

# CAMPAIGN

Issue 2 of 3 2017



**CAMPAIGN FOR  
DIGNITY  
IN DYING.**

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**Editor Sarah Bradley**

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**SARAH WOOTTON**

Chief Executive

## WELCOME.

**N**oel Conway's challenge to the law was heard at the High Court in July. I joined Dignity in Dying supporters on the steps of the court to make the case for change and tell the assembled media about the huge support for Noel, as shown by people demonstrating across the country. Pages 3 to 12 of the newsletter explore the case and action surrounding it.

Noel was not well enough to make the trip to London, so other witnesses supporting his case spoke out. I spent the first day of the hearing talking to journalists with Christie and her husband Jon. I would like to thank them for their contribution to the court case and for speaking so frankly and passionately about her incurable breast cancer and the need for greater choice at the end of life. You can read Christie's own account of her support for assisted dying on page 6.

The importance of personal contributions to the success of the campaign cannot be understated. Personal testimony by people affected by the problems of the current law has a huge impact with the public, the media and, in particular, parliamentarians. So I would also like to thank Yvonne Pryor and Sandy Briden for their touching and candid stories and, critically, for sharing them with decision makers (pages 13 and 14).

It was with much sadness that we said goodbye to Joel Joffe in June. Joel's life, and in particular his contribution to progressive causes like the assisted dying campaign, was an inspiration. Read my tribute to Lord Joffe on page 28.

Thank you to everyone who attended our AGM. The day was a wonderful opportunity to meet with members, to reflect, and look to the future. Those of you who were unable to come can read more on page 24 along with the results of the 2017 board election.

Across the world assisted dying campaigners are gathering evidence and building momentum. A report into the first six months of assisted dying working in California was published in June, providing further evidence that the safeguards work and the legislation is well- drafted. Victoria in Australia may soon approve an assisted dying law. Read more about these developments on page 20.

On page 16 you can read the account of Dr David Nicholls, who discusses his reasons for changing his mind on assisted dying following a personal experience. I'm pleased to say that Dr Nichols has already shared his story in the British Medical Journal. The more medics speak out, the more the tide turns in our favour.

With new supporters joining us as we continue to support Noel's case, the strength behind our campaign continues to grow. Thank you for being part of this.



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# NOEL CONWAY'S CASE IS HEARD AT THE HIGH COURT.

BY DAVINA HEHIR

**N**oel Conway's case was heard by three judges in the High Court in London, from the 17th to 20th July.

The case launched on Monday 17th July amidst a flurry of media coverage and to an unusually busy court room with both the press and public galleries completely full.

Noel's legal team made the case that Noel's right to private life under the Human Rights Act, which includes the right to make decisions about the end-of-life and death, is being unjustifiably interfered with by the 1961 Suicide Act, which places a blanket ban on all assistance to end life, regardless of the circumstances.

The key arguments in court focused on legal issues, particularly whether the courts or Parliament are better placed to decide these cases; the right balance of Noel's - and other dying people's - autonomy and dignity in relation to the potential impact of law change on others; and whether the purpose of the blanket ban under the Suicide Act is to protect people, or also to protect moral standards and the sanctity of life.

Noel's case is opposed by the Secretary of State for Justice and we worked closely with Noel's legal team to challenge the arguments put forward. This involved making the case that the current law is not





protecting vulnerable people, and that the law change Noel seeks is limited to allowing safeguarded choice for people who are already dying and simply want to control the manner and timing of their death.

Whilst Noel was too ill to travel to London to hear the arguments in person, he was able to attend Telford Crown Court to hear one day of the case through a live internet link between the courts. He was accompanied by his wife Carol, some of their friends and several members of the Dignity in Dying Shropshire local group.

The court closed from the end of July and re-opens on the 1st of October. We anticipate that the Judges will spend the summer working on their decision, which we hope they will issue in early October. However, there are no guarantees on timing and it could be later. Whilst it is

frustrating to wait for a decision, it is part of the nature of legal cases of this kind where complex issues are considered.

Although the hearing went well, we anticipate that the case will need to continue to the Supreme Court in order to win. If the High Court find against Noel, we will continue to work closely with him and his legal team to appeal that decision.

Noel has had to fight hard to get his case heard in court and it is likely that the hearing in July is a step on the journey, rather than the end. We will continue supporting Noel every step of the way with the case and we are extremely grateful to him and his family for all they are doing to help us change the law.

# NOEL AND I DESERVE CHOICE AND CONTROL.

BY CHRISTIE ARNSTEN

*Christie Arntsen, a former teaching assistant from Oxfordshire, has incurable cancer. She has provided evidence in support of Noel's case because she too is denied the choices she wants at the end of life. Here she shares why she is fighting alongside Noel for a change in the law:*

**“ I AM 48 YEARS OLD AND HAVE SECONDARY BREAST CANCER. IT WAS DIAGNOSED IN NOVEMBER 2013 AND I NOW HAVE CANCER IN A NUMBER OF SITES. I WILL PROBABLY DIE WITHIN THE NEXT FIVE YEARS. ”**



Christie, her husband Jon and their children Rosie and Josh

**get up every day, knowing that the world is closing down for me. My heart breaks at the thought of not seeing my children mature, get married and have children of their own. Worse than all that is the thought of leaving my wonderful husband.**

Despite the overwhelming sadness this causes me, I still love my life, my family and friends and I plan to stay being myself until such time as I can no longer do so.

