

# CAMPAIGN



Issue 1 of 3 2015

## VALUED CAMPAIGNER AND LOVING FRIEND, DEBBIE PURDY.

1963 - 2014

CAMPAIGN FOR  
DIGNITY  
IN DYING.

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**SARAH WOOTTON**

Chief Executive

## WELCOME.

**I** must start with the sad news of Debbie Purdy's death over the Christmas period. For over a decade Debbie was a huge presence at Dignity in Dying; from stuffing envelopes to leading her legal challenge, she was an integral part of the campaign and a dear friend. We will miss her greatly. You can read more about her life and impact on the campaign on the next page.

With three days debating Lord Falconer's Assisted Dying Bill in the House of Lords under our belt in the 2014-15 parliamentary year, the campaign is making progress. At the time of going to press, the second day of Committee saw a significant victory for the campaign in the House of Lords when nearly two thirds of peers vote in favour of a change in the law, you can read more about this on page 10

On the first day of Committee in November the House of Lords accepted an amendment to the Assisted Dying Bill, tabled by Lord Pannick and subsequently supported by Lord Falconer, which introduced the new safeguard of judicial oversight. I think this is a constructive way forward for Parliament because it helps to build consensus on the need to change the law and it puts pressure on those who, rather than identify appropriate safeguards, have placed barriers in the way of dying people having control over their death (read more on page 13).

We are winning the argument about whether the law should change, the debate is now shifting towards the specifics of the Bill, and how it will work in practice. Those who oppose assisted dying will be sticking their heads in the sand if they do not realise change is coming. It is time for them to start engaging with the debate helpfully, as we prepare to bring an Assisted Dying Bill to the House of Commons after the General Election in May.

Recognition that the tide is turning in our favour is demonstrated by the medical profession starting to catch up with the opinion of the general public. November saw the Deputy Chair of the British Medical Association (BMA) write in the Observer (acting in a personal capacity) about his support for a change in the law. In addition the

recent result of a major survey of the Royal College of Physicians' members showed that over a third would support an assisted dying law. It cannot be justified that the majority of Royal Colleges still remain opposed to a change in the law, they should move to neutrality to accurately reflect the range of opinions among their members (read more on page 16).

In December, Dignity in Dying's sister charity, Compassion in Dying, which I also lead, launched a new information guide, *Planning ahead: making choices for the end of life*. This explains how everyone has the right to make decisions about their health and care, even if they lose capacity at a later point in life. A November poll found that the majority of adults in Britain wish to make their own decisions about their end-of-life care, with only seven per cent wanting a doctor to have the final say, yet despite this 92 percent have not made a record of their preferences in an Advance Decision or appointed a Lasting Power of Attorney. *The Planning Ahead* guide for England and Wales is clearly laid out with practical information empowering people to make their own decisions (read more on page 22).

Best wishes,

# OUR PATRONS DEMAND A CHANGE IN THE LAW.

**O**n 29th December in a letter to The Telegraph nearly 80 Dignity in Dying patrons, including leading doctors, writers, actors, clerics and politicians, said an “overwhelming majority” of the public now supports a change in the law on assisted dying. The letter emphasised that it is Parliament’s duty to allow sufficient debating time to finally resolve the issue.

The signatories included: authors Julian Barnes, Ian McEwan CBE, comedians Jo Brand, Eric Idle, actors Sir Patrick Stewart, Hugh Grant, Sir Jonathan Miller CBE, key political figures Rt Hon Sir Richard Ottaway MP, Caroline Lucas MP, Sir Chris Woodhead, religious figures Rt Rev & Rt Hon Lord Carey of Clifton and academics Sir Michael Rawlins and AC Grayling.

“SIR – This year significant progress has been made in the campaign to legalise assisted dying for terminally ill people.

In light of pressure from the Supreme Court, Lord Falconer’s Assisted Dying Bill unanimously passed its Second Reading in the House of Lords, and at Committee Stage the majority of peers engaged

constructively, rather than seeking to block its progress. To that end, an amendment was agreed to include the additional safeguard of judicial oversight. If there is not enough time for the Bill to complete its stages before the General Election then it is imperative that Parliament continues this important debate afterwards.

Currently one Briton a fortnight is travelling to Dignitas. For each person who travels abroad, ten terminally ill people are taking their own lives in this country. The 2014 Reith Lecturer Dr Atul Gawande has commented on assisted dying, “we are heartless if we don’t recognise unbearable suffering and seek to alleviate it”. The overwhelming majority of the public supports law change on assisted dying, and no one believes that someone should face a prison sentence of 14 years for compassionately assisting a loved one to die.

We are closer than ever to allowing dying people to have safeguarded choice in how they approach their deaths. Whoever forms the next Government must allow time for Parliament to reach consensus on a safeguarded law.”•

## IN LOVING MEMORY OF DEBBIE PURDY.

BY DAVINA HEHIR

1963-2014



**D**ignity in Dying campaigner Debbie Purdy, died on 23<sup>rd</sup> December, aged 51. She lived with primary progressive multiple sclerosis (MS) for almost 20 years and died at a hospice in Bradford.

Shortly after Debbie’s diagnosis in 1995 she began to think about choice and control over her death, should she consider her suffering unbearable. She decided to make a difference and brought her case to the UK courts.

Debbie argued that it was a breach of her human rights not to know whether her husband, Omar Puente, would be likely to be prosecuted if he accompanied her abroad to die. Ultimately she was seeking peace of mind that her wishes would be respected, but also that her decisions would not risk the imprisonment of her husband. She wanted this not only for herself but for others in her position in the future.

Despite initial setbacks Debbie fought on and in 2009, with Dignity in Dying’s support, Debbie won her case in the House of Lords. This victory resulted in the publication of prosecuting guidance making it

clear that a loved one acting wholly on compassionate grounds and in an amateur capacity is unlikely to be prosecuted for helping a person with a clear and settled intention to die.

In the end, despite the success of her case, Debbie rejected the option of travelling abroad to die, instead wanting to die in this country, and chose to hasten her death by intermittently stopping eating.

