

## Simplifying Medical Treatment Decision Making and Advance Care Planning Feedback on the Position Paper

### 1. Introduction

Palliative Care Victoria supports improvements to the law regarding medical treatment decision making and advance care planning.

This submission responds to the proposals outlined in the *Simplified Medical Treatment Decision Making and Advance Care Planning Position Paper*, issued by the Department of Health and Human Services, Victoria. It has been approved by the Board of Palliative Care Victoria and incorporates feedback on an earlier version submitted to a range of PCV members for feedback. We also invited all PCV members to provide comments on the position paper.

### 2. Summary

Our submission addresses a range of relevant matters; the most salient of these are outlined below and our submission provides further discussion of these and other issues.

- a) It is appropriate that any new legislation regarding medical treatment decision making and advance care planning apply to the relevant range of health practitioners. This will need to be supported by appropriate education and agreed processes and systems to support its effective implementation by health practitioners and the community.
- b) The definition of medical treatment in the new legislation should exclude the provision of reasonable medical procedures for the relief of pain and suffering and discomfort and/or the reasonable provision of food and water offered by mouth. However, this should not be called 'palliative care' and palliative care should not be excluded from the definition of medical treatment.
- c) The paper probably assumes that such medical treatment is clinically indicated and evidence-based; this should be clearly indicated in the legislation.
- d) We support the use of instructional directives for current conditions and values directives for current and future conditions. We do not consider it advisable to legislate for instructional directives for future conditions for a range of reasons outlined below.
- e) We recommend that the legislation require that an instructional directive for a current condition be accompanied by a values directive, as this will assist with its interpretation. It should also be a requirement that an instructional directive is discussed with the person's primary health practitioner and endorsed by them as being an accurate reflection of the

person's wishes based on informed discussion with them about the condition and clinically indicated medical treatment options.

- f) We suggest the active encouragement of the use of values directives to indicate personal preferences about culturally responsive decision making processes regarding a person's medical treatment. The position paper assumes a cultural value of individual autonomy regarding medical treatment decision making which may not be shared by everyone.
- g) Reference to the use of trained and accredited interpreters where appropriate should be included in the process for assessing a person's capacity to make decisions about their medical treatment.
- h) We consider that the legislation should include a requirement on health practitioners when making medical treatment decisions about a person who no longer has capacity to make reasonable efforts to locate the person's appointed medical treatment decision maker or the relevant person in accordance with the proposed decision-maker hierarchy. This important feature of sound health care practice should not be bypassed because an advance care directive is in place. We consider this is important to support the correct interpretation and application of their wishes in the context of the person's situation at the time.
- i) We do not support the abandonment of the 'best interests' tests as a guide to medical treatment decision making in the absence of a clearly applicable preference regarding medical treatment by the person. We consider that the 'best interests' test is not subjective, and offers more guidance (and a strong body of case law) compared to reliance on a general statement of rights. Consideration of rights could be included but should not replace the 'best interests' test.
- j) We consider that the legislation should provide that when a younger person under the age of 18 is deemed to have capacity to prepare an advance care directive, the approved form/s for this purpose should require signed declarations by the most appropriate person as per the proposed hierarchy of decision-makers and their primary health care practitioner indicating it has been discussed with them. This would help to highlight any issues in advance of recourse to the directive.
- k) The forms for advance care directives and the appointment of a medical treatment decision maker should be legislated to ensure easy recognition and consistency. The legislation should also clarify the status of existing advance care plans and those prepared in other Australian jurisdictions.

### **3. Broader application**

Palliative Care Victoria agrees that it is appropriate that the new legislation apply to the various health practitioners involved in making medical treatment decisions and that this should include paramedics.

The position paper proposes that the legislation apply to the health professions covered by the Health Practitioner Regulation National Law (Victoria) Act 2009. This includes:

- a. Aboriginal and Torres Strait Islander health practice
- b. Chinese medicine

- c. chiropractic
- d. dental (including the profession of a dentist, dental therapist
- e. dental hygienist, dental prosthetist and oral health therapist
- f. medical
- g. medical radiation practice
- h. nursing and midwifery
- i. occupational therapy
- j. optometry
- k. osteopathy
- l. pharmacy
- m. podiatry
- n. psychology
- o. physiotherapy.

We support the proposed scope of the legislation to cover the health practitioners listed above and paramedics.

