



Dying *with* Dignity

Tasmania (Inc)

NEWSLETTER – FEBRUARY 2013

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CONSULTATION ON VOLUNTARY ASSISTED DYING PROPOSAL FOR TASMANIA - Please make your support known by 15 March

The big news is that the consultation process that is now underway on a detailed proposal for voluntary assisted dying legislation for Tasmania. **We cannot stress too strongly the importance of expressing your support and getting as many others as possible to do so.** We know from opinion poll after opinion poll that the vast majority of Tasmanians support a legal option of voluntary assisted dying in some circumstances, and we need to get that support made clear in the consultation process.

Included with this newsletter is a brief summary of the proposal and copies of a response form that enables you and others to act quickly and easily to express your support. We strongly recommend that you support the proposal as a very good approach based on principles of compassion and respect, thorough research and sound arguments. There are some additional issues that people have been asked to comment on as part of the consultation, including ones that we know many of our members feel strongly about. This includes the issue of whether voluntary assisted dying should be legally available to people who have unbearable and unrelievable suffering and their medical condition is incurable but they are not regarded as 'terminally ill'. It also includes the issue of whether you should be able to access voluntary assisted dying through an advance care directive. (See more details in this newsletter.) We have also included in the form these and other DwDTas issues and recommendations.

We depend on you to spread the word and get others who support legislation for a voluntary choice of assisted dying to express that support during the consultation process. If you need additional copies of the summary and response for family, friends or to distribute to any groups you are involved in, contact us by phone, 0450 545 167 or through the website, www.dwdtas.org.au . We also now have a Facebook page.

The Premier, Lara Giddings, and the Leader of the Greens, Nick McKim, announced their proposal for voluntary assisted dying legislation on 3 February and issued both a long discussion paper and a shorter companion paper. The papers set out the details of what they intend to include in the Bill including safeguards and requirements that would need to be met by the person making the request for voluntary assisted dying and by the doctors, the procedures that would need to be followed and the reporting and monitoring arrangements.

We strongly recommend that, if you have time, you read one of the consultation papers and make an individual submission. The long paper is very detailed paper (over 100 pages) and the short companion paper that includes the main details and information (36 pages). The papers include more details of the proposed law, along with a large amount of quality research information and well-reasoned supporting arguments. Copies of the paper/s can be obtained by phone, 62333464, email, premier@dpac.tas.gov.au, or downloading from www.premier.tas.gov.au or <http://mps.tas.greens.org.au>. If you have views about the extent of the proposal or about particular details, it is best if you look at the papers before responding through an individual submission.

After the consultation process, a new Bill will be drafted and Lara Giddings and Nick McKim will jointly move it a Private Members Bill in the Tasmanian Parliament before the end of 2013.

KEY POINTS

The proposal is based on very good evidence on, both the overseas situations where voluntary assisted dying legislation has now been in place for many years, and on the situation here that shows very clearly the need for the legislation. This is a very important point – the need for an evidence based approach, as well as one that is compassionate, respects people’s right to make choices about their lives in accordance with their own beliefs and values and is consistent with the views of the vast majority of the community.

In the media release that DwDTas put out at the time of the launch, the President, Margaret Sing, commended the Premier and Nick McKim on the consultation paper because of its valuable contribution to a **well-informed, rational debate** on the issue of voluntary assisted dying law reform. “As for all legislation, parliamentarians need to base their decisions on sound evidence and carefully reasoned arguments, as well as on community views,” Ms Sing said. “We know how strongly people feel on this issue on both sides of the debate. Those views need to be heard but feelings and convictions alone are not a good basis for important decisions on law reform. Nor can good decisions be made on the basis of ill-informed speculation and unfounded fears.”

Ms Sing said that it was now very clear from extensive evidence that the public and parliamentarians can be confident that voluntary assisted dying legislation is needed, that it is safe and, in fact, safer and more responsible than allowing very unsatisfactory aspects of the current situation to continue.

“When the legislation comes up for debate in Tasmania later this year, it will be the first time that parliamentarians will have such a high level of assurance that assisted dying legislation is not a threat to vulnerable people in our community and that risks can be overcome with careful safeguards,” she said. “They can be confident that it is responsible to vote for the legislation, and also to act with compassion, ensure the law keeps up with community changes and act in a way which is consistent with the views of the vast majority of the community.”

She said that there was evidence that people are dying with prolonged suffering that cannot be relieved adequately. “This is terrible for them and everyone close to them and the effects can last years,” she said. There is also evidence that assisted dying is occurring but without the safeguards and scrutiny that legislation provides.

