

CAMPAIGN FOR  
DIGNITY  
IN DYING.

CAMPAIGN.

**ESTHER  
RANTZEN:  
"THE LAW  
IS A MESS".**

MAY 2024

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**Sarah Wootton**  
Chief Executive

Welcome to your spring edition of *Campaign*.

In the last edition I said that we were gearing up for an exciting year, and it's living up to that promise as the campaign reaches some critical milestones.

The campaign for a more compassionate law has shifted from a hypothetical question to an imminent reality. Politicians and commentators increasingly recognise the human cost of the status quo. This suffering is evidenced time and again, by people denied choice and forced to suffer against their wishes and by those who travel overseas, earlier than they would choose, to gain access to legal assisted dying. At the end of February we saw the first ever House of Commons inquiry into assisted dying. They reported "it looks increasingly likely that at least one jurisdiction among the UK and crown dependencies will allow [assisted dying] in the near future" and called on the UK Government to consider how to respond (page 16).

Lifelong campaigner Dame Esther Rantzen, who has terminal cancer, has joined our campaign. Esther has used her platform to fight for greater choice at the end of life for those who find themselves in her position in the future; a selfless act given that the law is unlikely to change in time

# WELCOME.

to provide her with the choice. At a time when Esther should be able to enjoy what may be her last spring with her family, she has to consider travelling abroad for an assisted death should her suffering become unbearable. The current law not only fails Dame Esther and those like her, but also her family and loved ones who want to be there for her in her final days (page 4).

Following Dame Esther's decision to share her experience, in an historic move, both the Conservative and Labour leaders have committed to giving assisted dying the time it needs to be fully and fairly debated in the next UK Parliament. This is of course a significant breakthrough for all of us fighting for this choice, and for people in Dame Esther's position it can't come soon enough (page 8).

Liam McArthur MSP learned, from a visit to California, that the comfort afforded by assisted dying is immeasurable (page 28), and the publication of his Assisted Dying for Terminally Ill Adults (Scotland) Bill (page 20) marks an important milestone towards people in Scotland having the choice at the end of their lives that is so urgently needed.

The next stage of Dr Alex Allinson MHK's assisted dying bill in the Isle of Man will be reached in early May, when the various clauses will be debated in the House of

Keys, and on 21st May the Jersey States Assembly will start to debate and vote to shape the Jersey Government bill (page 18).

Further afield, President Macron has launched his French end-of-life care bill which includes plans to dramatically increase investment in palliative care, as well as open up the option of assisted dying for terminally ill and mentally competent adults.

With an imminent General Election in the UK, it now falls to parliamentary candidates to set out where they stand on this issue, and to us to ask them to state their position before we choose who we want representing us as we head to the polling booths. We know from our groundbreaking new polling, the largest and most in-depth ever conducted, that every single constituency in Britain supports law change (page 14).

We take these wins and continue to build on them in what will, with your help, be the most significant year yet for the campaign. Together, we will change the law.

A handwritten signature in pink ink that reads "Sarah Wootton". The signature is written in a cursive style and is underlined with a single pink stroke.



# ESTHER RANTZEN: "THE LAW IS A MESS".

By Ellie Ball

As Dame Esther Rantzen was looking forward to a precious Christmas she was not sure she would see, she unintentionally lit a fire under the campaign for assisted dying in the UK. Her forthright honesty forced politicians to face up to the current untenable situation for those facing the end of their lives.

In an interview with Radio 4's The Today Podcast in December, she shared that she had joined Dignitas and may travel to Switzerland for an assisted death if her pain and symptoms from stage four lung cancer became unbearable.

***"It is a possibility that my life will become too painful, that my suffering will be too great...we need is for people to have individual choice, at that moment, which is literally life and death."***

She was motivated to join Dignitas, in part by her desire to protect her loved ones from witnessing her suffer a bad death, and therefore endure long lasting painful memories. She acknowledged the difficult position her family and friends would be in should she choose to have an assisted death in Switzerland. They understandably would want to be by her side but could therefore face prosecution, something that has not escaped her daughter Rebecca Wilcox who said ***"I can't go to prison, I can't go through a court case at the worst point of my life, when I've lost my person and I'm suddenly being prosecuted with her death...It's unfathomable. I can't believe this is the situation we're in"***.

Dame Esther's revelation inspired a huge outpouring of public support and sparked

several other high profile names to share their heart-breaking experiences of the current law. In national TV interviews Vanity Fair star Susan Hampshire said the "trauma" of her late sisters' deaths would never leave her, and former Labour MP Dame Joan Ruddock admitted she came within hours of ending her husband's life as she watched him die, in agony, from cancer.

Dame Esther spoke out again when the Health and Social Care Committee published their long-awaited report. It found that legalising assisted dying has improved palliative care, not diminished it as opponents to change would lead us to believe. She also held parliamentarians to account once again by expressing her disappointment that the Committee didn't call for a debate and vote on the issue, based on their new evidence.

She summed up the comfort that an assisted dying law would afford so many: ***"My life would be completely different if I was absolutely confident I could have a painless death surrounded by my loved ones and if palliative care wasn't working for me. It's my choice and if I choose it then I think the law should allow me to."*** She added that the fears that being denied that choice bring is a constant background to her life.

