

CAMPAIGN

Issue 1 of 3 2016

CALIFORNIA

LEADS THE WAY

**CAMPAIGN FOR
DIGNITY
IN DYING.**

2016 IS A YEAR FOR CHANGE
ASSISTED DYING LEGALISED

SAVE THE DATE! DIGNITY IN DYING AGM 2016.

Dignity in Dying will be holding its Annual General Meeting on: Thursday 30th June

**It will be taking place at: 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 early May, when the times and agenda will be confirmed.

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Editor Mike Hamilton

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SARAH WOOTTON

Chief Executive

WELCOME.

2016 is set to be an important new chapter for the assisted dying campaign. After the defeat of the Assisted Dying Bill in September, we have been regrouping and making plans to reinvigorate the campaign.

Your good work in the run up to the Marris Bill enabled us to discover in detail where MPs stand on the issue – thank you for that - and the bottom line is that for most MPs their stance is in complete contrast to the people they represent. Of course we now know who might change their mind; we achieved huge media and public attention for the cause, and we secured some senior behind-the-scenes support that will be critical in the future.

What was also clear from the Commons debate is that our opponents effectively played to MPs' risk-averse nature by scaremongering. Organisations such as the British Medical Association (BMA) used their authority and

credibility to sow the seed, without hard evidence, that assisted dying is riskier than the status quo. We need to demolish these scare tactics and challenge unrepresentative and unaccountable opposition.

With your help, we are vastly expanding Dignity in Dying's Activist Network in order to put pressure on MPs at a constituency level. We know so many of you contacted your MPs before the Bill but we know that many of our parliamentary representatives did not engage with the issue until the final days before the debate. We cannot expect MPs to change their minds overnight so we must put the hard work in now and over the coming years. We must make the case again and again for law change in a variety of innovative ways; persistence will bring success.

The network is expanding in strategic locations across the UK. To find out what being an activist involves I recommend reading the article on page 6. If you decide to take part there will be training provided. As well as opportunities to meet and discuss campaigning ideas with other inspirational members who have already done great work for the assisted dying campaign.

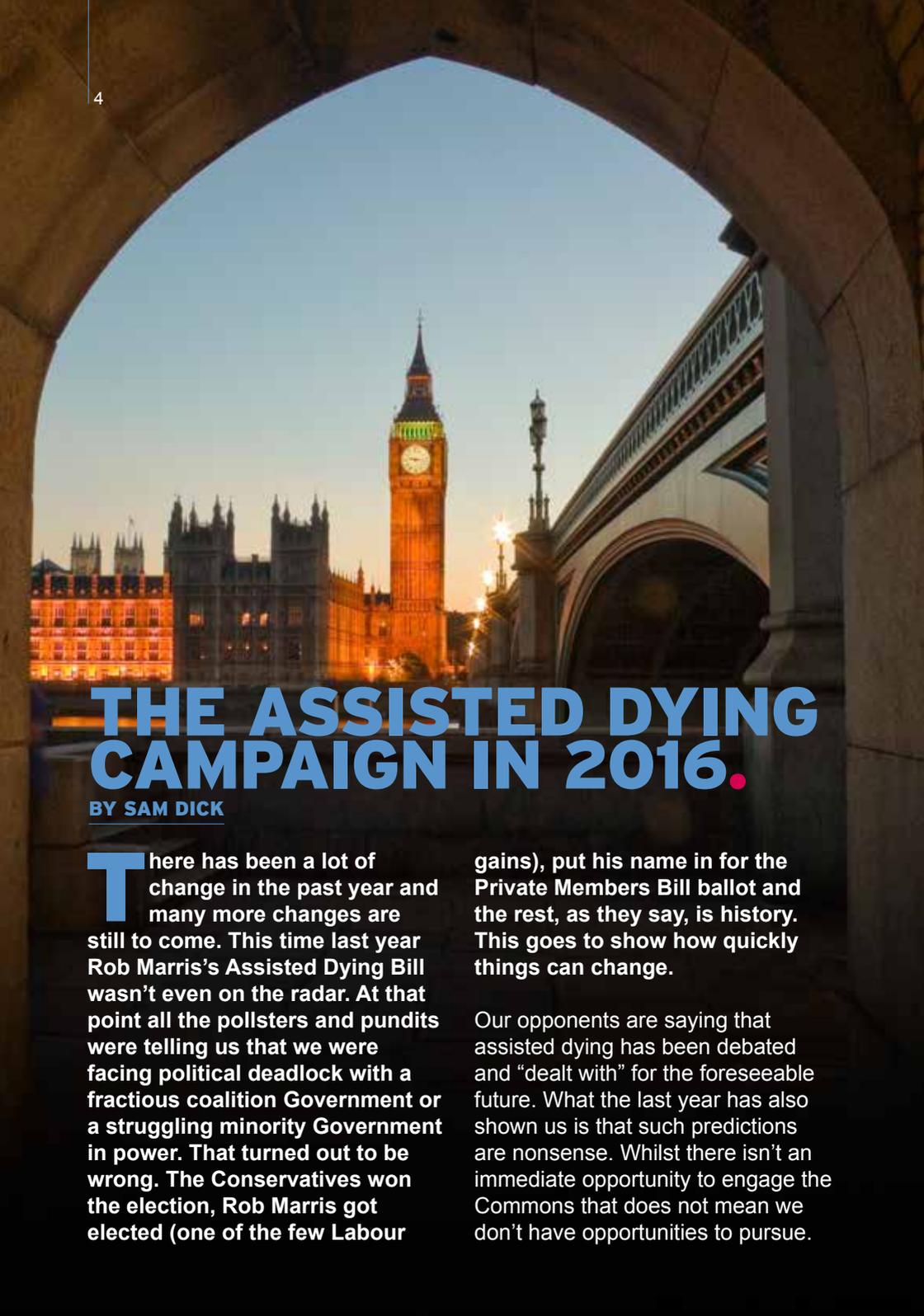
We must focus the public's attention on organisations such as the BMA which use their clout against the interests of 82% of the British public. The equivalent medical associations in both Canada and California