Even since the last debate in the Tasmanian parliament in 2009 on the *Dying with Dignity Bill*, there has been an enormous growth of information from respected and reliable reviews that consistently supported assisted dying legislation after thorough examination of evidence and arguments for and against.

“Too much of the argument against assisted dying legislation is based on out of date, poor quality and incomplete, piecemeal information that cannot be relied on for a responsible debate on our law. There’s no excuse for ill-informed speculation that ignores reputable evidence to the contrary from years of experience with assisted dying legislation,” she said.

“We respect the right of everyone to their beliefs and values and to express their views on this important issue,” Ms Sing said. “But with the right to express our views, there’s a responsibility to check claims so we don’t mislead parliamentarians.” She also said that there was a particular responsibility for community leaders and those in positions of trust in our community who have the resources to check information to ensure it is dependable.

KEY ISSUES

There are a few key issues for the consultation that are highlighted in the summary and response form. We recommend you consider these ones in particular whether you are responding using the form or you are making an individual written submission to the consultation.

1. Person’s medical condition

One of the most important issues involves the requirements being proposed about the medication condition of the person eligible for voluntary assisted dying. The proposal is that to be eligible the person would need to be “terminally ill” which is defined as: (a) the advanced stages of an incurable and progressive medical condition due to disease or injury, that can be **reasonably expected to cause the death of that patient without significant medical intervention**, and (b) The person should have to come to the conclusion, together with two doctors, that there is no reasonable alternative to improve their condition and to relieve their suffering adequately, to the person’s satisfaction.

The definition supports the aim of providing for a ‘last resort option’ when there are no other reasonable options left that are acceptable to the patient. We do not believe it is necessary to add an extra eligibility criteria that the person must have unbearable or unrelievable suffering, because it is implied in part (b) of the definition.

We believe, and we know that many of you do too, that there should also be a ‘last resort option’ for those people who have unbearable and unrelievable suffering and who have incurable medical conditions but those conditions are not expected to cause their death. We therefore recommend that you support the extension of eligibility to people with non-terminal yet progressive illnesses who have unbearable and unrelievable suffering.

‘Advanced stages’ means as determined in line with accepted medical practice, guidelines or protocols. The paper also says: “We believe that this will include the situation where the patient’s

condition has advanced to the stage where the medical treatment reasonably available to the person is unacceptable to him/her or is confined to palliation to provide relief from pain and other distressing symptoms.” The person’s condition may include just one illness or, as in many situations, multiple ones or what can be called “multiple pathology”.

2. Advance directive

The proposal in the paper/s is that a person will not be able to access assisted dying through an advance care directive. The consultation paper argues that it is a major safeguard in the proposed legislation that the person remains competent and is able to confirm their request is voluntary and persistent right up to the time immediately before either self-administration or doctor-administration of the medication.

We know that many people are concerned about getting dementia and other similar diseases that will mean they are no longer regarded as mentally competent to request assisted dying. On the other hand, there is nowhere in the world where legislation provides for access to assisted dying through an advance care directive in the same way as through a request by someone who is competent at the time.

Lara Giddings and Nick McKim have indicated that they are aware of concerns, are sympathetic and have reached their conclusion only after considerable thought: “We recognise that dementia is a devastating and challenging illness, both for the patient and their family and carers. We also recognise that for those people who have watched family members suffer with dementia, or are in the early stages of the disease, the thought of being able to access an assisted death through an advance directive could provide a sense of security and peace of mind. However, we do not have the level of evidence about how to ensure sufficient safeguards, nor do we believe that there has been wide community consideration of, or support for, this option.” (Long paper, page 36)

We believe that, given the latter comment, it is important that you express your views on this matter if it is of concern to you. It is also important that, if possible, you suggest a process that could be followed and that would have adequate safeguards for a request made through an advance care directive to be regarded as acceptable even if the person concerned has lost competence.

3. Waiting periods

We are concerned that the proposed waiting periods may be too long in some circumstances, for example, if a person’s condition has deteriorated quickly and their suffering has suddenly increased to become unbearable. It is proposed that there must be 48 hours between the initial oral request and the written request, and “once both doctors have certified that the patient is eligible for assistance and have signed the doctors’ declaration form a 14 day ‘cooling off’ period commences.”

We therefore recommend that you support the inclusion in the legislation of provisions for shorter waiting periods in exceptional circumstances. Please include in your response the details of actual situations where 14 days would have been too long a waiting period.

