

dying with dignity

JULY 2012 - NEW SOUTH WALES

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Our goal is law reform so that people suffering unrelievably from terminal or incurable illness can receive, on request, medical help to end their lives.



www.dwdnsw.org.au

respect for the right to choose

Dying with Dignity NSW is a not-for-profit company
limited by guarantee
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Syd Hickman

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President's Message



I am very pleased to take up the challenge of the Presidency of DWDnsw, and my thanks go to my predecessor - Dr Robert Marr - for his contribution over the past three years and for his willingness to continue to offer advice and support.

We need to increase public awareness of end-of-life choices. Fortunately, there is now more media interest in encouraging the conversation about death and dying, but there are still some who find the topic too controversial or uncomfortable.

The focus of our efforts in recent months has been on giving talks to community groups such as Probus, National Seniors, Community Services and University of the Third Age. These have been successful in spreading the word and leading to new memberships, and we have at least eight talks planned for the rest of the year.

But we need to do more. We have had some professional advice on how we could increase our membership via an improved communications strategy and the development of our activities, especially in country regions.

* * * *

We are very pleased to appoint Syd Hickman as our Campaign Manager to focus our efforts on influencing politicians and to speed up the introduction

of legislation to permit assisted dying. Syd has very considerable experience in political campaigning and will be focusing his attention on improving our communications materials, including the website, and translating the popular support we know is there into effective political action.

* * * *

Fundraising is a perpetual challenge. DWDnsw plans to hold some events which will generate extra funds whilst giving our members a chance to be part of the community working for legislative change. As we want to hold events that appeal to you, we are seeking your feedback. **Please write your ideas on the insert "What would you like to do?" (which has been posted with this newsletter) and send it back to us.**

* * * *

DWDnsw is holding a lavish fundraising dinner on Tuesday October 16th at 7pm at Marigold Regal Chinese Restaurant (level 5 / 683 George St Sydney).

There will be a delicious banquet (*with a vegetarian option - please request this at the time of booking*).

It will be a very special night, with a stimulating MC in Prof Simon Chapman, a Professor in Public Health at the University of Sydney. He has published 439 articles in peer-reviewed journals and 17 books, including co-authoring the groundbreaking research work in 1995 "*The Last Right?: Australians takes sides on the right to die*". He is also a pioneer

in campaigns such as anti-smoking.



Prof Simon Chapman

Our main speaker for the night will be John Bell, the founder of The Bell Shakespeare Company and one of Australia's most acclaimed theatre personalities.



John Bell

We are also holding fundraising raffles and auctions on the night. This evening of good food and exciting speakers **will cost \$130 per person.**

Please email dwd@dwdnsw.org.au or leave a message on 02 9212 4782 if you are interested in attending.

* * * *

I am very grateful to the number of volunteers who have offered their time and skills to help DWDnsw. *We would be particularly interested to hear from anyone with **Events Management experience**, to help us with regional events.*

As always, we look to you for continued support. Given the enthusiasm and talents of our team, I am looking forward to great achievement for DWDnsw during the next six months.

Richard Mills
DWDnsw President

Campaign Manager's Message



In campaigning for medically assisted dying legislation, it is important to remember that Newspoll Surveys have consistently shown that the vast majority of Australians agree that we should have the choice of an assisted death if we are suffering and have no hope of recovery. The challenge is not to get more people to agree with us but to get action on an issue most people prefer not to think too much about.

Our aim is to get more DWDnsw members and more media attention. Politicians will only pass the legislation we want when they see enough people demanding it. As a first step, the DWDnsw website front page will be made more simple and welcoming. Printed materials will also focus less on the details of related issues and more on the need for action. We will also be trying to get more items into the various media outlets.

To help attract more members and to get people to think harder about this issue we have included some DWDnsw green pamphlets and yellow posters with all mailed newsletters. We would appreciate it if you can hand out pamphlets to friends, put posters on notice boards or refer people to the Dying with Dignity NSW website and phone number.