Debbie was one of the first Dignity in Dying members I spoke to when I started working here and even in that first phone call she made a huge impression. Her warmth and passion had an impact on people – many times when I was with Debbie, people she didn’t know would come up and congratulate her on the case, and on her bravery in actually talking about dying in public.

Debbie leaves a legacy of greater clarity in the law and an increased awareness of the need for more choice at the end of life. Debbie Purdy was always thoughtful and never shied away from arguing her point, one of the reasons why she was such an impassioned campaigner. She will be sorely missed. •

“My dearest wish would be to die with dignity in my own home, with my husband and other loved ones around me. I hate the idea of having to travel to another country when I will be at my weakest and most vulnerable, both emotionally and physically”

## DEBBIE PURDY: IN HER OWN WORDS.



### Debbie speaking before her case reached the High Court in 2008:

*“I am not asking for the law to be changed so it is made compulsory for people at the end of their lives to be dragged off to the knacker’s yard. But for those with insufferable pain, this should be one of the choices available and for it to be available we need to be clear on the law.”*

*“My dearest wish would be to die with dignity in my own home, with my husband and other loved ones around me. I hate the idea of having to travel to another country when I will be at my weakest and most vulnerable, both emotionally and physically.”*



### Debbie speaking outside the House of Lords in 2009, after winning her case in front of the Law Lords:

*“It means my life will be longer, because without this new policy I would have to go to Switzerland earlier under my own steam without any assistance. It now means I can ask my husband for some help “*

*“If the DPP will now clarify the difference between malicious encouragement of suicide and pressuring somebody to end their life early and compassionately assisting someone who has made a decision, who is competent, somebody who is able to make a decision. Someone like me. Somebody who would like help and support to die, who wouldn’t otherwise be able to carry out their wishes.”*

### Following the DPP’s change in policy in 2010:

*“I’m ecstatic - I feel like I’ve been given a reprieve. This decision means that I now don’t have to think about travelling abroad to die in the near future. I want to live my life to the full, but I also don’t want to suffer unnecessarily at the end of my life. This judgement means that Omar and I can make an informed decision about whether I go abroad to die and whether Omar should accompany me in light of a clear prosecuting policy. I am so thankful to the Law Lords for listening and rising to the challenge that this case presented.”*

### While residing at the Marie Curie hospice in 2014:

*“The few years since that historic moment, have been truly wonderful; time to spend with my husband, meals with friends, and trips around Britain, even abroad (well, it was a plane that took me to Belfast), none of which would have happened without the House of Lords and Keir Starmer (then Director of Public Prosecutions) giving me permission to ask for help when, and if, I needed it. I would have ended my life by myself in 2009, rather than allow my husband, Omar, to face legal problems later.” (from Debbie Purdy’s article in the Independent newspaper 04/01/15)*

### On putting pressure on Parliament to act on a change in the law:

*“The guidelines were great as far as they went, but they were not embodied in law, rightly so; only the House of Commons can do that. But it seems our elected representatives would rather risk our lives than their jobs and have consistently refused to consider legislation that would help make many deaths more tolerable. Lawyers should not be responsible for, or allowed to, make the rules by which we live.” (from Debbie Purdy’s article in the Independent newspaper 04/01/15).*

# “I WANT TO DIE ON MY OWN TERMS” - BRITTANY MAYNARD.

BY BRITTANY MAYNARD



**In the spring of 2014, 29-year-old American Brittany Maynard learned that she had terminal brain cancer. After careful assessment of her prognosis and end-of-life options, she and her family reluctantly decided to move from their San Francisco Bay Area home to Oregon, one of five American states that allow assisted dying. Here is Brittany’s story in her own words:**

On New Year’s Day, after months of suffering from debilitating headaches, I learned that I had brain cancer. I was 29 years old and been married for just over a year, at the time my husband and I were trying for a family. But my doctors had given me a prognosis of just months to live.

Because my tumour is so large, doctors prescribed full brain radiation. I read about the side effects. The hair on my scalp would have been singed off. My scalp would be left covered with first-degree burns. My quality of life, as I knew it, would be gone.

After months of research, my family and I reached a heart-breaking conclusion: there is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left.

Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have suffered - with no means

to control the pain - for weeks or even months, while my family watched.

So I started researching death with dignity. It is an end-of-life option for mentally competent, terminally ill patients with a prognosis of six months or less to live. It would enable me to use the medical practice of aid in dying: I could request and receive a prescription from a physician for medication that I could self-ingest to end my life if the dying process becomes unbearable.

I quickly decided that death with dignity was the best option for my family and I. We had to uproot from California to Oregon, because Oregon is one of only five states where death with dignity is authorised.

I’ve had the medication for weeks. I am not suicidal. If I were, I would have consumed that medication long ago. I do not want to die. But I am dying. And I want to die on my own terms.

I would not tell anyone else that he or she should choose death with dignity. My question is: Who has the right to tell me that I don’t deserve this choice? That I deserve to suffer for weeks or months in tremendous amounts of physical and emotional pain? Why should anyone have the right to make that choice for me?

Now that I’ve had the prescription filled and it’s in my possession, I have experienced a tremendous sense of

relief. And if I decide to change my mind about taking the medication, I will not take it.

I plan to celebrate my husband’s birthday on 26th October with him and our family. Unless my condition improves dramatically, I will look to pass soon thereafter.

**f Brittany Maynard controlled her death on Saturday 1st November.**

**She posted a final message on Facebook:** Goodbye to all my dear friends and family that I love. Today is the day I have chosen to pass away with dignity in the face of my terminal illness, this terrible brain cancer that has taken so much from me ... but would have taken so much more.

The world is a beautiful place, travel has been my greatest teacher, my close friends and folks are the greatest givers. I even have a ring of support around my bed as I type.

Goodbye world. Spread good energy. Pay it forward!

Thank you to Brittany’s family for allowing us to share her story. If you have personal experience of why the law needs to change please get in touch with Mickey Charouneau by email Michael.Charouneau@dignityindying.org.uk or call him on 020 7479 7732. You can read more about the assisted dying campaign in the US on page 21.

