

# ANNUAL REVIEW 2019-20



Paul Lamb

**MY DEATH,  
MY DECISION**

# PATRONS

Sir Iain Chalmers

Professor A.C. Grayling

Dr Phil Hammond

Canon Rosie Harper

Virginia Ironside

Dr Michael Irwin

Paul Lamb

Miriam Margolyes, OBE

Dr Henry Marsh, CBE

Professor David Nutt

Baron Rees of Ludlow, OM

Baroness Richardson of Calow, OBE

Professor Wendy Savage

Polly Toynbee

# FROM THE CHAIR

The past year saw considerable strides in My Death, My Decision's campaign, as we continued to develop our own initiatives and supported those of others, especially our colleagues in the Assisted Dying Coalition that we co-founded in early 2019.

Our activity has also had to respond to major external events that influenced the focus of our campaign – key among them being assisted dying consultations by the Royal College of GPs and the British Medical Association, as well as the General Election in December.

However, we never forget what drives our work: compassion for those who are terminally ill or incurably suffering. Indeed, visits to Paul Lamb, Phil Newby, Alex Pandolfo and Melanie Reid have served as a welcome reminder to me that our campaign is not some mere abstraction – real lives lie at the heart of what we do. We must therefore be relentless in keeping the debate in the public eye.

As our thinking has evolved during the year, so has the legal position in Canada, where legal cases challenging their legislation have succeeded in forcing the government to remove a criterion that had limited the availability of medical aid in dying.

We now consider Canada to be the model that best fits with our campaign objective of medical aid in dying for both the terminally ill and the incurably suffering (discussed in more detail later in this report.)

While our brave patron Paul Lamb launched a case for judicial review that remains to be heard, we continue to press the

Justice Secretary for a formal call for evidence (i.e. an independent public inquiry). We see the latter as the only way that specious arguments raised by opponents with questionable motives will be shown for what they are.

We have co-opted two new board members, Liz Murphy and Simon Menneer. We are fortunate that candidates of their calibre responded to our advertisements, bringing us back to full strength with their complementary skills (By the way, all of the board members are volunteers and our constitution prohibits remuneration to them).

Our achievements this year are of course entirely down to the commitment, determination and generosity in their various ways of our volunteers, patrons, members and supporters – as well as the dynamism of our Campaigns and Communications Manager. To all of them we owe a huge debt of gratitude.



*Trevor Moore*



# MDMD Directors



## **Trevor Moore - Chair**

Trevor spent much of his professional career as a partner in a City law firm, followed by several years as a consultant and freelance speaker. In the course of his current work as a humanist celebrant, he often meets people who are approaching the end of life. That experience, as well as meeting grieving families after someone has died, has deepened his interest in end of life matters.



## **Robert Ince - Finance Director & Campaign Director - Religious**

Robert trained as an engineer and spent his professional career in the international oil industry, with a short time in banking. Subsequently, he became Treasurer and then Convenor of the Unitarian Church. He is currently President of the International Association for Religious Freedom and chair of a number of other charities.



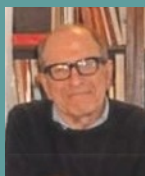
## **Claire Macdonald - Development & Groups Director**

Claire started and ran a chain of children's nursery schools. She has been a founder trustee of a family support charity, an independent school governor and an Independent Monitor of one of HM Prisons. Claire believes in personal autonomy and that it is ethical and compassionate to legalise medically assisted death, for mentally competent adults whose suffering has become more than they can endure.



## **Carrie Hynds - Campaign Director - Political**

Carrie serves as the Co-Chair of the UK and Channel Island's Assisted Dying Coalition. Carrie first got involved in assisted dying campaigning in 2015, and she is a passionate advocate of individual autonomy. She works as a freelance editor and proofreader based in Brighton & Hove, and stood as the Liberal Democrat candidate for Hove in May 2017. Through MDMD she looks forward to working together to secure a much-needed change in the law.



