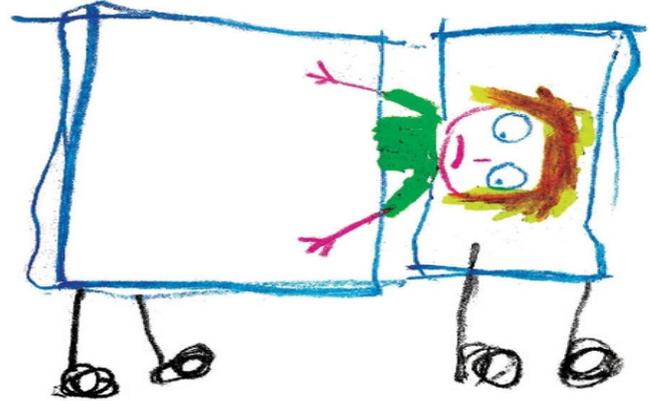




# Should patients be told they are terminally ill?



(BMJ, 2013; 346:f2589 doi: 10.1136/bmj.f2589)

## **YES** (E. Collis & K.E. Sleeman) <sup>1</sup>

Collis and Sleeman argue in favour of telling the patient based on the principle of respect for autonomy. Giving patients the full picture of their disease trajectory offers the possibility of timely, non-crisis oriented advance care planning. Outcomes may include a power of attorney document, finalizing financial arrangements, naming a decision-maker, clarifying wishes regarding place of death, and determining goals of care. Patients have the right to any information that might aid in this decision-making unless such information would cause undue hardship or suffering. Withholding this information, partially disclosing it, or disclosing in a biased manner has the potential to undermine trust, autonomy, and quality of life and possibly increase the patient's sense of isolation and anxiety.

## **NO** (L.J.Blackhall) <sup>1</sup>

Blackhall argues against telling the patient his/her prognosis based on the principle of respect for autonomy being an outmoded justification. The author suggests such disclosure can lead to unnecessary suffering, thus undermining principles of beneficence and non-maleficence. She argues that a lack of consensus on the definition of the "terminal" phase in many illnesses results in no consistency about when such a disclosure should be made. She also suggests that "choice" is a misguided concept because end-of-life is so unpredictable that reality seldom aligns with the sort of "choices" described in advance care planning discussions. Blackhall suggests that the real goal should be a "best care" discussion encompassing what can be done, the risks and benefits of each option along with the potential trajectory of the patient's illness. Interventions that have little chance of a positive outcome, such as options for which the burdens outweigh the benefits, should be excluded from this discussion because they unreasonably muddy the decisional waters.

## **SYNTHESIS**

A simple "yes-or-no" argument cannot adequately address the issue of truth-telling in the highly complex, uncertain context of terminal prognosis. In a health care culture and system attentive to values of patient/family-centred care and shared decision-making, truth-telling is better considered as a continuum rather than an either/or choice.

The goal then becomes one of ensuring patients (or their delegates) receive the information they want in a timely, accessible way. A number of years ago Benjamin Freedman, an ethicist at the Jewish General Hospital in Montreal, described this



approach as “offering truth.” It requires a practitioner-facilitated dialogue with the patient to discern what, how much, when, and with whom prognostic and treatment information should be shared. This discussion should be revisited often over the course of a terminal illness because information preferences may shift as symptoms advance. Offering truth honours the goal of patient-centredness as the practitioner seeks to balance respect for autonomy with non-maleficence and beneficence, thereby enabling patients to set their own clinical information agendas<sup>3</sup>. While the when of the dialogue is important, the how is equally so. “While the truth may be brutal, the telling of it should not be.”<sup>4</sup>

As in any informed choice process, a dialogue with the patient (or delegate) about a terminal illness should include an accessible description of disease trajectory, possible treatment options (including doing nothing), the associated potential benefits and burdens, relevant uncertainties, recommendations based on best practice, and the practitioner’s clinical insight. While a patient (or delegate) has the right to refuse any and all treatment options/recommendations, the reverse is not true; a practitioner does not have a reciprocal obligation to provide a treatment just because the patient (or delegate) requests it.

Interestingly, results from a recent study<sup>2</sup> on possible effects of awareness of a terminal diagnosis on care decision-making and achievement of a good death suggest that such awareness can be associated with reductions in discordance in care-related decision-making and enhanced patient voice. Study results from the Good Death Inventory indicated better scores related to “control over the future” and “maintaining hope and pleasure” for those patients who were aware of their diagnosis. Such evidence highlights the importance of continuing to seek the most right answer to questions about when, how, and to whom to offer truth concerning terminal prognosis.

Submitted by Cathy Simpson, NSHEN Ethics Collaborations

## References

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2. Ahn, E., Shin, D.W., Choi, J.Y., Kang, J., et. al. (2013). The Impact of Awareness of Terminal Illness on Quality of Death and Care Decision Making: A prospective nationwide survey of bereaved family members of advanced cancer patients. *Psycho-Oncology Online*, Vol 22 (12): 2771-2778.
3. Kogan, N. (2005). Offering Truth: the Ethics and Angst of Informing Patients. *Benjamin Freedman Newsletter for Patients and Families, The Sir Mortimer B. Davis - Jewish General Hospital*, Vol 13.
4. Hebert, P., et al. (1997). Bioethics for Clinicians 7: Truth Telling. *CMAJ*, Vol 156 (2): 225-228.

Questions?  
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**Here are some reading recommendations about truth telling:**

1. Glass, E & Cluxton, D. (2004). Truth-telling: Ethical issues in clinical practice. *Journal of Hospice and Palliative Nursing*, 6(4): 232-243.
2. Gillotti, CM. (2003) Medical Disclosure and Decision-Making: Excavating the complexities of physician-patient information exchange. In TL Thompson, AM Dorsey, KI Miller, & R Parrot (eds). *Handbook of Health Communication* (pp163-181). Mahway, NJ: Lawrence Erlbaum Associates, Inc.
3. Tuckett, AG. (2004). Truth-telling in clinical practice and the arguments for and against: a review of the literature. *Nursing Ethics*, Sep; 11(5): 500-13.
4. Bergum, V and Dossetor, J. (2005). *Relational Ethics: the full meaning of respect*. Hagerstown, MD: University Publishing Group.

## NSHEN: Upcoming Events...

**March 2-8, 2014** The Canadian Bioethics Society, in collaboration with NSHEN, will present the first ever National Health Ethics Week. NSHEN will also be coordinating a provincial event - stay tuned for details.

The theme of this National Health Ethics Week 2014 is Health Ethics from Coast to Coast to Coast. It invites participants to consider what health ethics issues are most relevant to their community or organization and why.

All organizations, groups, and individuals who are interested in health ethics issues are invited to participate. To register, please download and complete the registration form found here <https://www.bioethics.ca/resources/NHEW/NHEW%20registration%20form.pdf>, or contact Amy Middleton, National Health Ethics Week Coordinator, [ethicsweek@bioethics.ca](mailto:ethicsweek@bioethics.ca)

For more information please visit the National Health Ethics Week information site <https://www.bioethics.ca/ethicsweek>

**April 14, 2014** CEC Follow-up Workshop. For individuals who participated in the beginner CEC workshop this past year. This event will be in Truro, NS. Registration is now open. Please check our website.

### What Makes NSHEN Unique?

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- \* Our collaborative structure facilitates dialogue between partners
- \* Our strategic goals are collectively established by the collaborating partners
- \* NSHEN involves academia, government, and health care organizations in a single network

This results in a network that is innovative, efficient, and responsive to ethics needs in Nova Scotia.