

# Campaign

for choice, for compassion, for change

Issue 1 Spring 2009

## Debbie loses appeal but wins argument



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# Chief Executive

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**Sarah Wootton**



Chief Executive

**Tomasz Włodarczyk**



Director of Strategy, Operations & Fundraising

**Rachel Watt**



Fundraising Finance Officer

**Jo Thomas**



Trusts & Operations Support Officer

**Lucinda Lodge**



Head of Finance

**W**elcome to the Spring edition of Campaign. Let me say a big thank you to all those members who returned their subscriptions to us, and a further thanks to all those who included a donation too. If you have not yet had the opportunity to renew your membership, I would urge you to do so. Your support is invaluable to us, particularly now as the House of Lords has the chance to debate the Coroners and Justice Bill.

There are some recent events which demonstrate that the grain of social change is moving our way. The General Medical Council's consultation on withholding life-prolonging treatment is intended to shift control from doctors to patients and will be a key driver to breaking down the paternalism which currently informs end-of-life decision-making, as evidenced by Dr Alex Paton's story on page 5.

Debbie Purdy's appeal judgement in February confirmed that people accompanying loved ones abroad for an assisted death are unlikely to be prosecuted (see page 4). If this is current prosecuting policy, it highlights the fact that the law deserves reform and puts the focus firmly on Parliament. So we were delighted that former Secretary of State for Health, Rt Hon Patricia Hewitt MP, tabled an amendment to the Coroners and Justice Bill

to prompt the long overdue Parliamentary debate necessary to bring the law on assisted suicide in line with the practice of the Director of Public Prosecutions and the Courts. Your efforts have resulted in over 100 MPs supporting the call for a Parliamentary debate by signing our Early Day Motion 230. See pages 8 and 9 for information on how to get involved with the next stage of the campaign.

Gordon Brown, who has publicly opposed assisted dying legislation, has been quoted as saying privately that he is concerned that any debate will be "dominated by the most shrill and reactionary voices and produce legislation that is not progressive." Whatever the Prime Minister's personal position it is essential that he is aware of yours (see page 6). It is certain that our opponents, those the Prime Minister is referring to as shrill and reactionary, are organising against us, so we must act in force.

Finally, you will see that **Campaign** now features the entire Dignity in Dying team so you get a sense of who we are and what we work on. We're a small team but committed and determined. With your help I believe we can move mountains!

Dignity in Dying campaigns for greater patient choice at the end of life and a dignified death for all. We are supported entirely by voluntary contributions from private individuals and

are independent of any political, religious or other organisation.

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**W**elcome to the new edition of the **Dignity in Dying** newsletter, renamed as **Campaign** to reflect the importance of your contribution to our work. Following feedback and consultation with members, this newsletter has been refreshed and redesigned to make it easier to read and more importantly, to focus the newsletter on you - our valued supporters.



You will find a new letters page (pages 14 and 15), personal stories (pages 4 and 10), campaign updates (page 6) and crucially, calls to action throughout the newsletter. We hope you agree that the redesign of the newsletter makes our campaign more accessible, our messages more visible and the action you can take much clearer.

Building on the exciting events of the last 12 months, we are now calling on you to go that bit further, to do that bit more for our campaign. Momentum for change is growing and we are calling on you to be part of our mass movement of supporters. On the centre pages of each edition

you will find the most urgent of all our campaign activities. If you only have time to do one thing, please focus here. If you can spare more time for our campaign, look out for the action boxes (see below!) throughout the newsletter.

Since its creation in 1935, Dignity in Dying has fought tirelessly for greater patient choice, control and access to services at the end of life. Without our supporters we would not have been able to achieve the significant advances we have with our campaigns over the years.

With your continued support and activism, we will bring about a more compassionate approach to end-of-life decision making in the near future.

# New look newsletter

**Davina Hehir**



Head of Legal Strategy & Policy

**James Harris**



Head of Campaigns & Communications

**Jen Hardy**



Campaigns Support Officer

**Emily Halsall**



Membership & Communications Officer

**Jo Cartwright**



Campaigns & Press Officer

## ACTION! SEND US YOUR STATEMENT OF SUPPORT

Why do you support a more compassionate approach to end-of-life care and choice? Please tell us in approximately 50 words. By submitting your name and statement you agree to us publishing this for a Dignity in Dying campaign later this year.

If you would rather your statement remain anonymous, please do not include your name. Unfortunately we will not be able to acknowledge statements sent in to us.

I support a more compassionate approach to end-of-life care because...

Name \_\_\_\_\_ Town of residence \_\_\_\_\_

# Letter from Debbie

**On the 19th February Debbie Purdy was notified that her case to the appeal court, seeking to clarify the law on assisted suicide, was dismissed. Here she tells us about her involvement with Dignity in Dying from the very beginning of her legal case, why she now feels one step closer to clarification but why her battle is not yet won.**

“ I am really pretty happy. I love my husband, have some great friends, generally enjoy life. A few years ago I followed Diane Pretty’s legal case and felt feeble and useless when she died the way she most feared.