## **Colin Brewer MB.MRCS.DPM - Campaign Director - Medical**

Colin, formerly directed the Westminster Hospital's alcoholism unit and the Stapleford Centre. In 2015 he co-published the book *I'll See Myself Out, Thank You*, in which he admitted to conducting mental capacity assessments for six British citizens hoping to end their life in Switzerland. His new book *O Let Me Not Get Alzheimer's Sweet Heaven!*, explores the dilemma of dementia and assisted dying. He has previously served as a committee member for the Voluntary Euthanasia Society (now Dignity in Dying).



## **Ruth Eyre-Pugh - Company Secretary & Campaign Director - Disability**

Having worked in veterinary private practice and the Royal Army Veterinary Corps Ruth is now retired and currently the Director of Bridal Re-Dress Ltd, a company which she set up in 2005. Since her father's death in 2015, Ruth has self-published a book and written two academic papers about end of life issues which have been published on our MDMD website.

## Directors (continued)



### **Simon Menneer - Operations Director**

Simon spent two decades working in Corporate Finance, after which he worked for Millwall FC and the London Development Agency before moving to Cornwall where he was until recently CEO of Cornwall Cricket. Simon has been a lifelong believer in the right to choose the manner of your own death. This was reinforced when he watched his close friend Tony suffer terribly with late-stage pancreatic cancer.



### **Liz Murphy – Director of Marketing and Communications**

Liz has been in marketing and communications for all of her working life. She started her career with Unilever, moved on to one of the worlds most notable advertising agencies, then Wedgwood China, and Barclays Bank. For the last 15 years, she has been part of the senior leadership team in the University world, most notably as Associate Dean. Understanding people is at the heart of good marketing so it is hardly surprising that Liz is compassionate and drawn to issues around assisted dying.

## Non Board Members



### **Phil Cheadle - Lead Campaign Commentator**

Phil worked as a research scientist before getting involved with the assisted dying campaign. The unpleasant end of life experiences of his mother and aunt, who both suffered from dementia and other conditions, convinced him of a need for a change in the law. He formed Dignity in Dying's Bristol and Bath local group but left this when it became clear that Dignity in Dying's approach would not legalise assisted dying for people like his mother and aunt. He became Coordinator of SOARS in 2015, leading its development and growth to become MDMD, before passing the leadership to others in 2019



### **Keiron McCabe - Campaigns and Communications Manager**

Keiron is a long-standing advocate of the right to die, and a published critic of the UK's current legal regime. Prior to his involvement in assisted dying, he worked on Hillary Clinton's 2016 election campaign and the 2017 UK General Election. He is a full-time assisted dying campaigner and shares his time between My Death, My Decision, Humanists UK and the Assisted Dying Coalition



### **Susie Ince - Membership Secretary**

In the early '1970's Susie co-founded and ran a Women's Circle for a large Northern Newspaper group before becoming advertising manager for a prestigious departmental store. In the 1990's, she spent nine years in the Charity sector co-ordinating volunteer groups for Arthritis Research. Since 2000, she has endured the agonies of her mother's prolonged death through gangrene, her father dying with vascular dementia and her father-in-law suffering a brain tumour. She believes their suffering was unnecessary and vehemently supports assisted dying for those who wish it.

# FUTURE MEETINGS

Due to the COVID-19 outbreak, we unfortunately had to cancel not only the 25th April MDMD/FATE meeting in London, but also a Parliamentary event on 23rd April. Dr Stefanie Green (co-founder and President of CAMAP (the Canadian Association of MAiD Assessors and Providers) planned to brief MPs and Peers on the Canadian model and what lessons we can learn from their recent experience of legalising Medical Assistance in Dying. We hope to schedule another MDMD Parliamentary event in the near future.

We also hope to run an MDMD campaign workshop on Saturday 17th October 2020 at the Midland Arts Centre in Birmingham.

For more information, please email

[carrie.hynds@mydeath-mydecision.org.uk](mailto:carrie.hynds@mydeath-mydecision.org.uk)

## HOW YOU CAN HELP

In the meantime, there are key actions we can all take. In the past year, Carrie Hynds has individually met with several MPs and Peers to discuss assisted dying and introduce them to MDMD, but nothing beats the personal touch of being approached by a constituent. The single most important thing you can do is request a meeting with your MP at their constituency surgery. Full details of how to do this are in the MDMD Campaign Toolkit, **Be Bold to Be Heard**.