Although it has been unbearably hard, I have coped with finding out I have secondary breast cancer, chemotherapy, losing all my hair, surgery and radiotherapy. What I find so hard to cope with is that I have no choice about when and how long it will take me to die.

Why can't I go, when the time comes, as myself, and prevent the distress of barely clinging on to life in my last few weeks or months? The thought of my family watching me suffer as I slowly die is incredibly painful.

Taking my own life at home is not feasible because I am so afraid my family would be held responsible for my decision. Currently my only option is to go to Switzerland, but this would mean having to end my life earlier to make sure I was well enough to plan and make the journey myself.



*Christie with Sarah Wootton outside the High Court*

The ability I have to be positive and carry on enjoying life would be so much easier to maintain if I had the knowledge that, when the time comes, I was able to seek an assisted death in this country. It is difficult to explain in words what this would mean to me and how much peace it would give me while I am living, when I am dying and in my last days.

I am speaking out because I believe that otherwise change will not happen. I am so grateful to Noel and his family for bringing assisted dying back into the foreground. I know that my life would be better if I knew I had a choice about when and where I die – it would make me want to live longer as I would know I was in control of when enough was enough.

To me it is obvious that assisted dying should be an option available to terminally ill people. To have this choice is a fundamental human right.



# UPDATE ON LOCAL GROUPS.

BY FRAN HALL



*Pauline Carroll is the deserving winner of the inaugural Romey Brown Memorial Prize*

**T**he enthusiasm for campaigning at a grassroots level has continued into 2017, with more people joining the assisted dying movement during Noel Conway's historic legal challenge. We now have 29 campaign groups across the UK – we're pleased to welcome new groups in Shropshire (home to Noel and Carol), Northampton and Reading. We've had our first meetings with campaigners in Glasgow and there are plans to roll out further Scottish groups this year, as well as student groups.

Our local campaigners are helping us to ensure that the campaign remains on the public agenda in all corners of the UK. They rally into action, sometimes at short notice like during the snap general election (see page 15). Here are just some of the fantastic ways they are campaigning:

## SPREADING THE 'I'M WITH NOEL' CAMPAIGN.

We launched the 'I'm with Noel' public awareness raising campaign to ensure that Noel's case gains the maximum public support. Many of our local campaigners joined the boat demo (see page 10) from as far as the Isle of Wight, Portsmouth and Brighton. Others have taken the



'I'm with Noel' campaign to their local towns and cities – including Bath, Islington & Hackney, Shrewsbury and even a stand at 'Pride Cymru' in Cardiff – attracting attention in bright t-shirts, making signs and asking members of the public to pledge their support for Noel.

### **CAMPAIGNER OF THE YEAR 2017 - ROMEY BROWN MEMORIAL PRIZE.**

At this year's AGM we awarded the inaugural Romey Brown Memorial Prize to our most committed campaigner, scored against six criteria: persuading politicians, identifying supportive clergy and disabled people, putting pressure on the medical profession, raising public awareness, influencing the media, and fundraising for the campaign. It was certainly a difficult task to pick a winner.

After much deliberation we did come to a conclusion and the deserving winner was Pauline Carroll, who leads the Bath & Bristol group. She's a proactive advocate for change who seizes any opportunity to further the cause of the campaign, a fierce debater who has tackled local MPs head on at hustings and constituency surgeries and persuaded them to be open to change. She's spoken to her local Clinical Commissioning Group (CCG), a CEO of a local hospice and encouraged her GP to support their campaign. She frequently writes to local and national press, runs down our supply of leaflets and posters

and even managed to raise £400 for Noel Conway's case. Congratulations again to Pauline.

### **WE'RE COMING TO A UNIVERSITY NEAR YOU!**

Earlier this year we met Austen Waite, a philosophy student who's setting up the first Dignity in Dying student society at the University of Glasgow. This prompted us to draw up some guidelines and encourage more students at other universities to get involved. If you know any university students who might be interested in setting up their own society, please tell them to visit our website to find out more: **www.dignityindying.org.uk/students**

### **COMING UP.**

Our Portsmouth group are furthering their talent for fundraising by holding the very first 'DiD Fest' on 29<sup>th</sup> September. It's a 1960s themed night featuring live music from the Fab Beatles, optional fancy dress and some fabulous raffle prizes! Tickets are selling fast; tell your friends and family in Portsmouth to grab the remaining ones at **www.tinyurl.com/didfest**

Later this year we are excited to be launching new groups in Essex and Bangor.

Do you live in the West Midlands or East Anglia? Do you fancy starting a local campaign group? Please get in touch:

**E activism@dignityindying.org.uk**



## DEMONSTRATING 'I'M WITH NOEL'

**T**hree days before Noel's case was heard at the high court, hundreds of Dignity in Dying supporters descended on London to demonstrate their support and send a message to Parliament. That message was simple – we're backing Noel all the way in his campaign for choice at the end of life.