dropped their opposition to assisted dying prior to legislative successes in 2015. This year sees the conclusion of BMA-commissioned research on end-of-life care and assisted dying which leads up to a debate at its annual conference this June (more on page 14). Whilst we don't expect them to change their position of opposition perhaps on this occasion, we will be asking for your help to hold the BMA to account.

We will also look to challenge the law in the Courts this year, building on the Supreme Court ruling in the summer of 2014. In Canada, their courts struck down the prohibition of assisted dying (something that is not possible for the Supreme Court in the UK). Nonetheless we are seeking to learn from such experiences abroad to bring our own case to the Courts (page 8) in the coming months.

Finally, thanks once again for all your messages of support for the team. As the brilliant Sir Graeme Catto, who has retired as our Chair, acknowledges on page 16, we united to support the Bill in the Lords and then the Commons. We know that historic campaigns are made up of both progress and set-backs, but, unlike our opponents, we also know that in the end we will win.





THE ASSISTED DYING CAMPAIGN IN 2016.

BY SAM DICK

There has been a lot of change in the past year and many more changes are still to come. This time last year Rob Marris's Assisted Dying Bill wasn't even on the radar. At that point all the pollsters and pundits were telling us that we were facing political deadlock with a fractious coalition Government or a struggling minority Government in power. That turned out to be wrong. The Conservatives won the election, Rob Marris got elected (one of the few Labour

gains), put his name in for the Private Members Bill ballot and the rest, as they say, is history. This goes to show how quickly things can change.

Our opponents are saying that assisted dying has been debated and "dealt with" for the foreseeable future. What the last year has also shown us is that such predictions are nonsense. Whilst there isn't an immediate opportunity to engage the Commons that does not mean we don't have opportunities to pursue.

A big focus this year will be on those organisations that have used their power and reputations to spread anecdotal fears about assisted dying for the terminally ill. The British Medical Association is one of those organisations that has wielded its influence against the interests of the majority of the British people. It is listened to by many MPs on assisted dying who believe its assertions are evidence-based and trustworthy. This year they will be publishing their response to their own research on end-of-life care and assisted dying. Whilst it might look like an opportunity for the BMA to review its position, it is highly unlikely that they will change their policy in response so we must hold them to account (see page 14). Scope is another organisation that uses its influence to spread anecdotal and unreliable assertions (see page 18) which we will be holding to account.

They may be under the assumption that they have maintained the status quo but in effect MPs have endorsed the fact that people are having unsafeguarded assisted deaths. We need to show them exactly what it is that they have endorsed, in greater and starker detail than before. We will conduct research into the true financial, legal and emotional cost of the current situation, explore how disabled people who become terminally ill are being served by the end-of-life care sector (and by many of the disability organisations that oppose assisted dying 'on their

behalf'), and highlight through cases and campaign tactics how ridiculous and impossible the law is to police.

Another change is taking place in Scotland, where the Scottish Parliament election is taking place in May (although it is highly unlikely we will see a change in Government). Whilst a Bill was defeated there in 2015 we have a new opportunity in a new Parliament to revisit the issue.

Changes will be taking place abroad in California and Canada too. They provide us with an opportunity to both mark progress there and demonstrate how we are lagging behind other jurisdictions in affording choice and control to dying people.

It's critical that we dive into the campaign, strengthen our case, work hard and improve our networks in the House of Commons. Building a robust campaigning machine, collating new evidence and detailed research on the experiences of dying people, picking apart our opponents' claims and expanding our network of activists are all things that take time but which will be really beneficial in the long run.

One thing we really hope won't change is the overwhelming support we have from our members and supporters. As ever it is with your help that we can make gains and together we will eventually change the law. •



THE CAMPAIGN IS HEADING TO A TOWN

Over the past couple of years Dignity in Dying has been bringing together some of its members to campaign in their local area, so that conversations in support of assisted dying happen in communities up and down the country.

In order to take the campaign to the next stage, and to ensure that we win in the House of Commons the next time around, the Activist Network is expanding far and wide. Dignity in Dying is putting plans and resources in place to support hundreds of activists across the country in tactical locations.

Volunteers and activists are the backbone of every social campaign that has seen law change, whether that is the abolition of slavery, women's rights or abortion. Activists are becoming one of the linchpins of the Dignity in Dying campaign, without which law change almost certainly will not happen.