In no small part due to Dame Esther's courage, openness and tenacity, assisted dying will get the time it needs to be fully and fairly debated in the next Parliament; a promise made by both the Conservative and Labour leaders.



# THE CASE FOR CHANGE REACHES 10 DOWNING STREET.

By Molly Pike

Dignity in Dying campaigner Matt Ryan's father, David Minns, launched the Express newspaper's Give Us Our Last Rights campaign in support of law change back in February 2022. David had watched his daughter Katie die in agony from terminal sarcoma not long after he was diagnosed with terminal blood cancer himself. He wanted the choice of an assisted death to avoid a similar fate but, tragically, David's worst fears came true, and he died in pain just a year after launching the Express' campaign.

Matt was invited by the paper to meet Prime Minister Rishi Sunak at Downing Street to ask a question about assisted

dying, saying it was his dad's "dying wish" to see the law changed.

At their meeting, Mr Sunak told Matt how he had been very moved to read David's submission to the Health Select Committee's inquiry into assisted dying, something Matt later said his father would have been "so proud" to hear.

As the political appetite for a full and fair debate in Parliament continues to grow, the public's calls for change are louder than ever. In January, in partnership with Dame Esther and the Daily Express, we launched a Government petition calling for parliamentary time and a free vote



on assisted dying. Our expectations were well and truly exceeded when the petition smashed its 100,000 signature target in less than a month. At time of printing, it has secured the backing of over 200,000 supporters. Thanks to you, a Westminster Hall debate took place on 29th April. During the debate MPs from every major political party voiced their support for a change in the law and even opponents of law change agreed there must be a vote in the next parliament. Full details of the day will be in our next newsletter.

As Media Officer at Dignity in Dying, my phone has been ringing off the hook, with countless journalists wanting to speak to

those who are determined to see the law changed: people like Sophie Blake, who as someone with terminal breast cancer wants the choice for herself, to others like Gareth Ward, whose dad Norman took his own life while dying of prostate cancer. We've secured near-constant coverage across the national newspapers, TV and radio, which is showing no signs of slowing down.

With the help of Dame Esther, Matt, Sophie and Gareth, to mention but a few, our campaign has reached tipping point in the UK. They are giving a voice to many, ensuring the case for law change is impossible for MPs to ignore.

# POLITICIANS COMMIT TO DEBATE.

By Tom Davies

In response to Dame Esther's intervention in December, Michael Gove MP called for assisted dying to be revisited in the House of Commons. Just days later, Labour leader Sir Keir Starmer called for a free vote on the issue. In a phone call with Dame Esther, broadcast on ITV in March, he went further and said ***"I'm personally in favour of changing the law...I think we need to make time. We will make the commitment"***.

Sir Keir's in-depth knowledge of the issue was informed by his previous role as Director of Public Prosecutions (DPP), when he reviewed the files in every case of 'assisting a suicide' that the Crown Prosecution Service was responsible for. When Dignity in Dying campaigner Debbie Purdy won her case to clarify the law surrounding those accompanying loved

ones to jurisdictions where an assisted dying is legal, Sir Keir was responsible for publishing a new prosecuting policy on cases of 'encouraging or assisting suicide'. It acknowledged the compassionate motivations of loved ones who are often begged by dying relatives for help to die.

We later heard from two former Health Secretaries: Conservative Stephen Dorrell and Labour's Alan Milburn, both





backing a change in the law. With Milburn saying ***“When people today expect to have control over so many aspects of their lives, it feels paradoxical that we are denied the same about how we want to die. It’s perhaps the most important decision any of us can make. To deny that choice feels increasingly anachronistic. The time has come for a free vote in parliament on the issue”***.

Dorrell felt that the time wasn’t right when it was last debated, but that attitudes have changed, and his personal view has changed to one of support.

Tory MP Lucy Allan has also challenged the government to prioritise the issue, giving it proper parliamentary time rather than leaving it to the ‘lottery’ of a Private Member’s bill.

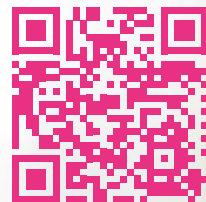
In response, at the aforementioned meeting at Downing Street with campaigner Matt Ryan, Prime Minister Rishi Sunak indicated that he too would allow Parliamentary time for a new debate on assisted dying, stating that ***“if Parliament decided that it wanted to change the law then of course the Government would facilitate doing that in a way that was legally effective”***.

Parliamentarians were then forced to consider the issue again when the Health and Social Care Committee report was published, calling for the Government to engage with the issue given that legislation in the British Isles is coming. Chair of the Committee, Steve Brine said ***“the inquiry on assisted dying and assisted suicide raised the most complex issues that we as a committee have faced, with strong feelings and opinions in the evidence we heard. We intend the information and testimony we present in our report today to have a lasting legacy and, as we set out in the initial terms of reference, be a significant and useful resource for future debates on the issue.”*** Debates which have now been promised from all sides of the political spectrum.