# WHAT HAPPENED AT THE BILL'S COMMITTEE STAGE?

BY THOMAS DAVIES

## ASSISTED DYING BILL RECEIVED ITS FIRST DAY OF DEBATE IN COMMITTEE STAGE IN THE HOUSE OF LORDS ON FRIDAY 7<sup>TH</sup> NOVEMBER.

The Committee Stage allows for members of the House of Lords (peers) from all parties to make suggestions on how to amend draft legislation. Many peers took the opportunity to do so, with almost 200 proposed amendments for debate. Some of these were well-intentioned, aimed to improve the Bill's safeguards. Others were clearly designed to make the Bill unworkable or were intended to waste time and therefore slow down the Bill's progress through Parliament.

## JUDICIAL OVERSIGHT, BUT IN WHAT FORM?

The main subject for discussion was on the proposal for judicial oversight, with a High Court judge having oversight of whether the safeguards and criteria had been met. This was a recurrent theme during the Second Reading debate, with support for such an amendment from peers who spoke both in support and others against the Bill.

Two rival groups of amendments were put forward – one by Lord Pannick, a long-standing supporter of change [see page 13 for more on this amendment], and one by Lord Carlile, who is opposed to changing the law. Lord Carlile's amendments would have provided a complicated, difficult and potentially very expensive process. As Baroness Mallalieu said in the debate, Lord Carlile's model would:

“...appear to present a bureaucratic, legalistic obstacle race which is bound to be both lengthy and costly to the applicant.”

Many peers who had been opposed to the Bill at Second Reading suggested that they could accept the Bill with the addition of the judicial oversight proposed by Lord Pannick. Lord Winston and Lord Condon both agreed that introducing judicial oversight addressed many of their previous concerns.

After agreement from the Bill's sponsor, Lord Falconer, Lord Pannick put his group of amendments to a vote and they were agreed upon unanimously. Lord Carlile's more onerous amendments were automatically withdrawn.

## WHAT NEXT?

Speaking to peers since the debate, despite the efforts of opponents to delay progress it's clear that a corner has been turned in the campaign for a change in the law. The unanimous endorsement of the Pannick amendment showed that there is considerable support for the Bill that opponents cannot defeat.

We are of course concerned that this judicial oversight will not be onerous, expensive and time-consuming for dying people, and we will be working to ensure that this is taken into account. [See page 13 for a discussion on this]. Progress made with Lord Falconer's Bill this side of the General Election allows us to hit the ground running when the new Parliament returns.

## SECOND DAY OF COMMITTEE, FRIDAY 16<sup>TH</sup> JANUARY.

Lord Falconer's Assisted Dying Bill secured a victory as it returned for its second day of Committee Stage. The morning featured a debate on a series of amendments which sought to change the terminology around the Bill, namely that a dying person who wants to control the manner and timing of their death is actually 'suicidal'. After the opposition tabled a vote, supportive peers defeated the amendment by a huge majority, with the final result 106 – 179. This was repeated again in the afternoon when a second vote was called, this time on Lord Carlile's attempt to

restrict doctors who could consult with a patient. The amendment was defeated 61-119.

Some news outlets picked up on the fact that the Bill would run out of time before the General Election. This is true - and has been very likely from the beginning - having been tabled less than a year before the public go to the polls. However any and all progress made now will build a foundation for future legislative change.

The progress of the Bill has sent a clear signal to Parliament that not only should they act, but they can do so with success. This debate saw two votes be called, by peers principally opposed to assisted dying, in an attempt to destroy the hard work and effort that has been put into this legislation over the last few years. These attempts were overwhelmingly rejected. Opponents must be seriously regretting putting these issues to a vote. What they demonstrated is what we suspected, but didn't know with certainty only a few weeks ago. There is now a substantial majority who support a change in the law in the House of Lords.

# THANK YOU TO OUR SUPPORTERS, AGAIN!

BY MIKE HAMILTON

## THANK YOU FOR YOUR LETTER WRITING.

Yet again we have been overwhelmed by the level of support Lord Falconer's Bill has received from our members and supporters. Thousands of you got out your pens, laptops and typewriters to diligently write to peers, encouraging them to show their support for the Bill by attending the Committee stage debate on 7th November and 16th January.

Peers were inundated by letters supporting the Bill, most articulately outlined the desperate need for a change in the law, with many describing personal experiences which demonstrated the problems with the current law which too often prevent dying people from having a peaceful death.

These letters have been absolutely crucial to ensure that peers understand the importance of Lord Falconer's Bill and the various debates that have occurred throughout the year. Without these letters some peers, especially those wavering about their decision, are unlikely to appreciate the reality that faces so many dying people.



Thanks to help from Dignity in Dying members peers understood the gravity of the situation and that the decision which lay in their hands.

## THANK YOU FOR DEMONSTRATING.

On Friday 7th November Dignity in Dying held a demonstration outside the Houses of Parliament, in order to show peers approaching the debate that morning that there is overwhelming support from the British public for this Bill.

More than 150 people braved the blustery cold morning as well as the London commuter traffic to be there. Supporters chanted "we want change" throughout the morning; all of which was captured on camera by BBC News 24 who came to interview Dignity in Dying Chief executive, Sarah Wootton. When we decamped at lunch I felt everyone left in high spirits, believing we were on the cusp of change.



# THE ASSISTED DYING BILL AND JUDICIAL OVERSIGHT.

BY JAMES HARRIS

*Lord Pannick (above) proposed judicial oversight as an amendment to Lord Falconer's Bill.*

**The campaign for a change in the law on assisted dying is, at its core, about choice and control at the end of life. Dying patients should not have to suffer against their wishes when death becomes inevitable and unavoidable. Dying adults, who are mentally competent, should have the choice to control the time and manner of their death with medical support. But crucially, the campaign is also about greater protection. A law with upfront safeguards would ensure that dying patients who request an assisted death are able to make an informed decision aware of all their care and treatment options. There are no such safeguards in the current law**

It is important that we get the balance of safeguards right. They must protect potentially vulnerable people whilst not creating an insurmountable barrier for dying people to overcome

in order to access the choice of an assisted death. As set out in the overview of the first day of Committee (see page 10) a new safeguard on judicial oversight has been introduced and agreed by the House of Lords.

