extended family. We would have been at home and everybody would have been around. We would have all been there for my mum, and for each other. 》》

“He wrote about how different it would have been. He said that he would have liked to die in the bay window of his flat. He had this window that faced west so he could see the sunset, and there was a stand of trees. The sun would have gone down behind them. He could have been listening to the music of his choice. He loved music. He was always listening to something. In the last few months of his life, he explored so many different things he'd not listened to before. He would probably listen to Beethoven, actually. It just would have been so different.

Our mother could have been there, because she could get to Milton Keynes, she couldn't get to Zurich. Lots of things would have been much more peaceful. It was a peaceful death. It was a dignified, and peaceful, and comfortable death, but it could have happened later. John had to have a certain amount of bodily strength to get to Switzerland. If it were legal in the UK, instead of dying on

May the 26th John might have died on July the 26th, or he might even have made it to the middle of August.

If we'd been organising an assisted death in this country, it would have all been just so much easier. 》》

“The quality of time that we would have had, it just would have been much better. There would have been more time. There's a lot of guilt that I didn't get to spend the time that I wanted with her. I'm very fortunate, we did get to sit down and we did talk. We really cleaned up our relationship and everything else, because there was a death sentence. But all the administration, days when I should have been there but was running around at the dentist or making calls. 》》

“Elaine was quite clear in her decision to go ahead. The courage she showed was amazing. Just unbelievable. Of course, if it had been possible to die at home with her friends and family around her, with medical supervision, in her own home, she would have preferred that 100 times over. There's no question whatsoever.

I think for all of us, the necessity to go through that was traumatic. The fact that Dignitas provides that facility is

How things could be different

very precious for people who are in that situation. I admire them immensely for what they do. But for the people subjected to it, it's a process they really shouldn't have to go through. 》

“We'd have been able to talk to the medical specialists who were treating her, 'This is one of the options on the table.' With regard to the hospice movement, there's no question that there's no conflict between the two, these should be complementary parts of a total end-of-life care plan.”

“If it had been legal, there'd be less worry for her about what may or may not have happened to her husband because once you're gone, you don't know. It's not like she could find out if he was okay. More of the family would've been involved, she would've probably had a party on the day it happened. That's denied to you. You're just with one or two people who are your travelling companions. That's it.

The current legal situation, as far as I'm concerned, is completely unacceptable. Even with the DPP guidelines, the fact that there are no up-front safeguards and the fact that the medical professionals who are involved in the care of the individual still dare not be involved – it

encourages botched amateurism. The only people who can afford the medical attention that this demands, are people with the money to get to Switzerland. It is absolutely unacceptable. 》

“He may have been here longer. Probably not much longer, because we were quite close to the end, but for other people in different circumstances, 100%. Also, he may well have been worrying about the legal side of it... He would have had more people with him, not just a couple. 》

Relatives of those who died in the UK are still in recovery from the ordeal that they experienced. They experience feelings of guilt at not being able to arrange the peaceful death their loved one wanted and anger at the current law's failure to provide that option.

“It would just have solved all of his problems, if it was legal in this country you wouldn't have to jump through hoops. He would have had his whole family around him. Everybody supporting his decision. He'd have died a happy man. It would have been so different. I think I feel guilty that I didn't help and support him and push harder for him to be able to go over to Switzerland. 》

“If I knew that if I get a terminal illness I can die peacefully, without having to go through the suffering she did, then I’ll be so much more comfortable and happy in my life, without fear.”

“If it was legal here then there wouldn’t have been all this drama at the end of her life. And she could’ve talked about it with somebody. She wouldn’t just had to depend on me. She would’ve had more support.”

“She would have seen her family, she would’ve said goodbye to everybody. And she wouldn’t have suffered for the last eight weeks, and it was

true suffering. It was horrible. And to put anybody through that...

We talk about, ‘We wouldn’t do it to an animal.’ It’s not about animals, it’s about how we treat other human beings. It’s about kindness. It’s about humanity and anybody who can’t see that hasn’t gone through a loved one dying in horrible circumstances.”