The pdf can be downloaded at

<https://www.mydeath-mydecision.org.uk/wp-content/uploads/2020/01/My-Death-My-Decision-Campaign-Toolkit-1.pdf>

Three other key campaign actions you can take are:

- Follow MDMD on Twitter (@MyDeathMyDecision) and Facebook (@MDMDmydecision)
- Write to your MP (especially if they were newly elected in December) – introduce MDMD, ask if they support a change in the law, and share your story
- Ask trusted friends or family members to become a supporter

<https://www.mydeath-mydecision.org.uk/get-involved/>

# CAMPAIGNING IN WESTMINSTER

There are 650 MPs in Westminster, and when it comes to the issue of assisted dying, individual conscience takes precedence over party policy.

The government looks to Parliament, the party whips fall silent and each MP must arrive at their own decision. A variety of factors can come into play: lobbyists' material, constituents' views, loved ones' experiences, religious beliefs, and the MPs own hopes and fears.

## A Call for Evidence

But what about evidence?

This is what has been missing from previous debates. With objective evidence in front of them, MPs would not only be better equipped to debate the issue but could also consider the merits of different models.

With evidence, MDMD will make the case that all adults of sound mind who are terminally ill or facing incurable suffering should have the choice of a medically assisted death.

During the December 2019 General Election campaign, MDMD wrote to members and supporters asking them to contact their Parliamentary candidates, and they helped put the issue of assisted dying firmly on the agenda.



When we followed up with an email from MDMD to all candidates, there were an incredible 517 respondents, with 97% favouring a call for evidence on assisted dying whether or not they believe in a change in the law.

We know there is a strong appetite amongst MPs to be supplied with objective facts, and we will continue to push for a call for evidence on assisted dying.

**We have asked the Justice Secretary, Robert Buckland, to issue a formal call for evidence so that MPs can debate the issue from an informed position.**

*Keiron McCabe*





# COURT CASES

My Death, My Decision is a committed supporter of legal challenges to change the law on assisted dying in the absence of any political will to do so. We need only look to Canada (discussed elsewhere) to see what impact legal challenges can have.

Last year, we supported Phil Newby's legal fight to change the law on assisted dying. Phil, a 49-year old father of two, has motor neurone disease and can no longer walk, or use his hands or lower arms. At the centre of his case was the issue of whether judges should thoroughly examine a large amount of expert evidence - including from countries where assisted dying is legal - before deciding if people deserve the right to choose how and when they die.

We also received widespread attention on the tenth anniversary of Debbie Purdy's legal case - which resulted in the Director of Public Prosecutions guidelines on assisted dying - after we organised an open letter signed by 34 doctors, politicians, religious leaders, academics, and campaigners highlighting Parliament's inaction. Our letter (which we delivered to the Lord Chancellor) sparked a public debate on the need for law reform and prepared the way for a future inquiry from MPs.

Five years after the Supreme Court's invitation for someone to bring a new case, we also supported our patron, Paul Lamb, to renew his campaign for a right-to-die.

Paul, who was severely injured in a car accident in 1990 and has almost no movement below his neck, had previously challenged the law with Jane Nicklinson in 2014.

His case builds upon the unprecedented offer the Court made to him, and argues that the ban on assisted dying discriminates against those with a disability.

By the end of 2019, MDMD had generated stories in BBC News, The Guardian, The Daily Mail, and the Associated Press, among others about Paul and Phil's cases.

This coverage highlighted the injustice of their situations and allowed their stories to be told, which, in part, enabled Phil to raise more than £48,000 and launch his case in the first place.

MDMD also secured an assurance from the General Medical Council that doctors do not necessarily have to report patients to the police if they disclose a plan to end their lives abroad, paving the way for those who are incurably suffering or terminally ill to have open and honest conversations about death, without fear of imprisonment.

Our strategic litigation work remains a key means of widening the public debate and securing changes in the law; though Paul's case remains on appeal. If he obtains permission, we plan to intervene in support of his case.