What this means is that in addition to two doctors assessing the patient, a High Court judge (of the Family Division) has to be satisfied that the relevant criteria has been met and that the dying patient has reached "a clear and settled decision" to control the time and manner of their death.

Dignity in Dying is open-minded to reasonable and well intended proposals to strengthen the safeguards in the Bill whilst also ensuring that eligible adults can have choice in how and when they die. We were pleased that this amendment gave reassurance to long-standing opponents of assisted dying, like Lord Winston. Such reassurance will help ensure that a change in the law becomes a reality in the near future. However, we do of course need to ensure that the change in the law that reaches the statute book is workable.

We will therefore carry out research to make sure that judicial oversight works well in practice. Feedback so far indicates that it would in terms of speed of access and judgment. But, we do have some concerns about the potential financial costs of seeking judicial approval. We are looking into this as a matter of urgency, and will keep our supporters updated.

**ERIC AVEBURY IS A LIBERAL DEMOCRAT PEER WHO HAS SERVED IN PARLIAMENT FOR OVER FIFTY YEARS. HE HAS TERMINAL BLOOD CANCER AND SPEAKS FROM PERSONAL EXPERIENCE ON THE ASSISTED DYING CAMPAIGN.**

## **LORD AVEBURY: A VERY PERSONAL STORY.**

BY LORD ERIC AVEBURY

**I am committed to campaigning for terminally ill, mentally competent people to have the right to an assisted death. I have an incurable disease, a form of blood cancer called myelofibrosis, where the inside of the bone marrow turns to fibre and it no longer produces blood, so you suffocate. I have been told that it can be very terrible in the last stages. I know that having the right to control my death if it gets unbearable will be a great comfort to me, especially in the final weeks of my life.**

I have been in Parliament for over fifty years and have worked on many important issues. To have the opportunity to legalise assisted dying is one of the most crucial parts of my political career. Due to my health I am sometimes unable to participate in certain debates that go on late but the Assisted Dying

Bill is an obvious exception! I am pleased that it has so far been a great success; it was passed unanimously through Second Reading, and was constructively amended during the first day of Committee Stage. The House of Lords received much praise for the way it has so far conducted the debate, and my colleague Lord Falconer quite rightly won the Spectator's 2014 Peer of the Year award. I am confident that what has been achieved so far in the Lords will influence the Commons in the next Parliament.

It is a debate that the public have been engaging in for many years and finally Parliament has decided to catch up. I have had my own conversations with my family. My wife comes to all my consultations and we have discussed assisted dying. She knows that the ideal would be to have a peaceful death at home and for palliative care to deal with any serious

pain, but if it doesn't she would respect my decision to have an assisted death - assuming the Bill is passed by then. I am not keen on the idea of travelling to Switzerland and we haven't discussed that option. My four children know my views and don't object to them either.

**“I know that having the right to control my death if it gets unbearable will be a great comfort to me, especially in the final weeks of my life.”**

I don't know how anyone could hear the views of dying people, explaining why they want choice at the end of life, and seek to deny them that right. Assisted dying already exists in several states in the US. My feeling is that this will expand, in part thanks to the extraordinary story of Brittany Maynard (on page 8) who at only 29 spoke out about assisted dying before ending her life. It is very

hard to see real, dying people talk about what they want for their own death, and still be convinced by the misconceptions and scaremongering from opponents. It is even harder to believe, as some would have us believe, that there isn't a problem in the first place.

I obviously have a personal stake in the Bill and the future of the assisted dying campaign. Currently I am not in the latter stages of my illness and I am very hopeful that this year will not be my last. However, it would be useful before departing on any journey to know when the flight leaves and plan the things to be done before taking the trip to Heathrow.

I am confident that, when this time comes for me, assisted dying for terminally ill people will be a legal right in the UK, and I will be able to plan the death that I want.

# MEDICAL OPINION IS CATCHING UP WITH THE PUBLIC.

BY DR JACKY DAVIES, Chair of Healthcare Professionals for Assisted Dying



**I**n November I took over from Professor Ray Tallis as Chair of Healthcare Professionals for Assisted Dying (HPAD). I feel privileged to have been asked to take on the challenge of leading this valuable group, which consists of an active 1,300 strong membership of practising, retired and student healthcare professionals who all speak out in support of greater patient choice at the end of life.

I am a consultant radiologist based in London, a founding member of the campaign to Keep our NHS Public, and co-chair of the NHS Consultants Association. I am also a member of the British Medical Association (BMA) Council, though I speak out on assisted dying in a purely personal capacity.

I have been a member of HPAD and a supporter of a change in the law on assisted dying for many years. I also have a personal connection to the campaign following the death of my brother Kevin, who ended his life after suffering from renal cancer. I saw my brother go through months of planning and ultimately he died alone because

he didn't want anyone to face criminal repercussions for helping him. Kevin was found in a pool of blood at the bottom of the stairs. We believe he had tried to hang himself. This convinced me of the need for a compassionate law that allows patients to choose how they want to die, if they know that death is inevitable.

There is a common misconception that the majority of doctors and other healthcare professionals are opposed to such a change in the law on assisted dying, this is simply not true - opinion is divided and support for our aims is rapidly growing.

## SENIOR DOCTOR BACKS ASSISTED DYING.

The Deputy Chair of the BMA Council, Dr Kailash Chand, speaking in a personal capacity, has predicted a change in the law on assisted dying will happen within two years, recognising that it is now a question of how the law will change, not if. A poll conducted last year by Medix UK revealed that the majority of doctors now think that a safeguarded assisted dying law is the best way to protect terminally ill people who want to die. More recently, the Royal

College of Physicians (RCP) ran a consultation with its members on assisted dying and found that 56% of respondents expressed a wish for the College to change its stance of opposition to one of support or neutrality. Additionally, when compared with results from their previous consultation in 2006, there was a 44% increase in the number of Physicians who felt that a change in the law was necessary.