People came together from all over the county to a unique demonstration outside the Palace of Westminster –

unique because this demonstration was on a boat on the River Thames. Chants of 'I'm With Noel' could be heard from Parliament's canteen!

On the boat were hundreds of people all with their own unique reasons for backing Noel's case, including people facing death from a terminal illness, disabled activists and many long-standing Dignity in Dying members. A camera crew joined us to make a mini-documentary and a series of short videos in support of



## ON THE THAMES.

Noel, which we are now using to reach new people and recruit them as supporters of the campaign for a more compassionate law.

The energy on the day was amazing, with a great atmosphere of solidarity with Noel. You can watch the video of what happened here: [www.bit.ly/imwithnoel](http://www.bit.ly/imwithnoel)

Support Noel Conway's campaign to change the law

 [www.imwithnoel.co.uk](http://www.imwithnoel.co.uk)





# REAL OPPOSITION DOESN'T NEED FAKE COFFINS. BY DAVID PEARCE

**B**y the time Noel Conway's case was heard at the High Court, Noel was too unwell to make the trip to London. At first I was disappointed for Noel but when I was outside court and saw the behaviour of our opponents, I was actually pleased he was not there.

## LIES, THEN PUPPETS.

Before the case Not Dead Yet announced that they were intervening in Noel's case. Baroness Jane Campbell said that *"In every country where assisted suicide has been made legal, original safeguards have been watered down, allowing the parameters to widen."* This is simply not true. Of course Baroness Campbell is entitled to disagree with Noel, but I don't think she needs to lie.

I was prepared for Not Dead Yet and other opponents to try to make the debate about something it's not. I was not prepared for Noel's hearing to be turned into a cheap circus with the presence of fake coffins and ridiculous puppets. Despite the obvious insensitivity of having fake coffins at a dying man's case, both Dr Peter Saunders of the Christian Medical Fellowship and Not Dead Yet have ignored my request via Twitter asking them to respect Noel's views and condemn these hurtful campaign tactics. Christian Concern has even made a video featuring the coffins. How this is 'speaking for Jesus in public life' I don't know.

## LISTEN TO NOEL.

My message to opponents of assisted dying is simple. You're entitled to oppose Noel, but please do so with respect and listen to what he has to say. This is what Noel told *The Telegraph* about the fake coffins:

“I found this particularly hurtful... Members of these groups falsely claim to understand what it is like to be me. But they cannot possibly understand - they are not terminally ill.”



Some opponents brought fake coffins to Noel's hearing

# WHY I'M SHARING MY STORY IN SUPPORT OF DIGNITY IN DYING.

BY YVONNE PRYOR



**M**y name is Yvonne Pryor and I have stage four bowel cancer. At the moment I am responding well to chemotherapy and remain positive. Cancer won't beat me any time soon, but its progress is inevitable. When I come to the end of my life, I want the choice of assisted dying. But that choice is not an option in Scotland.

I have great support at home from my husband, James, and I still have a young(ish) family. My youngest daughter is 12 and my youngest son 15. I also have two grown up children. My eldest daughter has left home and my eldest son is studying at university. I also look after a man with learning disabilities who has lived with my family for over 25

years. We are a happy loving group and I have lots to live for.

But, when the cancer takes hold, I would get great comfort from knowing I could control my death at home. Sadly, Scots law denies me that.

When it is the end, I want to be with my family, I don't want to die in a hospice or hospital. I want how and when I die to be my choice.

I want the choice of assisted dying. I don't want to have to wait until it is too late or have to take steps to take my life without medical guidance. I don't want to lose any of what precious time I have. I want to die in a dignified way that allows us all to celebrate my life and acknowledge its worth.

I am asking others to support my campaign for assisted dying so that people like me don't have to suffer at the end of life. So that we are all able to die with dignity.

If you, like Yvonne, have a terminal illness and would like to share your story in support of the campaign, please contact Dignity in Dying.



## FOR ME, ASSISTED DYING IS ABOUT LIVING.

BY SANDY BRIDEN

Sandy Briden has sarcoma, a rare and incurable form of cancer, and knows she may not have long left. She wants to live as fully as possible in her remaining time, without the fear of a painful death hanging over her. For Sandy, having the option of a dignified, peaceful assisted death is as much about living as it is about dying.

**I'm 57 and live in Twickenham with my daughter and two granddaughters. My partner, son and father also live nearby - we're all very close. I'm a chemistry lecturer and scientist by trade and, until recently, I had the job of my dreams. I had a brilliant life.**

Then, in December 2015, I was diagnosed with a tumour in my abdomen. In the months that followed I was seriously ill and underwent a major operation. In April, I was told that I had no evidence of the disease and returned to work. However, my six month scan results in August 2016



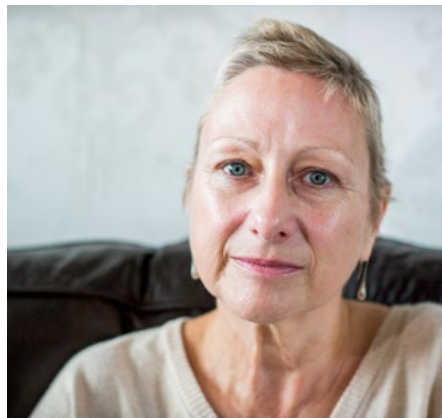
were devastating. I had multifocal, inoperable tumours – so aggressive that I was immediately put on palliative care and warned I may only have a few weeks left.