I was diagnosed with Primary Progressive Multiple Sclerosis in 1995, I knew it wasn’t going to get better but I didn’t, and still don’t, know how bad it will get. Diane’s case made me start thinking ‘what would happen if...?’. My husband Omar really didn’t want to think about worst case scenarios, it’s not his style, but I’m louder than him and I did.

I got involved in the Dignity in Dying campaign around Lord Joffe’s Bill, I just couldn’t believe that

Parliament wouldn’t provide me with a safety net. All the while my condition was deteriorating and by 2008 my problems travelling alone were beginning to affect my independence. If I couldn’t travel alone, going to Zurich would no longer be my decision. I decided I didn’t have enough time to wait for Parliament to see sense.

I met with Saimo Chahal at Bindmans law firm and she agreed to ask the Director of Public Prosecutions (DPP) to explain his policy around prosecuting family members who accompany a loved one abroad to end their life. As of yet, no one has been prosecuted but I wasn’t going to take a chance on Omar being the first. The DPP said he didn’t feel he needed to clarify his position so we asked the High Court for a judicial review. While this was denied we were given leave to appeal on the grounds of overwhelming public interest.

My appeal hearing was held on 3rd February and on the 19th my case was dismissed by the court judges. At first I was devastated but when I read the judgement I could feel the compassion and empathy of the courts. They referred specifically to the decision not to prosecute Dan James’ parents back in October 2008 stating that this case highlighted “the kind of broad circumstances in which ...the ultimate decision would be that a prosecution should not be mounted”.

I feel the Appeal Court did everything they could to clarify that Omar would be unlikely to be prosecuted if

he were to accompany me abroad for an assisted death. That said, I still don’t have the absolute clarity that I was seeking. Besides, I ultimately want the option of an assisted death in this country and don’t want to travel abroad should my condition become unbearable; the travelling itself would actually hasten my decision.

During the legal appearances a number of things kept me going. The media, not just journalists, but the letters pages showed how much public support there was for my case. Strangers stopped Omar or I to offer support. One lady spoke to us as she got off a train, she said she was in remission from cancer and she was glad I was fighting this one because she didn’t think she would have found the courage alone. I thought about her all the way home. I realised she was the reason this fight must be won but also that she was wrong. I’m not alone. I’m a member of Dignity in Dying and all the members are with me in this. ”



Debbie Purdy

# Advance Decisions update

Over the last few months, Dignity in Dying has become increasingly aware of a number of cases in which medical professionals fail to follow the wishes set out by patients in their Advance Decisions. Here we hear from Dr Alex Paton, a retired hospital consultant and Dignity in Dying supporter, whose wife's Advance Decision was not respected in the last few weeks of her life.

“ Ann died on 19th November last year.



Alex & Ann Paton on their diamond wedding anniversary

She fractured a femur while gardening in the summer of 2007, but made a good recovery. She had two further falls in early 2008, lost her confidence in walking, gave up driving, and could barely maintain her passion for gardening; double vision interfered with her two favourite occupations, reading and needlework. One day in autumn she said her pulse seemed slow and indeed it was just 30. She was admitted to hospital for a pacemaker but that evening she had a cardiac arrest from which she was resuscitated, in spite of an Advance Decision that stated she did not wish to be. This was justified on the grounds that a temporary pacemaker could then be inserted.

Ann woke up to describe how peaceful dying was and how hellish it was to return with a terrible pain in the chest where she had been shocked (which persisted for a couple of weeks) and surrounded by shadowy demons flitting around her bed!

After a miserable week in hospital with a pacemaker for “observation”, saying she wished she could die, we took her home against the advice of the doctors. She remained virtually bed ridden, but we had a wonderful last ten days with our family –younger son and wife back

from Bangkok where they work, two daughters doing the caring - and superb backup from general practitioners and overworked district nurses. Ann maintained her sense of humour ‘til near the end and our vicar said her death should be regarded as a celebration rather than something to be regretted.

My wife and I have been firm believers in assisted dying for 40 years; it is time doctors learnt to let people go instead of doing everything to keep them alive. Personal experience convinces me that proper management of death when the time comes can be a fulfilling experience for everyone.

## About Advance Decisions

The Dignity in Dying pro-choice Advance Decision is fully compliant with the Mental Capacity Act and allows you to refuse life-sustaining treatment should you no longer be able to communicate. This refusal is legally binding upon doctors. It also allows you to request life-sustaining treatment, no matter what your prospects of recovery, although requests for treatment are not legally binding on doctors.