Adequate lead time prior to the commencement of the new legislation will be needed to implement the associated information and education strategies required for health practitioners and the community (including our culturally diverse communities and people with special needs). This will also need to be coupled with the development of sound processes and systems to support the effective implementation of the new legislation.

#### 4. Definition of medical treatment

Palliative Care Victoria agrees that it is preferable for Victorian laws to use a consistent definition of medical treatment.

We support the development of a more contemporary definition of medical treatment (compared to the definition in the Medical Treatment Act 1988), and that this should include the provision and prescription of pharmaceuticals.

##### Palliative care definition

The Medical Treatment Act 1988 defines palliative care as:

*“palliative care includes -  
 (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or  
 (b) the reasonable provision of food and water.”* (Part 1 section 3);

This definition was prepared when palliative care was in the very early stage of development and when it was focused primarily on terminal care. It no longer reflects the contemporary practice of palliative care as defined by the World Health Organisation (<http://www.who.int/cancer/palliative/definition/en/>).

The intent of the exclusion of palliative care (as defined) in the Medical Treatment Act 1988 was to avert a situation where health practitioners are not able to provide reasonable relief of pain and suffering where a person lacks capacity to make decisions. It is also advisable to have such a provision in the event so that a substitute decision-maker is not able to refuse this minimal level of care.

Palliative Care Victoria recommends that the new legislation exclude from the definition of medical treatment:

- (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or*
- (b) the reasonable provision of food and water offered by mouth*

but that this is not called 'palliative care'. This would avoid the confusion of using an outdated and limited definition of palliative care which does not reflect the contemporary practice of palliative care.

#### Proposal to exclude palliative care

Palliative Care Victoria does not support the proposal to exclude palliative care from the definition of medical treatment used in the legislation for the following reasons:

- Palliative care has a strong focus on effective communication, informed participation in decision-making and the provision of person-centered care that is respectful of the person's preferences, values and choices.
- Palliative care practitioners have specialized expertise in the management of complex pain and other symptoms and the provision of holistic care. The exclusion of palliative care from the definition of medical treatment could perpetuate misperceptions that palliative care means that nothing more can be done and that it is only about providing basic comfort to people as they die.
- The exclusion of palliative care from the definition of medical treatment could imply a paternalistic approach that overrides a person's opportunity to consent to or refuse treatment, which is contrary to the philosophy and practice of palliative care.

The position paper indicates that the exclusion of palliative care from the definition of medical treatment would preclude people from refusing palliative care in an advance directive. This is at odds with the proposed aims of the legislation. This situation could be averted by ensuring palliative care is appropriately described and discussed in the context of preparing advance care directives. The proposed legislation includes a provision for applications to the Tribunal if the practical effect of a directive would not be consistent with a person's preferences or values.

Instead of excluding palliative care from the definition of medical treatment, it would be more appropriate to implement strategies designed to inform the community and health professionals about palliative care, its specialized expertise and holistic person-centered approach, and the benefits it can provide during an advanced chronic illness and at the end of life.

## **5. Values directive for current and future conditions**

Palliative Care Victoria supports the proposed provision for people to make their advance care wishes known through a documented values directive that describes the person's views and values regarding the medical treatment they would wish to receive in relation to current and future conditions if they are no longer competent to make those decisions.

Such a provision will need to be supported by effective community engagement, information and education strategies to assist people to prepare clear values directives that are a helpful guide to

medical treatment decisions and that can be interpreted consistently and accurately by medical treatment decision makers and health practitioners.

It is appropriate that the legislation would require medical treatment decision makers and health practitioners to give effect to the person's written values directive as far as reasonably possible when making treatment decisions.

We strongly support the proposed provision that health practitioners would not be able to rely solely on a values directive but would be required to turn to the person's medical treatment decision maker to consent to medical treatment prior to its commencement. In the majority of cases the medical treatment decision maker will have had a long-standing relationship with the person and can assist if there are any ambiguities or doubts regarding the interpretation of the person's values statement as it applies to medical treatment decisions for that person at that time.

Wishes for future care should as much as possible be seen as an iterative process involving conversations with the person's health practitioner/s, appointment medical decision maker and people close to them and likely to be involved in their care (such as family). One-off decisions that are not reviewed regularly should be avoided.