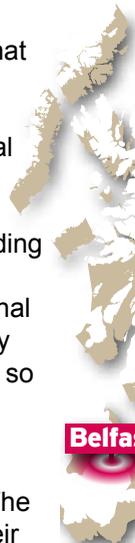
We believe a powerful national network of activists taking action and standing in solidarity for a more compassionate law at the end of life, is the most likely way to win the hearts and minds of MPs. We need activists to articulate the need for law change to their MP through meetings, letter writing, community rallies and petitions. We need activists educating their communities

about the campaign and the problems with the current law.

Recent private polling of MPs by Dignity in Dying has suggested that they are not aware of the support among the British public for a change in the law. There is a correlation between MPs who are opposed to change and those that also think that their constituents do not support it. Without activists lobbying their MP it is difficult to communicate the real and significant support that exists among the general public for law change. Without many people building a relationship with their MP and telling them their compelling personal reasons for changing the law it may be difficult for them to see why it is so important to their constituents.

Campaigning at the local level is essential to bringing law change. The specific actions activists take in their communities will vary from location to location, and in a large part guided by activists themselves. Nonetheless, in every constituency we need to make clear the need for an assisted dying law, inspiring others along the way while dispelling the scaremongering myths of those who oppose change.

If you are passionate about the campaign and are frustrated by politicians not listening to the wishes of the public on this issue, then you are ready to campaign for assisted dying.





NEAR YOU, COME AND BE A PART OF IT!

Being an activist does not need to take up a lot of your time, we do not expect activists to be supporting the campaign every day of the week; it may involve anything from organising events through to speaking with fellow activists in your area every couple of months.

Existing activist hubs are shown on the map below in red. We are seeking to create further local groups in the locations on the map in blue. Please get in touch with Dignity in Dying if you live nearby and would like to get involved: **Birkenhead, Birmingham, Cardiff, Leeds,**

Leicester, Manchester, Newcastle, Portsmouth, Sheffield, Stockton on Tees and Torquay.

If you do not live near these locations but would like to meet and take action with other members near to you please also get in touch – it would be great to welcome you on board as well.

T 020 7479 7109

E activism@dignityindying.org.uk

To find out more about the Activist Network please go to

W www.dignityindying.org.uk/activism



WHAT DO ACTIVISTS DO?

- Collectively go and meet their MP
- Set up stalls at markets and community events
- Gathering local signatures for petitions
- Screen supportive award-winning documentary films
- Hold debates and presentation evenings
- Influence local party chair people and members
- Meet and discuss the campaign with other local organisations.

At present Dignity in Dying is not creating activist hubs in Scotland, while we await the outcome of the Scottish elections in May. Following this we will implement a new strategy, of which we will keep you updated.

New Liberal Prime Minister, Justin Trudeau, was elected to office in October

CHANGING THE LAW THROUGH THE COURTS IN CANADA.

BY DAVINA HEHIR

Canada continues to grapple with the question of what its law will look like after the Supreme Court struck down the ban in Canada's criminal code on helping another person to die. In its judgment in February last year, the Court gave the Canadian Government a year to propose alternative legislation that did not contravene the rights of seriously ill people who wanted to end their own lives at a time of their own choosing.

In response to this decision, the then Conservative Prime Minister Stephen Harper set up an expert panel to examine how the law should change, but progress was slow, in part due to the General Election in October last year.

Following the election of a new Government, led by Liberal Prime Minister Justin Trudeau, the expert panel's remit was altered. In addition,

the new administration has charged a number of MPs and Senators with responsibility for investigating the way forward.

The deadline for a new law was looming, with the ban on assisting someone to end their life set to expire in February this year. As a result, the new Government asked the Court for an additional six months to draft a new law, but were instead given just four months – so we can expect a new law by the summer.

Whilst some Canadians may be frustrated at the slow progress since the Supreme Court ruled on this issue back in February 2015, it is clear that progress is being made. It's also clear that the legal case which started all of this, *Carter v Canada*, has been an absolutely instrumental force for change. It has taken time – the case was filed back in April 2011 and has progressed through many stages since then – but Canadians can now be assured that their politicians have to engage with the issue of assisted dying and develop a new law.

Dignity in Dying is working with some of our members to launch a new legal case here in the UK. If you are terminally ill and would like to get involved, please get in touch with Davina Hehir

T 020 7479 7730

E Davina.Hehir@dignityindying.org.uk

'DIGNIBASH' AND DIGNITAS.

BY SAM DICK

In summer 2015 the story broke on the front page of the Sun of two daughters who were trying to raise funds by holding an event to help their mother who was suffering from motor neurone disease, Jackie Baker, to travel to Dignitas – the newspaper coined the event a *dignibash*. The story led to opponents of assisted dying, Care Not Killing, calling the police on them. Police visited the family and the fundraising event was subsequently cancelled.

What didn't get nearly as much coverage was the news in November that Jackie travelled to Dignitas and ended her life. Somehow they found the means to allow Jackie to have an assisted death.

This story goes to show the lengths people have to go to in order to have an assisted death in Switzerland (and also the depths our opponents will stoop to) and the unimaginable position it puts their loved ones in. Interviewed after Jackie had died, her daughter Tara told reporters:

“We understand the police will probably question us - but we would do it again. We wouldn't change it.



Jackie Baker traveled to Dignitas with her two daughters in November

We stick to the reasons why we have done it. It was our mother's choice not our choice so I know it sounds crazy but I am really happy.”