The General Medical Council is currently consulting on end-of-life decision making. We will be responding to this consultation and we would like to hear your stories about Advance Decisions, whether good or bad. Specifically, if you or a relative are having difficulties with getting your Advance Decision respected, please do get in touch - we may be able to help. For further guidance on Advance Decisions please contact Emily Halsall on [emily.halsall@dignityindying.org.uk](mailto:emily.halsall@dignityindying.org.uk) or on 020 7479 7732. To read the guidance, and find out more about the consultation, go to: [www.gmc-uk.org/end\\_of\\_life\\_care](http://www.gmc-uk.org/end_of_life_care)

# Parliamentary news

## ACTION!

### WRITE TO RT HON GORDON BROWN MP

Let him know that you think that terminally ill, mentally competent adults should have the choice, within safeguards, of an assisted death if they feel their suffering is unbearable. Ask him to share the evidence his views are based on.

Given the amount of correspondence the Prime Minister receives, it is likely that you will receive a reply from a Government minister instead. However, as the Prime Minister has expressed his personal opinion on an issue of conscience state that you would like to know the view of the Prime Minister, not those of the Government.

Write to Rt Hon Gordon Brown MP at 10 Downing Street, London, SW1A 2AA.

If you can only spare a few minutes, please write a few lines on the enclosed postcard and send this instead of a letter.

## Good news! Dignity in Dying supporters lobby MPs and achieve record number of signatures on Early Day Motion 230



House of Commons

In the last edition of our newsletter we called on you to ask your MP to sign Early Day Motion (EDM) number 230. EDM 230 calls on MPs to acknowledge there is a problem with the current law around assisted dying and calls for full Parliamentary time to debate the issue.

## Prime Minister publicly announces opposition to assisted dying

On Radio 4's Today programme in December, in an interview with the head of the Catholic Church in England and Wales, Cardinal Cormac Murphy O'Connor, Gordon Brown said he had "always opposed legislation for assisted deaths". He went on to say "it's not really for us to create any legislation that would put pressure on people to feel that they had to offer themselves because they were causing trouble to a relative".

As an issue of conscience, we respect the Prime Minister's right to air his personal view on this issue. However, we do not believe this view is based on evidence, and this can and

At the time of going to print 103 MPs have signed the EDM, tabled by Dignity in Dying supporter David Winnick MP. Brian Iddon MP, Chair of Care Not Killing, reacted to EDM 230

by tabling his own motion, EDM 589.

This EDM stated that the Suicide Act 1961 "is working as it should" and to date has received only 84 signatures.

This level of support for a debate is

very encouraging and generated significant press coverage for Dignity in Dying. Thank you to all members and supporters who took the time to lobby their MP on this important issue. For a full list of MPs who have signed EDM 230 visit their website:

[edmi.parliament.uk/edmi/](http://edmi.parliament.uk/edmi/)



Rt Hon Gordon Brown MP

should be challenged. We know that Care Not Killing have asked their supporters to write to Gordon Brown to thank him for his "clear principled stand on assisted suicide". With a General Election due next year at the latest, Gordon Brown needs to be made aware that your vote is just as important as those of the anti-choice campaigners and that they are in the minority.

**The past few months have been exciting times in Scotland, as MSPs, the media and members of the public have engaged with issues around care, choice and decision-making at the end of life.**



Scottish Parliament

### **Margo MacDonald MSP proposes End of Life Choices (Scotland) Bill**

Margo MacDonald MSP, who has Parkinson's disease, generated a media storm last year when she said in the Scottish Parliament that she thought she should have the option of ending her life if the suffering caused by her condition became too much.

Since then Margo MacDonald has continued to keep the issue of assisted dying in the news, filming a documentary for BBC's Panorama on the subject and launching her own proposed Bill on End of Life Choices for public consultation. The proposed Bill for Scotland suggests that a physician should be allowed to lawfully assist a patient to die, following the patient's request and given that all legal requirements have been met.

We welcome this initiative by Margo MacDonald to seek clarification of the law in Scotland relating to assisting someone to die. The recent publicity around several individual cases and the

genuine interest among the public demonstrate the need for an open and well-informed debate on assisted dying.

Whilst we do not agree with every aspect of the proposed Bill, we do fully support a debate in Scottish Parliament on this issue. The Bill needs support from 18 MSPs in order to be debated in the Scottish Parliament.

We will keep readers posted on the progress of the End of Life Choices (Scotland) Bill.

### **The debate continues...**

On 24th March Edward Turner, Dignity in Dying Board member, spoke at a debate on end of life choices in Glasgow.