Remember that the personal approach is often the most effective, so if you know people who are interested please

give them a nudge to become members of DWDnsw.

If your newsletter is emailed to you and you would like us to post you some pamphlets or posters please email dwd@dwdnsw.org.au or leave a message on 02 9212 4782.

Now is a good time to promote our cause, as the community and media are increasingly interested in the topic of end-of-life issues. There have been a number of well-attended events around this theme in the last few months. For example, The Australian Catholic University hosted a panel discussion "*Ethics and euthanasia*" lead by Geraldine Doogue. UTSpeaks hosted a discussion "*Your Certain Death*". Wolper Jewish Hospital hosted a discussion "*Euthanasia vs Palliative Care: debating the hot issues*" lead by Julie McCrossin. Our VP - Dr Sarah Edelman - was a panelist at this event.

There has also been quite a bit of media coverage, including the ABC radio program "*Sundays with James O'Loghlin*", which dedicated a session to a discussion of ethics and voluntary euthanasia.

DWDnsw is focusing on talks to community groups to build enthusiasm for our cause and boost our membership. These talks are given by unpaid committee members. We have already seen an increase in our

membership from this increased activity. Please see graph below of membership by month. We hope that this trend will continue.

Pease email dwd@dwdnsw.org.au or phone 9212 4782 if your club or social group would like to have a speaker OR if YOU would like to volunteer to help give presentations to community groups.

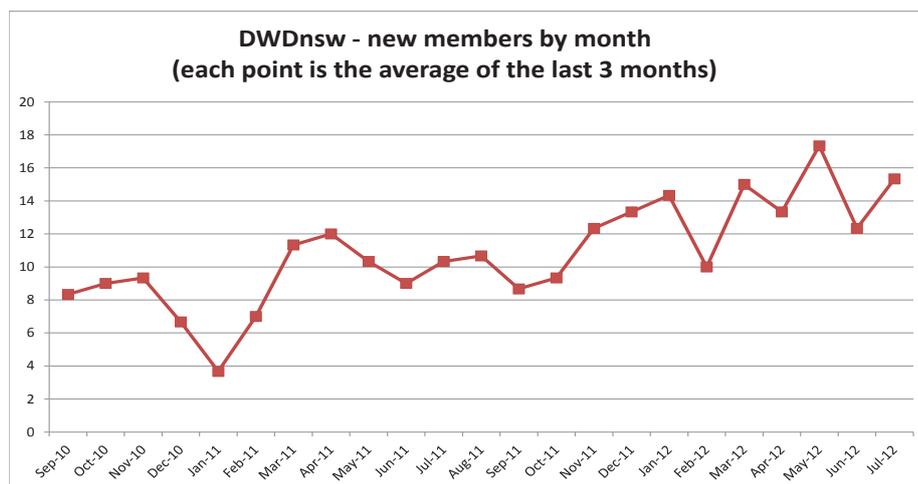
Syd Hickman
Campaign Manager DWDnsw

Treasurer's Message

At our AGM in March 2012, I presented a conservative financial estimate that showed the urgent need to arrest the decline in our financial situation, in order to avoid my forecast of an insolvent Dying with Dignity NSW by 2016.

Despite the fact that DWDnsw has conducted its affairs professionally and with a continuing view to keeping expenses under control, we have substantially reduced the pot of money that we held prior to 2006. This was in large part because of the Global Financial Crisis, which substantially reduced the value of our high interest Mortgage funds.

It costs money to run any organisation and without a continual flow of membership



payments, donations and bequests, these costs are greater than the income. The more members we have the greater our ability to absorb these costs.

From July 1st we have increased the membership fees by a small amount to help us cover our costs. Fees have not been increased for 4 years.