The family were reported to have felt the need to stay out of Britain immediately after the story broke so that they could have some space and peace to grieve.

There is a complacent assumption that going to Dignitas is 'easy' and that most people can probably find the funds somewhere. We know this is not true, which is why this year we will be undertaking ground-breaking pieces of research that will really lift the lid on the true cost of Dignitas.

That cost is not just financial. The more we explore and talk to those whose loved ones have travelled to Dignitas the more we realise the emotional, legal, financial and bureaucratic hurdles they have to jump simply to respect their loved ones' wishes. These don't end when their loved one dies, but continue well after their death, at a time when they should have space to grieve.

We hope the research will once and for all demonstrate that, due to the state of the law here in the UK, there is nothing easy about dying at Dignitas.



MEDICAL TREATMENT AND PATIENTS' RIGHTS IN THE COURTS. BY RACHEL HUTCHINGS

In the autumn you might have seen news coverage of some important cases about medical treatment and patients' rights. We've summarised below four of the key ones, which concerned three areas of law.

WITHDRAWAL OF TREATMENT.

In a landmark case in November the Court of Protection (which makes decisions on behalf of people who lack capacity) allowed the withdrawal of artificial nutrition and hydration from a woman in a 'minimally conscious state.' The woman, known as *Mrs N*, was 68 and in the end stages of multiple sclerosis. She lacked capacity to make decisions about her medical treatment. *Mrs N* was being given treatment (artificial nutrition and hydration) that was keeping her alive, but her family argued that it would be in her best interests for treatment to be withdrawn. They felt that providing treatment was prolonging a quality of life that *Mrs N* would not have wanted.

The case demonstrates the significance of the person's wishes in deciding whether providing a treatment is in their best interests. It also emphasises the importance of making your wishes for future treatment and care known, to help avoid these difficult and distressing cases.

CAPACITY.

A case that has attracted a lot of media attention was that of *C. C* had attempted suicide by taking an overdose but survived with kidney damage. She was refusing dialysis, which was necessary to save her life. The question for the court was whether she had 'capacity' to refuse life-sustaining treatment.

After considering evidence from C, her family and three healthcare professionals, the judge concluded that C did have capacity to refuse the dialysis. She died shortly after the hearing.

The case reiterated a very well-established principle of medical law, which is that an individual who has capacity has an absolute right to refuse medical treatment, even if it is necessary to save their life. It also reiterated Principle 3 of the Mental Capacity Act 2005, which says that a person with capacity has the right to make any decision, even if it appears unwise to others.

DO NOT ATTEMPT RESUSCITATION (DNAR).

In June 2014, a very important case called *Tracey* stated that there is a duty to consult patients and their families before putting a DNAR order on their medical records.

Two more recent cases have also discussed DNAR and showed that the principles in *Tracey* apply equally to patients who lack capacity, stating that families and carers should be consulted before a DNAR order is placed on the patient's records. The first concerned Carl Winspear, a 28-year-old man with cerebral palsy, who had a DNAR order placed on his records without the knowledge of his family. The court said that this was unlawful. Even though the final decision to issue a DNAR is a clinical one that lies with the medical

professional, the patient should be involved in the consultation, or their family or carers should be if they lack capacity.

The second case concerning DNAR was that of Andrew Waters, who was 51 and had Down's Syndrome and dementia. The hospital placed DNAR orders at numerous times on his medical records, without informing or consulting his family. His Down's Syndrome was given as one of the reasons for doing this. The hospital trust later acknowledged that it had been unlawful not to discuss the DNAR form with Andrew's family.

Both of these shocking cases demonstrate how the rights of patients to be involved in decisions about their care apply equally to people who do and do not have capacity.

As always, legal cases play a vital role in reiterating the importance of patient autonomy at the end of life. For person-centred end-of-life care to be achieved it is crucially important that people are given the information and support needed to make decisions and record their wishes.

For more information on the withdrawal of treatment, DNARs and the Mental Capacity Act visit Compassion in Dying's website



ACCESS TO PALLIATIVE CARE BILL.

BY TOM DAVIES

October saw the House of Lords debate Baroness Finlay's Access to Palliative Care Bill. The Bill is intended to give greater access to palliative care across the country and improve existing education, training and research in end-of-life care.

While the Bill passed its Second Reading without opposition, the Government was clear that it would not give support to the Bill's progress. It has not been subject to further debate in the House of Lords and will have insufficient time to become law in the remainder of this session.

"We support the underlying intent of the Bill", Health Minister Lord Prior of Brampton said, "[but] we do not believe that legislation is the right way to address the problems that the noble Baroness has outlined".

Compassion in Dying supported the aims of the Bill and particularly welcomed the Bill's focus on the need to encourage the take-up of Advance Decisions. We believe they play an incredibly important part in ensuring that people can have their wishes respected by healthcare professionals.

We argued and continue to believe that improvements in end-of-life care would be better achieved if they were proposed in a comprehensive new approach to ensure that dying people are right at the centre of decision-making at the end of life. Baroness Finlay's Bill is one of a number of well-intentioned proposals to improve end-of-life care in recent years.