The debate was organised by the Equality and Human Rights Commission in Scotland and the panel consisted of Edward Turner, Peter Brawley, Manager of the Scottish Personal Assistant Employers Network, John Degan, Parliamentary Officer for the Bishop's Council and Professor Sheila McLean, Director of the Institute of Law and Ethics in Medicine at Glasgow University. A recording of the event will be made available to view online, for more information see: [www.equalityhumanrights.com/en/scotland/](http://www.equalityhumanrights.com/en/scotland/)

# Parliamentary news Scotland

### **Proposed Palliative Care Bill for Scotland**

Dignity in Dying has also recently submitted a response to the consultation launched by Roseanna Cunningham MSP, which was recently taken over by Gil Paterson MSP, on a Proposed Palliative Care Bill for Scotland.

Dignity in Dying supports the overall aim of the proposed Palliative Care Bill which aims to achieve universal access to high-quality palliative care across Scotland by placing a statutory duty on NHS Boards to provide high-quality palliative care for all on the basis of need. It is widely accepted across the UK that access to palliative care services is currently uneven and we continue to campaign for equal access for all.

Our response to the consultation was informed by the views and experiences of our members and supporters in Scotland. We'd like to thank everyone who took the time to fill out the form and to share their experiences with us. Your contributions have added more weight to our call for universal access to high-quality palliative care and have highlighted the importance of including people's needs and wishes in the delivery of care at the end of life.

# Coroners & Justice Bill

## Coroners and Justice Bill presents real opportunity for us to clarify the law

The Coroners and Justice Bill is currently making its way through Parliament. The Bill proposes the first substantial changes to our laws on murder in 50 years and to the Suicide Act since it was enacted in 1961.

Dignity in Dying welcomes in part the amendments to the 1961 Suicide Act, which aim to better protect young and vulnerable people who may be encouraged to commit suicide

by others. However, these reforms fall short. Crucially the reforms fail to distinguish between entirely different situations. This means that somebody who accompanies a loved one abroad to die to a place where it is legal, would be liable to the same treatment by the law as somebody who encourages a vulnerable person to jump from a tall building. This is clearly wrong. The law needs to distinguish between those who maliciously or irresponsibly encourage suicide and those who compassionately assist the death of a terminally ill, mentally competent adult.

This is why it is vital that Dignity in Dying members and supporters, along with the staff and Board, do everything we can to change the provisions on assisting suicide in the Bill. The Bill has now passed through the House of Commons



The House of Lords

and is being scrutinised by Peers in the House of Lords. All amendments made by the House of Lords will have to be approved by MPs.

There is still some way to go, but at the time of going to press our campaign had already made a significant impact.

## ACTION! WRITE TO THREE PEERS

By the time you are reading this, the Bill will already be in its House of Lords stage. You can make a real difference to the content of this Bill, and the way the law treats the loved ones of terminally ill people who want choice at the end of life, by contacting Peers in the House of Lords to outline your concerns.

We have a list of Peers who we need to lobby at this vital stage. By writing to them you will reinforce how important this issue is and why they should seek to resolve it.

To take part in this campaign action please either:

- **Send a self addressed envelope to:**  
**3peers, Dignity in Dying, 181 Oxford Street, London, W1D 2JT**
- **Email: [3peers@dignityindying.org.uk](mailto:3peers@dignityindying.org.uk)**
- **Phone: 020 7479 7736**

We will then provide you with the names and addresses of three Peers to contact and an information sheet with key points for your letter.

We have also enclosed three postcards with this newsletter for you to use if you want to keep your comments short.

We know that anti-choice groups lobbied MPs in large numbers and are likely to do the same with Peers - your efforts are vital in making sure that members of the House of Lords get a true idea of public opinion on this issue.

## Rt Hon Patricia Hewitt MP joins our campaign on the Coroners and Justice Bill

We are clearly not alone in our concerns. Many members will have seen the media coverage of former Health Minister, Rt Hon Patricia Hewitt MP's intervention on this issue in March.

In order to bring about a long overdue debate Patricia Hewitt tabled an amendment to the Coroners and Justice Bill. The amendment would have removed the threat of prosecution to those who accompany a loved one to a country in which assisted dying is lawful. The purpose of this amendment was simply to start a debate and to highlight the problems with the current law.

Unfortunately due to a Government Motion, which restricted the time available for debate, MPs were not given the opportunity to discuss amendments to the laws on murder and suicide, including Patricia Hewitt's amendment. However, we are confident that supportive Peers will now pick up this issue.



Rt Hon Patricia Hewitt MP

It is hugely significant that a high-profile former Cabinet Minister has joined our campaign. Speaking to Dignity in Dying, Patricia Hewitt made clear her determination to ultimately achieve a change in the law on assisted dying, saying:

“ I have been increasingly worried by the cases of people who find themselves diagnosed with a crippling, terminal illness and who make a very thoughtful, conscious decision to end their lives. Currently, if someone in that situation travels to another country where assisted dying is lawful, any friend or relative who accompanies them is at risk of prosecution. The Director of Public Prosecutions said that he would not prosecute such cases and I believe that policy should now be given the force of law. Although I am disappointed that we did not get to debate my amendment this time, I am heartened by the support my amendment has received from colleagues on all sides of the House and by the many encouraging letters I have received from members of the public, and we will try again when the bill returns from the House of Lords.”