In the past, the largest pool of funds came from bequests left to our organisation in the wills of our supporters. Not having had many bequests in recent years, we are very grateful to have **recently received three generous bequests:**

* \$2000 from the estate of the **Late Noelyn Tunstall** of Port Macquarie

* \$10269 from the estate of the **Late Kathleen Friezer** of Queensland .

* \$4000 from the estate of the **Late Dorothy Simons** of North Sydney (*see the tribute to Dorothy on page 10*).

On behalf of the DWDnsw Committee, I would like to thank these generous ladies. Bequests like these really help us to campaign for change.

We also received two generous donations (\$400 and \$250) "*in loving memory*" of the **Late Patricia Thomson** (1925-2012) of Paddington, who was a member and long time volunteer of our society since 1988. Patricia's legacy to DWDnsw may include



introducing us to the lovely idea of suggesting to friends and relatives that they make a donation

to Dying with Dignity NSW in lieu of flowers.

Barry Hill - Treasurer DWDnsw

Sub-Committee meeting with Cate Faehrmann

In early July, a DWDnsw sub-committee met with Cate Faehrmann - the Greens Member of the NSW Legislative Council - to discuss her plans to introduce the "*Rights of the Terminally Ill*" Bill into the NSW Parliament. At the meeting, the group discussed important recent events in the UK and Canada (*reported on page 8 of this newsletter*) and made some suggestions on the drafting of the Bill.



Cate Faehrmann

Cate intends to have a thorough consultation process in developing the draft bill and is keen for DWDnsw to be closely involved at that stage. She is particularly interested in hearing your personal stories that may support the case for legislative change for medically assisted dying. **If you have a personal story that you are willing to share, please write to Office of Cate Faehrmann MLC, Parliament House, Macquarie Street, Sydney NSW 2000 or email cate.faehrmann@parliament.nsw.gov.au.**

When the Bill is being debated in parliament, we hope that our members will show their support by writing letters to newspapers, contacting talkback radio and urging their local Member of Parliament to vote for her Bill.



Inside posted newsletters is a copy of "The Greens PETITION in support of the right to die with dignity". Members can help by collecting signatures of support, and mailing the petitions back to Cate at the address on the form.

If your newsletter is emailed to you and you would like us to email or post you a copy of the petition please email dwd@dwdnsw.org.au or leave a message on 02 9212 4782.

Please see the Central Coast Branch Message below for more information about Cate and her plans for change.

Central Coast Branch Message

With DWDnsw Committee member John Hogan very ill, Doris Hart with a very nasty dose of pneumonia and Pippa Preston very much engaged with a complicated house move, the Central Coast Branch Committee was extremely short handed by March. Thus, they were delighted to welcome six new members, Margaret MacLean, Margaret Pashley, Suzanne Vesque, Filippi Diego and Jock and Joy Shannon (myself) who had volunteered to serve on the Committee.

The new members quickly found themselves immersed in the arrangements for

our meeting, at which Cate Faehrmann had kindly agreed to speak. A flyer was designed, printed and distributed locally and even printed in the local paper. It was great to see the willingness of everyone approached to display the flyers. 36 members and guests attended the meeting and asked many questions of Cate afterwards.

In summary, Cate said that the time was ripe for a fresh initiative in NSW, as the last ten years has seen increased support for the right to a dignified death, with a general rise in momentum and publicity. Cate spoke of steadily growing support from the younger, more free-thinking generation and a whole new group of MPs with different social values.

Cate stressed that while voluntary euthanasia was already legal and working well in several countries/ American states, their laws were not necessarily suitable for Australia. She favoured wide preliminary public debate, with emphasis on the countless stories of individual suffering, to ensure that what was finally put before Parliament would meet Australian needs.

At the end of the meeting, Chris Gavenlock - a new CC member - read aloud the letter she had written to her local MP expressing her support for the Green's Petition. She suggested that other members might want to send a copy (suitably personalised) to their own MP. There was a lot of interest in her letter.