This year the BMA will launch an initiative to engage with the public on end-of-life care, which will include

discussions around assisted dying. I welcome this opportunity for patients' voices to be heard. After all, this is a decision for society as a whole to make; doctors have no right to have undue influence in the debate.

The fact that the BMA and RCP both remain opposed highlights that there is still work to be done. HPAD will continue to provide evidence that the current law is failing a significant minority of terminal ill people who suffer against their wishes or end their own lives without any regulation or safeguards.

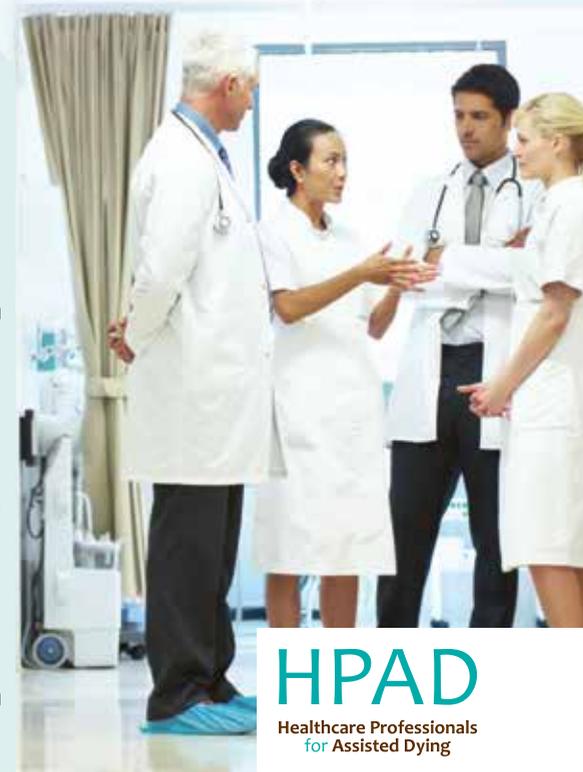
## THANK YOU.

Finally, I would like to thank Professor Ray Tallis. Ray's commitment and passion for the campaign had an immeasurable impact during his three-year tenure.

Membership trebled, media attention grew and HPAD's activities in the lead up to the debates in the House of Lords last year were instrumental in the Bill progressing. Fortunately for us, Ray will continue to be an active HPAD member and remains a patron of Dignity in Dying.

Membership of HPAD is open to any healthcare professional - student, practising or retired. If you or someone you know would like to join then please visit

[www.hpad.org.uk](http://www.hpad.org.uk)



**HPAD**  
Healthcare Professionals  
for Assisted Dying

# NEWS ROUNDUP.

BY MICHAEL CHAROUNEAU

## BBC'S REITH LECTURES FOCUSES ON END-OF-LIFE CARE

This year's BBC Reith Lectures were by Dr Atul Gawande, a practising surgeon and professor at Harvard Medical School. In his series of lectures he talked about the importance of allowing patients approaching the end of life to choose their own goals and make their own choices:

“We need to recognise that dying people have other priorities apart from living longer. It turns out the best way to find out people's priorities is to ask them....When people did have those conversations they were less likely to choose intervention, less likely to suffer and less likely to die in hospital. And they lived as long or longer than those having desperate medical interventions at the end of life.”

Dr Gawande expressed his concerns regarding the euthanasia laws in Belgium and the Netherlands; however, he gave his support to Oregon's assisted dying law.

## END-OF-LIFE RIGHTS POLL

A new poll commissioned by our sister charity, Compassion in Dying, found that only 7% of people wanted doctors in charge of decisions at the end of their life but 92% of people have currently not made their wishes legally known. The Independent on Sunday covered the poll:

The research, by YouGov for Compassion in Dying, suggests the remaining 91% have by default left these serious decisions to doctors, who may prolong their life against a person's wishes... A Health Department spokesperson said:

“We have commissioned an independently led review to provide advice on delivering greater choice and quality in end-of-life care.”

The review is expected to report early this year.

## END-OF-LIFE REVIEWS AND INQUIRIES

A review of choice in end-of-life care has been launched to make sure dying adults, their carers and family have more choice. The review will be undertaken by an independently-led programme board chaired by Claire Henry, Chief Executive of the National Council for Palliative Care (NCPC) which is the umbrella charity for all those involved in palliative, end-of-life and hospice care in England, Wales and Northern Ireland. The review findings will be used to advise government on improving the quality and experience of end-of-life care.

The House of Commons Health Select Committee has also decided to look at end-of-life care. The Committee is holding an inquiry which will examine the way that health and social care services, and the voluntary and community sector, support people who are likely to die within 12 months, what opportunities exist for better integration and for improving care quality, and the experience of those caring for people at the end of life. The Committee will also review the definitions of, and distinctions between, 'palliative' and 'end-of-life' care to examine how to provide more effective targeting of resources and management of interventions necessary to bring about service change.

Our sister charity, Compassion in Dying submitted evidence to the Committee focusing on the need for greater awareness among the public and health care professionals of the rights that we all have to plan ahead and make decision for our end-of-life care and treatment. Compassion in Dying also called for the introduction of an electronic record of whether a person has an Advance Decision or Lasting Power of Attorney for Health and Welfare which can be quickly accessed by care professionals involved in a person's care.

## MARY BERRY

In September, Mary Berry said, in an interview with the Daily Mail, that she would support a safe assisted dying law:

“Under current guidelines, if her son Thomas or daughter Annabel chose to help their mother die they would be committing a criminal offence. Miss Berry said: “under British law you can do nothing about it. But I would love my children to be able to give me a pill, although of course I do understand that could be abused.” Her mother Marjorie Berry died three years ago at the age of 105. That motivated the Bake Off star, who will turn 80 next March, to think about her future. “My mother was in very good health until the last few months - and health is key, isn't it?”