## About the Coroners and Justice Bill

The Coroners and Justice Bill covers a very wide range of issues including:

- The Coroners Service
- Secret inquests
- Data protection
- Criminal law and sentencing
- Vulnerable and intimidated witnesses

Dignity in Dying is concerned about two key areas of the Bill:

- Changes to the law on murder and manslaughter: we are worried that the proposed changes to the law in this area will mean that many genuine 'mercy killers' (people who have directly helped a seriously ill loved one to die at their request) will face life sentences in prison.
- Reform of the Suicide Act: we are concerned that the reforms to the Suicide Act do not go far enough, and that they should protect people who accompany a terminally ill loved one to die overseas, in a country where it is legal.

# A Short Stay in Switzerland

**O**n 24th January 2006, Dr Anne Turner died peacefully in Zurich with her three children. Anne had chosen to end her life with the assistance of the Swiss clinic, Dignitas, before her illness put her in a position of being unable to make this choice. On 25th January 2009, the BBC broadcast the Turner family story in their one-off drama - *A Short Stay in Switzerland*. Here Anne's daughter, Sophie Pandit, tells us about the effect the drama had on her and her siblings.

It was only after the broadcast of *A Short Stay in Switzerland*, as I started to get responses from friends and acquaintances saying how affected they'd been by the film, that I began to fully appreciate quite how powerful drama can be.

Up until that point, although I was well aware of the quality of the film and the integrity of the BBC's approach to it, I still didn't have confidence that the subject of assisted dying would appeal to the viewing public. So when the BBC confirmed the figures: 4.3 million viewers at the start, rising to 5.3 million by the end (in itself unusual as programmes are more likely to lose rather than gain viewers) and that it had received an unprecedented

audience appreciation rating of 93%, I felt elated that the film had been a success and that a drama about an assisted death could elicit such a strong response.

We were first approached by Liz Trubridge, the producer, and Frank McGuinness, the writer, a few months after our mother's death. Although I was excited at the prospect of the story being in such distinguished hands, I felt apprehensive about the potential for a dramatisation to

lines attributed to us, some of which were exactly as we'd said them and many that weren't.

Some minor details were changed and new dialogue created in order to allow the story to flow, but every important event and piece of dialogue at key moments was real. I found it hard initially to separate what I remembered happening from what was on the page, but soon realised the importance of giving Frank the latitude to tell the story he saw. There is no



Sophie (far left), her Mum and sister Jessica

misrepresent it. However, after meeting Liz and Frank, who reassured us that our input would be central to the process, I felt that this was too good an opportunity to miss.

We all agreed that in creating the drama, getting the right tone was the key element in presenting the truth of the story, rather than getting every last fact correct. We also felt that, when creating our characters, Frank should have the freedom to portray us warts and all!

The first draft arrived a few months later and it was a strange experience reading

single version of the truth, and we were too close to be able to be objective about our own story.

We met the director, Simon Curtis, in July 2008 and I was touched by his desire to represent us as accurately as possible, even to the extent of using real props: photographs of us as children and pictures from my mother's house. He also included my 10-month old daughter, Indira, in the final shots of the film. Julie Walters had now been confirmed as playing our mother, which we were delighted with, as her warmth, humour and feistiness



Julie Walters in *A Short Stay in Switzerland*

very much reflected our mother's own personality.

In December we saw a rough cut of the film and laughed and cried in equal measure: Julie's performance was excellent, particularly from when my mother's illness began to take effect, and we felt that the film was a very accurate portrayal of what we had been through.

After the broadcast, I realised that I had completely underestimated how powerful drama can be. Inhabiting our world for 90 minutes gave an insight into our story in a way that news media could never have done. Some of my friends have said that, even though I had already spoken at length about the events surrounding

my mother's death, it was only by seeing the film that they fully understood what we had experienced. I don't regard the film as a polemic for the cause of assisted dying, as it simply presents a true story. Indeed, some aspects of the film could be considered unfavourable to the cause - my mother was still relatively mobile when she had an assisted death and she experienced disturbing choking as a side-effect of swallowing the barbiturates too hastily. People on both sides of the assisted dying debate are unlikely to change their views on the subject. But I hope they will have a deeper understanding of the desperation that some

people feel at the end of their lives. I also hope that it helps bring the subject of death more out into the open; a friend of mine with a young baby said that, after watching the film, she and her husband were able to have a discussion about their own deaths - something they had never done before.