Alongside so many high-profile guidelines and ambitions for improving care at the end of life we risk creating an ever more confusing system of objectives and rules that don't get us significantly closer to patient-centred end-of-life care. The Access to Palliative Care Bill helps advance this conversation, but we think it's time for a fresh radical look at end-of-life care rather than making minor improvements to our existing provision.

CAMPAIGNING DEVELOPMENTS IN EUROPE.

BY TOM DAVIES

In addition to Canada and California, which have both seen recent campaign success, there have also been developments in Europe.



FRANCE.

In February the French Parliament passed a Bill that will permit patients to request terminal sedation from their doctors. This stops short of an assisted dying law, as it would not permit a patient to take the final act of ending his or her life. It will allow patients to request “deep, continuous sedation altering consciousness until death” but only when their condition is likely to lead to a quick death.

The new Bill will require doctors to follow end-of-life instructions regarding terminal sedation and stopping treatments, whether they are expressed by the patient themselves on the spot or written in advance through an advance directive.

President Francois Hollande’s manifesto in 2012 included a commitment to create an assisted dying law, but his Government later reneged on this pledge. Instead,

this Bill was a political compromise, bringing together socialist Deputy Alain Claeys and the conservative Jean Leonetti, who drafted an earlier law on end-of-life care.

Much of the debate in France had been informed by the case of Vincent Lambert, a man who has been in a vegetative state since a car accident eight years ago. His family has been divided on whether to keep him alive or to withdraw treatment and allow him to die and a long battle in the courts has followed.



IRELAND.

A new Assisted Dying Bill was introduced to the Irish lower house, the Dáil, in December. John Halligan, who represents Waterford as an Independent, brought in the Dying with Dignity Bill. Introducing the Bill, closely based on the Assisted Dying Bills considered in the House of Commons and House of Lords, Deputy Halligan said:

“People who fight to live and want to survive should be given the opportunity and all the help they require but a small percentage of people are unable to bear the suffering and they also should be allowed to have a dignified death.”

As a result of the impending election, the Bill was not granted a full debate at the Second Stage. We await and see if the Bill is reintroduced.

A WELCOME STEP: THE BRITISH MEDICAL ASSOCIATION RESEARCH INTO END-OF-LIFE CARE. BY DR PAUL TEED

The BMA's consultation with doctors and members of the public on their views and perceptions of end-of-life care and the assisted dying debate is a welcome step forward. It is critical for policymakers and policy influencers, such as the BMA, to engage with the public and listen to their wishes on issues such as assisted dying. Far too often this most important group has been sidelined in the debate.

In 2000 Dr Walter J Kade wrote of his initial opposition to the Oregon Death with Dignity Act and of his subsequent change of opinion after experiencing an assisted dying request from a patient. Initially he "did not choose to hear" the plight of his patient, yet, soon after providing her with the means to end her own life under the law, he realised that his dying patient was the person best placed to define her own suffering and that he had no right to impose his views on her decision. By consulting the public, the BMA has signalled a willingness to listen on behalf of the profession and to take that step towards humility.

Many doctors may have also experienced the complex reality of how the current law is failing. Some may have been asked for medical

records so a patient can travel to Dignitas (and subsequently put their career at risk), and some may have discovered that a patient has ended their own life, either abroad or at home. The BMA has a responsibility to listen to the voices of those within the profession too.

Yet the presentation of the evidence in an honest way is a vital part of any consultation process and unfortunately, this was not always the case during this research exercise.

For example, during the consultation various materials were provided to participants "to enable a more informed debate." In one exercise focused on how assisted dying is carried out in countries where it is legal. Participants were provided with three pieces of information regarding negative "lived experiences" from Oregon, yet they were not provided with information relating to, for example, the improved communication between doctor and patient, greater access to palliative care, and the reduction in anxiety.

Participants were told that the time between ingestion and death ranges from one minute to 104 hours, which resulted in some being "shocked," no doubt at the protracted death they might fear; yet they were not told



Dr Paul Teed is a Junior Doctor in A&E, he campaigns for assisted dying in his spare time.

that the time between ingestion and unconsciousness is 1-38 minutes, which would have allayed such fears. They were told that 23 out of 530 people have experienced complications in the Oregon cases and that known complications with physician-assisted dying include nausea and vomiting, seizures, and muscle spasms. They were not told that the only recorded complication from Oregon is “regurgitation” and, in fact, there are no records of anyone experiencing a seizure or muscle spasms in the 530 of 859 cases that Oregon has information on.

Participants were also not told why complications seem to occur, which is largely because in Oregon there is no requirement for a healthcare professional to be present when the life-ending medication is prepared and self-administered. Critically, the Bill proposed in the UK contained additional safeguards to the Oregon law to protect against such complications. Participants were not informed of this.

If the BMA holds genuine concerns about the safeguards of an assisted dying law then it needs to engage in the debate constructively and clearly. Concerns that the BMA has raised in its numerous briefings to Parliamentarians are the same concerns raised 18 years ago in Oregon prior to the law coming into effect; yet subsequently no medical organisation in Oregon has campaigned to repeal the law. Doctors who participate there recognise their privileged position of being able to respect their patients’ dying wishes.

BMA members will have a chance to debate policy at this year’s Annual Representatives Meeting in June. The outcome of that debate will depend on what, and who, they choose to hear.

