Select Committee on the Inquiry into the Voluntary Assisted Dying Bill 2023

ANSWER TO QUESTION TAKEN ON NOTICE

Asked by Mr Ed Cocks MLA on 29 January 2024: Kate Gorman took on notice the following question(s):

Reference: Hansard [uncorrected] proof transcript 29 January 2025 page 24-25

In relation to:

MR COCKS: In relation to the younger people issue, I am very keen to understand how you would draw that line, that I think the submission reflects that the age should be reduced to 14 year olds, and I understand that is intended to be actively considered in the future by the government. So what is it about 14 years old that makes that an appropriate age compared with say 14 or 12 as another suggestion?

Dr Stevens: Already under medical law people who are over 15 have the right to have a say in their medical care, so that is why we have taken that age, because it is already there with medical care.

MS CASTLEY: 15 or 14?

Dr Stevens: I think it is over 14. Once you turn—after 14. I mean I cannot be—I would have to talk to Alannah who is my co-chair, she is really across it all.

MR COCKS: Yes. I would be keen to understand what it is that makes that the line.

THE CHAIR: Maybe that is something, Ms Stevens, you can take on notice just to confirm as to why, but if I understand what you are saying now, it is that when you have looked into this matter it is consistent with what other medical provisions allow for the choice of care—Ms Gorman.

Dr Stevens: Yes.

Health Care Consumers Association: The answer to the Member's question is as follows:–

In our consultations with consumers, there was support for people under 18 years old accessing VAD. However, many participants in our consultation raised concerns about using age as the sole indicator of competence, as it is an arbitrary factor that may exclude some individuals who are otherwise competent. Instead, consideration should be given to how to assess competence for young people and children.

We suggest that Gillick[i] competence determination could and should be used to assess whether a young person can make decisions regarding VAD[ii]. The use of Gillick competence assessment, which evaluates an individual's capacity to make a decision independently, is effective in assessing competence in young people over 14 years of age[iii,iv].

Consumers emphasised in our consultation that parents/guardians should be included in discussions around VAD, while at the same time ensuring the process respects and upholds the young person's right to choose, if assessed as competent. We do not believe that young people should be considered for VAD unless they are deemed competent and are able to make the decision themselves. Our current understanding of neuro-development suggests that 14 years is an appropriate line to draw, where children are more likely to meet the competencies required to be determined Gillick competent[v]. For this reason we are not currently advocating for access to VAD for children younger than 14.

It is essential that young people considering VAD are health literate and understand their condition, and care options. We recognise that this may require additional steps in the eligibility process to assess the competence of young people, including their understanding of their condition, available treatments or palliative care options, as well as the profound consequences of VAD.

It would be beneficial to involve a range of stakeholders, including young people, parents, health professionals, and legal experts in the development of any such eligibility process.

<u>Legislative and government policy support for privacy and independent decision making from 14 years</u>

Medical consent
In relation to medical consent, Youth Law Australia says that:

'There is no set age at which a young person who is under 18 can consent to medical treatment without the approval of their parents or guardian.

Whether you can consent to medical treatment depends on things like how old you are and how serious the treatment is. Generally:

- if you are **over 16 years old**, you can consent to medical treatment without your parents or guardians;
- if you are **over 14 years old**, you may consent to your own medical treatment as long as you fully understand the medical procedure or treatment, and any risks or consequences. However if you are 14 or 15 years old, a doctor may still wish to obtain the consent of your parent or guardian unless you object to this;
- if you are **14 years or younger**, the consent of your parents or guardians to medical treatment is normally needed.'[vi]

Medicare Policy
In 2003, the Health Insurance Commission changed its privacy policy to require young people aged 14 and over to give consent before their parents could access their Medicare records.

The Medicare policy on access to records of an individual under 18 states that:

- if a child or young person of any age has his or her own Medicare card, no information related to the use of the card can be released to a parent or guardian without the consent of the child;
- for a young person aged 14 or 15 on his or her parent's Medicare card, information generally will not be released without the young person's consent, but a parent or guardian may request Medicare Australia to approach any treating medical practitioner to determine if the practitioner will disclose to the parent or legal guardian any information they hold about the young person's treatment; and
- disclosure of information relating to a young person aged 16 and over on his or her parent's Medicare card will be made available to a parent or legal guardian only with the young person's consent[vii].