You can watch the ITV interview by typing this URL into your browser or scan the code below on your phone.

[www.dignityindying.org.uk/starmer](http://www.dignityindying.org.uk/starmer)



SCAN ME TO WATCH



# A WEEK OF ACTION.

By **Martyna Wielecka**

*Monday 11th March saw the start of a week of action - a week of focused campaigning by Dignity in Dying supporters committed to making the case for change to their MPs and parliamentary candidates.*

With a General Election on the horizon and both the Conservative and Labour leaders promising to make time for a full and fair debate on assisted dying, we are looking forward to a free vote on the issue in the next Parliament.

Securing time on the agenda for an assisted dying bill in the next Parliament is a crucial step towards legislation. But critically, the MPs who win their seats after the election must vote as a majority in favour in order for a bill to pass. With an issue of conscience like this one, where

MPs will rightly have a free vote, engaging with as many prospective MPs as possible is vital.

The aim of the week was to gather as much information about the views of our future Parliament as possible and share the experiences of our supporters in order to inform parliamentary candidates.

The launch of our ground-breaking new polling, which shows a majority of support for assisted dying in every single constituency in Great Britain, kicked



off the week of activities and captured the attention of MPs and parliamentary candidates. We held a reception in Parliament to showcase our findings, and thanks to your email invitations, 40 MPs, candidates and Peers, many of whom were undecided, came to the event and were visibly moved by the research as well as being personally moved by speaking to people with personal experience of how the current law has failed them and their loved ones. The event and polling reached many more people than those in the room, securing significant media coverage from ITV News, the BBC and the Express journalists in attendance.

Over 1,000 of you said you would write a personal email to your MP or candidate to highlight this new research and nearly 400 said you would ask your MP or candidate for a face to face meeting. We have seen

that many of you have tweeted your MPs with the results of the polling in their constituency, and we know more of you plan to put pen to paper and share the research by letter. We are grateful for all of the campaigning you have undertaken; we know that as a result minds have been changed and politicians have felt the full force of the overwhelming public support for law change.

It's not too late to contact your MP or candidate about the polling if you've not already done so. If you have had a response from your MP or candidate, have a meeting in diary, want to find out the polling results from your constituency to share with those standing for election in your area, or want any support in contacting your MP or parliamentary candidate please get in touch on [activism@dignityindying.org.uk](mailto:activism@dignityindying.org.uk)



# LOCAL GROUP ACTION ACROSS THE UK.

By Fran Hall

Our local campaign groups have been ramping up their efforts in the first quarter of what is set to be a monumental year for the campaign. They've played a huge role in motivating their members to contact as many MPs and candidates as possible as part of our March week of action, as well as continuing to organise a programme of local events up and down the country.

The North London group have been continuing their relationship with the Finchley Reform synagogue, with their latest event 'From the Bedside to the Polling Booth' providing a unique opportunity for parliamentary candidates from three local constituencies to engage with the topic of assisted dying, not only by hearing from the invited speakers, but also from the local community. The attendees heard from Dignity in Dying Chair, Rabbi Jonathan Romain, and Dame Joan Ruddock who spoke powerfully about her personal

experience of the cruel consequences of the current law. The candidates and other participants had an opportunity to ask questions and express their own views, fostering a crucial dialogue at a time when assisted dying is on everybody's minds amid the recent publicity.

The West Berkshire group organised an event in Newbury, gathering 115 people eager to learn more about end-of-life choice. 'Open and Honest Discussion on Assisted Dying' sought to demystify the subject by defining what assisted dying is, exploring the moral and religious questions that surround it, and talking about the proposed law change. The impressive panel of speakers, who tackled a variety of interesting and challenging questions, included Kit Malthouse MP, former Archbishop of Canterbury Lord Carey, and retired intensive care consultant, Barry Newman.



Local groups are now using online tools to reach and inspire more people keen to engage with the campaign. The Nottinghamshire and Derbyshire groups held an online 'town hall' meeting on 21st February to encourage people to join each of their respective groups, sign the Government petition, and contact their MP or candidate. We plan to roll out town hall meetings across different regions of the UK, so do keep an eye out for one in your area.

While the Nottinghamshire and Derbyshire groups turned to technology to engage more supporters, community stalls and events remain the backbone of local campaigning. The Bath and Bristol group created posters of the names of absent group members to be photographed at the

stalls, allowing supporters to be counted, and be there in spirit, even if they cannot be there in person, visually demonstrating support. Campaigners unable to attend the events can send a photo of their poster at the stall when they next contact their MP, showing not only their personal stance but also that they are part of a movement of people in their local community all calling for change. This brilliant idea has been shared with the wider network of campaigners, and we are looking forward to seeing it replicated far and wide.

If you're interested in joining your local group or simply finding out more about what they do, please visit [www.dignityindying.org.uk/local](http://www.dignityindying.org.uk/local)

# GROUND-BREAKING POLL: EVERY CONSTITUENCY BACKS ASSISTED DYING.

By Bethany Fieldhouse

The majority of the public in every parliamentary constituency in Great Britain support a change in the law on assisted dying. Our ground-breaking poll by Opinium, the largest and most in-depth ever conducted in the UK, revealed consistently high levels of support for legalising assisted dying from voters of every political persuasion.

