



## **CSPCP Brief on Advance Directives for MAiD**

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Canadian Society of Palliative Care Physicians (CSPCP) recommends against advance requests for MAiD for the following reasons:

- 1. People are poor at anticipating what life would be like with a life-changing illness or disability under circumstances they have not yet encountered.**
  - a. Consistent gaps exist between healthy and ill populations' ratings of their well-being living with disability or illness. This "disability paradox" (1) is not due to an exaggeration of quality of life (QoL) by disabled individuals, but rather the inaccurate predictions of non-disabled individuals. People predict whether their feelings would be positive or negative, but cannot predict the magnitude and duration of emotional shifts from baseline. Studies have shown we focus on what we lose, rather than what will stay the same or be gained (2,3). Society is full of stigmatizing images of illness and disability, depicting broken and unfulfilling lives. When studied, non-disabled people who know disabled people, view living with disabilities more positively—perhaps because of realistic examples to imagine how they themselves could cope.
  - b. Research shows that when faced with decisions one has had little or no experience with, we are prone to construct preferences based on current issues and feelings rather than long-held values and beliefs (4). How information is presented can significantly influence a person, and decisions can be swayed by framing, context and priming (5). Professional providers, especially those inexperienced in discussing future care with patients or not mindful of their own biases for treatment influence these effects. Advance care planning has thus moved away from deciding specific treatments patients would not want (CPR, feeding tubes, etc.) and focuses on beliefs and values to guide decision-making. Focusing on treatments that patients would/would not accept has shown that patients can end up refusing treatments that could restore good quality of life when temporarily acutely ill (5,6).

**2. People adapt to illness and disability, and shift their requirements for what constitutes a tolerable quality of life.**

- a. People with serious health conditions, from paraplegia or renal failure to cancer, consistently rank their wellbeing higher than healthy controls asked to imagine what living in that particular health state would be like. At time of diagnosis or acute event, people experience a reduction in wellbeing but return to slightly below baseline levels within a year or two. The adaptation process takes time but when complete, the person recovers their sense of wholeness and wellness. With symptom control, therapeutic support and the necessary social or disability supports, most people show surprising resiliency (7).

**3. The idea of an advanced directive for MAiD comes primarily from degenerative brain diseases in which there seems a loss of the sense of self and cohesiveness of identity.**

- a. People with cognitive impairment can self-report their QoL, related to degree of functional impairment and mood, not degree of cognitive impairment. Pain and symptoms have a negative effect on QoL, while social engagement, good relationships with caregivers, and spirituality/religious beliefs have a positive effect. QoL is consistently rated lower by caregivers, than by the person with dementia (PWD). However, there is frequent correlation between the two on what is affecting QoL e.g. pain, disease symptoms (8,9).
- b. The PWD's voice has not been front and center, probably due to the stigma of losing one's cognitive functions. PWD have written and spoken eloquently about their frustration being ignored in a hypercognitive society that makes worth and personhood entirely dependent on rationality. We demean those whose memory has dissipated by treating them with indifference or cruelty; we act as if they aren't there. In general, QoL is a self-fulfilling prophecy. If those around the person with dementia make no efforts to relate to the person in ways that enhance their experience, then QoL will be abysmal. People feel like dementia is a label that leads society to believe a person has less purpose and value (10).
- c. The role society plays in the care of PWD directly effects their QoL (11). Many living in dementia-friendly communities where they are valued for their emotional, relational, spiritual and creative selves, with technological aides to remind them of their identities and memories, can continue to live meaningful lives. A palliative approach to care ensures that symptoms are treated to maintain QoL and values are reflected in their goals of care for treatment of new issues.

**4. Many medical conditions have a long and unpredictable trajectory, and suicidality in these conditions can wane over protracted periods of time.**

- a. A study of patients with stroke, traumatic brain injury, and spinal cord injury (12) showed a higher risk of suicidal ideation than those of the general population even

two years after initial disease or injury. Suicidal ideation was most closely associated with the presence of clinical depression (13). Treating the depression resolved the suicidal ideation. In those with illness, treating depression and providing support to avoid social isolation is key to reducing the desire for death.

**5. Clear lessons from other jurisdiction's experience with carrying out advance requests:**

- a. Physicians have a hard time adhering to advance directives requesting hastened death without being able to reaffirm consent and establish the presence of current suffering. Family members tend not to support carrying out these advanced requests as they are also conflicted about whether their loved one is suffering and whether the current condition matches conditions specified in the advance request (14-16). In Canada, those who advocate for advance requests say the healthcare system should be responsible for managing the advance request rather than family caregivers. It should be beyond consideration that a publicly funded system would bear responsibility for carrying out this decision.