*Joy Shannon
Secretary, CC Branch
DWDnsw*

UPDATE ON OTHER AUSTRALIAN STATES AND TERRITORIES

DWD ACT



DWD ACT is now incorporated, so it is no longer merely a branch of DWDnsw. DWD ACT will be writing to DWD NSW members who live in the ACT to join us in 2013. Members who live in NSW but close to the ACT are also invited to join us if they think they are likely to have medical treatment or die in Canberra. You are welcome to be a financial member of one or both of our DWD societies.

* * * *

In June the committee met with Dr Andrew Leigh, Federal MP for Fraser, to discuss the concept of medically assisted death. He acknowledged the need for changes to the law in the ACT. He threw out a challenge to us to demonstrate why politicians would be attracted to the idea of medically assisted death. This is easily done and we will be writing to him to outline why it is an idea that they can support.

* * * *

The ACT Human Rights Office has advised us to write to the ACT Attorney General asking him to refer sections 16, 17 and 18 of the Crimes Act 1900 (the laws on suicide) to the Law Reform Committee at the

ANU for review. The DWD ACT committee has decided to write to Simon Corbell, an ALP MLA, requesting such a review.

* * * *

There was agreement amongst the attendees at the ALP Law Reform Committee that we should develop an ALP policy on a peaceful death unit. The committee discussed ways of moving the proposal forward through the party. The ALP Health Policy Committee has invited me to speak to it about our proposal.

* * * *

I have been in Zurich attending the WFRtDS Congress. Please see my report on page 7 of this newsletter.

DWD ACT's next meeting general meeting will be on August 16th. The planned topic is ABS Death Statistics. We hope to see you all there.

*Jeanne Arthur
President, DWD ACT*

TASMANIA

Right now, the most exciting prospect for assisted dying law reform in Australia is in Tasmania, where Premier Lara Giddings is working together with the leader of the Greens, Nick McKim, to introduce a



Green Leader Nick McKim

private member's Bill. Premier Giddings hopes to have the Bill before Parliament this year, and will soon release a discussion paper. The public's response is expected to be overwhelming.

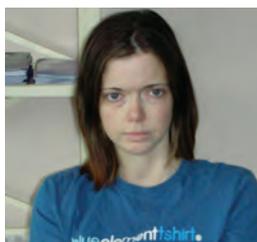
DWDnsw and our national umbrella organisation - YourLastRight.com - will be supporting our Tasmanian colleagues in any way we can.

SOUTH AUSTRALIA

In June, Independent MP Bob Such's Voluntary Euthanasia Bill was narrowly defeated in the Lower House of the South Australian Parliament. This was despite the backing of the Premier, Jay Weatherill, and some senior ministers. Dr Such said his proposal - which would only apply to people suffering from a terminal illness with pain that cannot be relieved - had all the possible safeguards. Nevertheless, a combination of Conservative Liberals and key members of Labor's Right faction combined in a conscience vote to defeat the Bill 22-20.

Dr Such and Labor MP Steph Key plan to introduce a reworked Bill into parliament again this year.

* * * *



The Late Angelique Flowers

Angelique Flowers lived a short life full of pain and suffering from severe Crohn's disease and then later aggressive terminal colon cancer. She was

diagnosed at 15 years of age and died in 2008 at age 31 in a horrific, undignified death.

July 2012 has seen the launch on Facebook of a new group set up in honour of Angelique Flowers. This group of young Australians supporting medically assisted dying is called SAVE-YA (South Australian Voluntary Euthanasia Youth Advocates). **Please support SAVE-YA on Facebook** or write to Ms Amy Orange at SAVEyouthadvocates@hotmail.com

INTERNATIONAL NEWS

World Federation of Right to Die Societies Congress – June 2012

At her own expense, Jeanne Arthur, the DWDACT President, represented DWDnsw and DWDACT at the recent Biennial Congress of the World Federation of Right to Die Societies Congress in Zurich. This is her report.