## > LORD FALCONER'S ASSISTED DYING BILL

The success of the first day of Committee Stage was covered extensively across all media outlets. The BBC reported that:

“The House of Lords has backed a proposal that would require judges to approve any cases of assisted dying in the event of it being legalised. Peers approved a series of amendments put forward by Lord Pannick to Lord Falconer’s Assisted Dying Bill. The crossbencher said he hoped his intervention would head off some of the objections that have been raised to the Bill to make assisted dying lawful. The Telegraph covered the fact that a number of previous opponents now look set to back the Bill: Leading opponents of euthanasia have signalled that they could accept a system of assisted dying in which judges rather than doctors take the final decision. Lord Carlile QC and Baroness Butler-Sloss, former head of the High Court Family Division – both vocal critics of the former Lord Chancellor, Lord Falconer’s Assisted Dying Bill – called for judicial safeguards to prevent vulnerable people being pressurised to end their life. The shift came as, during detailed scrutiny of Lord Falconer’s proposals, the House of Lords unanimously backed key amendments giving a High Court judge a role in any future system of assisted suicide in the UK. It was the first time Parliament has voted on the bill and was hailed by campaigners as a “significant step” towards a change in the law.”

## MILESTONES PASSED IN THE UNITED STATES.

BY MICKEY CHAROUNEAU

**The state of Oregon legalised assisted dying in 1997 and has been followed by Washington (2009) and Vermont (2013), while Montana ruled that there was “nothing in Montana Supreme Court precedent or Montana statutes indicating that physician aid in dying is against public policy” (2009). This year the US campaign has seen even more success, giving Americans more choice at the end of life, which will hopefully influence politicians here in the UK.**

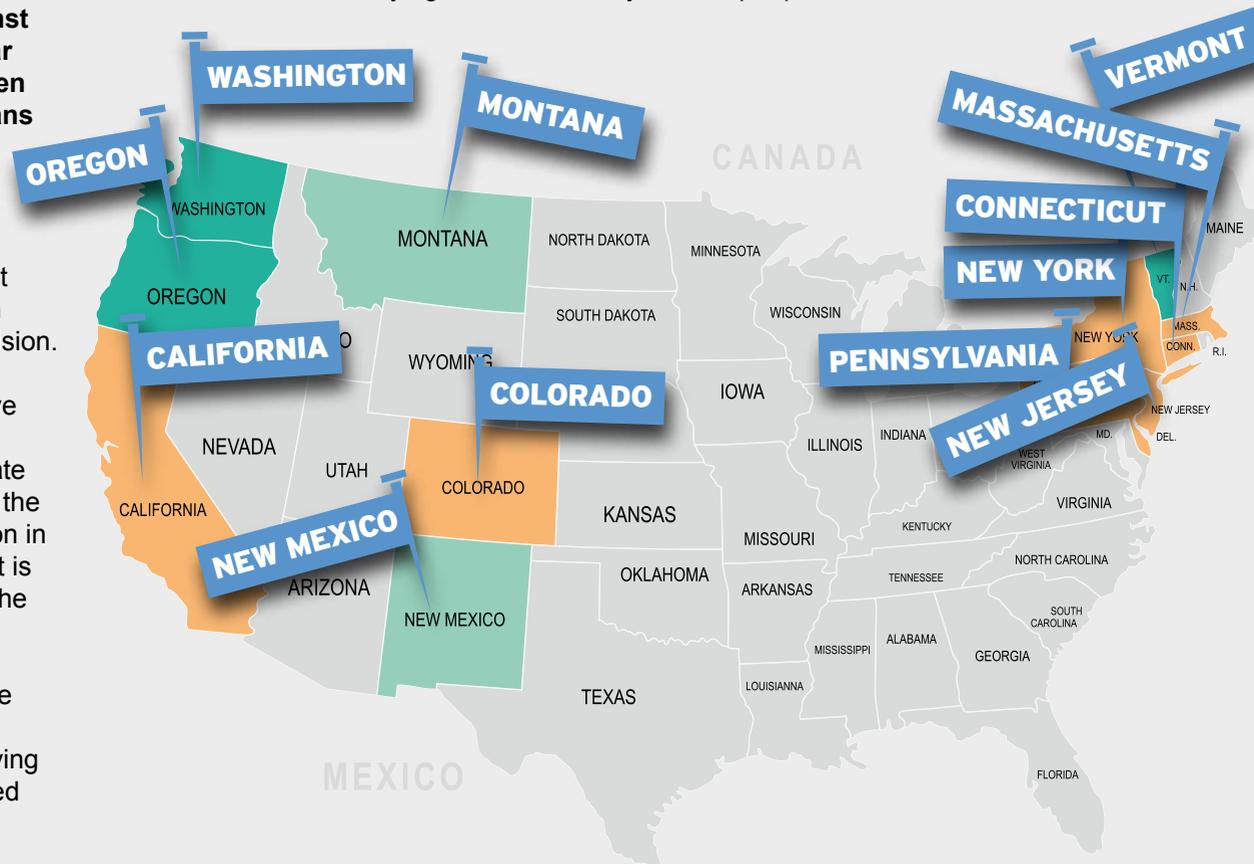
In January a lawsuit was brought to the New Mexico courts, which resulted in a landmark legal decision. A judge ruled that terminally ill, mentally competent patients have a fundamental right to assisted dying under the New Mexico State Constitution. The ruling protects the medical practice from prosecution in one county of New Mexico and it is expected to have an impact on the entire state.

In October Brittany Maynard (see page 8) became the face of the campaign to legalise assisted dying throughout the US. She explained

her reasons for moving to Oregon after being diagnosed with terminal brain cancer, and why she wanted every state in America to have an assisted dying law. Her story and experience has begun to influence politicians. In Pennsylvania Mark Rozzi introduced a Bill in the House of Representatives to legalise assisted dying, his Bill is closely based on the Oregon model. Brittany Maynard’s home state of California, where she had to move from, has seen a surge in support over the last few months and it has been suggested California will legalise assisted dying in the next five years.