CSPCP recommends the Canadian Dementia Strategy, in collaboration with federal and provincial partners, make sustained efforts to change the culture of stigma around degenerative brain conditions. All those with degenerative brain conditions should have access to care in communities and facilities that allow them to continue to lead a meaningful life with supportive caregivers aware of the needs of people with dementia, practicing a palliative approach to care.

**References**

1. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med.* 1999;48:977–988.
2. Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med.* 2008;23(10):1708-1712. doi:10.1007/s11606-008-0719-5
3. Bosch GJVD, Roos RAN, Otten R, Bockting C, Smulders YM. Are patients accurate forecasters of their emotional response to medical conditions? A scoping review on affective forecasting. *BMJ Open.* 2021 Dec 6;11(12):e053370. doi: 10.1136/bmjopen-2021-053370. PMID: 34873009; PMCID: PMC8650486.
4. Barnato AE. Challenges In Understanding And Respecting Patients' Preferences. *Health Aff (Millwood).* 2017 Jul 1;36(7):1252-1257. doi: 10.1377/hlthaff.2017.0177. PMID: 28679812.
5. Volhard T, Jessen F, Kleineidam L, Wolfsgruber S, Lanzerath D, Wagner M, Maier W. Advance directives for future dementia can be modified by a brief video presentation on dementia care: An experimental study. *Plos one.* 2018 May 24;13(5):e0197229.
6. Ellis EM, Barnato AE, Chapman GB, Dionne-Odom JN, Lerner JS, Peters E, Nelson WL, Padgett L, Suls J, Ferrer RA. Toward a Conceptual Model of Affective Predictions in Palliative Care. *J Pain Symptom Manage.* 2019 Jun;57(6):1151-1165. doi: 10.1016/j.jpainsymman.2019.02.008. Epub 2019 Feb 19. PMID: 30794937.

7. Hole B, Selman L. Illness as Transformative Experience: Implications of Philosophy for Advance Care Planning. *J Pain Symptom Manage*. 2020 Jan;59(1):172-177. doi: 10.1016/j.jpainsymman.2019.02.025. Epub 2019 Mar 1. PMID: 30831239.
8. Burks HB, des Bordes JK, Chadha R, Holmes HM, Rianon NJ. Quality of Life Assessment in Older Adults with Dementia: A Systematic Review. *Dementia and geriatric cognitive disorders*. 2021;50(2):103-10.
9. Martyr A et al (2018). Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychological Medicine* 48, 2130–2139. <https://doi.org/10.1017/S0033291718000405>
10. Turning Up The Volume: unheard voices of people with Dementia. Alzheimer's Society of the United Kingdom 2017. Accessed at: [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/turning\\_up\\_the\\_volume\\_unheard\\_voices\\_of\\_people\\_with\\_dementia.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/turning_up_the_volume_unheard_voices_of_people_with_dementia.pdf) on April 26, 2022
11. Morgan, J. A better, safer, fairer world for people with dementia. *The Lancet Neurology* 2017; 16(8): 587-588 DOI:[https://doi.org/10.1016/S1474-4422\(17\)30210-7](https://doi.org/10.1016/S1474-4422(17)30210-7)
12. Tsaousides T, Cantor JB, Gordon WA. Suicidal ideation following traumatic brain injury: prevalence rates and correlates in adults living in the community. *J Head Trauma Rehabil*. 2011 Jul-Aug;26(4):265-75. doi: 10.1097/HTR.0b013e3182225271. PMID: 21734510.
13. Kishi Y, Robinson RG, Kosier JT. Suicidal ideation among patients during the rehabilitation period after life-threatening physical illness. *J Nerv Ment Dis*. 2001;189(9):623–628.
14. Groenewoud AS, Leijten E, van den Oever S, van Sommeren J, Boer TA. The ethics of euthanasia in dementia: A qualitative content analysis of case summaries (2012-2020). *J Am Geriatr Soc*. 2022 Feb 20. doi: 10.1111/jgs.17707. Epub ahead of print. PMID: 35187649.
15. Schuurmans J, Crol C, Olde Rikkert M, Engels Y. Dutch GPs' experience of burden by euthanasia requests from people with dementia: a quantitative survey. *BJGP Open*. 2021 Feb 23;5(1):bjgpopen20X101123. doi: 10.3399/bjgpopen20X101123. PMID: 33172849; PMCID: PMC7960528.
16. Kouwenhoven PS, Raijmakers NJ, van Delden JJ, Rietjens JA, van Tol DG, van de Vathorst S, de Graeff N, Weyers HA, van der Heide A, van Thiel GJ. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. *BMC Med Ethics*. 2015 Jan 28;16:7. doi: 10.1186/1472-6939-16-7. PMID: 25630339; PMCID: PMC4350907.