*Keiron McCabe*



# CASE STUDY: Phil Newby



Following a diagnosis of motor neurone disease in 2014, Phil began thinking about how he might end his life. His options were bleak. Either he could put his family through the trauma of attempting suicide, forcing their final memories of him to be of a father/husband slowly deteriorating and succumbing to his illness, or he could pay more than £10,000 and try to end his life abroad - which carried the risk of imprisonment to those accompanying him.

Instead, Phil sought to change the law, to allow those (like him) who are either incurably suffering or terminally ill - choice and control over how they die. Phil brought an ambitious judicial review and asked our most senior judges to review the evidence on changing the law from experts from across the globe.

In response, the Government dismissed the need for Phil's case. They claimed that the law already provided dignified and compassionate choices: namely the horrifying prospect of starving yourself to death.

Unfortunately, despite providing more than nine box files of evidence - which showed there is now compelling evidence to support a change in the law - both the High Court and Court of Appeal denied Phil's case permission to be heard.

Instead, they judged, that *'the court is not an appropriate forum for the discussion of the sanctity of life, or for resolution of such matters which go beyond analysis of evidence or judgement governed by legal principle'*.

Despite the disappointing judgment, My Death, My Decision is continuing to support Phil to campaign for a humane change in the law. Together we called upon doctors and members of the British Medical Association to vote to drop its opposition and support assisted dying during its landmark survey, championed the case for a balanced and compassionate law in Parliament, and are continuing to raise awareness and broaden the public debate.

# ASSISTED DYING THROUGHOUT THE WORLD



The last 12 months have seen many encouraging developments related to assisted dying in other countries.

Experience in these countries brings additional pressure to bear on the UK government.

## **Australia:**

In November 2019, Western Australia became the second state to legalise a limited form of assisted dying, based on the Oregon model. This follows the state of Victoria where a Voluntary Assisted Dying Act was passed in 2017 and came into effect in June 2019. The first person to make use of the Victoria law died in August 2019. The WA and Victoria laws differ in that in WA doctors and nurses can raise the option of voluntary assisted dying with patients during a medical consultation, ensuring they are aware of all alternatives.

## **Canada:**

So many interesting things are happening in Canada we have devoted a whole article to it after these summaries.

## **Germany:**

In February 2020, the Federal Constitutional Court ruled that the German ban on assisted dying was unconstitutional. It will now be up to Germany's government to propose legislation to bring the law into line with the court's ruling.

## **Italy:**

In November 2019, the Constitutional Court established that, in certain situations, a patient who is unbearably suffering can be helped to die.

### **Jersey:**

In March 2020, the Jersey Health Minister announced a plan for a 'citizens jury' to hear evidence about assisted dying. This follows extensive campaigning by End of Life Choices Jersey, one of MDMD's partners in the Assisted Dying Coalition.

In August 2019, the Jersey group published results of a poll they commissioned, using MDMDs latest poll format. The Jersey poll demonstrated very strong support for assisted dying legislation. The results are in line with MDMD's UK poll last year. (See Public Opinions, Polls and Surveys)

### **New Zealand:**

In November 2019, the End Of Life Choices Act was voted into law, subject to a binding public referendum to take place in September 2020. The law will only apply to NZ citizens, resident in NZ. They must have mental capacity, be terminally ill with a life expectancy of 6 months or less, be in an advanced state of irreversible decline in physical capability and with unbearable and irremediable suffering.

### **Portugal:**

A Bill is progressing through Parliament which, if it gets its final approval, would make Portugal the fourth European country to offer assisted dying in cases of unbearable or prolonged suffering or incurable disease.

### **Spain:**

In February 2020, the Parliament voted in favour of accepting an assisting dying bill for consideration. This is just the first hurdle, but it shows a willingness of the current government to pass a final bill into law.

### **USA:**

In July 2019, Maine became the 10th US jurisdiction to legalise assisted dying, based on the Oregon model. This follows New Jersey where an assisted dying law was approved in April 2019. However similar Bills were defeated in Maryland and Nevada.

*Phil Cheatle*

# THE CANADA MODEL

Over the past year, My Death, My Decision has concluded that the evolving Canada model of medical assistance in dying (MAiD, as they call it) represents one that we should look to in our campaign to achieve a law change in England and Wales (Northern Ireland and Scotland have devolved powers). That is because it will soon allow assisted dying not only for the terminally ill (without time limitation), but also for the incurably suffering.