The polling canvassed the views of more than 10,000 people across the UK, and analysis of respondents based on both household income and home ownership suggest that these factors do not affect the desire to see a change in the law, with support amongst all groups around three-quarters in favour. Similarly, a consistent majority recognise that legalising assisted dying would be safer than our current situation.

The poll also asked respondents about travelling to Switzerland to access assisted dying. Our *Time for Choice* report published last year found the average cost of arranging this has risen to around £15,000 in recent years. The response highlighted that although a majority of people would consider going to Switzerland for an assisted death if they were terminally ill, most people would not be able to afford it. This highlights that under the current law, access to choice at the end of life is dependent on a person's wealth.

This new data shows that the appetite for change in the UK is high across

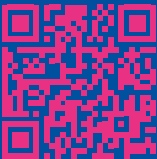
the board, uniting the country across demographics where we are often divided. The current outsourcing of assisted dying to Switzerland guarantees inaccessibility to the majority of the population and forces those who can't afford it to endure suffering against their will. This is unfair on us all, but particularly on those people considered 'working class', who in our poll were the most likely to be 'strongly supportive' of law change.

These results add robust data to support what we already knew, that the vast majority of the public support a change in the law on assisted dying. A closer look at the details confirm that these calls are coming from all corners of society, from every political affiliation, and it is time for our lawmakers to listen. Any MP, or incoming MP, can confidently take part in this debate. They can vote in favour knowing that whether left wing or right wing or anywhere in between, their constituents are crying out for this reform.





# EVERY SINGLE CONSTITUENCY IN GREAT BRITAIN SUPPORTS ASSISTED DYING



You can read the full  
polling results and search a  
map of the data here:

[www.dignityindying.org.uk/mrp](http://www.dignityindying.org.uk/mrp)

# ASSISTED DYING LAW FOR UK NOW A MATTER OF 'WHEN' NOT 'IF'.

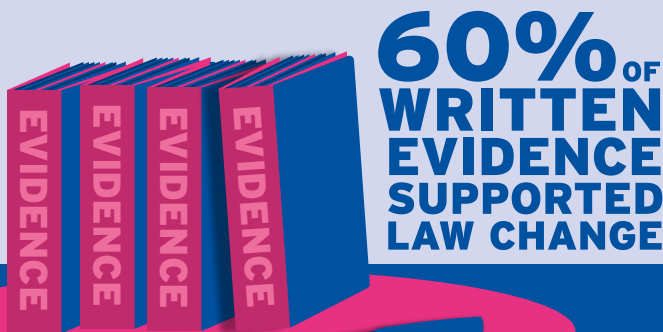
By Upeka de Silva

The first ever House of Commons inquiry into assisted dying revealed evidence that the current blanket ban on assisted dying is dangerous and cruel and calls on the Government to engage in the debate as reform becomes increasingly likely across the British Isles. The Health and Social Care Committee's report, published on the 29th February 2024, led to mass media coverage and shifted the prospect of an assisted dying law for the UK from a hypothetical to a reality.

Since the inquiry launched in December 2022, a cross-party committee of MPs gathered evidence from a range of national and international experts including parliamentarians, clinicians, academics and dying people and their loved ones.

Frontline experts from countries where assisted dying is legal provided substantial evidence showing these laws are effective and popular, benefiting from robust safeguards that protect dying people. Even opponents of assisted dying conceded to the Committee that there is a case for a tightly controlled law focused on terminally ill, mentally competent adults, like the laws that exist in Australia, New Zealand and parts of the US.

Our analysis shows that around 60% of all evidence submitted to the inquiry was in favour of reform, while every terminally ill person involved in the Committee's roundtable sessions said that the law must change.