For me, the manner of my mother's death was only a small part of our story. Just as prominent in my mind was the portrayal of the cruelty of degenerative neurological illnesses, such as Progressive Supranuclear Palsy (PSP). I was delighted to hear from Jane Hardy, the head of the PSP Association, that the film has helped promote awareness of the illness, which is all too often misdiagnosed and is actually more prevalent than other, more well-known degenerative illnesses.

Death really does seem to be our last taboo, but if we don't face up to it, we are more likely to condemn ourselves to a bad one. I want people not to be scared of talking about illness, suffering and death, and to face the future with knowledge and some humour. It would be a fitting legacy for the film, and it would have made my mother proud. ”

### **Praise for *A Short Stay in Switzerland* from Dignity in Dying members**

Following the airing of the drama, we received a number of telephone calls, emails and letters praising the drama. Here we print one of the many letters we received:

"I watched *A Short Stay in Switzerland* last night and the film has remained 'with me' all day today. It was profoundly moving and I would like to extend my warmest feelings to Edward, Sophie and Jessica for their great courage and love for their mother.

It was a heart-rending film and quite unbelievable that both parents should be struck down by such monstrous diseases. Thank goodness that Anne was able to go to Switzerland and to have all three of her children there with her. I'm sure that not one of them will ever erase her death from their minds but I hope that they have the comfort of knowing they did something amazingly brave in letting her follow her own choice."

Alexandra Hope, Derby

# News in brief

## Support for assisted dying from doctors

A recent survey by GP magazine shows a groundswell of support from GPs for a change in the law on assisted dying. The poll of 460 GPs across the UK shows support from GPs has doubled in just five years with two fifths of those polled in support of a change in the law.

A further British social attitudes published in March found that more than a third (35%) of the 4,000 doctors surveyed support a change in the law to allow assisted dying for mentally competent, terminally ill adults. The survey was carried out by Professor Clive Seale, from the Centre for Health Sciences, and updates previous findings from 2004.

## BBC journalist, Peter White, joins assisted dying debate

In his new regular column for Disability Now, Radio 4 presenter and BBC's Disability Affairs Correspondent, Peter White, demanded the right to choice in matters of life and death. In the article, which appeared in the February

**disability  
now**

edition of the magazine, Peter discussed how the heart of the disability rights movement had to be choice. He then went on to say that the ultimate control over life must be the right to choose how and when to end it. You can read the article online at: [www.disabilitynow.org.uk](http://www.disabilitynow.org.uk)

## Sky Real Lives documentary shows assisted death

Craig Ewart's assisted death at Dignitas in Switzerland was shown in the documentary *Right to Die* on Sky Real Lives in December; this was the first time an assisted death had been shown on UK television.

Craig Ewart was a 59-year-old university professor who had contracted Motor Neurone Disease three years prior. Craig and his wife Mary wanted the documentary to be shown to highlight the issues around assisted dying. The airing of this documentary caused much controversy in the UK media, and worldwide, with anti-choice campaigners saying it should not have been shown.

## Two more terminally ill UK citizens are forced abroad to die

In early March, Dignity in Dying learned that Bath couple, Peter and Penelope Duff, both suffering from terminal cancer, were assisted to die at Dignitas. This extremely sad case demonstrates, yet again, the difficult and often desperate decisions many people make so that they can take control of the time and manner of their deaths. Had Mr and Mrs Duff had the option of an

assisted death in this country they may still be alive, as their physical ability to travel would not have been a factor.

## Meet Joanna Thomas, Trusts & Operations Support Officer



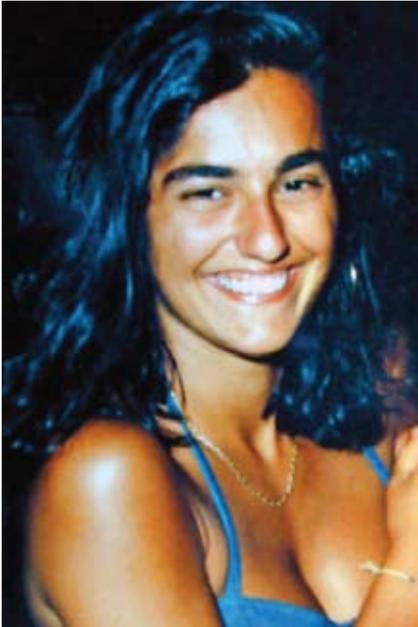
Joanna began working as the Dignity in Dying Office and Board Support Officer in August 2008. She comes from a background in service user involvement at the PCT Community Drug Treatment Service in Leeds.

Joanna is responsible for the day-to-day running of the Dignity in Dying office and duties relating to the Board of Directors. She is often the first point of contact for members and supporters and she also provides support to the Finance and Fundraising team.

Joanna said "Over the past nine months I have been overwhelmed by the dedication of Dignity in Dying members. Your backing is incredibly important to the success of our campaign and we are immensely grateful for all the support and encouragement we receive. I look forward to meeting many of you at this year's AGM."