## **6. Instructional directives for current and future conditions**

The position paper proposes that the legislation would enable a person with decision making capacity to make an instructional directive in relation to current and future conditions. This would provide specific directives in relation to particular treatments or general medical treatment with which health practitioners must comply.

It also proposes that where an instructional directive exists it may constitute consent to treatment or refusal of treatment. In both cases, the proposal is that the health practitioner may proceed to commence or not to provide the clinically indicated treatment.

However, there is no indication of a legislative requirement for a health practitioner to contact or consult the person's medical decision maker when an instructional directive exists.

Palliative Care Victoria supports the proposal for instructional directives in respect of current conditions. However, the legislation should require health practitioners to take reasonable steps to communicate with the person's medical treatment decision maker (or family member / person responsible) preferably at the time the medical treatment decisions are made and during the person's illness / medical treatment. This is consistent with good health care practice and it also provides a useful opportunity to check the interpretation and application of the instructional directive.

We anticipate that there will be many instructional directives that are not easy to interpret given the complexity of medical conditions and rapidly changing treatments, variable levels of health literacy and a general lack of experience in preparing advance care directives.

We also recommend that the legislation require that a valid instructional directive for a current condition include a values directive, as this will assist with its interpretation.

The legislation should also include a requirement that an instructional directive for a current condition is discussed with the person's main health practitioner and endorsed by them as being an accurate reflection of the person's wishes based on information discussed with them about the condition and clinically indicated medical treatment options. The Refusal of Treatment Certificate

requires a doctor to be involved so that the decision can be as informed as possible; this should continue with the proposed legislation.

Palliative Care Victoria does not support instructional directives for future conditions. We consider this would undermine the need to regularly review and update advance care plans. It would also be wise to defer consideration of this until after there has been substantial experience with the implementation of instructional directives for current conditions and values directives. This would provide an opportunity to work through issues and challenges before embarking on the more complex area of instructional directives for future conditions.

Instructional directives prepared for future conditions also pose additional challenges. For example, rapid changes in medical treatment may mean that clinically indicated and effective treatments have become available since the person prepared their most recent instructional directive. The person's values statement may be helpful but there are likely to be situations where it is not an easy determination to make.

Furthermore, there may be a significant divergence between the person's anticipated experience of a future condition, such as dementia, and how they are actually experiencing that condition when it occurs in the future and decisions are being made about their treatment in that context. This situation is reflected in a submission quoted in the End of Life Choices Inquiry Report:

"Giving evidence in a personal capacity, Mary Hocking, who holds medical power of attorney for her husband who has early onset dementia, observed:

*I know the man my husband used to be, and I know he would not want to be the man that he is today; however, he is happy as he is the man he is today, which brings me to another difficulty with advance care plans, which is: whose version do we hold with or think is more valid?*<sup>634</sup> " 1

Limiting instructional directives to current conditions may also assist in reducing the number of applications to the Tribunal due to concerns about interpretation or application.

Palliative Care Victoria recommends that the legislation provide for values directives only for future conditions and the associated requirement to refer to the person's medical treatment decision maker to obtain consent or refusal before initiating or withdrawing any clinically indicated medical treatment.

If the proposed legislation does provide for instructional directives for future conditions, then we recommend that it include a requirement that a doctor is involved in providing medical advice to facilitate informed consent and is required to witness the document. This is also important to minimize the risk of instructional directives being prepared under duress (in the context of family violence or elder abuse) or being used fraudulently at a later date.

## **7. Decision making about medical treatment**

### Autonomous decision-making

The position paper proposes that if a person has decision making capacity, they should always make treatment decisions for themselves.

This reflects the high priority placed on autonomy relative to other values in the proposed legislation. However, it is important to acknowledge that there is variation in the relative importance among Victoria's diverse and multicultural community in relation to the values that inform decision making about medical treatment.

It is important that legislation and health practitioners acknowledge that there may be individual and cultural differences (within and between cultures) with regards to medical treatment decision making. Provision needs to be made for culturally responsive processes for decision making about medical treatment where this is the preference of the person concerned. This can be facilitated in a culturally responsive way by asking the person if they wish to make the decisions for themselves or if they wish others to be involved and if so, who and how.

It would be appropriate for information, education and forms to support advance care directives to provide an opportunity for people to include preferred decision making processes. This could be included in a values directive.