In June this year the *World Federation of Right to Die Societies* held their bi-annual congress in Zurich. I attended as the DWD NSW delegate. 81 delegates arrived from all over the world and four new societies were added to the Federation.

For the Australians in the group, the appointment of Neil Francis (President of DWDV and YourLastRight.com Chair) as President was very exciting. The Federation has virtually a new organizing committee and with Neil at the helm there is an expectation that the WFRtDS might move quickly and energetically towards achieving its aims.



Neil Francis - the Chairman of YourLastRight.com Australia and New President of WFRtDS

The Congress was held in Switzerland, which has the most liberal laws on assisted suicide, but has recently undergone a legal challenge to that law. Groups, like Exit, maintain a large number of members in order to ensure they have political influence. They are constantly working to find doctors who will provide prescriptions of Nembutal.

Dr Philip Nitschke of Exit International gave a speech arguing that new technology, rather than assisted dying law reform, would be more likely to provide end-of-life choices for people. Later, there was a demonstration of some alternative techniques for ending life, including the use of a helium bag and a mask which utilized chemicals that can be bought legally.

There was some discussion about the idea of people seeking out Exit or Dignitas for help to die and the fact that some Swiss politicians argued that right to die organizations in Switzerland should be better regulated. However, we heard several examples of how right to die societies can, in enabling people to discuss their wish to die freely, help people to engage with life for longer than they otherwise might.

Emphasis was placed on the important work done in



This photo shows some of the WFRTDS Congress delegate, with Neil Francis (President) on far left, Faye Girsh (VP) on far right and Rodney Symes (WFRTDS committee) behind Faye. Alas, Jeanne Arthur of DWD ACT is not shown in this group.

developing the WFRtDS website by Rob Jonquiere, now with information in several languages We were encouraged to look at the site regularly (*there is a link on the Dying with Dignity NSW website*).

World Federation Right to Die Societies Congresses are vital occasions for pushing our thinking along. **The next congress will be held in October 2014 in Florida USA.**

I encourage other members to attend, as it is guaranteed to be a stimulating and thought-provoking experience.

*Jeanne Arthur
President, DWD ACT*

Also in attendance was Dr Rodney Syme from the DWDV (Victoria) Committee, who is also a member of the WFRTDS Committee. At our request, Rodney also wrote a report about the event. Amongst other things, Dr Syme concludes that the Swiss have the best situation in the world, with strong public support for their end-of-life legislation. Dr Syme's report can be read on the DWDnsw website.

THE UK

DWDnsw reported in the last Newsletter that the Falconer Commission had recommended an assisted dying law. Following on from that report, the UK Dignity in Dying organisation and an All Party Parliamentary

Group have produced a draft Bill and a consultation paper. The proposed Bill presents an assisted dying model which would allow terminally ill, mentally competent adults in England and Wales the choice of controlling the manner and timing of their death. The consultation paper is intended to assess the robustness of the safeguards in the Bill.

There has already been vigorous lobbying of Members of Parliament from both supporters and opponents, and this will doubtless continue to offer us lessons on the arguments and tactics used to influence opinion.

CANADA

Earlier this year, a multi-party Committee of the Quebec National Assembly recommended assisted dying (but not assisted suicide) legislation for Quebec. Both the Quebec Bar Association and the province's Federation of General Practitioners approved the Committee's conclusions.



Gloria Taylor

Interest in the Committee's report has been substantially revived by a major court case. In June, a judge in the British Columbia Supreme Court issued a 400-page decision on an appeal by Gloria Taylor, a woman with Motor Neurone Disease, to be helped by a doctor to die. Madam Justice Smith reversed a 1993 decision on a similar case and struck down laws banning doctor-assisted suicide as unconstitutional. She found that certain provisions of the Canadian Criminal Code prohibiting physician-assisted suicide violated important rights of equality, life and liberty.