## Italy: Ten year battle for father to allow daughter to die

For the last 10 years Beppino Englaro fought for the right to allow his daughter, Eulana, to die. Eulana Enlaro was in a car accident seventeen years ago that left her in a persistent



Eulana Englaro

vegetative state, kept alive by feeding tubes against her father's wishes.

Prior to Eulana's accident, a friend of hers had a similar accident which resulted in a coma, and Eulana's father recalls conversations they had about how if she found herself in the same situation she would not want to be kept alive artificially.

## Legendary punk band raise money for Dignity in Dying

On 12th February the pioneering post-punk band Magazine, founded and led by Dignity in Dying member Howard Devoto, kicked off their comeback tour.

Howard approached Dignity in Dying and asked if some of the voluntary contributions could be put towards our campaign, and of course we said yes! Several staff members, including our Chief Executive Sarah, went along to the concert which raised over £750 for Dignity in Dying.

After several court cases, Mr Englaro won his case at the Milan Court and Eulana was transferred to a private facility where her feeding tubes were removed. The Vatican and anti-choice groups strongly opposed the move and a number of protestors gathered outside the building to try and prevent the vehicle from leaving. Some of the protesters shouted "Eulana, wake up", and "Don't kill her".

Italian Prime Minister, Silvio Berlusconi, tried to reverse the decision by issuing a decree and introducing a Bill ordering doctors to continue life support. Neither attempt was supported by the Italian President and both ultimately failed. Four days later, on 9th February, Eulana died.

Following Eulana's death, a pro-life group launched a murder investigation against her father and 14 other people involved with her end-of-life care. However at the time of going to print no charges had been brought as a result of the investigation.

In Italy, refusing life-sustaining treatment is permitted, however, there are no provisions to make Advance Decisions.

## LDAs: charges cut. Reduced charges for people on a low income

As of 1st April 2009, the fee for registering a Lasting Power of Attorney (LPA) will be reduced to £120 per application. While we welcome the reduction in fee, we have raised our concern that this is still a significant barrier to many people.

However, many people are eligible either to register an LPA for free or at a reduced fee. If your gross annual income is less than £11,500, or if you receive a means-tested benefit including Pension Guarantee Credit, Income Support or Housing Benefit, you may be exempt from the fee for registering a Lasting Power of Attorney. If your gross annual income is £16,000 or less you may be eligible to pay a reduced fee to register your LPA.

For more information on eligibility criteria for a reduced or waived fee to register an LPA, please contact the Office of the Public Guardian on 0845 330 2900 or visit :

[www.publicguardian.gov.uk/about/exemptions-remissions.htm](http://www.publicguardian.gov.uk/about/exemptions-remissions.htm)

# Member's letters

**W**e are always happy to hear from our members and supporters and we apologise if, during busy periods, we do not get back to you promptly. Should you wish to write to us but do not want a reply, we would be grateful if you would state this in your letter.

Each week we receive a large volume of letters from members and supporters keen to share their thoughts and ideas with us on a range of end-of-life issues. Here we hear from members on the themes of human rights, Christianity, palliative care and personal stories:

## Dear Dignity in Dying,

I am puzzled in the last edition of DiD News by the absence of any reference to what I had thought was one of our strongest arguments for reform.

I heard Shami Chakrabati (Director of Liberty) say some time ago on Radio 4 that there are only two unconditional human rights listed in the European Declaration: freedom from torture; and freedom from degradation. It seems to me that some people seek an assisted death precisely in order to escape those two things. I also contacted my god-daughter, a human rights lawyer, for advice and she replied:

" I think it is certainly worth using this as an argument, even in terms of the importance we place on people not being subjected to torture or inhuman or degrading treatment. It may be more complicated to argue that the state is responsible for something it doesn't inflict as a strict matter of Human Rights law, but the point about the importance of the value is obviously relevant to any debate."

## Roger Martin, Wells

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Dear Roger,

Article 3 of the European Convention on Human Rights was used as a minor argument in the Diane Pretty case. However, the European Court did not agree around this article - (as your god-daughter points out, any torture or degrading treatment was found not to be inflicted by the state) - and as you know the Pretty case ultimately did not succeed.

I agree that the arguments you put forward do have force, although probably more so with the public and in Parliament than they would in the courts. However, one of the things that we must guard against is looking as if we are making judgements about each person's perception of what is dignified, (and what is 'degrading' or 'tortuous' taking the language of article 3). The concept of unbearable suffering or a dignified death is different for everybody and we are not trying to impose one kind of death on everybody. If we are using the language of the Human Rights Act, it becomes even more important that we stress these are personal judgements made by individuals, rather than a standard to be imposed on all people with terminal illnesses.