INFORMATION SESSIONS AND ASSISTANCE TO RESPOND TO THE CONSULTATION

We will be doing our best to have information sessions around the State about the proposal and to help people respond. *If you can help us organise one in your area, please contact us as a*

matter of urgency, even if it would be after 15 March. We will advertise them publicly and contact members directly about the session in their region to invite you and your friends and to ask you to spread the word. More information will be added to the website and we will do our best to respond quickly to phone calls or emails asking for information and advice.

A session has been organised in Hobart on Saturday 2 March, from 1.30 – 3.30 pm at the Glenorchy Library. Margaret Sing and Hilde Nilsson will speak at a public meeting in Scottsdale on Tuesday 26 February at 7.30 pm at the Scottsdale RSL Club, George Street and on Wednesday 27th at the Scottsdale Probus Club.

Our promotion of the consultation at Salamanca Market on 9 February received an overwhelmingly positive response, from locals and visitors alike. We distributed nearly 200 copies of an earlier version of the summary and response form. Unfortunately we have been unable to get a space for another one before 15 March but will aim to organise another opportunity soon. It would be great if you could spare an hour or two to help us. We promise you it is an uplifting experience!

CAN YOU HELP?

1. The importance of real-life situations and experiences

Real-life situations and experiences can demonstrate more effectively than anything else why voluntary assisted dying legislation is necessary and so important. If you are prepared to tell us your story for inclusion on the website or in an interview with a journalist, we would very much like to hear from you. It could be done anonymously if you do not want your name to be used.

What is being proposed for the legislation also needs to be assessed in terms of actual situations and experiences as a way of checking that it is workable. Please consider making your situation or experience known in your response to the consultation.

2. Donations:

If you could provide a donation to help our continuing campaign, it would be much appreciated. Every little bit will help it to be as effective as possible. You can now donate through the website using Paypal, as well as by more traditional methods.

We have had advice on an exciting media campaign and we will be seeking donations from as many sources as possible to make that happen. It will be extremely important for us to remain very active after the consultation process to keep the issue in the public eye in readiness for the debate in Parliament later in the year. We need people to continue to tell members of Parliament they support this kind of legislation.

ENDURING GUARDIANSHIPS – NEW FEES

We were very concerned by an announcement in the Public Notices of 26 January that new fees had been introduced in relation to Enduring Guardianships, including \$64.80 to register one and \$46.00 to revoke one. The Public Notice advised that an amnesty on all fees had been granted but only until 1 March 2013. After that date, fees may be waived in cases of “hardship”.

This was the first we were aware of the new fees. We have written to the Minister for Justice, Brian Wightman, asking him as a matter of urgency to reconsider this matter and, at the very least,

extend the amnesty period beyond 1 March. We are very concerned and disappointed that there was no consultation with DwDTas nor any mention of the intention to introduce the fees. We believe they will act as a very significant barrier to increasing the registration of Enduring Guardianships and to people keeping them updated regularly. They will also put a brake on the recent momentum when they have been promoted as part of effective advance care planning and through DwDTas and other workshops and information sessions.

While we hope he will respond positively and at least extend the amnesty, we recommend that you act quickly before 1 March if you can if you are considering registering or changing your Enduring Guardianship.

BRIEF NEWS FROM AROUND AUSTRALIA AND OVERSEAS

AUSTRALIA: There continues to be a great deal of activity by DwDNSW in the lead-up to a Bill in the NSW Parliament later this year. There are two Bills on the table in SA. The WA Opposition Leader Mark McGowan has said he would consider introducing euthanasia legislation into the Lower House this year if no other politician was prepared to do so.

OVERSEAS: The Quebec government is proceeding with medical aid-in-dying legislation; legislation similar to that in Oregon has been moved or is being reviews in other US States - Connecticut, Hawaii, Kansas, Massachusetts, Montana, New Hampshire, New Jersey and Vermont; and France's medical ethics council has said that euthanasia should be allowed in exceptional cases.

FORTHCOMING EVENTS

DwDTas Committee Meetings: These are usually held at the Glenorchy Library, on the second **WEDNESDAY** of each month, starting at 2.00pm. The next scheduled meeting will be Wednesday 8 March. Members are very welcome to attend and to contribute to the discussion but, as these details may change depending on the availability of committee members, please check with us beforehand.

Information session for the consultation on the proposal for voluntary assisted dying legislation: Hobart – 2 March, 1.30 – 3.30, Glenorchy Library. Please spread the word.

Dying with Dignity Tasmania Inc

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Supporting Your Right To Choose

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