A submission to the court made by Nica Cordover of Tasmania was mentioned in the judge's final ruling. This demonstrates the importance of a global dying with dignity campaign. It remains to be seen how the Canadian government will respond to this court ruling. Unfortunately, it seems that the decision may be appealed.

MASSACHUSETTS USA

As reported in our October 2011 Newsletter, the Massachusetts' Death with Dignity campaign is collecting voters' signatures in support of the proposal *Should the terminally ill have the right to physician-assisted suicide?* They have now collected almost

twice the number they needed to put the question on the ballot paper on 6 November.

A recent poll by the Western New England University showed that 60 percent of voters supported physician-assisted suicide. Interestingly, the poll found that 52 percent of all Catholic voters said they support the idea. This is especially significant because Massachusetts is among the most Catholic states in the country, and the Catholic Church is vigorously campaigning against the ballot measure.

If a majority of voters at the November election agree, Massachusetts will have an assisted dying law that is virtually identical to the laws in Oregon and Washington. This process is an alternative to the more traditional one of legislation being debated and passed by elected representatives in a parliament. This is a citizens' initiative that allows voters to decide directly on a legislative proposal, provided they obtain enough popular support. And in Massachusetts, so far they have done just that !

Christians Supporting Choice for Voluntary Euthanasia (Ch4VE)

Since the Co-founder of Ch4VE – Mr Ian Wood and his wife Nancy - moved from Adelaide to Mittagong NSW early this year, the DWDnsw Committee have had the opportunity to be more involved with this independent lobby group.



Ian Wood at S.Aust Parliament

Formed in South Australia in February 2009, the group has an important role to play in reminding politicians that

the overwhelming majority of Australian Christians support choice for voluntary euthanasia (as shown in surveys over the past 15 years). For example, a 2007 Australian Newspoll survey found that three out of four Catholics and four out of five Anglicans supported the right of a hopelessly ill patient, experiencing unrelievable suffering, the choice to have a medically assisted death.

Visit the website of Ch4VE at www.Christiansforve.org.au

Membership of Christians Supporting Choice for Voluntary Euthanasia is FREE.

By joining this lobby group, you are stating your willingness to be counted amongst the signatories on all Ch4VE letters going to Members of Parliament.

Please cut out the membership form below, and mail to Christians Supporting Choice for Voluntary Euthanasia Villa 1, Hampton Mews, 4 Wills Place, Mittagong, NSW 2575.



I WANT THE CHOICE OF A PEACEFUL DEATH !

I wish to join Christians Supporting Choice for Voluntary Euthanasia as a 'signatory' in their campaign to have Voluntary Euthanasia legalised in Australia as an option for people suffering unbearably from a hopeless or terminal illness. Such legislation would include stringent safeguards against abuse.

Mr/Mrs/Ms/Dr/Other _____ Name: _____

Address: _____

Email: _____

Signature: _____ Date: _____

Denomination (optional) _____ OR

OPTION I am not a Christian but wish to support the group (*please tick in box*) []

Return completed form to Villa 1, Hampton Mews, 4 Wills Place, Mittagong, NSW, 2575.



Tell the truth

A new regular feature in this Newsletter is a section devoted to exposing misinformation about assisted dying.

A common claim by opponents of assisted dying is that voluntary euthanasia legislation will inevitably be followed by involuntary euthanasia - which is killing people against their will. At the very least they argue it will lead to non-voluntary euthanasia - which is killing people without their explicit consent.

For example, the Catholic Archbishop of Sydney, Cardinal George Pell wrote last year: *“One important part of the Catholic task today...is to explain that just as winter follows autumn legislation to allow voluntary euthanasia or mercy killing would lead to widespread involuntary euthanasia, with many, perhaps a majority of those euthanized being subject to the procedure without their consent and often against their will.”*

There is no evidence whatsoever that the introduction of assisted dying legislation causes non-voluntary euthanasia.