In the latter context, we think of how such a law would have helped the late Tony Nicklinson and would now assist our patron Paul Lamb, who has a pending legal challenge against the government.

## **The Catalyst for Change**

With no political will in Canada to change the law, the events that brought it about show the importance of legal challenges made by individuals. The first, momentous case of *Carter v Canada* in 2015 forced the government's hand there. Since the law's introduction countrywide in 2016, there have been continuing developments, again brought about by further legal cases.

## **Eligibility**

In Canada the core requirement for requesting an assisted death, which is available only to competent adults aged 18 years and above, is that the person must have a 'grievous and irremediable' condition. (The language can vary by province - e.g. in Quebec) That in turn is summarised as one where the applicant:

- has a serious and incurable illness, disease, or disability
- is in an advanced state of irreversible decline in capability
- is enduring physical and psychological suffering that is intolerable to them
- has a reasonably foreseeable natural death

The question of intolerability is subjective to the applicant – it is not for the assessor to judge. The last of the criteria, regarding foreseeability, came as a late amendment to the legislation. Its subsequent application in practice caused considerable uncertainty for those seeking MAiD.



*Trevor Moore*

Only last September, however, the Superior Court of Quebec ruled in the Truchon case that the reasonable foreseeability test breached the Canadian Charter (akin to our Human Rights Act). No government appeal was made against the decision and consequently there is now a proposed parliamentary Bill that will, when implemented as expected, remove this requirement - but in any event cease to apply in Quebec from 11th July 2020.

### **Safeguards**

By way of safeguards, an individual's signed request for an assisted death must be countersigned by two independent witnesses. Two independent doctors or nurse practitioners are then required to assess eligibility, including whether there is any concern about coercion. In most cases there must be a ten day time interval between request and provision (exceptions include where it is considered that capacity may be lost in that timeframe).

### **Mental illness and Dementia**

The new Bill mentioned above aims to exclude assisted dying for those suffering solely from mental illness.

Although applicants diagnosed with dementia have successfully availed themselves of the right to an assisted death, the requirement to give informed consent at the time of receiving it forces people to end their lives sooner than they might otherwise wish.

### **Assisted death in practice**

Medical assistance can be either by intravenous injection or by self-administered drugs. Practitioners report that almost all applicants choose the former. Over 13,000 people have chosen a medically assisted death since the law came into force in 2016. Canada's statistics from the early years are not comprehensive, because of the somewhat piecemeal way in which the law was introduced, but the first formal report incorporating nationwide data is expected soon.

As in other jurisdictions with assisted dying laws, practitioners report that those approved for MAiD can find that status of considerable comfort, with the consequent restoration of autonomy meaning they feel able to delay ending their lives.

# THE ASSISTED DYING COALITION

The Assisted Dying Coalition (ADC) is the UK and Crown dependencies coalition of organisations working in favour of legal recognition of the right to die for individuals who have a clear and settled wish to end their life and who are terminally ill or facing incurable suffering.

It was launched in February 2019 with the aim of co-ordinating campaign efforts between member organisations.

MDMD and FATE are founding members, together with Humanists UK, the Humanist Society of Scotland and the MDMD Medical Group. We have since been joined by End-of-Life Choices Jersey and individual observers who have contributed from their life experiences.

Recent campaign actions include encouraging members of each organisation to write to their GP ahead of the Royal College of GPs' poll on assisted dying, publishing a joint letter in The Guardian during the BMA survey on assisted dying, and commissioning research that shows more than one person a week now travels from the UK to Switzerland for a medically assisted death.



<https://assisteddying.org.uk/>

# MDMD

## WHAT WE STAND FOR

- My Death, My Decision campaigns for an assisted dying law that would give adults of sound mind who are either terminally ill, or suffering from an incurable condition they consider intolerable, the choice of an assisted death.
- MDMD will press for any such law to include robust safeguards to satisfy independent medical assessors that the person is fully informed, has made a well-considered and consistent request and has not been coerced.