I opted for palliative chemotherapy with the understanding that it would not save my life – I knew it may not have any effect and at best may just hold the tumours back. The treatment was very difficult and the side effects horrendous. I spent much of the time in hospital, but it was worth it as I battled on and achieved my goals – to see my son married in the October and the birth of my granddaughter in the December.

How I am still here is a miracle, and I am grateful everyday. The tumours are currently being held at bay, but once they start growing again I could have just five weeks or less left. I may need an operation, not to remove tumours or to save or extend my life, but to remove any blockages. I have undergone dozens of medical interventions over the past 18 months and I dread any more if I am near to the end. In any case, an operation may not even be possible because of the placement and size of the tumours. My thoughts are filled with uncertainty and fear that my pain and sickness will not be controllable – but having the option of an assisted death would change all that.

I think about dying constantly – what will happen if the tumours on the left or the right grow fastest, how I am going to die, whether I will be in pain. I just want to say goodbye to my family and drift off peacefully. I don't want them to see me suffering; I don't want that to be their last memory of me.

“Knowing I had the option of an assisted death when things get too much would allow me to live now, without the constant fear of what might happen at the end. For me, assisted dying isn't about dying, it's about living. By backing this campaign I am fighting to live.”



Sandy recently spoke to Channel 4 News about her experience of cancer and campaigning for the right to assisted dying. The video has been viewed 6.6 million times on their facebook, and has been shared over 13,500 times. You can view it here:

 [www.bit.ly/Sandych4](https://www.bit.ly/Sandych4)



*David and Fabi with their friends Tim and Françoise.*

# WHY I'VE CHANGED MY VIEW ON ASSISTED DYING.

**BY DR DAVID NICHOLL**

*Dr David Nicholl is a consultant neurologist at City Hospital, Birmingham. After experiencing the death of his close friend he changed his view on assisted dying, and decided to share his experience in support of the assisted dying campaign.*

**O**n Thursday 23 March, I conducted my usual clinic, but this was like no other day. I knew that at 1.30pm precisely one of my closest friends was going to die.

Fabi's death, at age 51, by voluntary euthanasia – something which I had been utterly opposed to throughout my career – is legal in Belgium where she lived. I used to believe that if we got the balance of palliative

care right to minimise distress, then “assisted dying” was an irrelevance. Yet her death dramatically reversed my own views.

I first met Fabienne “Fabi” Vanheuverbeke in Florida in 1983 on our gap years – with two other foreign exchange students (Tim and Françoise) – we formed a life-long bond. On her return to Belgium, Fabi, then 24, fell ill with a pituitary tumour and then a more widespread disorder, multiple endocrine neoplasia (MEN). She could not have children and developed multiple tumours in her pancreas, stomach, and liver over the next 27 years. In September 2016, I got the call I’d dreaded. She was now terminal, and we must all meet. In November, the four former exchange students met for one final time, along with Jan, her partner. It was a truly precious weekend – we dined, laughed, and remembered a lifetime of fun.

I last saw her in February and was so impressed by Fabi’s palliative care – it wasn’t all about drugs. Jan and Fabi’s closest friend took paid compassionate leave to share her care. In the UK, they would almost certainly have had to give up work to do so. Gazing at Fabi’s frail frame, I could just imagine what would likely have happened in the UK – ending up at some point on an A&E trolley. Yet when Belgium invests 10.2% of GDP on health and social care compared with the UK’s 8.5%,

this makes the difference. Saying goodbye to my friend with a glass of Jan’s beer – he’s an award winning brewer – as she rested in her own living room seemed infinitely more civilised than a hospital corridor.

In March 2017, I got another call – Fabi was clear she’d had enough. The discomfort was too much, she was going to ask for euthanasia. Belgium legalised voluntary euthanasia – whereby a doctor can end the life of a patient at their request and subject to safeguards – in 2002. In 2003, it accounted for 0.2% of all deaths, rising to 1.7% in 2013. I was in a state of utter shock. She was clearly completely rational and with access to a superb palliative care team. Yet Fabi was asking to die, and die she would later that week. It could not be any sooner as a number of checks had to be made, to ensure that this was her fully informed decision. All patients have to give their written consent and be assessed by at least two doctors to ensure that they are mentally competent (a third doctor is required if they have a psychiatric condition).

“It is utterly vital that vulnerable people are protected, yet assisted dying is fundamentally about consent and autonomy.”

I began to question my previous views. I totally respected Fabi’s wishes – who was I to challenge them? Fabi was pleased that I had





changed, joking with a friend just hours before she died that when the UK law changed, they should call it Fabi's Law.

I couldn't be present for her death, but stayed with Jan on the eve of her funeral, and he explained what happened. Once the independent assessment had determined that her request was appropriate, her voluntary euthanasia was set for 1.30pm on the Thursday. That morning, Jan told me Fabi was positively counting the minutes to her time. Her family and friends were able to say their farewells by her bedside in her own home. Then, with Jan by her side, her GP, who had known her for decades, administered the injections. She smiled, gave a gentle wave to Jan and her family, drifted to sleep, and died within minutes.