It is true that doctors sometimes help people to die without their explicit consent, but this happens in all countries, including Australia. In fact, a

study published in the Medical Journal of Australia in 1997 reported that 3.5% of Australian doctors acknowledged that they had deliberately provided medication to help patients die, without an explicit request from the patient. This happens for compassionate reasons, usually at the end stage of illness. However, unlike in countries where assisted dying is legal, there is no monitoring or regulation of this practice.

In addition, in countries where voluntary euthanasia is legal, the very small proportion of deaths without explicit consent has decreased. For example, a recent study published in The Lancet reported that in the Netherlands the frequency of ending of life without an explicit patient request decreased from 0.8% of all deaths in 1990 to 0.2% in 2010. Analyses of these cases showed that they were nearly always patients who were very close to death, and with whom the hastening of death had been discussed earlier in their disease trajectory, and/or with their relatives.

It is to be hoped, but not expected, that Cardinal Pell acknowledges these facts.

Personal stories

A tribute to Dorothy Simons

Dorothy Simons, a Past President and Committee member of VES, died in January this year, aged 98. She had a remarkable life. She made an important and indelible mark in Australian crusades for civil liberties. Among other things, she was involved in adult education for women, worked for immigration reform against the White Australia Policy, and played a leading part in the Women's Electoral Lobby and in the Family Planning Association.

In the mid-1980s, Dorothy was in her 70's and began crusading for Voluntary Euthanasia. She became a pioneering stalwart of the Voluntary Euthanasia Society NSW.

For the next 20 years she made a great contribution as a Board Member, speaker and as a VE activist. She was always a superbly media-savvy lobbyist, telling one journalist in 1994 *“euthanasia has as much to do with murder as making love has to do with rape”*. Dorothy's energy, networking skills and her knack of finding excellent speakers and persuading them



Dorothy Simons (out front in purple) on a march for VES NSW

to donate their expert advice has been a special bonus for members and the media. She was instrumental in ensuring the overturning of the ban on the publication and distribution of "Final Exit".

Unfailingly supportive, Dorothy has left DWDnsw a generous bequest of \$4000, which will help us continue her work.

* * * *

A letter from Dallas

The following personal story sent to us by a DWDnsw member and friend of Dallas Hall illustrates that assisted dying should be one of the choices available to people whose suffering at the end of their lives cannot be relieved.

In August 2009, Dallas Hall emailed these comments to one of his friends. Dallas was a craftsman carpenter and social activist in the Illawarra, who died in October 2009 from motor neurone disease.

I was a completely independent person, to the point of doing my own car repairs and being a loner in my social life. I have gone from that to relying on people for just about everything and having people around me all the time. I have found great comfort and enjoyment in being with people and in hindsight should have done that years ago. So the experience of MND has been a wonderful thing in many ways.

But when you can't turn it off, when you can't say, OK the party was great now it's time to go home and rest in your own space, that's when I feel the burden of the disease. I can't create my timber work any more. I can't hang glide or walk in the bush at will. I loved the water and surf. I loved volunteering my time for charity. I loved designing people's homes and renovations and then building them for them and seeing the look on their faces when it was all done. All these things I have given up.



Food and drink are no longer there - a joy we all look forward to. Long conversations about complex intellectual and philosophical things were a joy to me. All these things I have given up. I am OK without them.

However, there are two things I can't give up and genuinely maintain a sense of dignity without. One is my independence. I don't see the sense of continuing on for the sake of an extra few months or years when my independence is so compromised. Secondly, is hope. Hope that the future will be better or at least not much worse. For me, both these things are dwindling to the point of extinction.

So before I do lose all, I want to say goodbye to my friends and leave with my head held high (figuratively speaking only as my neck now won't support my head, but you get the idea !). For the moment I will continue and see what each day brings. I want a rest from this life and hold no deep regrets about the love and friendship I have given and received.