## OUR YEAR IN NUMBERS

- **2861** new supporters joined our online community.
- **1000+** GPs visited our website to support legal, safe, and compassionate assisted dying.
- **500+** Parliamentary briefings on assisted dying
- **97%** of candidates who responded during the General Election supported a call for evidence.
- Nearly **90%** of the public favouring assisted dying.
- A Parliamentary debate on assisted dying.
- Our campaign was mentioned on the BBC News, on ITV, in the Guardian Newspaper, the Times, the Daily Mirror, Daily Mail, Financial Times, British Medical Journal - and several other publications.



# PUBLIC OPINION,

Last year, in 2019, MDMD commissioned independent research exposing a growing gap between public support for assisted dying and the attitudes of our politicians.

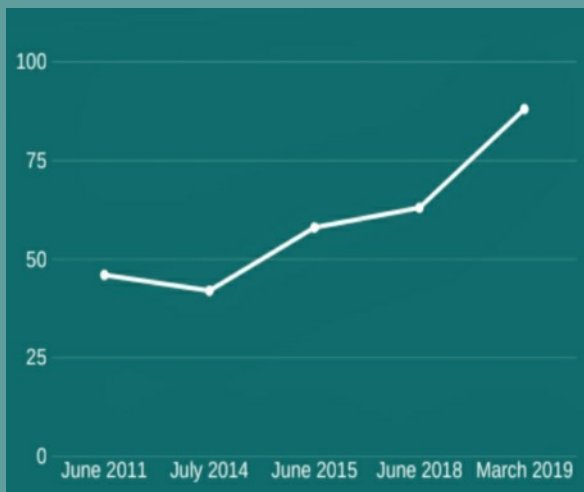
In 2015, only 18% of MPs voted in favour of assisted dying reform. But in March 2019, our research found that public support had reached its highest level for half a decade, with up to 93% of people in England and Wales now considering assisted dying *'acceptable'*, in at least some situations.

Support for a change in the law which would benefit those who are terminally ill (meaning they had six or fewer months left to live) remained widely popular with up to 88% favouring law reform. This was marginally higher than a similar finding (84%) from a poll conducted later in the year by Populus.

However, our findings also indicated that there has been a dramatic shift in opinion, favouring a change in the law for those who are incurably suffering, such as Paul Lamb and Tony Nicklinson.

## POLL TRACKER

Although direct comparisons should not be drawn between specific polls since their findings may reflect different questions or methodologies, this graph is a tracker of public opinion of assisted dying for those who are incurably suffering.



Polls Used: Natcen-Jan 2011, Comres-June 2011, YouGov-July 2014, Comres-July 2014, Populus March 2015, Ipsos Mori June 2015, Comres June 2018, NatCen March 2019, Populus April 2019.

# POLLS and SURVEYS

In 2014, a YouGov poll indicated that only 42% of the public supported assisted dying for the incurably suffering - whereas, our findings showed up to 88% of the public now favour a change in the law.

Our poll also uniquely discovered that up to 88% of the public would favour reform for those suffering from early-stage Alzheimer's.

These findings helped to ignite a debate on whether politicians had become out-of-touch with the public and generated multiple stories on *BBC News*, in *The Guardian*, in *i-News*, and in the *Financial Times*.

It also contributed to parliamentary interventions by Kevin Hollinrake MP and Steven McCabe MP. Mr Hollinrake said *'there is concern among the wider public that Parliament may be out of step with the public'*.

Further, a Labour Party MP, who had previously voted against changing the law, but acknowledged his views had changed said:

*'I think that we should be wondering whether things have moved on since 2015. The poll that was released by the My Death, My Decision group shows that the level of support for a change in the law is about now 88%. I think that is significant, and I am surprised that people would want to ignore that.'*

We have continued to highlight this chasm between popular and parliamentary attitudes through more than 100 parliamentary briefings, and by using it to demonstrate that there is now irrefutable and compelling evidence of public approval for assisted dying. This, thus, creates a powerful vehicle which we can use to push for a call for evidence (public inquiry) into the current law.