The doctors are required by law to report each case they attend to the Federal Control and Evaluation

Committee – any deviation could result in a murder charge. For most of us, death when it happens will be completely unexpected. For a small, but important minority, having a sense of control over how they depart this life – as Fabi did – is crucial to a good death. For those who oppose this as being a “slippery slope,” what right have they to impose their view on others such as Noel Conway?

Legalised voluntary euthanasia is available in the Netherlands, Canada, Colombia, and Luxembourg, as well as Belgium. In Switzerland, assisted suicide, where patients take the final action themselves, is legal. In the US, doctor assisted dying is legal in Oregon, Vermont, Washington, California, Colorado, Montana and most recently, Washington DC. No one is forced to opt for assisted dying, no more than anyone is saying you are forced to get married. But in some other countries, there is now a choice. Elsewhere, for those who can afford it, there is the desperate trip to Dignitas to die. Dignity in Dying estimates one person from the UK travels to there every 8 days. This is an outsourcing of assisted dying to a foreign land due to our failure to deal with the legal and ethical issues.

Doctors and politicians are out of step with the public. In 2014, a YouGov poll found that 56% of the public would consider assisted

dying if it were legal and they were suffering a painful and incurable disease. A 2015 Populus poll found that 82% support a change in the law to allow assisted dying].

In contrast, in a 2014 survey I helped organise for the Royal College of Physicians, 58% of doctors opposed a change in the law. One year later, MPs opposed a change in legislation. In the debate, Sir Keir Starmer – who, ironically, as head of the Crown Prosecution Service drafted the current guidance – stated:

“We have arrived at a position where compassionate amateur assistance from nearest and dearest is accepted, but professional medical assistance is not unless you have the means of physical assistance to get to Dignitas.”

I didn't agree then – I do now. A change in the law would enable those in the UK faced with a terminal illness the same choice that my friend Fabi had – a death with dignity on their own terms.

### HEALTHCARE PROFESSIONALS FOR ASSISTING DYING (HPAD)

is a group of practising, retired and student healthcare professionals who support choice at the end of life. Membership is free. Your doctor will be able to find out more from:

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

## DEMONSTRATING AT THE BMA ARM IN BOURNEMOUTH.

The British Medical Association (BMA) held their Annual Representative Meeting in Bournemouth at the end of June. The Dignity in Dying Bournemouth group ensured we had a fantastic presence outside the conference centre. Supporters donned brand new pink t-shirts as part of the 'I'm with Noel' campaign, handed out leaflets and spoke to doctors about Noel's case. The response from attendees was overwhelmingly supportive, with many doctors citing their frustration at the BMA's opposition stance.



# INTERNATIONAL DEVELOPMENTS.

BY HANNAH EASDOWN

## VICTORIA, AUSTRALIA.

Our friends on the other side of the world are working hard to legalise assisted dying in Victoria, Australia.

Parliament House,  
Melbourne,  
Victoria



This July an expert panel, chaired by Professor Brian Owler, the former Chair of the Australian Medical Association, presented a comprehensive report outlining their recommendations for how assisted dying should be implemented. The recommendations were underpinned by the guiding principles that every person has the right to quality end-of-life care and that open discussions about death and dying should be encouraged.

All the recommendations have been accepted by the Victorian government, and will now be made into a bill to be voted on by parliament at the end of the year. If

all goes well, assisted dying could be a reality for Victorians by 2019.

If the bill is passed, terminally ill, mentally competent adults with a prognosis of 12 months or less would be granted access to assisted dying. It would be limited to those who ordinarily reside in Victoria with Australian citizenship.

Mental illness and disability alone would not be grounds for an assisted death, but they would not prevent someone from having an assisted death if they otherwise met the criteria.

Those eligible would have to make two verbal and one written request for an assisted death, with at least 10 days between the first and last request.

Doctors would have to undergo specialist training before being able to assess a patient's eligibility and there would be a vast array of reporting mechanisms and oversight to ensure complicity with the law.

If a dying person meets all the eligibility criteria and has a request approved they would be prescribed

the medicine to take whenever they felt ready, but would be able to change their mind at any time. The report has been carefully put together after extensive consultations with disability groups and palliative care experts among others.

The report follows 40 failed attempts to pass similar bills in Australia, including a disappointing recent result in Tasmania earlier this year and a bill in South Australia being defeated by just one vote in 2016.

The Health Minister for Victoria, Jill Hennessy, stated that

“too many people have been denied compassion at the end of their lives. We can and must do better.”

This goes to show that we are not fighting this battle on our own. People across the globe are challenging the status quo and will not give up until the law changes. Progress in Australia would follow developments in a succession of US States and Canada in recent years.

The bill will be voted on in parliament by the end of 2017 and with approximately 80% of Australians backing voluntary assisted dying, we have our fingers crossed that Victoria becomes the next place to give dying people choice at the end of their life.

## USA.

The first report since California legalised assisted dying has been

published, along with the 2016 Washington State report.

In California, 111 people were assisted to die in the 6 months between June and December 2016, accounting for 0.06% of deaths in California over the same period.