Paul Teed is a junior doctor in A&E and a member of Healthcare Professionals for Assisted Dying. You can follow him on Twitter:

 **@DrPaulTeed**

FAREWELL TO OUR CHAIR SIR GRAEME CATTO.

CAMPAIGN FOR
DIGNITY
IN DYING

In the autumn Sir Graeme Catto stepped down from his position as Chair of the Dignity in Dying board, after nearly four years in post. Under his stewardship the campaign has progressed significantly, from winning debates in the House of Lords to assisted dying becoming one of the most prominent social campaigns in the country. His intelligence and good humour will be missed by all of us in the office. Graeme has agreed to become a Patron of Dignity in Dying so he won't be leaving the campaign. Here are some of his reflections on his time as Chair.

1. Why did you first get involved with the assisted dying campaign?

As a physician I cared for patients on long-term dialysis treatment. Rarely, a dialysis patient would choose to stop treatment and so bring about his or her death. I also looked after patients with terminal conditions.

I began to question the ethical distinction between stopping life-sustaining treatment and providing life-ending medication to a terminally ill patient.

As President of the General Medical Council, I became concerned that those opposed to Lord Joffe's Assisted Dying for the Terminally Ill Bill were ignoring evidence from Oregon. In due course I welcomed the opportunity to join the campaign.

2. As a doctor, what do you think of the medical profession's approach to assisted dying?

Assisting a patient to die is a criminal offence. I understand why individual doctors may be reluctant to express a view, even though more than 80% of their patients are in favour of a change in the law. That understanding, however, does not extend to medical organisations. With a few honourable exceptions, the contortions of the British Medical

Association and medical Royal Colleges to avoid a democratic vote on this topic of real importance to their patients are disgraceful.

3. What is your personal highlight of your time as Chair?

The debate in the House of Lords on the Committee Stage of Lord Falconer's Assisted Dying Bill in January last year. It was clear that the Bill had the backing of the House.

4. In your time as Chair you must have debated assisted dying a lot; which of these debates was most memorable and why?

The debate organised by the Royal Society of Medicine in 2011 made me aware of the personal invective directed at those proposing a change in the law.

5. You must have heard many arguments against assisted dying; which made you the most angry and why?

Those (and they are the majority) that either ignore or misquote the evidence from Oregon.

6. What do you feel is the most compelling argument for law change on assisted dying?

I think the Governor of California put the case well. In signing the Bill to legalise doctor-assisted dying, he wrote "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".

7. What is your proudest moment of your time with Dignity in Dying?

The way in which the entire organisation united to support the Bill proposed initially by Lord Falconer and then Rob Marris MP. While the vote in the House of Commons was lost, we won the intellectual argument.

8. What barriers do you think remain to law change on assisted dying?

The single biggest barrier is making MPs aware of the issue and the factual evidence available from Oregon. With a free vote, the overwhelming support of the public is frustrated by the vociferous opposition of such non-democratic organisations as the church, disability groups and some sections of the medical profession.

9. How soon do you think the law will change?

I fear not in this Parliament. But I have no doubt it will change eventually.

10. What advice would you offer to Dignity in Dying's new Chair?

Ignore your predecessor!

At the time of going to press Dignity in Dying is in the middle of a recruitment process for a new chair, the result of which is likely to be announced at this year's AGM on Thursday 30th June.

OPPONENTS OF ASSISTED DYING ARE CAMPAIGNING WITHOUT EVIDENCE.



BY GREG JUDGE

As we know disability organisations are some of the most vocal and organised opponents of assisted dying. In the face of overwhelming public support, including that of disabled people, organisations such as Scope use their influence to oppose any change to the law and do so in a way that exacerbates unnecessary fears some disabled people have about assisted dying. We believe this is irresponsible.

With that in mind, in October Disabled Activists for Dignity in Dying (DADiD) wrote to Mark Atkinson as the new Chief Executive of Scope, an organisation that is supposed to represent the views of disabled people in the UK. In the letter we took the opportunity to point out the inaccuracies and scaremongering of Scope's public campaigning in the lead up to the Assisted Dying Bill being debated in the House of Commons in September. We said:

“Scope has a responsibility to act in a way that creates a positive climate for disabled people: tackling discrimination, challenging negative stereotypes and empowering disabled people with choices and opportunities. It is difficult to see how telling disabled people

they face “widespread premature deaths”, when that claim cannot be substantiated by hard evidence, is anything but irresponsible. It is our strong belief that such scaremongering will simply amplify disabled people's fears and no doubt affect their well-being.”

We were disappointed (but unsurprised) that in his response Scope's CEO failed to provide evidence to substantiate their “widespread” claim. It is irresponsible for organisations to make such assertions with no hard evidence to back them up, especially if those assertions are likely to cause disabled people to feel unnecessarily anxious or fearful.

It is important that we continue to hold organisations like Scope to account. DADiD and Dignity in Dying will continue to counter the scare tactics of our opponents so that disabled people and the wider public are not made to unjustifiably fear terminally ill people gaining the right to have a choice in how and when they die. Disabled people can become terminally ill too and it's in all our interests to have a right to choice and control at the end of our lives.

In December the National Institute for Health and Care Excellence (NICE) published their guidelines for how to care for people who are dying.