### Presumption of capacity

The position paper indicates that the proposed legislation will provide that a person should be presumed to have capacity. It also states that a health practitioner would need to determine whether a person has decision making capacity. It is probably more accurate and helpful to indicate that health practitioners need to satisfy themselves that a presumption of decision-making capacity is accurate by using contemporary practice methods to assess capacity at the time each decision needs to be made.

The contemporary practice methods to assess capacity outlined in the position paper should include the use of trained and accredited interpreters (not family members) when communicating with people whose first language is not English and who would prefer to speak in their community language.

### If a person does not have capacity

The position paper indicates that the legislation will require that where a person does not have capacity, health practitioners will be required to make reasonable efforts to locate an advance care directive.

Palliative Care Victoria recommends that this also include a requirement to make reasonable efforts to locate the person's appointed medical treatment decision maker or the relevant person in accordance with the proposed decision-maker hierarchy.

## **8. Supporting people to make their own decisions**

Palliative Care Victoria supports the formal recognition in the legislation of the role of a 'support person' to assist a person to make a decision about their medical treatment.

The position paper indicates that a person can appoint a support person when preparing an advance care directive. If a support person has not been appointed by the person and it is considered that this would be helpful to support the person's participation in decision making about their medical treatment, would this be the responsibility of the Victorian Civil and Administrative Tribunal?

The Health Issues Centre identified in its 2015 report on the "Have the Conversation Consumer Project" a need for support for appointed medical treatment decision makers in carrying out their roles. Provisions for this should be included to support the successful implementation of the legislation. This may also help to reduce the workload on the Tribunal.

## 9. Preferences, values and rights

The position paper states that the proposed legislation will introduce a single test to guide medical treatment decision makers when there is not a relevant advance care directive. It outlines a hierarchy of considerations that would guide medical treatment decision makers, as follows:

*"In the first instance, the medical treatment decision maker will be required to consider any preferences expressed by the person."*

*"If there are no relevant preferences, the medical treatment decision maker will then consider the person's values they would likely consider if they [the person, not the decision maker] were making the decision."*

*"If these also cannot be determined, the medical treatment decision maker will be required to make decisions that are consistent with the person's rights."*

The first consideration acknowledges that the person may have discussed their medical treatment preferences with people who are close to them even though they may not have a documented an instructional directive.

The second consideration acknowledges that people close to the person may be able to provide insight into values that the person held (even though they may not have documented a values directive) that may be helpful in indicating the medical treatment decisions the person would have made in the current situation if they had capacity to do so.

These considerations support Palliative Care Victoria's recommendation that health practitioners should communicate with the person's appointed medical treatment decision maker (or the relevant responsible person, if there is no appointed medical treatment decision maker) about medical treatment decisions to facilitate a more accurate and appropriate interpretation and application of the person's documented advance care plans (including instructional directives).

The position paper indicates that if the preferences and values of the person cannot be determined, the proposed legislation would require the medical treatment decision maker to make decisions that are consistent with the person's rights. This situation seems most relevant when a health practitioner or a responsible person involved in decision making about the person's treatment do not have a good understanding of the person for whom a medical treatment decision needs to be made or to people who knew the person and could share this information.

Considerations of a person's preferences for medical treatment and values should be taken together where possible, as an understanding of a person's value will assist with the interpretation and application of person's preferences. While these are both very important and helpful, they

may not be sufficient to guide some medical treatment decisions due to the complexity of specific situations / options and the potential lack of clarity in how the person's preferences and values translate into concrete medical treatment decisions.

The position paper proposes that in the absence of information about the person's preferences or values, the medical treatment decision maker should make decisions on the basis of the person's rights. However, the position paper does not state what these rights are or refer to the relevant legislation. We presume that the paper is referring to the Australian Charter of Health Rights in Victoria. In brief, these rights are:

- Access – a right to health care that is needed regardless of ability to pay
- Safety – a right to safe, high quality care, based on open, clear communication
- Respect – the rights to be treated with respect, dignity and consideration, to be treated in a way that is responsive to the person's culture and beliefs, to be treated without discrimination and to be cared for in a safe, clean and comfortable (with personal privacy where possible)
- Communication – the right to ask questions about and receive clear, understandable information about one's health condition, treatment options, expected outcomes, side effects and costs and the right to seek a second medical opinion.
- Participation – the right to take an active role and to participate in decisions about one's health care, and the right to refuse treatment when competent to do so. This also includes the right to have family and other carers involved providing care and the right to appoint a person to substitute medical decisions in the event of loss of capacity.
- Privacy – the right to have the privacy of one's personal information protected and to have a say in what happens to personal health information. [Ref. Summary of the Australian Charter of Healthcare Rights in Victoria, Department of Health, 2010]

The position paper proposes that consideration of a person's preferences, values and rights (in that order) would replace reference to 'best interests' tests. It is not clear why all three considerations would not be made together in relation to medical treatment decisions given the potentially important impact of those decisions on quality of life and mortality.

