

Management of hope

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Margaret is 68 years old. She met her family physician 8 years ago when she presented with a lump in her neck. A biopsy confirmed lymphoma. She underwent chemotherapy and eventually a stem cell transplant. Recently, Margaret began having night sweats and increasing fatigue; widespread recurrence of her lymphoma was found. She returned to her family physician, with whom she had remained connected over the past 8 years. "I've been to the cancer clinic," she said. "There's no hope."

Hope has many definitions. Cassell states: "Hope is one of the necessary traits of a successful life. It ties into what we expect out of life as well as what the meaning of life is for us."¹ Nuland says that "hope is the anticipation of a good that is yet to come."² According to Sullivan, hopelessness is not an absence of hope, but rather an attachment to a form of hope that is lost.³ The absence of hope is not a state of "no hope," but rather one of fear and despair, the root of which is often related to losing a sense of life's meaning and purpose.

A number of sources of distress can lead to hopelessness and increased suffering. The concept of *total suffering* is described by Woodruff as encompassing the entire illness experience, including physical pain, other physical symptoms, psychological distress, social distress, and spiritual distress.⁴

Hope during the cancer experience changes over time; this is expected to be similar in other advanced diseases. Initially, there is hope that the lump (or fatigue, or blood in the stool, etc) is nothing to worry about. Then there is hope that there is treatment for the newly diagnosed problem. During therapy, there is hope that the treatment will be effective. If the cancer recurs and disease-directed treatment is no longer possible, many individuals will state that there is no hope. It is often difficult to get beyond this point, but most individuals and families eventually do. They manage to reframe their hope: hope for their children and grandchildren, hope for symptom control and a peaceful death, hope for meaningful time remaining, and hope for an afterlife, for example. Many writers have identified that in the time near the end of life, our focus shifts from doing to being. The general notion of hope, as well as individual specific hopes, reflects that shift.

One thing is certain for both patients and caregivers: None of us will get everything we hope for. The struggles that occur because of this certainty will actually help our hope mature. It is most helpful to have hope open to

possibility. Setting all of our sights on curing a realistically incurable disease will eventually result in failure, stalling or blocking the possibility of healing, even in the face of death.

A source of hope

Patients understand and interpret the language used by physicians in various ways. Margaret's case highlights this. Patients who return to their family physicians for palliative care often believe they have been let down. The family physician is well positioned to help the patient "pick up the pieces" and reframe hope.

Patients should be able to count on their physicians as sources of hope. Although it can be challenging, hope can be fostered at every patient visit. There is an important difference between fostering hope and ignoring, avoiding, or even denying the issues that create or destroy hope. Most individuals are keen to talk about their illness experiences. Avoiding or ignoring the issues indicates to our patients that we are not interested in their worries. Denying the issues through false reassurance confuses our patients, essentially telling them that they should not believe what they think is happening to them. In either case, we destroy trust and contribute further to hopelessness. It is within trusting relationships that reframing hope is possible, because in those relationships it is safe to grieve.³

A key to fostering hope is acknowledging the fears present in all of us as we struggle through difficult times or approach the end of our lives. Being open to discussing those fears fosters hope in all of us.

Nekolaichuck and Bruera⁵ have described one framework to assess hope in patients. **Table 1**⁵ is a hope-assessment framework. Questions are categorized by meaning, tolerance for uncertainty, and relationships; these questions might make it easier to discuss hope.

Fostering hope in patient encounters

- Increase self-awareness.
- Learn to be attuned to the issues the patient wants to address and discuss them.
- Acknowledge fears.
- Take time.
- Listen with an openness to learn from patients.
- Acknowledge the person behind the symptoms.
- Communicate honestly, in ways that enhance trust.
- Get help; use available resources.
- Encourage and celebrate small successes.
- Arrange follow-ups.

Table 1. Hope-assessment framework: Questions for clinical practice.

CATEGORY	REFLECTION	QUESTIONS TO ASK PATIENT
Meaning	What is meaningful for this person?	<ul style="list-style-type: none"> • How have you been able to take stock of your life? • What has been meaningful to you in the past? • What is meaningful to you now?
Tolerance for uncertainty	What is this person's tolerance for uncertainty?	<ul style="list-style-type: none"> • How have you dealt with uncertain times in the past? • How have you been able to handle the uncertainty of having cancer? • How, if at all, has your view of time changed?
Relationships	Who cares about this person? Does this person care about someone (or something)?	<ul style="list-style-type: none"> • Who cares about you? • Who (or what) do you care about?