NICE had been asked to develop the guidelines following widespread criticism and a Government review into the failings of the Liverpool Care Pathway (LCP). Criticisms of the LCP were that it did not provide healthcare professionals with the means of determining whether a person was dying. There were cases where drinking water and essential medicines were withdrawn and treatments were changed without forewarning.

The NICE guidelines aim to improve the level of practice by providing a series of recommendations, which include:

- Regularly assessing the symptoms that indicate a person may be in the last few days of life;
- Providing accurate information to the dying person and those close to them, ensuring there are opportunities to discuss fears and anxieties;
- Discussing the dying person's wishes and creating an individualised care plan, making sure it is recorded, shared and

updated appropriately;

- Supporting the dying person to drink if they wish to do so, assessing their hydration status on a daily basis;
- Stopping the use of previously prescribed medications that are not relieving symptoms, when it is recognised that a person is in the last days of their life.

The National Council for Palliative Care (NCPC) welcomed the guidelines, but called for ongoing training for staff to ensure a high standard of care is always delivered. 340 healthcare professionals wrote to The Telegraph expressing the view that the principles of individualised care and respecting the wishes of dying people are undermined by the current law prohibiting assisted dying.

Compassion in Dying and Dignity in Dying were recommended in the guidelines as sources of further support and advice. This is recognition of our expertise and the important role both organisations play in the continuing development of end-of-life care.

If you would like to find out more about the guidelines then you can do so at

 www.bit.ly/niceool

HOW TO DIE: SIMON'S CHOICE.

BY MIKE HAMILTON

The final days and moments of Simon Binner's life were shown in a BBC Two documentary on 10th February. It was a one-off documentary by award-winning directors Rowan Deacon and Colin Barr. It poignantly showed Simon facing the decision as to whether he should travel to Switzerland for assistance to die. Something we know at least 3 people a month face, while for many more in the UK this is not an option and are forced to take their lives without the support of loved ones or healthcare professionals.

Simon made the decision to travel abroad to die after being diagnosed with an aggressive form of motor neurone disease in January 2015 and being given only two years to live.

Simon's story gained significant media attention after he announced his decision to end his life in Switzerland on the social media site LinkedIn.

The documentary begins by him telling loved ones that he is considering having an assisted death. Simon, his family and friends grapple with the moral, emotional and legal dilemmas around his choice, and, as this observational documentary shows, their conflicting perspectives mean that his heart-wrenching decision lies in the balance until the very end.

Throughout the film Simon's wife, Debbie, was strongly opposed to Simon travelling abroad to have an

assisted death, saying "*I feel so strongly that this is not the right thing to do*". But she agreed to let Simon document his journey in order for the two of them to "*have a grown up debate*." Debbie concluded that "*After much soul searching, I think it was probably right for my husband, in his very particular circumstances. He had a rock solid personality and once he'd made a decision on something - well, that was usually that.*"

Adam Barker, BBC Two Channel Editor, said: "*Being part of the national conversation is very important to BBC Two and this film sensitively explores the issue of assisted suicide with intimate access to one family facing up to one of the toughest decisions there is to make.*"

This documentary follows on from the 2011 BBC documentary "*Choosing to Die*" that featured

Terry Pratchett. Terry followed Peter Smedley along with his wife to the Dignitas clinic, where Peter had an assisted death.

Simon hoped that by making this film it would yet again draw attention to the ridiculous legal situation where hundreds of Britons are forced to travel abroad to have a good death, often before they are ready.

Dignity in Dying
@dignityindying

Our official statement to tonight's documentary on [#simonschoice](https://www.bbc.com/news/health-35284848) bit.ly/1osVURG



RETWEETS 95 LIKES 111

8:05 PM - 10 Feb 2016

Michelle Dewberry
@MichelleDewberry

Just watched [#simonschoice](https://www.bbc.com/news/health-35284848) gosh what a powerful story. I believe in [@dignityindying](https://www.dignityindying.org/) we all deserve the choice. RIP Simon, bless his family



RETWEETS 23 LIKES 67

8:03 PM - 10 Feb 2016

Amanda Richards
@AmandaRichards

I wish [#assistedying](https://www.bbc.com/news/health-35284848) had been an option for mum. She wanted it. She went through hell. Surely it's time to change things? [#simonschoice](https://www.bbc.com/news/health-35284848)

RETWEETS 23 LIKES 105

1:23 PM - 10 Feb 2016

Secular Mad Forum
@SecularMadForum

'Unbearable suffering inflicted on a dying patient who wishes to die, is unequivocally a bad thing' QT [@ProfRayTallis](https://www.bbc.com/news/health-35284848) [#simonschoice](https://www.bbc.com/news/health-35284848)

RETWEETS 12 LIKES 25

1:22 PM - 10 Feb 2016

fiona phillips
@fionaphillips

So sad, so much still to give, yet Simon Binner has shown that assisted suicide is valid &, for some, necessary Remarkable man [#simonschoice](https://www.bbc.com/news/health-35284848)

RETWEETS 96 LIKES 316

2:23 PM - 10 Feb 2016

Allan Peterson
@Allan_Peterson

Hope [#simonschoice](https://www.bbc.com/news/health-35284848) fuels more discussion on this subject, nothing is more civilised than allowing individual the informed choice.