The position paper states dismissively that 'best interests' tests rely on subjective judgements about what the medical treatment decision maker believes would be best for a person. This is not an accurate reflection of the processes and considerations used in 'best interests' tests.

Guidance on 'best interests' assessments indicates that this is a process the purpose of which is to consider matters from the patient's point of view taking into account a range of factors.<sup>2</sup>

The Victorian Guardianship and Administration Act 1986 outlines how best interests should be determined in relation to the consideration of medical treatment decisions. This includes the wishes of the patient, so far as they can be ascertained, and several other important factors that may not be considered using a rights-based approach, including:

- *the consequences to the patient if the treatment is not carried out*
- *any alternative treatment available*
- *the nature and degree of any significant risks associated with the treatment or any alternative treatment*

- *whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient*<sup>3</sup>

According to Lindy Willmott et al<sup>4</sup>:

*“Supreme Courts in Australia have an important jurisdiction in resolving end of life disputes and their decisions provide authoritative guidance for guardianship tribunals and clinicians in their deliberations. Supreme Courts apply the test of whether the proposed treatment is in the patient’s “best interests”, and this term (or analogous concepts) is also one of the criteria used by guardianship tribunals.”*

They conclude that there is enough case law to provide useful guidance about assessing a patient’s best interests and this guidance is significant for both future Supreme Court decisions and those made by guardianship tribunals.

Palliative Care Victoria notes that the Australian Charter of Healthcare Rights in Victoria, while being very important and useful promoting healthcare rights in general, does not offer the same level of guidance to assist medical treatment decision makers as do the more specific considerations and body of case law relating to the ‘best interests’ test.

Palliative Care Victoria recommends further consideration of the advisability of the proposal for the legislation to move away from consideration of ‘best interests’ as a guide for substitute medical treatment decision makers and to replace this with reference only to the person’s preferences, values and rights. Where it is not possible to ascertain the person’s preferences or values, then reference to the person’s rights (at least as outlined in the Australian Charter of Health Rights in Victoria) provides much less helpful guidance than consideration of the persons ‘best interests’.

If the decision is taken to include reference to the person’s rights, then considerable work would be needed to provide guidance on how this can be applied to facilitate medical treatment decisions by health practitioners and substitute medical treatment decision makers and to promote consistency with how relevant courts and tribunals consider these matters. It would probably be advisable to include consideration of the person’s ‘best interests’ along with their rights.

## 10. Simplifying the medical treatment decision-maker hierarchy

The position paper states that *“If a person has not given a relevant instructional directive or appointed a medical treatment decision maker, a health practitioner will be required to identify a medical treatment decision-maker to consent to or refuse medical treatment.”* (p12)

This statement seems to imply that medical treatment decisions could be made solely on the basis of an instructional directive without any communication with an appointed medical treatment decision maker. As indicated earlier in this paper, Palliative Care Victoria has concerns about this.

The position paper indicates that the legislation would provide for a hierarchy for determining who the medical treatment decision maker is in the absence of a relevant instructional directive or appointed medical decision maker.

Palliative Care Victoria notes that this differs substantially from Section 37 regarding the person responsible in the Victorian Guardianship and Administration Act 1986. In comparison with that Act, the proposal lists people with a close and continuing relationship with the person but excludes

grandparents, grandchildren, uncles & aunts and nephews & nieces. It is not clear whether these relatives have been omitted for brevity, or, if intentional, the rationale. There would also need to be consideration of the willingness and reasonable availability of the candidates to take up the role of medical treatment decision maker and their consent to perform this role.

The proposal indicates that the legislation would allow the Victorian and Civil Administration Tribunal to recognize a person as a medical treatment decision-maker, even if they do not have one of the listed relationships. In that case, that person would be at the top of the hierarchy of the responsible person hierarchy.

