



# End-of-Life Choice

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## **Palliative Care and End of Life Choice, the Connection.**

*Libby Smales, CNZM, FaChPM wrote the following article, published in the Bay Buzz, Nov. 2012, and reprinted with permission.*

As a physician working in Hospice, I was focussed on maximising all the differences good Palliative Care can and does make to patients, their families and friends; in most cases managing to make possible a way of dying acceptable to each one.

This involved taking the time to listen, to work out what and who are important, to make accurate diagnoses, to deal with pain, nausea, vomiting, anxiety, grief, fear, suffering, complex family dynamics etc and to make a safe space for addressing whatever needs were still left unmet. Rarely, sedation was the only way to manage the situation, this is seen, in this context, as symptom control rather than euthanasia. Now, working outside Hospice, I am able to recognise that there are people who still die 'bad deaths.' The differences between a 'good death' and a 'bad one' are many; unimaginable suffering for those dying and their Carers, and a legacy of pain and grief. In some cases the suffering is so dreadful, that the individual and or family members are desperate and courageous enough to intervene to end the suffering, adding the fear of

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a court case.

In some cases we can 'fix it', in some, we cannot. Advances in medical care mean that many more interventions are possible. Sometimes these are wonderful, life-saving or life preserving. Sometimes, they merely get in the way of someone's dying and prolong suffering. Sometimes, the owner of the life absolutely wishes to end it. The challenge is to make the best decisions for each of us.

Here are examples of different decisions:-

Consider the big, young, previously fit farmer, dying of motor neurone disease, who tried to kill himself on his mobility scooter to protect his wife. He failed, and added fractured ribs to his problems. Later, immobile, unable to speak or swallow, he was persuaded to accept a PEG, (a feeding tube, directly into his stomach) which neither he nor his wife wanted, but which they felt unable to refuse; this prolonged the suffering for weeks until he drowned in his own secretions. He was not referred to Hospice. His widow is

struggling; she feels Voluntary Euthanasia would have been a much better decision.

Or the man with prostate cancer, who had been in severe pain for months, with painful tumours in many of his bones; who struggled into Hospice one day, pleading with us to kill him. We fixed his pain. He changed his mind. We continued to manage his pain and other problems until he died peacefully, years later. During this time he managed two UK trips and acquired and loved a new cat. Palliative Care was transforming in this man's life. Interestingly he initially self-referred, and inadvertently, caused some administrative hassles for us, because he lived longer than a year.

The objectives in Palliative Care and Voluntary Euthanasia are the same, to mitigate suffering, to make the most of each precious life, retain dignity and demonstrate compassion.

**(Continued, Page 2)**

## A message from the President

Ms. Carole Sweney,  
President,  
End-Of-Life Choice

Dear Members,

Here we are at the beginning of a new year with high hopes that Parliament will finally get to vote on the End-of-Life Choice Bill - a vote we have every reason to believe will be successful. Now it's time for all supporters to pick up the campaign, get our pens or computers ready, and continue our role of educating medical professionals, the public, MPs, and ourselves, about the Bill, which surveys show a majority of people support.

As you know, the EOLC Bill was accepted into the Ballot Box for Private members' proposed legislation in May 2012. We hope it won't be long before it is drawn and goes onto Order Paper ready for debate. February 14 is our next chance. We have a new database and website, brochures and posters. Check out our website for new information as the campaign proceeds. And let us know about articles on assisted dying in local and overseas media. These may have misleading information so it's important for us to clarify those points.

Let's ensure New Zealanders are aware of the Bill's true intent. You currently have the right to stop or withdraw treatment but adequate consultation, absence of coercion, and information about alternatives are not guaranteed. The End-of-Life Choice Bill monitors all of these in a full review process. And remember, it is the individual's decision, not the doctor's, a family member's or anyone else's. You live by your own values. You should be able to die by them too.

*Carole Sweney*, President, EOLC

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Of course we have concerns that need debate to ensure that the legislation is clear enough to prevent misuse and broad enough to cover as many of the harrowing situations that currently have no legal solution. Thirty years ago we were engaging in very similar discussions as we worked to establish Palliative/Hospice Care in NZ.

It is important to note that in societies where legislative change now allows Voluntary Euthanasia, The Netherlands, Belgium, Switzerland, Luxembourg and the States of Oregon, Montana and Washington in the USA, this change has resulted in improved Hospice/ Palliative Care services, and

“The purpose of this Bill is to allow all New Zealand citizens or permanent residents aged 18yrs or over to obtain medical assistance to end their life in certain specified circumstances. The request may be made in person or by means of a registered end of life directive.”

This issue is one that will not go away while the suffering continues and people and /or their friends and families are driven to the desperate measures that frequently make headlines.

2012 Maryan Street's End of Life Choice Bill currently in the Ballot Box.

On a personal level, I like many New Zealanders, prefer to be able to make my own decisions, the way we choose to live and the way we choose to die is intensely personal. I remain committed to good Palliative /Hospice Care and I absolutely do not want to suffer simply because someone else says I must.

Another nurse has joined Glyn Havill (A Nurse's Perspective, in the Dec/Jan newsletter) in supporting the End-of-Life

## Another Nurse Speaks on Behalf of Assisted Dying

Choice Bill with an article in the **Kai Tiaki Nursing New Zealand magazine**.

