



Ethics and Surrogate Decision-making

Julie Clegg, Parent and Member, IWK Health Family Leadership Council & Van Bernard, Patient

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:

- What stood out the most to you in this interview and why?
- Van's parents were encouraged by Van's medical team to involve Van in medical decision-making from a very young age. At what age do you think children should be involved in the decision-making process around their health care?
- What are some of the concerns that parents might have about involving their child in health care decision-making when they are as young as 7 or 8 years old?
 - How might you address some of these concerns as a health care provider?
- Van's parents and his medical team supported Van in various ways to enable him to work through his concerns and make decisions together with his parents around his health care. What are the benefits of this family centered approach to decision-making?
- Sometimes medical decisions need to be made urgently. How might you best support pediatric patients and their parents making health care decisions under time pressure?
- Van describes how he has become more knowledgeable about health care decision-making and how benefits and risks must be weighed in each decision. How does Van's extensive experience with health care decisions make responses to his decisions potentially different from how a health care team might approach a similarly-aged peer who is encountering health care decision making for the first time?

Resources.

Coughlin, K.W. (2018) Medical decision-making in paediatrics: Infancy to adolescence. *Paediatrics & Child Health*; 23(2):138–146. <https://doi.org/10.1093/pch/pxx127>

IWK health Centre: Patient and Family Centred Care. <https://www.iwk.nshealth.ca/pfcc>

Nemours Kidshealth: Giving Teens a Voice in Health Care Decisions. Website information reviewed June 2018. <https://kidshealth.org/en/parents/teen-health-care.html>

Harrison, C. Kenny, N.P., Sidarous, M., Rowell, M.(1997) Bioethics for clinicians: 9. Involving children in medical decisions. *CMAJ*; 156(6): 825–828. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1227047/>

Hopkins, K.A., Ott, M.A., Salih, Z., Bosslet, G.T., Lantos, J. (2019) When Adolescent and Parents Disagree on Medical Plan, Who Gets to Decide? *Pediatrics* 144(2): e20190291 <https://doi.org/10.1542/peds.2019-0291>

Lang, A. and Paquette, E.T. (2018) Involving Minors in Medical Decision Making: Understanding Ethical Issues in Assent and Refusal of Care by Minors. *Semin Neurol* 38(05): 533-538. <https://www.thieme-connect.com/products/ejournals/abstract/10.1055/s-0038-1668078>

Schuck, P. (2020). “How I’m Raising My Kids To Be Health-Care Self-Advocates.” CBC Parents, Published on November 6, 2020. <https://www.cbc.ca/parents/learning/view/how-im-raising-my-kids-to-be-health-care-self-advocates>

World Health Organization (2021) Assessing and supporting adolescents’ capacity for autonomous decision-making in health care settings: a tool for health-care providers. <https://apps.who.int/iris/rest/bitstreams/1398813/retrieve>

Websites:

For further information on Spinal Muscular Atrophy, see: [Home - Cure SMA](#)

Some articles require access with an institutional login. If you need assistance in accessing an article please email NSHEN administrator Krista Mleczko-Skerry at Krista.MleczkoSkerry@iwk.nshealth.ca