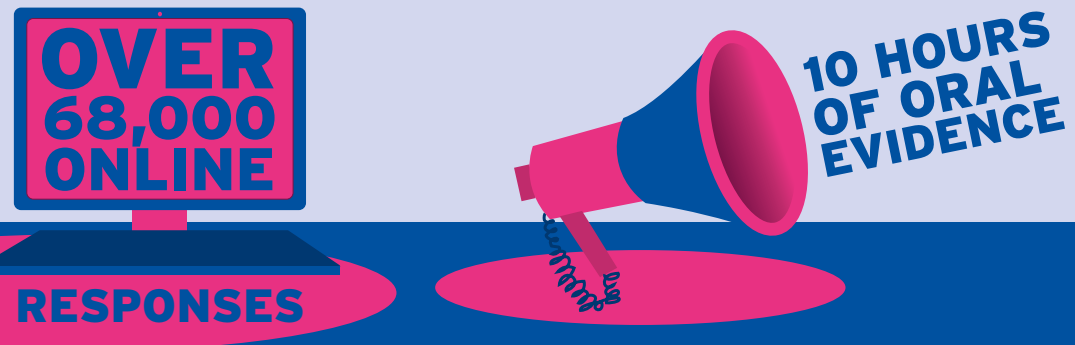




## KEY FINDINGS OF THE INQUIRY:

- **Palliative care cannot relieve all suffering.** The Committee found “there is not currently a medical intervention available to manage every symptom or pain”.
- **Assisted dying can improve end-of life care.** The Committee did not see any indications of palliative and end-of-life care deteriorating in quality or provision following the introduction of assisted dying; indeed, law change has been linked with an improvement in palliative care in several jurisdictions.
- **There are two distinct models.** The Committee established that although there are many ways different laws can operate, there are two distinct models: one focused only on terminally ill adults, and the other adding provision for unbearable suffering.
- **There is no ‘slippery slope’.** The Committee concluded that jurisdictions which have introduced assisted dying on the basis of terminal illness have not changed the law to include wider eligibility.
- **Law change is coming to the British Isles.** The Committee found that it looks increasingly likely that at least one jurisdiction among the UK and Crown Dependencies will allow assisted dying and called on the UK Government to consider how to respond.

The value and strength of this report is a result of your passionate and generous engagement with the Inquiry. You helped to ensure that the voices of people directly impacted by the current blanket ban on assisted dying were heard - thank you.





# JERSEY AND ISLE OF MAN LEAD THE CHARGE.

By Tom Davies

Momentum is building for change, and both Jersey and the Isle of Man are leading the charge - recognised in the recent Health and Care Committee report, which told the British Government to take an active role in the debate, given that change is coming. We couldn't have reached this critical point without our supporters. Every action taken by individuals brings us one step closer to a compassionate assisted dying law, as evidenced by the people of Jersey telling their Government that they needed to stop dragging their heels, and they have, with a debate on the proposed law due in late May.

If the proposals are approved at the vote, the Jersey Government anticipates that the legislation will take between a year and a year and a half to draft and will then be introduced to the States Assembly for final debate and scrutiny.

There has been an extensive and thorough consultation process in Jersey already, following a citizens' jury that in September 2021 recommended by a large margin that assisted dying should be legal on the island. In November 2021 the States Assembly agreed in principle that it should be legalised, and the Government then



launched a consultation with islanders and experts. Over the summer last year, an ethical review was also established, which in November 2023 declared that legalising assisted dying as a choice for terminally ill people was 'ethically appropriate', among other findings.

In the Isle of Man, the Manx Parliament, Tynwald, continues its work of scrutinising the Bill put forward by Dr Alex Allinson. In October, the House of Keys - the Isle of Man's elected Chamber - approved the Assisted Dying Bill at Second Reading and a special committee was established to look at some of the issues raised during the debate. Its report has now been published, suggesting amendments to strengthen the Bill, which will now be debated. Following that, the Clauses stage will provide further scrutiny of the Bill and amendments may be put forward.

While this legislation is rightly being drafted clause by clause, carefully considering every safeguard, dying people who want choice in how they die are currently left in a legislative no man's land that is unfair, unequal, and unsafe. Those with the means to do so can travel to Switzerland to die, costing on average £15,000, but this forces dying people to cut their lives short so they can travel while they are still well enough. Dying people facing a painful and protracted death who cannot afford, or do not wish to make, this traumatic journey, are left to face extreme suffering, or even consider ending their own lives behind closed doors.

A carefully considered assisted dying law, such as is being drafted for the citizens of Jersey and the Isle of Man, will be far safer and more just than the current situation.

78% OF SCOTS  
**SUPPORT**  
ASSISTED DYING





# SCOTLAND'S ASSISTED DYING BILL REACHES HISTORIC MILESTONE.

By Ally Thomson

Liam McArthur MSP, who was granted the right to introduce an assisted dying bill to the Scottish Parliament in October 2022 having receiving backing from 36 MSPs (double the required number) has now formally published his Bill - The Assisted Dying for Terminally Ill Adults (Scotland) Bill. This is an important milestone towards a safe and compassionate assisted dying law in Scotland. If passed, this Bill will mean that, for the first time, dying people in the UK will have meaningful choice at the end of their lives.

In Scotland, pollsters Opinium asked more than 4,000 Scottish people for their views and found significant majority support for assisted dying in every Scottish Parliament constituency and electoral region, with 78% of Scots confirming that they would support an assisted dying law in line with Liam McArthur's Bill.



In addition, the polling found that more than half of Scots, 55%, would personally consider travelling to Switzerland for an assisted death if they were terminally ill, but 57% would not be able to afford it, with costs increasing to £15,000 in the last five years.

**Liam McArthur, who is Liberal Democrat MSP for Orkney, said:**

***“Currently in Scotland assisted dying is illegal, a situation that I believe is failing too many terminally ill Scots at the end of life. It is leaving them facing traumatic deaths that impact not just them, but those that they leave behind. We can and must do better. That is why I am publishing my bill on assisted dying.***

***“For many years, polling has consistently shown overwhelming support for assisted dying. I believe we are now seeing the necessary political support, across all parties, to deliver this long overdue reform. The provisions I am proposing would be robustly safeguarded to ensure the process works as intended. Similar laws have been safely and successfully introduced in countries such as Australia, New Zealand and the United States where they continue to enjoy strong public support.***



***"I hope that as they consider the provisions of the Bill, my colleagues will look at the evidence supporting a change in the law and the wishes of dying Scots and vote to give terminally ill adults the choice they need."***

Under the proposed legislation, assisted dying will only be available to terminally ill, mentally competent adults, who have been resident in Scotland for at least 12 months and are registered with a Scottish medical practice, meaning non-residents could not travel to Scotland for an assisted death, like currently happens in Switzerland.