It is appropriate that the legislation would provide for the Public Advocate to be the decision-maker of last resort. However, the position paper proposes that this would be the case for medical treatment decisions for 'significant' treatments only, not 'routine' treatments. If a person no longer has capacity to make decisions about their treatment on an enduring basis and none of the other persons listed in the responsible person's hierarchy is able or suitable to perform this role, then it would be appropriate for a Guardian (or a substitute decision maker with a similar function) to be appointed. It would be advisable for the legislation to define what is meant by 'significant' and 'routine' medical treatments (and for this to take into account the risks/effects for the particular person, as these could vary significantly). There is a need for better guidance than currently about consent arrangements for minor treatment.

It is not clear how the Guardianship and Administration Act 1986 would be amended as a consequence of the proposed new legislation. As medical treatment decisions are just one aspect of a person's life, it will be important that the provisions of both pieces of legislation are compatible and consistent.

The paper states that "each form of medical treatment decision maker will have the same powers" (p7). What is not clear is how the power to make medical treatment decisions may be associated with other decision making powers a person may have, such as an enduring power of attorney, and how this would work administratively if there are two relevant pieces of legislation.

## **11. Removing the confusion about the powers of medical treatment decision makers**

The paper states that under the proposed legislation all medical treatment decision makers would only be empowered to refuse treatment if the medical treatment would cause unreasonable distress to that person or there are reasonable grounds for believing that the person, if they had capacity, after giving serious consideration to their health and wellbeing, would have refused the treatment.

The paper probably assumes that such medical treatment is clinically indicated and evidence-based; this should be clearly indicated in the legislation. It is important to clarify that neither a person or their substitute decision maker has the right to insist on non-beneficial treatment.

If these are considered to be the sole justifications for a medical treatment decision maker to refuse treatment, then the avoidance of medical treatment that causes unreasonable distress to the person should also be considered by a medical treatment decision maker when considering whether to consent to medical treatment (as is the case in a 'best interests' approach).

## 12. Better safeguards

The proposed safeguards providing for recourse to the Tribunal are appropriate in situations where: the practical effect of a directive would not be consistent with the person's preferences and values; there is reasonable concern that a medical treatment decision maker has refused medical treatment without sufficient information about the person's values or preferences; or where there is lack of clarity or disagreement about how an advance care directive should be interpreted or applied in the circumstances.

It is also reasonable that if treatment is required urgently and there is not sufficient time to apply to the Tribunal in any of the above situations, a health practitioner may choose not to follow an advance care directive. In this situation, consideration of what is in the person's best interests based on the knowledge and information available would be appropriate. It may be helpful for the legislation to clarify what is meant by urgent and to clarify that this would apply to treatment likely to have a significant impact on the person's quality of life.

It would be appropriate for data to be collected about the use of these safeguards so that the effectiveness of the legislation can be monitored and any issues or improvements considered.

## 13. Young people

This section of the position paper is confusing as it makes a number of statements that appear to be inconsistent or contradictory with one another or with other proposed provisions of the new legislation. It states:

- People under the age of 18 can consent to medical treatment if they have capacity to understand the nature and effect of the proposed treatment.
- The proposed Act will allow any person under 18 with the capacity to understand the nature and effect of the directive to make an advance care directive.
- The parent of a person under 18 will automatically be their medical treatment decision maker.

The position paper indicates that where a person has documented an instructional directive, a health practitioner would comply with that directive (unless some of the exceptional circumstances covered by the safeguards apply). This means that although the parent of a person under 18 is automatically the medical treatment decision maker of that person, a health practitioner is not required to refer to the parent when implementing the child's current or future advance care directive. There is no consideration in the paper as to what happens when the young person's instructional directive is not supported by their parent or guardian (including in situations where a young person under 16 years is in care or lives with a partner and/or is estranged from their family).

Palliative Care Victoria recommends that the legislation require that where a person aged under 18 years has capacity and prepares an advance care directive that the approved form require signed declarations by the relevant person in the decision-maker hierarchy and their primary health practitioner that it has been discussed with them and reflects the young person's informed preferences. This would help to highlight and resolve any disagreements and avert any misunderstandings before the need to make a medical treatment decision on the basis of the

directive arises. Once the person reaches 18 years, the adult provisions of the legislation would apply.

With regards to Cory's story, Palliative Care Victoria would appreciate the appropriate referencing of its publications.