The experiences of other countries, including the Netherlands, Belgium and Switzerland, do not support fears that the Bill would provide added dangers for nurses and doctors, Jenny Nichols, a cognitive behavioural nurse therapist in Hawke's Bay, wrote.

"Suggesting that legalising aid-in-dying will put both clients and nurses at risk could be regarded as scaremongering," she said.

Jenny said legal opinion suggested a secure legislative framework would increase security and support for patients, their families and health professionals involved in their care.

She said that while many people were able to access hospice/palliative care services that could enable death with dignity, some patients because of the nature of their illness or condition could not be supported to die in that way.

Noting that the majority of deaths in New Zealand did not

occur in hospices, Jenny wrote: "Hospice and palliative care services do not have the capacity to care for all dying patients and it is arrogant to suggest this is the whole answer."

Jenny agreed that decisions about end-of-life care should not be made on the basis of a few high-profile cases, but said there were many sad stories that did not make the headlines.

"There is no evidence to suggest the vulnerable will be exploited, should the Bill become law," she wrote, quoting an article headed "Safe laws on assisted dying are working worldwide" in the British Medical Journal.

"How much more vulnerable can you be when your life is intolerable and you need help to end it?"

"Millions of Americans and Europeans now have a legal right to choose to end their lives in a peaceful, dignified, way, according to their own beliefs and values. Why not us?"

*Read the entire article on our website: [www.ves.org.nz](http://www.ves.org.nz)*

## Facebook Page for Members

We are pleased to announce the launch of a new Facebook group - <http://www.facebook.com/groups/eolcnz/>

Facebook is a networking tool with the power to reach large numbers of people, often in a very short time. Social networking has provided the fuel to launch revolutions in the Middle East and elect an American president. Maybe it can help us bring about law change in New Zealand. The Facebook initiative is designed to attract a demographic of supporters who do not join organisations in the traditional sense. Facebook offers less-structured social networking.

EOLC/VESNZ Members can join the Facebook group and help grow the number of supporters for the EOLC Bill simply by joining and inviting friends to join.

**Support your right to aid-in-dying and other end-of-life issues by contributing to the campaign to pass the End-Of-Life Choice Bill. Your annual subscription pays for your newsletters. There is much to do in this campaign. Literature for distribution to audiences, office expenses, volunteer support, branch outreach and travel all cost money. There will be an expensive media campaign when the bill is drawn, to meet the financial expenditures of those who oppose End-Of-Life Choice. If you support this legislation, please help fund the effort by enclosing a cheque in this envelope, or through a bank transfer into the VES account. You may also pledge a certain amount to be deducted from your count each month, to help insure sustainable and reliable on-going funding for end-of-life issues and rights in the future.**

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## Upcoming Events

**Auckland: 16 Feb**, New Member Recruitment meeting with Yvonne Shaw, 1.30 PM – 3.30 PM, Bucklands Beach Yacht Club, Half Moon Bay.

**18 February** Noel Cheer and Yvonne Shaw discuss assisted dying for Triangle/Face TV.

**22 February** Grey Power Meeting with Maryan Street and Panel, Northcote, 1-3 PM (see announcement below). Open to public.

**25 March** Member's Meeting, details TBA.

**Kapiti-Horowhenua: 22 Feb**, Mahara Gallery, 12-1pm: The gallery is holding a series of forums. The topic is 'Health and Wellbeing' for which EOLC will conduct a brief presentation and distribute materials related to the Bill. **30 April** Fundraising Garage Sale Details in March.

**Waikato: 24th Feb.** Sunday . 2pm. 17 Willowfield Place, St Andrews, Hamilton Phone: 07 849 2266. This will be a combined meeting and potluck barbecue at Don Sandford's house. All interested welcome

**Wellington: 16 March** Public Meeting 2pm at Wellington Library (upstairs). Showing of DVDs of Janet Marsland's speech at the Museum of City and Sea 2012. and Evans Mott's account of his trials and tribulations 2012. Questions and discussion after and then tea.

**Whangarei: 26 March** Yvonne Shaw will address U3A in Whangarei. Meeting starts at 10:00 AM at St John's Church on Kamo Road.

*Additional March meetings in Whangarei and Keri Keri, To Be Announced.*

**South Island: 25 Feb** (Monday) Oregon Experience, 6 PM St John Room 10 Douglas St Frankton. Open to the Public; refreshments provided.

**26th Feb** (Tuesday) Oregon Experience, 5:30 PM, Lindisfarne Community Centre, Invercargill. Open to Public; refreshments provided.

## Mark Your Calendars:

**The 2013 End-Of-Life Choice and Voluntary Euthanasia Society of New Zealand AGM will be a two-day event, held in Wellington in June. Join us for guest speakers, education break-out sessions and strategies for forwarding The Bill. More information soon!**

### Public Meeting Grey Power

The Hon. Maryan Street will discuss the End-Of-Life Choice Bill at a meeting hosted by

### Grey Power North Shore, in Auckland.

AMI Netball Rooms, Northcote Rd. February 22nd 2013 1pm - 3pm,

Also present:

Dr Libby Smales, former President of Hospice NZ, and an eminent Palliative/Hospice care advocate.

Yvonne Shaw, MPA, Media and Political Relations Manager of EOLC (VESNZ, Inc.)

Special Guests: Phillipa Malpas Professor of Medical Ethics at Auckland University and Helen Yensen a long time advocate of assisted dying, who co-wrote a series of articles in the Grey Power magazine.