The Bill will set out the strict safeguards that will be in place for someone requesting an assisted death, including assessment by two independent medical practitioners, self-administration, stringent capacity checks, and a 14-day period of reflection following their initial request, which must come from the patient themselves. If the Bill passes, the legislation would be reviewed every five years to ensure it remains fit for purpose.

Following the publication of the Bill there was a flurry of media coverage, leading to people sharing their personal reasons for supporting the Bill. Valerie Fischbacher shared her experience in witnessing her beloved husband Graham, who was diagnosed with oesophageal cancer in September 2023, die in pain just four months later, having pleaded with her to end his suffering.

They tried to manage his symptoms at home, but his pain was unmanageable, so he was moved to a hospice. Valerie felt, despite this specialist palliative care, pain management was never fully achieved. Because of this experience and having had previous experience of family members who died from motor neurone disease, Valerie would like to see Liam McArthur's Bill enacted. She thought her husband's terminal diagnosis may have changed her mind; instead it strengthened her feelings in favour of assisted dying.

The Bill was formally published on Thursday 28th March 2024, and is now subject to Committee Scrutiny ahead of a Stage 1 Vote in the Scottish Parliament. After this the Bill can progress to Stage 2, where any amendments proposed by MSPs would be debated and decided on. If any amendments are agreed to at Stage 2, an amended version of the Bill would be published and considered at Stage 3; the final debate and vote before it would become law.

Scotland's progress comes as momentum builds in the Isle of Man, Jersey and Westminster. The Health and Social Care Committee highlighted that these laws are already working safely in many countries around the world, with tight safeguards that benefit and protect dying people, and improve end-of-life care as a whole. It's time dying Scots are afforded that compassion.



# REMEMBERING ROSEMARY WALKER.

By Molly Pike

*In February we heard the sad news that Rosemary Walker had died.*

Rosemary joined the campaign in early 2023, after she was diagnosed with myeloma, a bone marrow cancer. She endured gruelling treatment for this and for a previous colorectal cancer, often experiencing horrific pain. She feared dying a prolonged, traumatic death and wanted the choice of an assisted death; to go on her own terms, in a place that she loved.

Rosemary had planned to travel to Switzerland to die at Dignitas, and while she recognised that she was fortunate to be able to afford this option, she resented the fact that her only option was to leave the country in order to have choice over her death.

Rosemary longed to die at her home in Saddleworth looking at the stunning views of the Pennines and her beloved prize-winning garden; her "sanctuary".

A life-long campaigner, Rosemary set up the Northern Older Lesbians group and worked as a trustee of an LGBT trust focusing on advocacy and befriending. She was a much-loved member of her local community in Saddleworth, a place she said was a huge part of her identity.

After many years of campaigning for equal rights, Rosemary recognised that the current law is unequal and unfair, with only a privileged few able to afford the up to £15,000 it now costs to die at Dignitas.





When she joined Dignity in Dying Rosemary knew that the law wouldn't change in time for her, but she bravely took a stand for all of the people who would come after her.

Last year, Rosemary travelled to London to attend Dignity in Dying's reception in the House of Lords, which was hosted by Dame Prue Leith. By this time, Rosemary had lost much of her mobility due to her illness, but she was determined to be there to share her story with MPs and ask them to pledge to make time to debate assisted dying.

Rosemary also shared her story with the media, first being interviewed and photographed by the Guardian in her beloved garden, and later by ITV News. She

raised money for both Dignity in Dying and Compassion in Dying and engaged friends and neighbours in the campaign whenever she could.

Rosemary became too unwell to travel to Dignitas, and not long after gathering her friends for a night in her local pub to say goodbye, Rosemary died at home.

Rosemary was a warm and generous woman who made a big impact on everyone at Dignity in Dying. She will be greatly missed.

# CELEBRATING ROB.

By Liz Reed

I'd like to share my brother Rob's story with you. Rob lived in Australia, whereas I'm based in the UK, and our laws around assisted dying are very different.

In October 2022 Rob was diagnosed with terminal lung cancer, aged just 39. He was young, fit and healthy, and had two young children. After his diagnosis he quit his job and decided he would enjoy and cherish whatever time he had left with his family.

Six months later his health began to deteriorate rapidly. Fortunately, not only for him, but also for his family, he lived in Queensland, Australia, where assisted dying is legal. He set in motion plans to end his life on his own terms, whilst he still could, with the dignity and respect he deserved.