New Jersey is perhaps the most likely state to legalise assisted dying next. In June the Heath and Senior Services Committee in the state Assembly voted 8-4 for the Aid in Dying for the Terminally Ill Act. The campaign will now focus on a vote in the Assembly, and advancing a Bill in the state Senate.

There are also campaigns running in Colorado, Connecticut, Massachusetts and New York. British politicians are beginning to realise that we cannot be left behind as the world begins to give choice to dying people.



# MAKING CHOICES FOR THE END OF LIFE.

BY USHA GRIEVE

**L**ast year we launched a new publication *Planning ahead: making choices for the end of life* with a written foreword by our new patron, Dame Esther Rantzen.

Everyone will have to make a decision about their health or care at some point in their lives. Some people will be able to make and communicate their own decisions throughout their life. Others may, at some point, lose the ability to decide for themselves.

Understanding your rights to make decisions about your own health and wellbeing, and knowing what happens if you become unable to decide for yourself, is crucial in ensuring your wishes are respected and followed at the end of life.

The booklet explains the rights of individuals to make decisions about their medical treatment and care in England and Wales. It looks at how decisions are made if someone is unable to decide for themselves and examines the rights of family and friends to act on behalf of a loved one. Perhaps most importantly, it also sets out the steps people can take now to ensure that their wishes are followed in the future.

It can be difficult to understand all of the choices that you may be presented with when nearing the end of life. This booklet also looks at where you can be cared for. Other topics include how to complain if you are unhappy with a health or social care service you have received, the financial support available for older people, as well as those who are ill and bereaved, and practical information if someone close to you has died.

## YOU CAN DOWNLOAD PLANNING AHEAD HERE:

[bit.ly/planning-ahead](https://bit.ly/planning-ahead) or if you would like a copy posted to you, you can order your copy using the tear-off order form at the back of this Campaign Newsletter.



If you would like more information on this booklet or your end-of-life rights please contact us:

- T** 0800 999 24347
- E** [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)
- W** [www.compassionindying.org.uk](http://www.compassionindying.org.uk)

We also provide factsheets on how you can plan ahead for the end of life in Scotland and Northern Ireland.



“Planning for the end of life is something that few of us want to think about when we’re healthy. Lots of us don’t consider how we might want to be cared for until we witness the death of a loved one, or experience the first symptoms of an illness. Yet when we start to think about illness or our own deaths, most of us do have strong ideas about what we want for our future treatment and care.

Being at the centre of your end-of-life care, and being empowered to make your own decisions, is hugely important in achieving a good quality of both life and death. However, all

too often people aren’t aware of their rights, and aren’t supported to take the steps needed to make sure their wishes are respected.

Talking about the end of life can be difficult, and thinking about what you want can throw up all kinds of feelings and challenges. But I know from experience that understanding your rights and taking steps to plan ahead is vitally important to make sure you have the right experience for you at the end of life. Perhaps most importantly, the peace of mind gained from knowing that you have put your wishes in place can allow you to get on with living now.”

### DAME ESTHER RANTZEN

Patron of Compassion in Dying



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# MY LIFE, MY DECISION REACHING OUT TO OLDER PEOPLE.

BY FRANCES BENNETT

**M**y *Life, My Decision* is a new project from Compassion in Dying which supports people over 50 years old to ensure their wishes for treatment and care are known and respected. The project runs across seven different regions of England, in conjunction with local Age UKs, and is funded by the Big Lottery Silver Dreams Fund. We spoke to Sonia Dhillon, the Project Coordinator for Hillingdon, to tell us more.

Sonia began working with Age UK Hillingdon three years ago as a volunteer. She specialised in translating information for BME (black, minority, ethnic) groups in her community. She has been with *My Life, My Decision* since August 2014.

## WHAT MADE YOU INTERESTED IN MY LIFE, MY DECISION?

The advert captured my interest because I had no idea that we all had legal rights at the end of life – so when I saw the project

was about supporting people to refuse treatment and deciding who could make decisions on their behalf, I thought ‘Wow, I need to get involved.’

I’d had personal experience with my grandfather of what can happen when you can no longer speak for yourself and you don’t record your wishes. He was a Sikh gentleman and went into a care home where the nurses tried to cut his beard and hair stating that it would be easier to clean and feed him. His family stepped in, but it was sad to see someone with dementia being treated in such a way that was contrary to his beliefs. I want to make sure people know their rights and make their wishes known so that a similar thing doesn’t happen to them.

## HOW HAS YOUR BACKGROUND IN SUPPORTING BME COMMUNITIES ENHANCED YOUR ROLE?

I have been keen to raise awareness of the project within Hillingdon including those who do not speak English as their first language.



Everyone should know and be able to exercise their rights. I’ve done a few talks now where I translate between Punjabi and English, which has been a fantastic experience.

## HOW DO YOU SPREAD THE WORD ABOUT MY LIFE, MY DECISION?

Well, often people get in touch because they have seen it on the website or heard about it through Age UK Hillingdon. But I’ve also been doing a lot of work with GP surgeries and hospices near me. Many of the healthcare professionals just don’t know much about the rights open to people. Since I’ve been spreading the word about Advance Decisions and Health and Welfare Lasting Power of Attorneys, they’ve referred a lot of people to me so I can help them plan ahead and make their wishes known.

I even went to Barclays Bank a few weeks ago and they told me they get a lot of people coming to them to make a Lasting Power of Attorney for their financial and property matters. They agreed that next time this happens, they’ll refer them over to me to make a Lasting Power of Attorney for their health and welfare too!

“A Sikh gentleman went into a care home where the nurses tried to cut his beard and hair stating that it would be easier to clean and feed him. His family stepped in, but it was sad to see someone with dementia being treated in such a way that was contrary to his beliefs.”

