

Dying *with* Dignity



Tasmania (Inc)

JUNE 2014

GREAT NEWS FROM QUEBEC, CANADA - On 5 June, a Bill allowing voluntary assisted dying passed 94 votes to 22. For more details see section following AGM details.

MEMBERSHIP: Our financial year ended on 31 May. Your membership is due only if you have received a renewal form with your hard copy or email. We would greatly appreciate your renewal as we continue to work for law reform and better information and services for choices at end-of-life.

ALSO IN THIS ISSUE:

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- **QUEBEC LEGISLATION A GREAT STEP FORWARD**
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**ANNUAL GENERAL MEETING AND GUEST SPEAKER
- 22 JULY 2014 at 1.30 pm**

The AGM will be held on Tuesday 22 July, commencing at 1.30 pm, followed at approximately 2.00 pm by a public address by Associate Professor Jane Tolman. We look forward to seeing as many of you as possible and hope you will invite others to come along. As always, while only members can vote (if necessary) and participate in the AGM, we welcome others to hear what we expect to be a very interesting and informative guest speaker. There will also be afternoon tea following the public address.

We will also advertise the event in a number of ways. If you can put up a flyer with details of the event, please contact us.

The venue is the same as last year, the Nell Pascoe Room, Criterion Centre. This is next to Mathers House, formerly called the 50 and Better Centre, between Criterion St and Bathurst St, Hobart. There is some parking, including disabled parking, off Bathurst St, just past the State Library. There is also good parking opposite in the Melville St car park, with the first 1 ½ hours free.

AGM

Purpose and Agenda

In accordance with the Constitution, the purpose of the AGM is to consider particular general business. The Agenda for the 2014 AGM is as follows:

- 1) Apologies
- 2) Confirmation of minutes of the last AGM, 23 August 2013
- 3) Annual reports
- 4) Election of committee members and Office Bearers
- 5) Appointment of Auditor.

Please consider nominating for the Committee (See form at end of newsletter). We would greatly welcome your involvement if you would like to take a more active part in DwDTas activities.

Nominations close on 11 July. If you'd like more information, to talk about what's involved or ensure your nomination is proposed and seconded by other members, please ring us.

GUEST SPEAKER - Associate Professor Dr Jane Tolman

Dr Tolman regards this as the century of neurodegeneration and that is mostly about dementia. She will put the case that it's not more hospital beds we need to improve our health system, but a new approach to the management of end of life care for people who are elderly or with dementia. She also argues that a modern approach to care of elderly people will simultaneously improve the quality and economics of our health system, and will also provide much better care for frail elders.

She will talk about her approach which is that the best care will be a palliative approach from the time of diagnosis of dementia. She will outline her new staging system which makes dementia intelligible and provides a road map for carers and families to navigate the rocky journey.

About our guest speaker - Dr Jane Tolman is a geriatrician based in Tasmania. She has a special interest in person centred care, especially with reference to dementia and its impact on families and carers. She is Associate Professor of Aged Care at the Wicking Dementia Research and Education Centre at the University of Tasmania where she is involved in both education and research, and has been heavily involved in their Dementia MOOC- Massive Online Open Course which has provided education to 15,000 people from around the world. She has previously worked as a school teacher and counsellor. She regards her biggest professional achievement in recent times as the development of a new staging system for dementia, and it has gained widespread traction among carers, families and health professionals, for its emphasis on dignity and the importance of palliation.

GREAT NEWS FROM QUEBEC

On 5 June, the Quebec Parliament voted overwhelmingly in favour of a Bill that will allow voluntary assisted dying very similar to what was proposed in the 2013 Tasmanian *Voluntary Assisted Dying Bill*. There were 94 votes for the Bill, coming from all Parties, and 22 against.

This is a great step forward for voluntary assisted dying law reform in Canada and elsewhere. Quebec has become the first Canadian province with such legislation.

Support by Premier and the vast majority of Liberal Party MPs - The Liberal Premier, Pierre Couillard, a doctor, was a supporter of the legislation. He allowed a 'conscience vote' and all 22 of those who voted against the Bill were from his Party. However, they were less than 1/3 of Liberal Party MPs (compared to 100% of the Tasmanian Liberal Party MPs who voted against the 2013 Bill here).