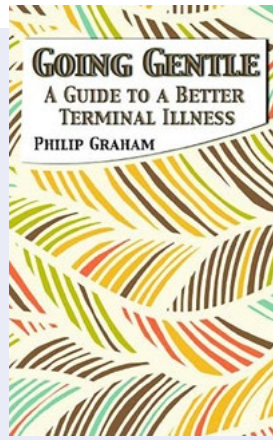
During his final months he lived his life to the fullest, enjoying the sun, the sand, and the surf that Australia is famous for, and made memories with his young family and friends, that they could carry with them after his death. On the 21st August, after a lunch of ribs and chips, a few laughs and a cup of champagne with his wife, our parents, and me, Rob ended his life peacefully and painlessly, without fear, surrounded by love.

Had he lived in the UK, this horrible illness could have robbed him of who he was. His young sons would have had the few memories they do have of their big, strong, funny Daddy, clouded. Alternatively, he would have had to have travelled abroad, alone and at great expense, to have the death he chose.



In celebration of Rob's life and courage we have raised £8,500 to support Dignity in Dying.

Rob was an avid rugby player, and his teammates organised a charity match in his memory in December. The players and crowd remembered Rob with one minute's applause at the start, and although no one took much notice of the score, we laughed, shared stories and had a good sing in the bar afterwards - Rob would have loved it. Every dying person should have the choice of a death as dignified and calm as Rob's was, and that's why we will continue to support Dignity in Dying's campaign for greater choice at the end of life.



## BOOK RECOMMENDATION

From Sarah Wootton

Professor Philip Graham, doctor and former Chair of Dignity in Dying, has published a thoughtful new book; *Going Gentle: A Guide to a Better Terminal Illness*. Based partly on interviews with close relatives of 20 of his friends who have recently died, this book acts as a helpful guide, covering topics such as improving communication between health professionals and family members, as well as between family members themselves, how you might navigate the situation when a terminally ill person has dementia, and practical matters such as sizing down, writing a memoir, making a will and planning a funeral. It also includes an interesting discussion on assisted dying in the chapter 'choosing the time you die'. Professor Graham will kindly be donating profits from sales to Compassion in Dying. Available from Amazon, and all good book sellers, £10.99





**ASSISTED  
DYING IN  
SCOTLAND:  
MY USA TRIP  
CONVINCES ME  
WE ARE RIGHT.**

By Liam McArthur, Liberal Democrat  
MSP for Orkney

I had the privilege of leading a cross-party delegation of Members of the Scottish Parliament (MSPs) to California in February 2024 to learn more about how assisted dying laws are working throughout the state, meeting families of people who had used the law, doctors and specialists, and the senators who wrote the act. The California End of Life Option Act came into force in 2016 and gives dying citizens the choice of an assisted death should they meet strict eligibility criteria.

Like the bill I will introduce to the Scottish parliament, the Californian law is open to terminally ill, mentally competent adults only. Other similarities include self-administration of medicine and the agreement of two separate doctors. Every bit of personal testimony was compelling and served to deepen my conviction that this choice must also be extended to dying Scots.

Without exception medical professionals emphasised that patients choosing aid in dying are not choosing between life and death: their illness has taken that choice away. It's simply a question of how much suffering they want to endure.

Interestingly they also pointed to evidence that about a third of patients who are approved for an assisted death do not go on to take the medicine. The knowledge that they can, should they need to, has a tangible palliative effect: lessening distress and fear. With choice comes peace of mind.

Evidence suggests that patients don't opt for an assisted death instead of palliative care. Instead, the vast majority are enrolled in palliative care and when they reach their limit use aid-in-dying as a part of that care.

The most powerful testimony we heard came from the loved ones of those who had an assisted death. Dan Diaz told us how he and his wife, Brittany Maynard, moved from

their home in California to Oregon in 2014, after she was diagnosed with brain cancer, aged 29.

Assisted dying has been legal in Oregon since 1997. Brittany's case attracted widespread media attention, captured the public imagination and was pivotal in California and several other states subsequently passing their own laws.

Dan's story about the obstacles they faced reminded me of conversations I've had with dying people here in Scotland, facing desperate decisions in the absence of a compassionate and safe law.

Senator Susan Talamantes Eggman and former Senator Bill Monning provided invaluable insights on the legislative process, underscoring the careful attention paid to ensuring that the law worked to give dying citizens what they needed while applying appropriate safeguards. In the seven years since the act came into force there has been no evidence it is not working as intended, nor has it been extended.

Jerry Brown, the governor in post at the time said: ***"I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."*** A sentiment I hope will be adopted by MSP colleagues across the parties when my bill comes before them later this year.

# Compassion in Dying.

Your end of life. Your way.

# Compassion in Dying's 2023 Impact Report

By Jennifer Noel

At Compassion in Dying, Dignity in Dying's sister charity, we recently published our first Impact Report showcasing our work in 2023. It outlines the problems people are facing, the difference our services make, and the wider impact our research has on health and social care policy.



## 2023 - our year in numbers



**4,007** people supported through our nurse-led information line



**30** people given in-depth support to advocate for their loved ones



**Two** new public-facing services opened



**One** new website launched



**4,330** people supported to make an advance decision



## Supporting people

We support people to make informed decisions, start honest conversations about death and dying with loved ones, and record and revisit their wishes whenever they want to.