**SONIA DHILLON**

## CAN YOU GIVE AN EXAMPLE OF SOMEONE YOU HAVE BEEN ABLE TO SUPPORT?

Last month a gentleman got in touch with me and told me his brother-in-law had recently had a very bad death, suffering a heart attack and then being resuscitated with major complications. He told me he didn’t want to end up that way himself. I talked through with him what treatment he wanted to refuse and was able to support him to record this in an Advance Decision (often called a Living Will). He really valued the ongoing support the project offered; he could go away for a few weeks to think about things, and then come back and the same faces are here to support him. That meant something to him.

To find out more about planning ahead to make your wishes known, or whether *My Life, My Decision* is near you, call Compassion in Dying’s free Information Line or email us:

**T 0800 999 2434**  
**E [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)**  
**W [www.compassionindying.org.uk/services-near-me](http://www.compassionindying.org.uk/services-near-me)**

# WINNING THE CAMPAIGN WITH EVIDENCE.

BY LLOYD RILEY

**L**ast year Dignity in Dying commissioned a poll that set out arguments both for and against a change in the law on assisted dying and then measured levels of support. The results revealed that a large majority of respondents remained supportive and there was no increase in opposition.

We commissioned this research in response to an earlier poll commissioned by CARE (Christian Action Research and Education) which presented members of the public with misleading, one-sided statements about assisted dying. Unsurprisingly, in this poll support fell in response to the unbalanced depiction of the key issues.

What our, evidenced-based, results demonstrate is that **when the public are given the opportunity to examine the arguments for themselves their view does not change - they understand the nuanced debates that surround assisted dying.**

This work coincided with the publication of *Assisted Dying: setting the record straight*, which dispels many of the common myths that are often raised by those opposed to a change in the law. For example

during last year's debates in the House of Lords, a number of peers claimed that "the current law works". This is a fallacy, the current law turns a blind eye to the fact that:

- Every two weeks somebody from the UK travels to Dignitas to die;
- Over 300 terminally ill people end their own lives in England every year;
- A significant minority of people die without relief of their symptoms despite receiving high quality palliative care.

Dignity in Dying's campaign to change the law is based on evidence, not the manipulation of facts or reliance on subjective concepts of morality. We are winning the fight. In recent months we have seen the fatigued arguments of opponents starting to crack under the weight of an increasing body of evidence. It is vital that we continue to guard against scaremongering and correct any misinformation. Dignity in Dying will continue to shed light on the extent of the problem until politicians are courageous enough to enact the will of the public and change the law on assisted dying.



## THE FREE WILLS SERVICE: EXCLUSIVELY FOR DIGNITY IN DYING MEMBERS.

We've joined up with local solicitors all over the country to provide a free Will-writing service. As a member of Dignity in Dying you are able to take advantage of this service which has absolutely no cost to you. At the same time it will enable you to support the campaign in the most effective way possible.

We offer this service because the campaign is reliant on the generosity of its members, and leaving a gift in your Will is the most powerful way to ensure greater choice at the end of life for future generations.

Legacies are vital to sustain our efforts to change the law; a large proportion of the campaign's income comes from legacies, without which Dignity in Dying would struggle to exist. A gift in your Will does not have to be a large sum; whatever the size, your gift will help us to ensure decision makers do not ignore the public majority who support change.

Please contact us in order to receive your Free Wills pack in the post:

**T 020 7479 7109**  
**E mike.hamilton@**  
**dignityindying.org.uk**  
**M Mike Hamilton**  
**Dignity in Dying**  
**181 Oxford Street**  
**London, W1D 2JT**

## IN MEMORY OF JEAN DAVIES.

In October last year Jean Davies, former chair of the Voluntary Euthanasia Society and long-time supporter of the campaign died aged 86. Following a series of chronic health conditions Jean, a former maths teacher, began refusing food in late August. Her daughter described her as a "fiercely independent lady until the very end". She will be remembered as a strong campaigner for people's autonomy at the end of life.

## SAVE THE DATE: DIGNITY IN DYING AGM 2015.

Dignity in Dying will be holding its Annual General Meeting on Tuesday 9th June 2015. It will be taking place at the **new location** of Conway Hall, 25 Red Lion Square, London, WC1R 4RL.

Please save the date in your diary. We will be sending out invitations for the AGM to members in the next couple of months.

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## ORDER YOUR PLANNING AHEAD GUIDE.

Compassion in Dying's flagship publication is aimed at anyone wanting to understand their rights to make decisions about treatment and care (for more information please go to page 22).

To order your **free** copy please complete the form below with your details and return to:

**Dignity in Dying 126 Fairlie Road, Slough, Berks, SL1 4PY**

Title

Forename

Surname

Address



Postcode

Membership number (if known)



# ORDER YOUR PLANNING AHEAD GUIDE.

# 2014 AS IT UNFOLDED.



Photo credit: McPix Ltd/REX



**JANUARY.** Coronation Street has a major storyline that concludes with assisted dying.

The Sun publishes an editorial in support of Lord Falconer's Assisted Dying Bill.

**JUNE.** Decision by the Supreme Court puts Parliament on notice that they can no longer ignore this issue.

**JULY.** Former Archbishop of Canterbury Lord Carey and Desmond Tutu both come out in support of assisted dying.

Lord Falconer's Bill passes unopposed at its second reading in the House of Lords.

Hundreds of supporters join Dignity in Dying's demonstration outside the Houses of Parliament.

**OCTOBER.** The Director of Public Prosecutions adds to the guidance on assisted suicide with relation to healthcare professionals in light of the ruling on the 'Martin' case.

**NOVEMBER.** Lord Falconer's Bill reaches Committee Stage, where Lord Pannick's amendment is backed and an opposing amendment quashed. Hundreds of Dignity in Dying members demonstrated outside Parliament.

Deputy Chair of the BMA Dr Kailash Chand says that assisted dying will be legal in two years.

**DECEMBER.** Fortright right-to-die campaigner, Debbie Purdy, dies aged 51 after 20 years with progressive multiple sclerosis.

In a letter to the Telegraph, nearly 80 Dignity in Dying patrons from the world of medicine, politics and the arts sign a letter urging Parliament to act on assisted dying.

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