**Davina Hehir, Head of Legal Strategy and Policy, Dignity in Dying**

## EXTRACTS FROM OTHER LETTERS



As a church-goer, although not a very orthodox Christian, I really cannot understand anyone objecting to assisted suicide on religious grounds as long as the law is rigorous and the necessary safeguards are in place. If it is right to interfere with nature to keep people alive when the much quoted "will of God" clearly means them to die, then why can't the opposite view be held? Each individual is responsible for her or his actions and to deny people the right to help in ending their own lives is just cruel.

There are laws which everyone must obey and these must always have careful consideration when they are controversial. A law to allow assisted dying is not such a law. No one has to take advantage of it and even the most ardent supporters of such a law may find that they want to continue living as long as possible whatever the circumstances, but in a free society the choice should be there. I find it quite impossible to believe in any kind of God that would not look on such people with infinite compassion and expect a civilised society to grant them the right to "cease upon the midnight with no pain" so aptly quoted by Esther Rantzen in the last edition of Dignity in Dying News.

**Kathryn Dobson, Liverpool**

I have been close to two people who have died of Motor Neurone Disease and all they wanted was to die in their own home with their family around them.

My Mother died at 10pm in a single room in hospital and my dad had left at the end of visiting hours, luckily I was in the hospital and stayed with her while she died but there was no time to gather the rest of the family around.

Another person I knew, Lillian, was in a hospice 20 miles away. She wanted to go home and stay with her family but social services would not allow it, she died alone in the middle of the night with no family by her side.

We have to get the law changed for so many reasons, if people know they are going to die, they should have the right to choose where and when. Not just for them but for the whole family.

**Wendy Currie, Bedfordshire**

It would be wonderful if the hospice movement could amalgamate with Dignity in Dying's aims. Hopefully palliative care would be the greater part of a joined up charity's provision, but, for those without religious objections, there would be the option of arranging for an easeful death when they felt they and their loved ones had suffered long enough. Obviously those with strong religious beliefs against the 'easeful death' route need not avail themselves of it, but could still benefit from the provision of greater accessibility to palliative care for all.

There needs to be no 'either or' situation which would be tremendously reassuring I would have thought.

This is such an important debate.

**Sandra Davidson, Isle of Man**



### **ACTION! SEND US YOUR EMAIL ADDRESS**

Email is a cost effective way for us to contact supporters urgently. If you do have access to email, please send your address to

**[emily.halsall@dignityindying.org.uk](mailto:emily.halsall@dignityindying.org.uk)**

and we will add you to our email group of supporters.

**Send your letters to  
Emily Halsall,**

**Dignity in Dying, 181 Oxford Street, London, W1D 2JT.**

**Or email your letter to  
[emily.halsall@dignityindying.org.uk](mailto:emily.halsall@dignityindying.org.uk).**

# Recruit a member

**W**e know that many of you use our newsletter as a way of informing your friends and family about our work.

As the Coroners and Justice Bill makes its way through Parliament we need more

supporters than ever to join our campaign.

We know that our organised opposition groups are already very active. We recently heard of a church group who, after the close of the Sunday evening service, distributed different sizes and colours of writing paper and envelopes to members of the congregation. The church group then invited members to write to their MPs asking them to oppose our amendments to the Coroners and Justice Bill, even offering to post the letters afterwards.

We know however that we have numbers on our side with over 80% of the population in support of a change in the law. This means we have a staggering 56 million potential Dignity in Dying supporters out there! Please photocopy this back page and pass to friends, family members and neighbours who are interested in hearing more about becoming a Dignity in Dying supporter. Remember, all new members will receive a Dignity in Dying Advance Decision and a copy of **Campaign** magazine three times a year.

**Please send me more information on becoming a Dignity in Dying member.  
My details are as follows:**

Title: \_\_\_\_\_ Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Postcode: \_\_\_\_\_

Occupation (optional): \_\_\_\_\_

**I would like to be kept informed on Dignity in Dying's campaigns with email updates:**

Email address: \_\_\_\_\_

Please complete and return this form to Dignity in Dying, 181 Oxford Street, London, W1D 2JT

## **ACTION!**

### **ARE YOU A MEMBER OF A SOCIAL NETWORK?**

We know that a number of our supporters are also members of other social networking groups such as Women's Institute, the British Humanist Association, and the University of the Third Age.

If you are a member of such a social network you could increase support for our campaign by raising Dignity in Dying's work with the other members of your group. This could be through a newsletter article for your group magazine or through a talk at one of your regular meetings (we may be able to write a comment piece for you and can occasionally supply speakers).

If you would like any more guidance on engaging your social network with Dignity in Dying's work please contact Emily Halsall by email at [emily.halsall@dignityindying.org.uk](mailto:emily.halsall@dignityindying.org.uk) or by telephone on 020 7479 7730.