191 prescriptions were dispensed by 173 different doctors, suggesting that ‘doctor-shopping’ is yet another hypothetical fear put forward by those who oppose law change that is simply not borne out by the evidence.

In California, 83.8% of people who had an assisted death were enrolled in hospice or palliative care, as well as 77% in Washington, further debunking the myth that assisted dying and end-of-life care are incompatible.

In Washington, where assisted dying laws have been in place since 2009, medication was dispensed to 248 patients.

In both states, people with terminal cancer made up the majority of those receiving an assisted death.

Both reports demonstrate that assisted dying laws are working exactly as intended.

Terminally ill people in California now have greater choice at the end of their life and the rest of society is better protected thanks to clear, upfront safeguards.



# LECRETIA'S CHOICE.

BY MATT VICKERS



**E**arlier this month, Noel Conway appeared in the London High Court to plead his case to have a choice about how he dies. I completely and utterly support him. His story has extraordinary parallels to the experiences of my late wife.

Two years ago, my wife, Lecretia Seales, launched a similar challenge in the High Court of New Zealand. My wife was a brilliant and youthful lawyer, who had been dealing with a terminal brain tumour diagnosis for four years, since the age of 37. For most of that time, she focussed on living. She continued to work as a law reformer, but took holidays whenever she could, travelling with me and her parents to exotic places like Morocco, Bermuda, Argentina and the Cook Islands. Her appetite for life was boundless, and undimmed by the various

treatments - surgery, radiotherapy, chemotherapy - that she had to endure in order to maintain her quality of life.

But in late 2014 her treatments ceased being effective. Being a fiercely independent woman, her response was to take charge of her circumstances, just as she'd taken charge of her illness. After viewing a famous lecture by Sir Terry Pratchett, and following the case of Californian Brittany Maynard, she decided she too believed she should have a choice about how she died. She wrote at the time:

“I am unable to see anything left of centre. The left side of my body does not move very well. I have difficulty walking, typing with my left hand and eating with a knife and fork. I require assistance from my husband to get dressed each morning. I am not allowed to drive. I have lost spatial awareness and get lost easily in new places. I constantly bump into things. My balance has been affected and I have falls... My head is scarred and bald in patches from radiation burns. From time to time I have searing headaches. My dreams for the future have been dashed.”

“I am not afraid of dying but I am petrified by what may happen to

me in the lead-up to my death... If I get to a point where I can no longer recognise or communicate with my husband, then I will already be dead. Why string out the process of actually dying? Why can't we make informed choices regarding the timing and manner of our death, so death is as pleasant a process as possible? I believe it is a fundamental human right to choose to die when life will become intolerable because of the effects of a terminal illness or debilitating condition.”

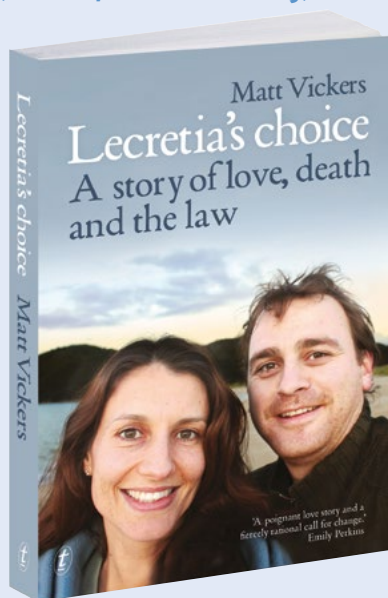
Lecretia passed away shortly after the judgment in her case was delivered. Though the judgment went against her, Lecretia's court case pushed forward progress by years, perhaps decades. A parliamentary select committee agreed to investigate assisted dying for the first time in New Zealand's history. Lecretia was named New Zealander of the Year 2015 by a major New Zealand newspaper. The committee's report, released in August, does not recommend a law change, but it does not recommend against one either, and it dispels several of the spurious claims made by opponents of reform.

An End of Life Choice bill is now before parliament, and will likely be voted on in the next few months. We remain hopeful that the law will pass, and that New Zealand will join the growing list of enlightened countries that allow people to have a say over the ends of their lives. We hope that

the UK joins that list too, and that Noel Conway is successful in his campaign for change.

Supporters of Mr Conway may be interested to read my book *Lecretia's Choice*, which was released in the UK in late July. In it, I tell the story of our love, my wife's illness, her campaign, and the arguments presented in the courtroom by proponents and opponents of change. Mr Conway will no doubt face similar challenges, but it's the bravery of people like him and my wife, and their stories, that will one day ensure sensible legislation for the benefit of all of us.

**Lecretia's Choice:**  
**A Story of Love, Death and the Law by Matt Vickers, out now (£12.99, Text Publishing)**





# MINUTES AND BOARD ELECTION RESULTS FROM OUR 2017 AGM.

BY UPEKA DE SILVA

## FORMAL BUSINESS

- Minutes of the 2016 AGM approved
- Accounts for the year ended 31<sup>st</sup> December 2016 approved and adopted
- Mark Jarman-Howe and David Spenser elected as Board Members

The AGM took place on 29<sup>th</sup> June 2017. **Baroness Molly Meacher**, Chair of Dignity in Dying opened the AGM by paying tribute to Lord Joel Joffe, a passionate campaigner for the legalisation of assisted dying. She then drew on personal experience campaigning in the House of Lords to emphasise why our vision – a safeguarded assisted dying law for terminally ill, mentally competent adults – is the right policy for this country and one that will succeed. She concluded by expressing her deepest gratitude to

Noel and Carol Conway for devoting their precious time together to fighting our campaign.