## Amplifying voices, driving changes

Everything we do starts with what dying people tell us. We listen to what they say and amplify their voices. We shift attitudes and drive changes to the healthcare system. So people's end-of-life decisions are heard, understood and respected when it matters most.

“Over several phone calls, Compassion in Dying’s nurse gently helped me to understand that having an advance decision wasn’t giving up on my husband, but supporting and empowering him when he needed me the most. When those sad days actually came, I felt confident I could make sure his wishes were followed. In the end, having thought about and recorded his wishes before a crisis, saved his death.”

**Elizabeth, Information Line caller**

## Highlights from our research and policy work:

### A call for national clinical and public guidance on voluntarily stopping eating and drinking (VSED).

Some dying people tell us that they are considering VSED. They turn to us because, here in the UK, there is no clear information to help people and clinicians make informed decisions together. They face problems finding trustworthy information about what it would be like, accessing support with symptom management, and sometimes face wrongful detainment under the Mental Health Act. We launched a call for guidance so that people making complex end-of-life decisions can have the right support in place.

“Voluntarily stopping eating and drinking is not an easy process. Mum was forced to endure not one but two battles. Foregoing food and water, and also convincing professionals that she wished to die the way she lived - on her own terms.”

Annie, who supported her mum through VSED

## Campaigning to overhaul the way end-of-life wishes are shared electronically.



Almost everyone we speak to wants an easier way for healthcare professionals to see their end-of-life wishes. How and whether this vital information is available to clinicians is a postcode lottery. We conduct research and campaign to change the way end-of-life records are shared electronically. So that peoples' decisions can be accessed when it matters most.



See our full impact report at

[www.compassionindying.org.uk/impact](http://www.compassionindying.org.uk/impact)



Please, will you donate now to support our work?

Demand is only increasing, yet our team is stretched to capacity helping dying people make the decisions that are right for them.

[www.compassionindying.org.uk/donate-impact](http://www.compassionindying.org.uk/donate-impact)





# What people need from a DNR decision and discussion

By Upeka de Silva

Compassion in Dying was commissioned by the Parliamentary and Health Service Ombudsman to conduct research into older people's experiences of do not attempt cardiopulmonary resuscitation (known as DNR) decisions – a topic that callers to our free nurse-led information line regularly need support with.

DNR forms are used by healthcare professionals to communicate that a decision has been made not to attempt resuscitation, a helpful way to protect people from being given potentially harmful, futile or unwanted treatment. Sometimes these decisions are recorded on a RESPECT (recommended summary plan for emergency care and treatment) document.

We held in-depth focus groups with older people from across England to explore what is happening for people when DNR conversations occur, and what they would like to see done differently in the future.

Our research found that DNR decisions are an important part of end-of-life care, but the system isn't working for everyone.

We found those who had a good experience were grateful for the opportunity to consider their wishes. Many felt peace of mind, even if the conversation was challenging at first. They talked about trust, honesty, respect and feeling like an equal partner in the conversation.



“What matters most is ensuring my family don’t have to make hard decisions about me and my health.”

“The consultant dealing with my wife’s dialysis was very good - towards the end of our first annual review she said, ‘don’t be alarmed, I’m not saying it’s going to happen tomorrow but if your heart were to stop I don’t think it would be a good idea for you to have CPR. We don’t need to make a decision now so why don’t you go away and talk about it and next time we meet, we can discuss it further along’. At first, we were taken aback and surprised but on reflection it seemed a very sensible and humane thing to have done.”

#### Focus group participant

For those who had a poor experience, the impact was often significant, and it left a lasting mark on the lives of the people affected.

“A doctor had put a DNR in place using the RESPECT form for my husband who was in the latter stage of Alzheimer’s. I was not aware of the decision being made and found out accidentally. I felt devastated that no-one had contacted or included me for involvement in the decision. I take a realistic view and appreciate the risks

in CPR on a frail person but I should have had the right to be involved in decisions.”

It was revealing that regardless of whether their experience was positive or negative, everyone we spoke with saw the value of a DNR decision, once they had been given time and support to understand why these decisions exist and the realities of CPR. Everyone wanted to play an active role in such a conversation.

When asked how they would redesign the DNR process, people spoke passionately and consistently about their wish for DNR discussions and end-of-life conversations to happen earlier, before a crisis, and to be a normal and expected part of life.

“There needs to be training for all health practitioners, and the training should be about communication, and the absolutely vital need to be compassionate, to be respectful, and to have empathy.”

The work to improve DNR decisions and conversations remains urgent and unfinished. So, we will continue to listen to the people we support and work with partner organisations to make sure that real experiences inform the improvement of policies and practices around DNR.

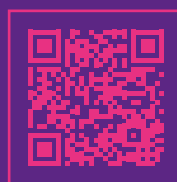
Visit: 

[www.compassionindying.org.uk/  
resource/what-people-need-dnacpr/](http://www.compassionindying.org.uk/resource/what-people-need-dnacpr/)



# GIFTS IN WILLS ARE VITAL TO THE CAMPAIGN

Find out more in our free booklet



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- Definitions of common Will writing terminology
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