

Having Conversations with Patients about Serious Illness

By Dr. Anne Frances D'Intino, MD, CCFP, FCFP, MScPallMed, Palliative Care Physician, Eastern Zone, Nova Scotia Health Authority

...most patients want their health care provider to give them honest information about their disease, its progression and prognosis.^{1,4,5}

Background

Conversations about serious illness between patients and their health care providers are essential to providing care that aligns with the goals, wishes, and values of patients.¹ Evidence has demonstrated that patients who are engaged in early and iterative conversations about their goals of care are more likely to be satisfied with their care, will require fewer aggressive interventions towards end-of-life, and are more likely to take advantage of hospice resources or to choose to die at home.^{1,2} Having ongoing conversations about serious illness enables patients and families to

interact in a shared decision-making process about preferences for care.¹⁻³

Despite common misconceptions, most patients want their health care provider to give them honest information about their disease, its progression and prognosis.^{1,4,5} Research has demonstrated that 'hope' is not lost when facilitating conversations about serious illness as patients' definition of 'hope' can hold many different meanings.³ For example, 'hope' may not only be for cure, but may also be to live longer than expected, to have a good quality of life, to achieve personal goals, or to have a peaceful death.^{4 (p467)}

Key Points: "Best Practice for Conversations About Serious Illness"^{1 (p2001)}

- ▶ Patients want the truth about prognosis.
- ▶ You will not harm your patient by talking about end-of-life issues.
- ▶ Anxiety is normal for both patient and clinician during these discussions.
- ▶ Patients have goals and priorities besides living longer.
- ▶ Learning about patient goals and priorities empowers you to provide better care.

...health care providers should confirm the patient is comfortable having the discussion by first asking permission.¹⁻⁵

Background (cont'd)

As patients' health status changes or declines over time, conversations between patients and their health care providers will become more focused,⁵ changing from "What if something happens" (advance care planning), to "What if this happens" (goals of care), and finally "This is happening" (decision making). **Figure 1** illustrates how a conversation about serious illness will address advance care planning, goals of care and decision making at various points in time.

The Role of Family Physicians and other Primary Care Providers

Your longstanding relationship with your patients puts you in an ideal position to facilitate conversations with them about serious illness.⁵

When to have a Conversation about Serious Illness¹

Common situations may trigger a conversation with patients about serious illness:

- Realizing you would not be surprised if your patient died within the next year
- Noticing a recent functional decline in your patient
- Being aware that your patient is receiving third-line chemotherapy.

Prior to initiating conversations about serious illness, health care providers should confirm the patient is comfortable having the discussion by first asking permission. Then, the provider should ask what type and how much information the patient wants.¹⁻⁵

Figure 1: The Various Levels of Communication Between Patient and Provider



Health care providers are encouraged to begin engaging patients in these conversations early in the disease trajectory.

Available Tools to Assist in Initiating and Facilitating Conversations About Serious Illness

The *Serious Illness Conversation Guide* resources are tools designed to trigger conversations about serious illness.

The primary goal of these tools is to assist with communication regarding care preferences between health care providers, patients and their families.¹ Three conversation guides, outlined below and included with this publication, may be helpful resources.

The Serious Illness Conversation Guide (practitioner conversation tool)

Assists health care providers to confirm the patients' understanding of their illness and decision making preferences, provides conversational tips on how to share prognostic information according to patient preferences, explores the goals, fears, views on trade-offs and impaired function, and addresses the patients' wishes for family involvement.¹

Talking with your clinician about the future (patient conversation tool)

Guides patients to review and reflect on the issues important to them prior to their appointment with their physician.¹

Talking about your illness with loved ones and caregivers (patient/family conversation tool)

A resource to help patients discuss their values and goals with their loved ones or caregivers.¹

Conclusion

Considering Nova Scotia's increasingly aging population, and the growing number of individuals who are living longer with advanced illnesses, it is essential that health care providers feel prepared to have conversations with patients about their goals within the context of serious illness. Early and ongoing conversations help ensure that patients receive care that is in line with their wishes.¹⁻⁵ The *Serious Illness Conversation Guides* are effective for initiating and facilitating a conversation about serious illness and may be a helpful resource in your practice. Additional resources are described below.

Supporting Resources

Ariadne Labs: Serious Illness Community of Practice

The Serious Illness Care Community of Practice is a private space for collaboration between interdisciplinary teams. This virtual community provides sharing of experiences and lessons learned from those who have implemented the Serious Illness Conversation tools in practice, and provides access to materials such as videos and webinars.

<https://portal.ariadnelabs.org>

Vital Talk

Vital Talk specializes in developing and facilitating advanced communication skills courses and faculty training courses focused on balancing honesty and empathy with having a conversation about serious illness. This resource also provides access to conversation learning videos.

<http://www.vitaltalk.org/clinicians>

Nova Scotia Health Authority Library Guides: Conversations About Serious Illness

To learn more about Serious Illness Conversations, and to access resources and tools to further enhance your understanding of these conversations, visit 'Conversations About Serious Illness' through NSHA's Library Guides. <http://library.nshealth.ca/SeriousIllness>

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Cancer Care Nova Scotia is part of the Program of Care for Cancer. Its mandate is to evaluate, coordinate and strengthen the cancer system in Nova Scotia.

Cancer Care Nova Scotia works with and supports professionals and stakeholders in the health care system to bring about patient-centred change. Its ultimate goal is to reduce the burden of cancer on individuals, families, communities and the health care system.

In Practice is written specifically for primary care practitioners with information that we hope will make a difference in your cancer practice.

Please contact Christine Smith, Communications Manager, Program of Care for Cancer, by phone at 902.473.2932 or by email at christine.smith@ccns.nshealth.ca with comments or suggestions for future topics.



1276 South Park Street
5th Floor Bethune Building
Halifax, NS B3H 2Y9

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Conversations About Serious Illness Workshop

Tips and Tools for Identifying Patient-Centred Goals (available across Nova Scotia)

This three-hour workshop is designed to increase health care providers' comfort and skill in having conversations about goals of care within the context of a serious illness. Learners are guided through the evidence, rationale and importance of conversations about serious illness in cancer patient care and are introduced to using the *Serious Illness Conversation Guide* resources in their practice. This Workshop is in the process of being CME accredited.

For dates and locations of upcoming workshops, contact ccnsadmin@nshealth.ca.

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References

1. Bernacki R & Block S. Communication about serious illness care goals: a review and synthesis of best practice. *JAMA Intern Med.* 2014; 174(12): 1994-2003.
2. Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families and healthcare providers. *Psycho-Onc.* 2016; 25: 362-386.
3. Larkin J, Block S, Billings A, Koritsanszky L, Cunningham R, Wichmann L et al. Improving communication about serious illness in primary care: a review. *JAMA Intern Med.* 2016; 176(9): 1380-1387.
4. Clayton J, Hancock K, Parker S, Butow P, Walder S, Carrick S et al. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Onc.* 2008; 17: 641-659.
5. Brighton L & Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J.* 2016; 92: 466-470.

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