**Sara Cutting** spoke passionately about the choice of an assisted death being a basic human right and insisted that a dignified death is worth fighting for.

Newly appointed Vice Chair, **Rabbi Jonathan Romain**, explained that there is nothing sacred about suffering and that forcing terminally ill people to live on against their



will is not loving your neighbour as yourself, but forcing your neighbour to live by your rules.

Chief Executive, **Sarah Wootton**, noted the value of the new strategic plan which focuses on parallel activities in the courts and in parliament, supported by a strong public facing campaign and thanked all the members for their generous support which gives the campaign the fortitude required to persist.

Treasurer, **Cameron Brown**, reported that Dignity in Dying is in a healthy financial position with a good fighting fund to support the legal case.

The **Romey Brown Memorial Prize**, celebrating local campaigners, was awarded to **Pauline Carroll** who leads the Bath and Bristol group, for her tireless efforts with MPs, GP surgeries, hospices and local media.

**Alyson Thomson**, our Director of Scotland, shared achievements from Scotland highlighting the support of the Herald and Sunday Herald which recently stated that “the right to die is the last great human rights battle”.

**Usha Grieve**, Director of Partnerships and Services at Compassion in Dying, discussed the success of the *Make It Your Decision* campaign in encouraging people to plan ahead for their treatment and care, and highlighting the value of Advance Decisions, which speak for you when you cannot speak for yourself.

Finally, **Lu Spinney** shared the tragic story of her son Miles and reminded us of how important it is to record our treatment wishes to avoid heart breaking situations like that experienced by her family.



# FEEDBACK FROM OUR MEMBERSHIP SURVEY.

Thank you to everyone who has taken the time to complete our membership survey. The responses we received offered an encouraging insight into your commitment to the campaign.

The most rewarding aspect of the results of the survey was the trust that you, our members, have in

Dignity in Dying. Overall trust in charities and not-for-profits was rated as 7 out of 10 by respondents, whilst Dignity in Dying received 9 out of 10.

The personal reasons given for supporting the campaign were incredibly varied, and very moving. We have sought the permission of some respondents to publish them.

*“It is morally wrong for people with terminal illnesses to be prevented from making the decision to terminate their life, under agreed acceptable conditions, when the only alternative they have is to suffer.”*  
John

*“I want a good death, for myself and those I know and love, and for everybody else. I believe the work of Dignity in Dying fits with my Christian beliefs and ethos.”*  
Jane

*“Because I believe totally that terminally ill people should have the right to choose where and when they die. They should not be forced to suffer or to travel to a strange country to die. Death is tough enough without prolonging the suffering of the patient or their family.”*  
Sue

*“Because my Mum had a ‘bad’ death 3 years ago, totally against her wishes. I am determined that nobody else should have to go through that against their wishes.”*  
Steve

*“I have been a nurse for 37 years and I firmly believe that we are intelligent, independent human beings who have every right to make informed choices, as with our medical care, and die as we choose. Having cared for many people who have suffered a long, distressing death, I fully support the right of people to die quickly and peacefully and the comfort that brings to families.”*  
Jane

*“Individual informed choice is at the heart of our lives. It should be so for our death.”*  
Maggie

# POLITICAL UPDATE.

BY TOM DAVIES

**T**he announcement of the snap General Election was a shock to almost everyone. MPs, Peers, journalists and, yes, even us campaigners, were all taken aback at an election called with apparently no briefing in advance.

That said, Dignity in Dying's supporters leapt at the chance to raise awareness of the campaign and thousands of emails were sent to election candidates. When standing for election, candidates tend to be more in touch with their constituents' views. Thanks to the tremendous efforts of our supporters, we found a number of new supporters in the intake of new MPs and there can be no doubt that many more were made aware of the strength of feeling amongst their (prospective) constituents.

Given the short run-up to the election, we were unable to plan a full campaign of action for our local activist groups. Instead, we urged people to attend hustings and raise the question of assisted dying directly with candidates in public. This resulted in media attention as well as some interesting insights into the feelings of candidates, many of whom were fighting their first election.

Thank you to everyone who, at such short notice, made such an effort to influence their candidates before the election.

The new Parliament has introduced some new faces and new opportunities to engage MPs on the issue of assisted dying. The All-Party Parliamentary Group on Choice at the End of Life has been re-established, with Conservative MP Kit Malthouse chairing the group. We know Kit will be an excellent advocate for greater choice for dying people.

The make-up of Parliament will not affect the progress of Noel Conway's legal case. We will continue to brief MPs and Peers on the progress of the case and it is always helpful to raise Noel's case with MPs when it appears in the press. It is likely to be some time before Parliament will have to take another view on assisted dying, but keeping the campaign fresh in your MP's mind is a great way to ensure they are fully informed when it does happen.