RETWEETS 10 LIKES 21

1:11 PM - 10 Feb 2016

Sam Dick
@samdick

Debbie questions 'Did I do enough?' We'd all agree she did. Did MPs do enough for people like Simon? No they didn't. [#simonschoice](https://www.bbc.com/news/health-35284848)

RETWEETS 211 LIKES 452

2:25 PM - 10 Feb 2016

Dave Jones
@WishGodDc

It is the patronising paternalism of religious leaders, medical professionals and know-it-all politicians that denies [#simonschoice](https://www.bbc.com/news/health-35284848).

RETWEETS 33 LIKES 77

1:10 PM - 10 Feb 2016

'How to Die: Simon's Choice' was aired on 10th February 2016. At the time of writing the documentary is available to watch on the BBC iPlayer until 11th March 2016.

ADVANCE DECISIONS AND STATEMENTS CAN NOW BE WRITTEN ONLINE.

In January Compassion in Dying launched an innovative free website - www.mydecisions.org.uk

BY GREG LEWIS

MyDecisions was created in response to growing concerns over the low number of individuals planning ahead for their treatment at the end of life should they lose the capacity to make decisions for themselves.

The MyDecisions website allows you to draft an Advance Decision or Advance Statement online for free. Designed in collaboration with patients, clinicians and lawyers, the website takes you step by step through the process of making an Advance Decision. It presents different conditions and scenarios you might experience if you lose capacity to make decisions, whether due to illness or an accident. These scenarios include dementia, brain injury and terminal illness. The site prompts you to consider what you would want in these situations.

At the end it generates a personalised Advance Decision or

Advance Statement to print, sign, get witnessed and share, something which could make a significant difference to getting the care that is right for you at the end of life.

Findings published by Compassion in Dying in 2014 revealed that whilst 82% of people have strong feelings about what treatment they would or would not want at the end of life, only 4% of them have made either an Advance Decision or a Lasting Power of Attorney. Further findings published in September 2015 showed that where wishes of patients were recorded they were 41% more likely to be judged by loved ones to have died well. Where such wishes were not recorded, loved ones were 53% more likely to feel that the patient received treatment they would not have wanted.

Since the site was launched in January over 1,000 people have started their Advance Decision or Advance Statement.

MyDecisions.org.uk has been designed with patients for patients, to make it as straightforward as possible for you to make your decisions known. For more information visit the website or call 0800 999 2434.



THANK YOU MARGARET, YOU WERE A STAR CAMPAIGNER.

BY
SARAH WOOTTON

In memory of Dignity in Dying campaigner, Margaret John, who died in November 2015. Sarah Wootton, Dignity in Dying Chief Executive, spoke at her wake.

“ Margaret was an outstanding campaigner; forceful and direct and never in the many years that she was on board with the campaign did she ever stop advocating for assisted dying. Margaret made her thoughts clear. She did so in countless interviews, whether it was national media such as *The Independent* or *Newsnight*, or to her regional paper in York.

Before the General Election last year Margaret appeared in a Dignity in Dying video titled *My Last Vote*. The film crew followed Margaret for the day and one of the most surprising aspects they encountered were her diaries. Boxes and volumes of Margaret’s writings and musings on her cancer diagnosis, from when she was first diagnosed on holiday up to the present day which incorporated all her work for Dignity in Dying. The matter-of-fact style embodied how Margaret got her point across, and numerous journalists over the years have remarked on what a strong, brave and up-beat person Margaret was.

Margaret’s commitment to the campaign was astonishing. It would not be unusual for Margaret to schedule interviews around her hospital appointments or treatment, fitting in as much as possible in a day. In fact I think the only thing that was non-negotiable was her many opera and theatre visits with friends. She would make sure that she was free to travel down to London for our AGM or demonstrations outside Parliament – an incredible amount of resilience required especially when she neared the end of her life.

When we started to prepare a new legal case Margaret, again in trademark straight-to-the-point style, pointed out that she was on the ‘final straight’ and so it was not best for her to take a case all the way to the highest courts in the country. That didn’t stop her contributing a written statement for us, she always put the campaign first.

It is with great sadness that the assisted dying law she so desperately wanted and campaigned for was not changed in time for her own death. Instead, Margaret’s impact will continue long after today and will contribute to thousands of others having the choice that was denied to her.”



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CAMPAIGN FOR
DIGNITY
IN DYING.

**I'M SUPPORTING THE
ASSISTED DYING CAMPAIGN**

GIVE CHOICE TO FUTURE GENERATIONS BY LEAVING A GIFT IN YOUR WILL TO THE ASSISTED DYING CAMPAIGN.

Write your Will for free with local solicitors

By leaving a gift in your Will it will be a tribute to your beliefs and principles, by helping to bring a compassionate change in the law for future generations.

Supporter bequests fund 25% of the assisted dying campaign. Whether your gift is large or small, it will make a difference.

As a member of Dignity in Dying you are entitled to use a free Will-writing service with solicitors local to you. It allows you to support the campaign in the best way possible at absolutely no cost.

Please send me a Free Wills Pack so I can leave a gift in my Will to Dignity in Dying

Name:

Address:

Postcode:

Membership number (if known):

CANADA

SUPREME COURT
STRIKES DOWN BAN ON
ASSISTED DYING

**CAMPAIGN FOR
DIGNITY
IN DYING.**

2016 IS A YEAR FOR CHANGE