In line with the decision taken by Medicare, ACT Health's Digital Health Record (DHR) Consumer Experience Committee (DHRCEC) decided that: from 14 years of age a consumer will be given their own MyDHR (DHR consumer portal) account, in line with the Medicare provision for information access. Prior to this age, parents or legal guardians will be the sole and exclusive person with access to a consumer's MyDHR. From age 15, the consumer will be able to consent to the level of proxy access, therefore come under the same criteria as an adult.

Information privacy
The Information Privacy Act 2014 (Information Privacy Act), *the Health Records (Privacy and Access) Act 1997 (HRPA Act),* existing Medicare policies and the ACT's own Digital Health Record policies, lend support to the acceptance of young people over the age of 14 managing their own health decisions and health information with the assistance of their parents.

While the Information Privacy Act 2014 (Information Privacy Act), the Health Records (Privacy and Access) Act 1997 (HRPA Act) nor any other relevant legislation specify an age at which an individual can make their own privacy decisions. The general principle is that a young person's capacity to make decisions in respect of their personal information, and in particular, their capacity to consent to who can have access to their personal information, is dependent on whether they have sufficient understanding and maturity to know what is being proposed. The Australian Information Commissioner is of the view that an entity may presume that an individual aged 15 or over has capacity to consent (and hence make decisions about their personal information), unless there is something to suggest otherwise. An individual aged under 15 is presumed not to have capacity to consent unless capacity is specifically demonstrated[viii].

<u>Determining Capacity</u>
Capacity is decision specific and must be assessed on a case-by-case basis. We have not encountered any compelling reason that this should not be assessed and acted upon accordingly in the context of this specific health decision. From our perspective, VAD is a health service available to decision competent community members, young people should not be excluded from this service if they are assessed as competent to consent to this care and meet the other eligibility criteria.
We want to be sure that adult discomfort around the death of young people is not prioritised over the best interests, wishes and care needs of young people with terminal illnesses.

Rationale

If we have provision for a young person to seek health care and (potentially) consent to treatment independently of their parent/guardian from 14 years of age (and we do), it seems to sensibly follow that they are able to seek and (potentially) consent to any medical treatment their condition warrants and for which they are otherwise eligible. This does not negate the role of rigorous Gillick assessment of competence and parental input into decision making. However, a young person's request for access to VAD should not be dismissed without full consideration of the specific merits of the individual's request.

We accept that this would require development of a rigorous framework for consideration for access to the scheme and how decision makers weigh the wishes and decisions of parents/guardians verses the wishes and decisions of the (competent) child.

Approved for circulation to the Select Committee on the Inquiry into the Voluntary Assisted Dying Bill 2023

Signature: Date: 8/2/2024

By the Health Care Consumers Association, Jessica Lamb

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[i] 'Gillick competent' refers to the decision of the House of Lords (UK) in *Gillick v West Norfolk and Wisbech Area Health Authority* which effectively found that the authority of parents to make decisions for their minor children is not absolute, but diminishes with the child's evolving maturity.

[ii] RACGP - Children and consent for medical treatment

[iii] Corporate Governance and Risk Management 2020, *Consent to Medical and Healthcare Treatment Manual*, NSW Ministry of Health, Sydney, pp 43-48.

[iv] For example, the age of 14 as a possible age for competence in decision making is supported by: Grootens-Wiegers P, Hein IM, van den Broek JM, de Vries MC. *Medical decision-making in children and adolescents: developmental and neuroscientific aspects*. BMC Pediatr. 2017 May 8;17(1):120.

[v] For example, the age of 14 as a possible age for competence in decision making is supported by: Grootens-Wiegers P, Hein IM, van den Broek JM, de Vries MC. *Medical decision-making in children and adolescents: developmental and neuroscientific aspects*. BMC Pediatr. 2017 May 8;17(1):120.

[vi] Young people's rights at the doctor in New South Wales | Youth Law Australia (yla.org.au)

[vii] Capacity and health information | ALRC

[viii] Children and young people | OAIC