One is reported to have voted against it because "Life must be glorified, which Bill 52 does not do, according to me and to the people of my riding." [President's note: How 'life' is 'glorified' by forcing people against their wishes to endure prolonged, intolerable end of life suffering is totally beyond me!]

Support by Quebec Medical Association - The Quebec Medical Association has spoken in support of the passing of the Bill. The President, Dr. Laurent Marcoux, is reported as saying: "The QMA applauds all the provisions intended to increase the quality of and access to palliative care. ... All citizens have the right to end-of-life care,

including palliative care. Henceforth, patients will be able to decide on the conditions of their end-of-life care if they meet the criteria. As for physicians, they will be able to accompany their patients the entire time. This bill will transform the role of physicians because they will be able to openly discuss palliative care, anticipated medical directives and medically assisted death with their patients, families and health care teams. Furthermore, we are pleased that this legislative framework allows physicians to avail themselves of their right to conscientious objection." (<http://www.newswire.ca/en/story/1368481/the-quebec-medical-association-welcomes-the-adoption-of-bill-52>)

The Canadian Medical Association, like the Australian Medical Association (AMA), remains opposed to voluntary assisted dying but has at least engaged in a nationwide consultation about end-of-life issues and will reveal the results very soon.

Based on extensive inquiry and report - The Bill followed an extensive Parliamentary Committee inquiry and a lengthy report that recommended the legislation. (That report was fully considered as part of the research for the consultation paper, "Voluntary Assisted Dying: Proposal for Tasmania" issued in February 2103 by Lara Giddings and Nick McKim.)

This process contributed to the huge level of cross-Party support and resistance to the usual false and misleading fear-mongering claims, particularly by religion-based groups. (Key opponents included the Euthanasia Prevention Coalition (CEO - Alex Schadenberg) which was active in the campaign in Tasmania both directly and

indirectly through its strong links with Real Dignity Tasmania, the Australian Christian Lobby and Family Values Australia (formerly Festival of Light)).

Broad coverage of end of life care - The Bill was called, “An Act respecting end-of-life care”, and also covered other end of life care issues including palliative care, terminal sedation, advance medical directives, etc. As the Explanatory Notes state: *“The purpose of this bill is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy and to recognize the primacy of wishes expressed freely and clearly with respect to end-of-life care.”*

The Bill defines ‘end-of-life care’ as “palliative care provided to persons at the end of their lives, including terminal palliative sedation, and medical aid in dying”.

To receive ‘medical aid-in-dying’ (what we call ‘voluntary assisted dying’), a person must be adult, “at the end of life” (not defined), capable of giving consent to care and be suffering from:

- an incurable serious illness,
- an advanced state of irreversible decline in capability and from constant; and
- unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable.

Opposition response - Response to the vote has been predictably rabid by those opposed to it, with descriptions of the law as allowing “homicide” and “euthanasia on demand”. Legal challenges are being proposed by them.

DR RODNEY SYME’S GREAT COURAGE

In an act of great courage, Dr Rodney Syme has publically admitted giving the lethal drug Nembutal to Steve Guest in 2005 two weeks before he killed himself with it. Steve Guest was dying from oesophageal cancer, was suffering intolerable physical and psychological pain and needed control over the end of his life.

This admission puts Rodney at risk of prosecution and gaol for assisting a suicide but he has taken this step to try to get a legal precedent to assist doctors who are too scared to help terminally ill people end their own lives.

We congratulate and thank Rodney for his courage and his long commitment and work for law reform. We really hope it leads to the success of the long campaign for legislation in Victoria, in keeping with the wishes of the vast majority of the population.

Rodney’s admission has led to a significant amount of publicity and debate in Victoria in particular. For links to many media items go to <http://www.dwdnsw.org.au>. In a very positive new development, an editorial in the Fairfax press supported the proposal to refer the matter to the Victorian Law Reform Commission “to reach sensible legal proposals that can then be adopted by Parliament. It should not take a trial of a respected medical specialist to prompt this obvious progression. History has enough martyrs.”

