



Ethical Challenges in Substitute Decision Making

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The following discussion questions are provided as an additional educational tool to accompany this fireside chat video. Please feel free to select the questions that are most relevant to your committee or group, revise and adapt them as needed, etc. As always, we welcome feedback on this or any other NSHEN resource.

Questions:

- In your opinion, what is the biggest challenge associated with being a substitute decision maker (SDM)?
- Gail highlights the importance of establishing a good working relationship around decision making for patients who can't make health decisions for themselves.
 - What are some of the things that SDMs and health care team members can do to promote communication and a good working relationship around the goals of care for the patient?
- Gail talks about the importance of having support among other family members when acting as an SDM.
 - Who else might provide support for people in the SDM role?
- Substitute decision-making should reflect the patient's wishes and values.
 - What do SDMs do if the patient's wishes are not known?
 - Can you give some examples of what it means to make decisions based on someone's values?
 - How can families and health care teams ensure that the decisions that are made for the patient reflect the patient's best interest if the patient's wishes and values about the decision are unknown?
- What can SDMs do to prevent their own values and beliefs about health care from influencing the decisions they are making for someone else?
- What can the health care system and health care teams do to better support people in the role of SDM?
- People sometimes change their minds. What a patient once said they about what they would or wouldn't want may not apply in a new situation.
 - If you were to make health care decisions for someone else, how would you address this uncertainty?
- How can personal directives help the substitute decision making process?

Resources

Dawner, J. et al. (2017). Balancing the interest of patients, substitute decision-makers, family and health care providers in decision-making over the withdrawal and withholding of life-sustaining treatment - Improving the Last Stages of Life. Report commissioned by Law Commission of Ontario (2017). <https://www.lco-cdo.org/wp-content/uploads/2015/05/Downar-et-al.-Final.pdf>

Shalowitz DI, Garrett-Mayer E, Wendler D. The Accuracy of Surrogate Decision Makers: A Systematic Review. *Arch Intern Med.* 2006;166(5):493–497. <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/409986>

Tan, A., Manca, D. Finding common ground to achieve a “good death”: family physicians working with substitute decision-makers of dying patients. A qualitative grounded theory study. *BMC Fam Pract* 14, 14 (2013). <https://doi.org/10.1186/1471-2296-14-14>

Webster, G.C. and P. Murphy. “Section 1, 1.4 Substitute Decision Making”. Royal College of Physicians and Surgeons Canada. <https://www.royalcollege.ca/rcsite/documents/bioethics/substitute-decision-making-e.pdf> [document accessed on March 18, 2022]

Ya Su, Michiko Yuki, Kengo Hirayama. (2020) The experiences and perspectives of family surrogate decision-makers: A systematic review of qualitative studies. *Patient and Education Counselling*, Vol 103(6): 1070-1081. <https://doi.org/10.1016/j.pec.2019.12.011>

<http://dx.doi.org/10.1136/bmjspcare-2012-000250.62>

Brochures and Tools:

Ethics NSHA Tool: An Approach to Working Through Ethical Questions. Nova Scotia Health, 2017. https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwjv3IONzvj1AhV_kIkEHfnvAyIQFnoECAIQAAQ&url=https%3A%2F%2Fwww.cdha.nshealth.ca%2Fsystem%2Ffiles%2Fsites%2F87%2Fdocuments%2Fethics-nsha-tool.docx&usq=AOvVaw2yy-pxgtUyZY1GphYNcmBN

Informed Choice, Subject Guide for health care professionals, Nova Scotia Health <https://library.nshealth.ca/InformedChoice>

Frequently Asked Questions on Health Care Decisions. Public Trustee website, Nova Scotia Government. https://novascotia.ca/just/pto/FAQ_hcd.asp [Accessed March 21, 2022]

Making Personal Care Decisions for a Loved One Under the Personal Directives Act, Nova Scotia. https://novascotia.ca/just/pda/docs/Personal_Directive_3-panl_brochure.pdf

[This brochure specific to the Nova Scotia Personal Directives Act, but also relevant for SDMs who are the highest on the statutory list]

Patient and Family Ethics Tool, Help with Ethical Issues.. Patient and Family Guide. Ethics Nova Scotia Health.2020. <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/2056.pdf>

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