17th July 2017

The Hon. Trevor Khan MLC
Deputy President and Chair of Committees
Member, NSW Parliamentary Working Group on Assisted Dying

Via email: voluntaryassisteddying@parliament.nsw.gov.au

Dear Mr Khan,

Re: Cancer Council NSW Submission on the Voluntary Assisted Dying Bill 2017 (NSW)

Cancer Council NSW is an independent charity with over 60 years' experience in reducing the burden of cancer on the community. Our work includes funding and conducting research; preventing cancer; providing information and support for people and families affected by cancer; and advocacy to ensure governments take action on cancer.

Latest published data show that 42,079 new cases of cancer were diagnosed in NSW in 2012, and 14,099 people died from cancer[i]. This represents a significant impact on families, carers and communities across NSW and a challenge in terms of how governments, health services and organisations best deal with suffering and distress caused by terminal cancer.

Our position

1. **Cancer Council NSW does not support, nor do we oppose, assisted dying**

Assisted dying is a complex topic and one which understandably evokes very strong feelings, of both support and opposition, among members of the community. We respect the rights of individuals to take a position on this very complex issue, however as an organisation which supports all people and all cancers, Cancer Council NSW takes a neutral stance. While maintaining neutrality, we are cognisant that if assisted dying is legalised in New South Wales this will impact on cancer patients and families. In jurisdictions that have legislated for assisted dying in some form, cancer patients comprised the largest group of patients to access some form of assisted dying[ii],[iii]. Cancer Council makes a submission on this draft NSW Bill to ensure that should it be passed by Parliament, the resulting legislation in this area is compassionate, feasible and contains appropriate safeguards.

2. **Any change to the law regarding assisted dying must not compromise resourcing for palliative care, indeed it would amplify the need to ensure access to appropriate palliative care for all communities**

The practice of palliative care does not include assisted dying or euthanasia; the two are distinct. Adequate provision of specialist palliative and non-specialist care is critical and organisations and governments must ensure that programs and investment continue in line with growing community need. Furthermore, we note that in this Bill, and Clause 15 specifically, the medical practitioner would be required to provide the patient with information on all care options. In relation to palliative care, for this to be feasible, additional training and

development of the NSW medical workforce must be considered. A situation where assisted dying is accessed as an option due to an absence of available palliative care, or knowledge and an understanding of available palliative care and its potential benefits, would be unacceptable.

3. There are a range of areas requiring greater clarity or consideration in relation to assisted dying

In Cancer Council's view, there are a range of aspects of this Bill where the rationale for the provisions could be clearer. We've also identified a range of important issues, some covered in the Bill and some that seem to be absent, that are relevant to assisted dying and where further consideration appears to be required.

3.1. Aspects requiring clarification as the Bill is redrafted and discussed further:

3.1.1 Nominated person: Clause 7 allows for administration of the lethal medication by a nominated person, who does not need to be a medical practitioner. As far as we are aware, NSW is the only Australian state to be considering this approach. Proposals in other Australian jurisdictions that are currently considering assisted dying in some form, allow for self-administration, or administration by a health professional only. We see a great range of possible risks and problems with a "nominated person" approach and while we outline some of those here, there are likely many more. We firmly believe that greater exploration of this proposal and its risks is warranted.

If administration by a nominated lay (non-medical) person approach is to be adopted, guidelines about and for nominees will need to be developed. For example, should a nominee be required to have a close relationship with the patient? Should beneficiaries under the patient/principal's will be prohibited from acting as a nominee? Should there be competency or other eligibility requirements? What support will be provided for nominees, for example around drug administration actions post death of the patient or in the event that the medication fails or is incorrectly administered? Further exploration of this proposal, and clarity of the rationale for the nominee approach is required.