*Keiron McCabe*



# MEDICAL PROFESSION - BARRIER OR NOT?

A significant barrier to legal, safe, and compassionate assisted dying has been the perception that medical professionals are opposed to a change in the law. Yet, at the beginning of 2019, a recent survey of more than 1000 GPs found the exact opposite. Unfortunately, this was not reflected in the positions of the major Royal Colleges or professional associations. Hence, a key focus of our work was to support doctor-led efforts to spark debate.

In March 2019, with our support, doctors within the Royal College of Physicians were able to drop their College's hostile stance in favour of neutrality. Thus bringing the College into line with a number of other colleges who have either not taken, or have adopted neutral stances on assisted dying. These include The Royal Society of Medicine, The Royal College of Nursing, The Royal College of Anaesthetists and the Royal College of Psychiatrists. It also prompted other Colleges, such as the Royal College of General Practitioners, to survey its members as well.

Also in 2019, though our medical group remained quite small relative to groups against assisted dying, such as the Christian Medical Fellowship, MDMD consistently punched above its weight and we were able to support our distinguished patron, Professor Wendy Savage, to secure a decision from the British Medical Association to ballot its membership on assisted dying. In achieving this we gave more than 100,000 doctors the opportunity to express their views on assisted dying for the first time. (The outcome is expected to be announced at the 2020 BMA's policy making conference).

Equally, we used several well placed articles in the British Medical Journal to highlight emerging trends and new evidence from abroad, notably in Canada, showing that the best way a physician can respect their patient's autonomy, is through a safeguarded but inclusive law on assisted dying.



Our Medical Campaigns Director was invited to the Cambridge Dignity in Dying group to discuss the issue of dementia and assisted dying. His talk was

well received, but hardly any of the attendees knew that Dignity in Dying had changed its campaign goals from those of the old Voluntary Euthanasia Society. It was clear that many would not support that change, if asked.

In addition, we discovered that the deaths of patients, who choose to end their lives by voluntarily deciding not to eat or drink (VSED) instead of going to Switzerland, are not regarded as suicide, even when their resort to VSED was well known. MDMD has been in correspondence with the Director of Public Prosecutions to understand his attitude to doctors who might want to give more generous (but definitely non-lethal) sedation during VSED. While some answers have been predictably evasive, the DPP has stated that it is not his job to tell coroners what verdicts to bring in or to advise governments to change the law. Clearly, if a death is not ruled as suicide, then providing good palliative sedation cannot constitute the offence of assisting a suicide. Coroners have quite a lot of discretion in reaching their verdicts, but it seems that the custom of not regarding VSED as suicide is a well-established one, possibly dating back at least to the IRA hunger strikers of the 1980s.

If any MDMD member hears of such cases, please let me have a name, the approximate date of death and the town or area where it occurred so that I can request a copy of the death certificate for our continuing research.

*Colin Brewer*  
[colin.brewer@mydeath-mydecision.org.uk](mailto:colin.brewer@mydeath-mydecision.org.uk)

# FAITH

We understand the difficult conversations surrounding the sanctity of life and the will of God. But many people of faith, also have a tremendous compassion for those who suffer intolerably.

Although there is a reluctance for faith group leaders to embrace assisted dying, we know from the multitude of letters we have received that many people of faith support our cause.

Liberal faiths are now seriously debating the subject; Unitarians declared their support in 2013. Quakers are actively discussing it as we speak.

And even in the Church of England things are stirring with The Rt Rev and Rt Hon Lord Carey of Clifton backing calls for a government review into assisted dying.

Lord Carey's support for an inquiry mirrors the official position of the Church of England, which in 2014 called for a royal commission on assisted dying. This was backed by senior clergy including the Archbishop of York, John Sentamu, during debates in the House of Lords on Lord Falconer's Assisted Dying Bill.

*Robert Ince*



MDMD has produced a film on Faith and Assisted Dying providing a major contribution to the debate on the difficult questions that people of faith face.

You can see the film here:

<https://www.mydeath-mydecision.org.uk/info/lectures/apr-2019-faith-and-assisted-dying>

# DISABILITY

Disabled people **MUST** be given the same options in life and death that non-disabled people have.