(<http://www.smh.com.au/comment/the-age-editorial/samesex-marriage-and-euthanasia-should-not-produce-martyrs-20140508-37ybh.html#ixzz31BafPbnz>)

Others also came out in support of voluntary assisted dying legislation. This included Peter Short, also suffering from oesophageal cancer, whose moving story and video can be found at <http://www.theage.com.au/national/-39r5u.html>. He has also set up a blog at <http://pgs28.wordpress.com> to document his experience and encourage discussion.

STATE ELECTION

The State election held on Saturday 15 March resulted in the election of a majority Liberal Government with 15 seats, Labor reduced from 10 to 7 seats and the Greens from 5 to 3 seats. This has made the task of getting voluntary assisted dying legislation passed much harder during this term of Parliament but not impossible. Eight of the MPs who voted for the 2013 Voluntary Assisted Dying Bill retained their seats. This means that 5 votes are needed from Liberal MPs.

We were pleased to have had a good response from our survey of the views of candidates in the election. Regrettably, none of the Liberal candidates in favour of voluntary assisted dying law reform was elected. However there were several elected whose views are not known.

In a recent conversation with Nick McKim, he indicated his and Lara Giddings' continuing support for another Bill but not for a while. We aim to discuss the matter and work with them towards another Bill.

PALLIATIVE CARE

Whittle Ward - Some of you will have followed with great concern the proposal to shift the Hobart hospice service, known as

the Whittle Ward. This would have been away from its current purpose-built facility and then back again in several years time. The move was to allow another group of patients from the Royal to move in during the re-development of the RHH.

The move was announced without any consultation with key groups such as TAHPC (Tasmanian Association of Hospice and Palliative Care) which strongly opposed it. The result of the public outcry was a decision to leave the Ward where it is.

DwDTas entered the debate by writing to the Minister for Health expressing our concern for a number of reasons, and, as a result of a call from a *Mercury* journalist, making a comment that a public announcement needed to be made to confirm what staff had been told.

New Developments - Hospice@Home and other newly funded palliative care - In

April, a new \$35 million palliative care program commenced to allow more Tasmanians to die in their homes. The new Hospice@Home program is funded by the Federal Government from the Tasmanian Health Assistance Package for the next three years.

It will be delivered by The District Nurses through 2000 community-based packages of palliative care from new offices in Launceston and Burnie and the Hobart office bolstered by more staff. It has been described as the first program of its type to deliver comprehensive around-the-clock home-based palliative care across a state, and to offer more control and choice of treatment for people with life-limiting illness or who are nearing the end of their lives.

Packages include face-to-face visits and telephone advice/support which is - accessible 24/7. District Nurses chief executive Kim Macgowan has been reported as saying more families would now be supported at home with their loved ones at life's end.

The Tasmanian Association for Hospice and Palliative Care (TAHPC) has received \$2.66 million of the money to help establish education and support for palliative care workers and volunteers as well as focus on the implementation of palliative care in regional, rural and remote parts of the state. It has launched the new project, "Networking End of Life Care across Tasmania: Integration, Innovation and Inclusion"; It has opened offices in Launceston, Devonport and Hobart and employed Project Officers to establish Regional Community Working Groups which will represent the interests of local palliative care communities.

The Department of Health and Human Services will also get \$11 million in Commonwealth funding to support existing palliative care teams.

This is a very welcome boost to palliative care services, particularly in rural parts of Tasmania. We hope it will be very successful. However, the future of the program after the 3 years is uncertain given the announcement in the Federal Budget to cut funding to the States for health and education after 2017.

State Liberal election commitment - In another welcome move, Michael Ferguson on behalf of the Liberals committed

\$100,000 to a feasibility study into a stand-alone 10-bed hospice for Launceston.

This resulted from the hard work of the dedicated members of the Friends of Northern Hospice. The North of the State has been significantly worse off for hospice beds than the South that has had the Whittle Ward. Since the closure of the Philip Oakden House hospice, hospice beds have been at the St Vincent's Campus of Calvary Healthcare.