3.1.2 Age limit: The rationale for the minimum age requirement of 25, for accessing assisted dying, is unclear. The age limit is inconsistent with existing legal frameworks in NSW, and the age requirement of a "nominee" to administer assisted dying under the draft Bill. Eighteen is the age limit in NSW for drinking, marriage, voting, buying cigarettes and gaining a passport without parental consent. At age 16 people in NSW can consent to their own medical treatment without the consent of a guardian or parent. The age limit of 25 is also inconsistent with the proposals made in a range of other Australian jurisdictions that have recently, or are, considering assisted dying in some form. Furthermore, that Clause 7 allows for the person accessing assisted dying to have the lethal drug administered by a nominee who need only be 18 seems unusual. Consistency in age of those who are eligible to access assisted dying, and those who can legally administer a lethal drug to those accessing assisted dying, would be prudent. While we are not

necessarily calling for a lowering of the age limit, we believe the inconsistencies we've noted need to be explored, and, at least, the rationale clarified.

3.2. Relevant issues, contained within the Bill, or absent, where more consideration is needed:

3.2.1 Mandatory assessment by qualified psychiatrist or psychologist: Clause 16 outlines that once a patient is examined by the primary medical practitioner and secondary medical practitioner, the patient must also be examined by an independent qualified psychiatrist or psychologist, who must assess whether the patient is of sound mind; that the decision-making capacity of the patient is not adversely affected by his or her state of mind, and the patient's decision to request assistance to die has been made freely, voluntarily and after due consideration. We assume that the intention of this is to act as an additional safeguard, which it may do. Whether all eligible patients would have access to an independent psychiatrist or psychologist also needs to be considered. For example, for those who may be eligible for assisted dying and living in regional and rural areas it's important that this requirement doesn't become an additional barrier they face due only to their postcode. We also note that under the common law there is presumption of capacity. For example, should a patient refuse treatment, they are not required to be assessed for decision making capacity. We would recommend greater consideration of this requirement, and whether this may in fact be a step better implemented at the discretion of the primary or secondary medical practitioner (as has been proposed in other jurisdictions), who could refer a patient on for psychiatric review if they think decision making capacity is compromised by a mental illness.

3.2.2 Authorised substances: Clause 10 outlines that the regulations will determine what is an "authorised substance", and therefore able to be lawfully used to end the patient's life. Clause 25(5) outlines that unused substances will be governed by existing controlled substances regulation. It may be appropriate that detailed, technical matters, or those likely to deal with changing conditions, be dealt with via regulation rather than legislation. However there are a range of issues in relation to authorised substances that we believe need to be actively considered at this stage as this Bill is developed further; and which need to be considered in the context of the specific substance/s that will be used should an assisted dying scheme be implemented. Issues for consideration include safeguards (at all stages of the process), access and prescribing, and guidelines for use. Consideration of these issues is important in determining whether any scheme resulting from this Bill is likely to be considered feasible/workable, compassionate and accessible, yet with the appropriate level of safeguards. It may be that such issues have already been considered. If so, clarity of the scope and status of discussions is required.

Access to authorised substances

With a view to ensuring access for all eligible patients, consideration should be given to what substances may be authorised, and the cost of such substances. Furthermore, consideration should be given to how authorised substances will be accessed by the patient. For example, would authorised substances be available in all pharmacies or only selected pharmacies? If the latter, have

possible implications on eligible regional and rural patients been considered? Furthermore, would only the patient be able to fill a script for such a substance, or could a nominee or the medical practitioner do so? Depending on the answer to this question, further thought may need to be given to how to ensure access, manage relevant risks and develop appropriate safeguards.

Guidelines and support for practitioners and nominees

In the recently proposed Tasmanian Voluntary Assisted Dying Bill 2016[iv], the role of the medical practitioner in prescription, delivery and handling of unused substances is detailed, including how the substance can be administered. While we do not necessarily suggest this need be the case in the proposed NSW Bill, these are areas which we believe should be considered as the Bill is drafted. Furthermore, if a nominee is able to administer the authorised substance as currently proposed, guidelines on the substance and its use will be needed, including what to do after a patient has died.

3.2.3 Insurance

From our reading of the Bill, it seems as though Clause 26, relating to contracts and wills, also applies to insurance. We note that the Tasmanian Assisted Dying Bill 2016 contains a clause on wills and contracts and a separate clause relating to insurance. Whether through two relevant clauses or one, we believe that any will, contract or insurance shouldn't be adversely affected by a patient making or fulfilling a request for assisted dying, or rescinding a request for assisted dying.

Clarity on how this Bill deals with issues related to insurance would be useful.