Notes

1. Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, the Director of Public Prosecutions, 2010, updated 2014
2. Policy on Prosecuting the Offence of Assisted Suicide, Public Prosecution Service for Northern Ireland, 2010
3. Swiss Criminal Code, The Federal Assembly the Swiss Confederation, December 1937, status as of 1 January 2017
4. All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 1,648 adults. Fieldwork was undertaken between 24th - 25th August 2017. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+)
5. British Social Attitudes 34: Moral issues, NatCen Social Research, 2017
6. There is no publically available data for the number of people from the UK who have died at Eternal Spirit and EX International or the number of members those organisations have.
7. Dignitas, Statistics, accessed October 2017
8. Google AdWords Keyword Planner, August 2017
9. 'Assisted dying clinic comes under fire for telling patients to hide suicide from GPs', Sunday Express, 15 February 2015
10. What's important to me. A Review of Choice in End of Life Care, The Choice in End of Life Care Programme Board, 2015
11. Our Commitment to you for end of life care, Department of Health, 2016
12. 'We hospice CEOs shouldn't stay silent - the sector must accept assisted dying', The Guardian Voluntary Sector Network, 2 August 2015
13. Lancaster H, Finlay I, Downman M, et al Commissioning of specialist palliative care services in England BMJ Supportive & Palliative Care, 2017
14. When a patient seeks advice or information about assistance to die, General Medical Council, 2015
15. Guidance for the Investigation Committee and case examiners when considering allegations about a doctor's involvement in encouraging or assisting suicide, General Medical Council, 2013
16. Ibid.
17. Responding to patient requests relating to assisted suicide: guidance for doctors in England, Wales and Northern Ireland, British Medical Association, 2015
18. 'Measuring the cost of living worldwide', The Economist, 21 March 2017
19. Dignitas, Brochure of Dignitas, accessed October 2017
20. The lower estimate is based on a stay for 2 people for 3 nights, eating in and one hotel room. The upper estimate is based on a stay for 4 people for 5 nights, eating out and two hotel rooms. Exchange rate 1 GBP = 1.236 CHF, 25/08/2017.
21. The Money Statistics, The Money Charity, April 2017
22. 'Household savings, income and debt in the UK by tenure', National Housing Federation Blog, 14 April 2016
23. Dignitas, Articles of Association/Statutes, accessed October 2017
24. 'Daughters forced to cancel Dignitas party for mother over fears of prosecution', The Telegraph, 16 July 2015
25. Get your document legalised, Gov.uk, accessed October 2017
26. 'Assisted dying: more than 300 terminally ill people a year committing suicide', The Telegraph, 15 October 2014
27. Suicide Data, World Health Organisation, accessed October 2017
28. "'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', MailOnline, 10 March 2017
29. Homicide: Murder and Manslaughter, The Crown Prosecution Service, accessed October 2017
30. End of life care, NHS Choices, last updated 2015
31. Palliative Care Explained, The National Council for Palliative Care, accessed October 2017
32. The Quality of Death Index, Economist Intelligence Unit, 6 October 2015
33. 'Facing up to death and palliative care', Baroness Finlay of Llandaff, The Times, 17 July 2009
34. National Bereavement Survey (VOICES): 2015, Office for National Statistics, 2016
35. Baroness Finlay of Llandaff, Noel Conway v Ministry of Justice, 2017
36. Though this doctor's willingness to discuss the issue was helpful it is questionable whether a medical professional is qualified to provide a legal opinion on the implications of helping someone arrange an assisted death.
37. Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease – Guidance for professionals, Association for Palliative Medicine, 2015
38. 'Lord Falconer's Assisted Dying Bill', Dr David Brooks, Professor Rob George and Dr Tim Harlow, 9 January 2015
39. FAQs, Living and Dying Well, accessed October 2017
40. See 'Lord Falconer's Assisted Dying Bill', Brooks et al., 11 July 2014 and 'Pressure to end lives', Williams et al., The Telegraph, 24 August 2015
41. What to do after someone dies, Gov.uk, accessed October 2017
42. When someone dies abroad, nidirect government services, accessed October 2017
43. If someone dies outside Scotland, mygov.scot, accessed October 2017
44. 'Man risks jail after admitting he helped terminally ill partner in assisted suicide', The Telegraph, 16 June 2009
45. Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, the Director of Public Prosecutions, 2010, updated 2014
46. Dignitas, Statistics, accessed October 2017
47. 'Police in Britain increasingly turn a blind eye to assisted suicide', The Economist, 14 January 2017

Support

The following organisations can provide information and support to people who are bereaved or who would like information on terminal illness or hospice care. These organisations are not affiliated with organisations in Switzerland that can provide an assisted death.

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

Progressive Supranuclear Palsy Association

0300 0110 122

www.pspassociation.org.uk

Samaritans

116 123

jo@samaritans.org

www.samaritans.org

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
www.dignityindying.org.uk

Contact us

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

 020 7479 7730

 info@dignityindying.org.uk

 www.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

November 2017