The eHospice website reports on a packed meeting of 200 people in Launceston in January at which the commitment was originally made. The meeting had heard from Dr Ian Mavor, Executive Director of Hopewell Hospice in the Gold Coast, who gave a very inspiring address emphasising the need for a hospice over an acute hospital for end of life care. The article also reports Mr Ferguson's commitment to update the 2004 Palliative Care Report and look at current unmet and future demand for palliative care .

<http://www.ehospice.com/australia/Default/tabid/10688/ArticleId/8494>)

The commitment is repeated at <http://michaelferguson.com/2014/02/liberals-plan-to-rebuild-essential-services-over-27-million-on-restoring-health-services-in-northern-tasmania/>.

We look forward to hearing of progress on the study and to the eventual creation of a 10-bed hospice. Programs as welcome as Hospice@Home cannot satisfy all needs of dying people and their families and carers.

PRESIDENT'S REPORT

The last 6 months have been a quieter time after the very hectic last year. The major activity was the survey and report on the views of candidates in the State election.

The formation of a NW group appears unlikely at present but if you are interested please let us know.

It is with great sadness we noted the death of our oldest and long term member, Eve Masterman.

The sad death also occurred in May of Alastair Henderson, DwDQ President and Treasurer of YourLastRight.com. Alastair, and his wife, June, have worked for the cause for many years. He will be greatly missed.

OTHER NEWS FROM AUSTRALIA AND OVERSEAS

AUSTRALIA:

- Every week there are numerous items in the media throughout the country related to voluntary assisted dying. The issue is well and truly alive even if we get none of that coverage in Tasmania.

If you're interested, Dying with Dignity Victoria regularly summarises this news and you can access other news at <http://www.dwdv.org.au>.

DwDNSW also provides up to date news on its website.

- Recently, police have raided premises in a number of States searching for the imported prohibited drug Nembutal. Some charges have resulted from the raids.

CANADA:

Other Canadian news includes:

- The Supreme Court of Canada is taking another look at whether Criminal Code provisions against assisted dying violate the rights of the gravely ill. It is expected to rule later this year. The B.C. Civil Liberties Association brought that case after the federal government successfully appealed a lower court ruling in the Carter case.
- At the Federal level, a Conservative MP, Steven Fletcher, has introduced two private members bills that, together, would allow doctors to help people die in a restricted set of circumstances.

USA:

- In March New Hampshire voted against a Bill similar to the Oregon Bill.
- In April, the Connecticut Senate passed a Bill allowing terminally ill people to declare their wishes for end-of-life care, but the Aid-in-Dying Bill did not get through the public health committee for the second year in a row, despite the fact that it is supported by a majority of the population.

UK

- Actor, Sir Patrick Stewart has publically expressed support for dying with dignity legislation. Sir Patrick Stewart has been reported as saying, "My friend's shocking suicide convinced me I want the chance to kill myself with dignity". For more details - <http://www.dailymail.co.uk/news/article-2638340/My-friends-shocking-suicide-convinced-I-want-chance-kill-dignity-An-electrifying-deeply-personal-intervention-assisted-suicide-debate-one-theatrical-knights.html> .

COMMITTEE FOR 2013 - 2014

Margaret Sing (President)
Helen Brookfield (Treasurer)
Mike Harris
Hilde Nilsson
Noel Woodrow
Dr Helen Cutts

Bill Godfrey (Vice President)
Keith Anderson (Secretary)
Trish Kershaw
Barbara Porter
Allan Cameron AM
Frank Webb (co-opted Dec 13)

Patron: Professor Colin Wendell-Smith AO

Next meeting: After the AGM on 22 July meeting, dates will be set by the Committee. It is expected they will continue to be held on the second Wed in the month, at 2pm at the Glenorchy Library but may not be held every month.

Please detach - - - - -

Dying with Dignity Tasmania Inc - Proposal Form for Positions 2014 – 2015

Name of nominated member:

Signed:**Signature of nominee**

For the position of:
(President/Vice President/Secretary/Treasurer/General Committee)

Name of Proposer member:

Signed:

Name of Seconder member:

Signed:

Date:/...../ 2014

Please mail this form to: DwDTas, PO Box 1022, Sandy Bay Tasmania 7006, by 11 July 2014.