3.2.4 Monitoring and evaluation

Clause 28 outlines that deaths from assisted dying would be reportable deaths, and Schedule 2 outlines that deaths be reported to the Minister annually. Furthermore, Clause 33 outlines that the Minister must review the Act as soon as possible after the period of 5 years from commencement of the Act. However, there is little detail in the Bill as to how the operation of Act would be monitored and evaluated. This is inconsistent with the approach in a range of Australian jurisdictions that have recently considered, or are currently considering, an assisted dying scheme of some form. The Victorian Assisted Dying discussion paper[v] recommends the establishment of an Assisted Dying Review Board to report on the operations of an assisted dying scheme, among other aspects. The Tasmanian Voluntary Assisted Dying Bill 2016[vi] provided for a Registrar appointed by the Minister, and other officers if needed, who would have a range of possible roles including reporting on operations and administration of the Act. The South Australian Death with Dignity 2016 Bill[vii] outlined that the Minister would report on the operations of the Act annually. Cancer Council NSW recommends that more consideration be given to how the operations of a NSW assisted dying scheme would be best monitored and evaluated, and with what frequency.

3.2.5 Preparing for implementation

If this Bill is passed, a large amount of work will be needed between the passage of legislation and the implementation of the assisted dying scheme to ensure that community, health practitioners and health services are prepared.

This will include regulations, carefully tested information for patients and families, clinical guidelines or other forms of professional guidance and support or training, clarification of how the scheme will be financed, and how the scheme will be monitored and evaluated. Some specific issues have already been foreshadowed within this submission. We question whether the intended commencement 6 months post assent provides enough time for this complex work to take place, and recommend that the timeframe be given further consideration.

Summary

Cancer Council NSW does not support or oppose assisted dying. We make this submission because any change to the law in this space will impact cancer patients and their families in NSW. Our interest is in ensuring that should this Bill be passed, the resulting legislation is compassionate, feasible and contains appropriate safeguards. We recommend further consideration and clarity on the range of issues we have outlined in this submission. We reiterate that assisted dying and palliative care are distinct, and if assisted dying is legalised, palliative care becomes even more important and the community must have knowledge of and access to appropriate palliative care services. The passage of the legislation should not result in a reduction in palliative care or in the efforts to improve palliative care, nor should it result in a reduction in the focus on, and funding for, the prevention and treatment of cancer.

Given Cancer Council NSW takes a neutral stance on assisted dying, I ask that no reference be made to Cancer Council's submission that could be interpreted in any way as support, or opposition, for the Bill.

Thank you for your consideration of the points we raise. Should you have any questions about this submission, please contact Kelly Williams, Manager of Policy and Advocacy on 9334 1748 or kwilliams@nswcc.org.au.

Yours sincerely,

Jeff Mitchell

Chief Executive Officer
Cancer Council NSW

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[i] https://www.cancerinstitute.org.au/Understanding-cancer/Cancer-in-NSW/all-cancers-nsw-data

[ii] Emanuel, E, Onwuteaka-Philipsen, B, Urwin, J, and Cohen, J (2016) "Attitudes and Practices of Euthanasia and Physician Assisted Suicide in the United States, Canada and Europe" *JAMA* 2016;316(1):79-90

[iii] California End of Life Option Act 2016 data. Accessed 29th June 2017 https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH%20End%20of%20Life%20Option%20Act%20Report.pdf

[iv] http://www.parliament.tas.gov.au/bills/Bills2016/pdf/73_of_2016.pdf

[v] Victorian *Voluntary Assisted Dying Bill Discussion Paper*. Accessed 23 June 2017 https://www2.health.vic.gov.au/about/publications/researchandreports/voluntary-assisted-dying-bill-discussion-paper

[vi] http://www.parliament.tas.gov.au/bills/Bills2016/pdf/73_of_2016.pdf

[vii] https://www.legislation.sa.gov.au/LZ/B/CURRENT/DEATH%20WITH%20DIGNITY%20BILL%202016_DR%20DUNCAN%20MCFETRIDGE%20MP/B_AS%20INTRODUCED%20IN%20HA/DEATH%20WITH%20DIGNITY%20BILL%202016.UN.PDF