My life is full and if it can end with dignity I will be a very lucky man. My sense of independence and hope revolve around the self determination of that one final act.

Dallas Hall

Sonnet By member Terry Kemp

DYING WITH DIGNITY

*Whose life is it anyway?
The question surely is this.
Life choices to be made,
And many roads to bliss.*

*Family and friends unite
To celebrate a life worth living.
Not a passing into night,
But measured by love and giving.*

*What's the purpose of a life?
To bravely cope with dreams and strife.
Enjoy the triumphs and the toil,
And not let death this purpose soil.*

*For me, my life is only truly whole,
If I am master of my fate
and captain of my soul.*

My Dad in Palliative Care

My dad was diagnosed with inoperable stomach cancer in February 2012, and was admitted to Cabrini Palliative Care in April. Initially his mood lifted. The nursing staff were caring and attentive, and he received daily visits from a doctor. He felt that he was in good hands and he was determined to maintain some independence for as long as he could. Unfortunately, it didn't last long.

It is impossible to describe the weakness and fatigue that beset my father in those last few weeks of his life. The weakness was utterly debilitating, progressively robbing him of every capability. By the second week, Dad no longer had the strength to get out of bed. Toileting became an ongoing problem and treatment for constipation sometimes lead to humiliating mishaps in bed. Even using a bottle was problematic, as being so weak, he was unable to manage it, and much of its contents would spill on to him or in the bed.

Dad was devastated. Whilst initially reluctant to ask for help, he now sought it, but was often too weak to locate the call button. Some nights were, in Dad's words "a nightmare", as he would lie wide awake for hours. As even tiny amounts of food caused severe stomach pain, dad gave up on eating. A distressing side effect was painful inflammation in his mouth. With time, even speech became difficult, and Dad became frustrated that we could not comprehend his words.

The doctors visited daily, and enquired about pain and nausea (which could be medicated), but they had nothing to offer for weakness and malaise. As his quality of life diminished, Dad started longing for death. Repeatedly, he told the doctors that he could not bear it anymore and that he wanted to die. He described the process as "torture" and he wanted it to end.

In the last few days of his life, Dad lost the ability to swallow and his attempts to drink resulted in fluid pouring into his lungs. He was severely dehydrated and utterly wretched. My sister and I repeatedly asked the doctor if he could be put on morphine, so that he would not have to endure this suffering. Eventually, they attached a dispensing device which slowly released morphine into his blood. While initially Dad went into a deep sleep, he had several periods of breakthrough symptoms, which required a top up of medication.

I asked the nurse if Dad could be put on a higher baseline dose to avoid breakthrough symptoms, but she said that they have their instructions from the doctor. The protocol was obvious – drugs like morphine, which could potentially hasten death, were to be kept to a minimum. So it meant that rather than drifting off into oblivion, Dad had to suffer intermittent distressing symptoms right until the last hours of his life.

Dad looked like a concentration camp victim when he died. He was totally emaciated, skin and bones, his face barely recognisable. My first response to his death was relief - at last his suffering was over ! But I also felt anger that he had to go through so much torment, when death was always inevitable.

I have been an advocate for end-of-life choices for many years, but until this experience I never fully appreciated how difficult the process of dying can be, both for the patient and their loved ones. I also never understood the limitations of palliative care. Dad was in one of the best palliative care facilities in Australia, but this did not prevent suffering. In spite of the reassurances of the palliative care team before dad entered the hospital, dying was a cruel business.

My dad was never interested in euthanasia and if there had been any hope of some improvement he would have seized it with both arms. But he repeatedly asked to die because he was suffering and he was not going to get any better.



Sarah and her father Max Edelman - March 2012

It is hard for me to imagine how anyone who goes through this process could emerge thinking that the current system is working well. For me, the experience has reinforced the need to keep up the good fight. No one should be forced to endure pointless suffering at the end of their lives.

*By Dr Sarah Edelman,
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