MDMD agrees that:

*'Demoralisation in people with disabilities is often based on internalised oppression, such as being conditioned to regard help as undignified and burdensome, or to regard disability as an inherent impediment to quality of life. Demoralisation can also result from the lack of options that people depend on'.* (Report from The National Council on Disability, USA)

This is where Government, and society in general, need to step in to ensure that disabled people receive all the help they need to live the most rewarding quality of life achievable for their present condition.

We are delighted to be joined this year as a patron by Paul Lamb. As he said when launching his legal challenge:

*'I am paralysed from the neck down and live in a state of constant pain. In the future my suffering will inevitably become too much to bear. When that happens, I want to be able to control and choose the circumstances of my death.'*

Two well known advocates for change, journalist and author, Melanie Reid (who is tetraplegic after a riding accident) and Phil Newby (who has motor neurone disease), recorded short video clips for MDMD in connection with the BMA consultation, that were well received on social media.

In a recently produced article submitted by MDMD and NatCen to the Journal for Medical Ethics about the results of our 2019 survey into assisted dying which includes the views of people with a longstanding condition affecting their everyday life.

*Ruth Eyre-Pugh*

To know more about MDMD's position statement on disability, go to <https://www.mydeath-mydecision.org.uk/info/issues/protecting-vulnerable-people/>

# VOLUNTEER GROUP ACTIVITIES



My Death, My Decision's most active and committed supporters attend our local Groups.

In 2019-20, MDMD developed a Group Framework and a Campaign Toolkit '**Be Bold. Be Heard.**' which can be downloaded at

<https://www.mydeath-mydecision.org.uk/wp-content/uploads/2020/01/My-Death-My-Decision-Campaign-Toolkit-1.pdf>

Members and supporters are becoming increasingly effective in campaigning for a change in the law: contacting MPs, writing and speaking to GPs and Health Trusts, proposing Council Motions, encouraging debate and raising awareness of My Death, My Decision's work.

Nearly 90% of the public believes the law on assisted dying must change. It's Parliament we need to convince. We want every My Death, My Decision member and supporter to write to or go and see their MP and demand the same choice here on medical assistance in dying as people in Canada have.

In the past year, MDMD Groups have discussed the philosophical, legal, medical and ethical issues around assisted dying.

Groups have organised small events and workshops and contributed to research projects.

Dedicated volunteers help with organisational administration and contribute to our annual events. The Board of Directors is most grateful for all the assistance and support received.

In 2020-2021, we aim to increase the number and geographical spread of our MDMD Groups. There are clusters of MDMD supporters in Oxford and Bournemouth - it would be great to be able to start new groups in those places and many more. If you would be interested in setting up a local Group in your area, or if you have time and administrative skills to offer to MDMD, please get in touch - email [claire.macdonald@mydeath-mydecision.org.uk](mailto:claire.macdonald@mydeath-mydecision.org.uk)

As a grassroots, volunteer campaign organisation, My Death, My Decision is totally dependent on the generosity of its supporters. Thank you.

*Claire Macdonald*



# FINANCIAL REPORT

We are continually grateful to our members and supporters for their financial contributions to our campaign, which has raised sufficient money to keep our campaign moving forward, producing increasingly important information for the general public, the media and Parliamentarians, including video material of debates, experience in other countries and from those who are suffering. Our income and expenditure grows year by year.

We intend to expand our contribution to the debate in the coming year through professional social media contributions, a completely revised website and, pandemic permitting, more contact with Parliamentarians.

Whilst we still rely heavily on volunteers and particularly the efforts of the directors, who receive no payment for their time, we anticipate that we will have to expand our income to cover this increased activity.

Many members already donate more than the £15 annual membership, and we really appreciate their generosity; the greater our income the more we can achieve. We also have the potential to benefit from legacies that will allow us to take even larger steps forward.

If you are considering helping us by making large donations or legacies, please contact us beforehand so that we can advise on the best arrangements in individual circumstances.

MDMD is a campaigning organisation rather than a charity, which means donations and bequests will not be tax exempt; we have to manage our expenditure to match our income. To discuss this, or any other aspect of leaving a bequest to MDMD, feel free to contact us.

Email either:

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or our Finance Director, [robert.ince@mydeath-mydecision.org.uk](mailto:robert.ince@mydeath-mydecision.org.uk)



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