Information from Nekolaichuk and Bruera.⁵

Hope is not something that can be forced. Its development might require great patience. Perhaps one of the most important things we give to our patients is our time. Active listening requires time. By listening to and trying to understand our patients' stories, we validate them, providing a safe place to allow the process of grieving to begin or develop. Finding out who a patient is (his or her past and present) and discovering what is important to the patient is key to what has been described as dignity-conserving care.⁶ As we listen to our patients, it is helpful to identify our own issues and feelings and set them aside so they do not get in the way of the development of our patients' hope.

In the face of reality

Over time, you can ask questions that might help patients find hope and meaning in their dying: "What would you still like to accomplish?" or "What would be left undone if you were to die early?" There is often the opportunity to help patients establish more realistic hopes and goals, or recognize alternative ways to achieve them. As well, general encouragement reinforces hope. Look for something specific to encourage—small successes are worth celebrating.

Hoping and coping are linked. Those with higher levels of hope have better coping skills. Those who cope well have more hope than those who do not. Helping our patients hope and cope calls for a team effort. As physicians, we need to acknowledge our limitations and collaborate with team members from other

disciplines, including nursing, psychosocial oncology, pastoral care, and volunteer groups.

Reality must be balanced by compassion. It is important to avoid creating "false hope." Encouraging hope in something very unlikely to occur will usually be incongruent with how the individual feels physically. This breaks down trust, a cornerstone of hope. Even if the individual is willing to put all of their hope into an unlikely outcome, the more realistic outcome, when it happens, will result in more stress and, again, a breakdown of trust.⁷ False hope reflects our own pain; it is a lie to ourselves. At the same time, truthful disclosure without a balance of compassion will erode the relationship and might result in a situation of "false no hope."

Closing time

As illness advances, there is progressive loss of control and independence. Help to foster as much independence as is possible. Build on existing support systems, especially friends and family. Remember to arrange follow-ups. Consider telephoning in between visits to make sure pain and other symptoms are under control. As patients deteriorate and find it more difficult to get out, intermittent home visits are a welcome alternative and will help them conserve their energy.

In palliative care, the unit of care includes not only the dying individual, but also the family. A further challenge is to deal with the hope of family members, which might be vastly different from the hope of the patient and one another. Although it can be difficult, the ultimate goal for families is the best care for their loved ones. This can be used effectively as a starting point to develop a mutually agreed-upon plan of care. Willingness to be with families, to listen actively, and to hear and discuss their questions and struggles will help families come to a new collective vision of hope.

After a number of visits with her family physician, Margaret reframed her hope, looking at shorter, attainable goals. She had wished to take a trip to Europe. After discussion and planning, she and her husband chose to travel to the East Coast of Canada instead. She enjoyed the summer at a friend's cottage with her family. She spent time with her 2 granddaughters, creating scrapbooks and communicating her hopes for them.

Margaret's condition deteriorated slowly. She saw her family physician regularly—first at the office, then, when she found it more difficult to get out, at weekly home visits. When she became weaker, home-care nursing was involved, and the local palliative care program arranged for her to have regular visits from a volunteer, who helped provide emotional support. Margaret experienced the attention and love of her family, who was with her even in her dying hours.



BOTTOM LINE

- Providing care at the end of life gives physicians the opportunity to witness a transformation of hope within the context of multiple losses and suffering.
- By helping patients reframe and increase their hope, patients and their families can better cope with serious illnesses. This is important work, and it can be very rewarding for all involved in treating patients and their families.

POINTS SAILLANTS

- Dispenser des soins en fin de vie donne aux médecins la possibilité d'être témoins d'une transformation de l'espoir dans le contexte de pertes et de souffrances multiples.
- Les patients et leur famille peuvent mieux faire face aux maladies graves si on les aide à recadrer et à accroître leur espoir. C'est un travail important qui peut être très enrichissant pour tous ceux qui participent au traitement des patients et de leur famille.

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Competing interests

None declared

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Fast Facts from the National Physician Survey on family physicians in palliative care is available at www.cfp.ca. Go to the full text of this article on-line, then click on CFPlus in the menu at the top right-hand side of the page.

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