#### **14. Consolidating and clarifying laws**

Palliative Care Victoria supports the retention of the Mental Health Act and the consolidation of law relating to medical treatment decision making, including provisions governing medical research procedures. As indicated above, there will need to be careful consideration regarding how the new legislation relates to other substitute decision making legislation, particularly given medical treatment is just one aspect of a person's life.

#### **15. Other matters**

##### Legislated forms

We recommend that the forms for advance care directives and the appointment of a substitute medical treatment decision maker are legislated.

If instructional directives are to be binding, they will need to be recognisable by those who must implement them and they will need to meet certain standards to be valid. This is best achieved through a standard legislated form for these. It would also make sense to co-locate the values statement while making it possible to complete the values statement without an instructional directive.

Given our multicultural community and the Government's commitment to cultural responsiveness, bilingual versions of the forms should be available in English and the relevant community languages.

The forms must be as easy to understand as possible while still conveying the legal meaning. Access to assistance to understand and complete the forms is also very important.

##### Status of advance care planning undertaken before the new legislation

The new legislation will also need to clarify the status of arrangements completed before the new legislation takes effect. In the case of the appointment of the Enduring Power of Attorney (Medical) this is straightforward as they have the same authority as proposed under the new legislation.

What will be the status of instructional advance care plans written prior to the new legislation? Some have been prepared by the person's substitute decision maker rather than the person they relate to. Some are poorly written highlighting the need for support in preparing such documents.

##### Status of undocumented preferences

The position paper does not indicate what status would be given to a person's preferences discussed in conversations with family members and health practitioners but not documented in an advance care directive. This is an important consideration given the low rate of documented advance care plans currently and possibly for some time. The 'best interests' provisions of the Guardianship and Administrative Act 1986 include consideration of "the wishes of the patient, so far as they can be ascertained". In the absence of any documented advance care directive, the proposed legislation requires that the medical decision maker would then make a decision on the

basis of the person's rights. The proposed legislation should clearly state that the wishes of a person expressed verbally or via some other means than an advance directive are given due consideration along with their rights and other matters taken into account in a 'best interests' approach.

#### Persons who have never had capacity to express their preferences

Some people for whom medical treatment decisions need to be made have not at any stage had the capacity to express their preferences in a manner that could be reflected in an advance care directive. Consideration of the person's 'best interests' can take into account that person's response (verbal, behavioural, etc.) to previous medical treatment. Palliative Care Victoria considers that the 'best interests' test offers more guidance in these situations than reference to rights alone.

#### Status of advance care plans completed in other jurisdictions

It would be helpful to clarify the status of advance care plans completed under legislation in another Australian jurisdiction in respect of a person who is temporarily travelling in Victoria or has permanently re-located to Victoria.

## 16. Conclusion

Palliative Care Victoria appreciates this opportunity to provide feedback regarding the *Streamlined Medical Treatment Decision Making and Advance Care Planning Position Paper* published by the Department of Health and Human Services, Victoria.

We support the aim to introduce new legislation which provides a clear basis for medical treatment decision making and advance care planning so that there is a much greater opportunity for a person's preferences and values to inform decisions about clinically indicated treatment when they are no longer able to participate in those decisions.

Achieving these aims will require significant community education to foster advance care conversations and the associated health literacy to indicate treatment preferences. There will also need to be associated education and systems development for health practitioners. It would be valuable to have an opportunity for public submissions on the draft legislation once it has been prepared as well as opportunities to contribute to implementation plans.

In relation to implementation strategies, we strongly recommend against the use of targets or key performance indicators for the number or percentage of advance care directives completed as this provides a perverse incentive to fill out forms rather than to have the discussion about end of life care wishes.

### End Notes

---

<sup>1</sup> Parliament of Victoria, Legal and Social Issues Committee, 2016, Inquiry into end of life choices - Final Report, Victorian Government Printer, Melbourne, p 157)

<sup>2</sup> Alex R Keene et al, 2015, Mental Capacity Law Guidance Note: Best Interests Assessments, <http://www.39essex.com> accessed 1 July 2016

<sup>3</sup> Guardianship and Administration Act 1986, Part 4A, Medical and other treatment, section 38, <http://www.austlii.edu.au/> accessed 1 July 2016

---

<sup>4</sup> Lindy Willmott et al, 2014, *Withholding and withdrawing life-sustaining treatment in a patient's best interests: Australian judicial deliberations*, MJA 201 (9) pp545-547