## REMEMBERING LORD JOFFE: 12 MAY 1932 - 18 JUNE 2017.

BY SARAH WOOTTON

**F**ew people will be able to fit so much into a life as Joel did. Representing Nelson Mandela in court, founding a FTSE 100 insurance company, chairing Oxfam and leading the campaign for assisted dying – Joel managed to make the most of his time on this planet. His death was a great loss, but his legacy will live on for some time.

Joel left his native South Africa after representing Nelson Mandela and other anti-apartheid campaigners at the Rivonia trial in 1964. In the UK, he was known for being one of the co-founders of the insurance firm that later became Allied Dunbar. He supported the international development charity Oxfam for many years and chaired the organisation for six years.

He became a member of the House of Lords in 2000. Amongst his many other causes, Joel became renowned for his passionate and dedicated campaigning to legalise assisted dying. While his attempts to change the law did not succeed, Joel's continued support behind

the scenes played a big part in managing to ensure that Lord Falconer's Assisted Dying Bill received the support of the House of Lords in 2014 and 2015.

Before becoming chief executive of Dignity in Dying, I had heard Joel's Desert Island Discs and was hugely impressed not only by the breadth of his achievements but also by his humanity. It was the latter that was the key to his involvement in the assisted dying debate. Joel felt sure that we have enough humanity to provide the choice of assisted dying, at the same time as protecting the vulnerable. He showed this humanity through his support for Dignity in Dying's staff and for me; as well as for the values of a campaign that has at its heart compassion.

While his career as a lawyer was far behind him by this stage, his advocacy for assisted dying laws was certainly that of an attorney. His sharp wit, his astute analysis and his fiercely intelligent arguments convinced many of the finest minds in the Lords and gave encouragement to those of us on his side.

Joel's keen eye for evidence was a particular boon for our campaign. He was enormously frustrated at the use of reckless allegations and spurious arguments that assisted dying laws would not work. He fearlessly took up those arguments with opponents of assisted dying.

More than anything, he held the highest respect and compassion for people who campaigned for assisted dying, particularly those who had been directly affected by the suffering of their loved ones. He spoke movingly about the unnecessary suffering that was being imposed on dying people by a law that was broken:

“As a caring society, we cannot sit back and complacently accept that terminally ill patients who are suffering unbearably should simply continue to suffer for the good of society as a whole.”

When I visited Joel a few days before he died, I saw the same humour, intelligence, passion and integrity that we had all come to know so well. While his health was deteriorating, I saw no dimming of that brightness that we all benefited from so much. He'll be very sorely missed by all of us at Dignity in Dying, by his friends and family, and by the uncountable beneficiaries of his lifetime of good causes.



# COMPASSION IN DYING LAUNCHES NEW ADVANCE DECISION FORM.

BY JENNIFER NOEL

**T**hroughout our lives we make countless decisions about our health, and being in control of these choices is something many of us value. Unfortunately, often it's only once we or a loved one has lost this autonomy that we realise just how important it is to us.

Fortunately, there is a way to remain in control. We've just made it easier and simpler than ever with our new and improved Advance Decision form.

An Advance Decision, previously known as a 'Living Will', allows you to record any treatments that you do not want to be given in the future, in case you later become unable to make or communicate decisions through injury or illness. It allows you to remain at the heart of these choices, giving you peace of mind that if the worst does happen your wishes will still be followed.

Our new form is free, simple, and easy to complete. We've consulted with the public, doctors, and lawyers over several months to develop a form that works for everyone and can be personalised to reflect who you are.

The form is now shorter and simpler, taking you through different conditions in which you could lose capacity so you can record what

you wouldn't want in each scenario clearly and concisely.

It includes a section in which you can state your values and preferences, such as your beliefs, where you'd like to be cared for, and your wishes regarding pain relief, and organ donation. There is also space to include details of your Lasting Power of Attorney for Health and Welfare or anyone else you want to be involved in your care.

The peace of mind you'll gain for you and your loved ones, knowing that your wishes are recorded and will be known about when it matters most, is invaluable. Make an Advance Decision and ensure you stay in control of your health – now and in the future.

Please contact Compassion in Dying to order the new Advance Decision pack for free:

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

# BACK CHOICE AT THE END OF LIFE WITH A GIFT IN YOUR WILL TO THE ASSISTED DYING CAMPAIGN.

**Write your Will for free with local solicitors**

**Dignity in Dying relies on the generosity of people like you to continue campaigning for real choice at the end of life. Legacies are essential to the future of the campaign.**

By leaving a gift in your Will you can create a lasting message about your beliefs and help to make a more compassionate law a reality for future generations.

Gifts in people's Wills funded in excess of 40% of the assisted dying campaign last year. Whether your gift is large or small, it will help the campaign to make a difference.

As a supporter of Dignity in Dying you are eligible 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 to you.

**FIND OUT MORE TODAY.** Visit our website to find out more and order your **Free Will Pack**: [www.bit.ly/didlegacy](http://www.bit.ly/didlegacy) or give us a call on 020 7479 7733 or email [info@dignityindying.org.uk](mailto:info@dignityindying.org.uk)



**CAMPAIGN FOR**  
**DIGNITY**  
**IN DYING.**