



Hope and Denial

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What is hope?

For people who are healthy, hope is linked to the future and to the plans and wishes you have for the future. A serious illness puts question marks over how much future you will have and what it will be. It threatens your control over your future. This loss of control can be one of the most difficult aspects of serious illness and may cause you to feel hopeless.

You may wish to focus on positive things that can be done about your illness and not think about the worst possibilities. This positive way of looking to the future is hope.

You and your family may feel your hopefulness challenged when you are referred from acute care to hospice palliative care. You may feel that your treatment team has given up on you and is telling you that your situation is hopeless.

You may find it helpful to share your inner struggles with family members, a trusted friend, a spiritual care provider, your doctor or another health care provider. Voicing your concerns about receiving palliative care will help you prepare for the change and may help you find some new ways of seeing hope in your situation.

What can I hope for?

Your illness has moved into your life like an unwelcome guest, changing your way of life and your plans for the future. When you had your first symptoms, you may have hoped that they would turn out to be nothing to worry about and that your life would go on as usual. When you learned you had a serious illness, you may have hoped that the treatment would take care of this intruder in your life. Perhaps that is still your hope – but you may be holding your breath whenever you have checkups, wondering whether your treatment has been successful or is working. To make things even more complicated, family members may have different expectations and may hope for different things.

How hope may change as illness progresses

- **Diagnosis**

The focus of hope often changes during a serious illness. Initially, you focus on what has gone wrong with your body and on your hope to restore your body to physical health. You hope that your treatments will work or that perhaps some new drug or treatment will cure you or prolong your life.

- **When a cure is not possible and illness progresses**

If it becomes clear that there is no cure, your hope may shift to living the rest of your life as well as possible. There is the hope to love and be loved, to feel good about the life you have lived, and to live in the present moment with satisfaction and a measure of peace. On the other hand, if you find yourself fighting for a cure when all indications are that your illness cannot be treated, you may find it difficult to find hope in day-to-day life.

- **As death approaches**

If your illness continues to worsen, your hope may focus on the timing of your death and the circumstances surrounding it. You may try to answer questions like this:

- *"Will I be able to experience an important personal or family event before dying?"*
- *"Where will I die?"*
- *"Will my symptoms be well controlled and my death be peaceful?"*
- *"Who will be with me when I die?"*

Your hope may also shift to finding meaning in the mystery of death and to affirming beliefs about life after death.

What is denial?

Denial is avoiding thoughts and feelings that are painful or that you cannot deal with. It occurs to some degree in everyone who has a serious illness. It is a shock absorber that helps you bear an overwhelming situation and cope with it.

Can denial be good or useful?

Denial can help you to deal with your illness in a hopeful way. It helps you to focus on the things that you have control over and to ignore those you do not. It encourages you to take a problem-solving approach to your illness and to expect that something positive will come out of your efforts.

When can denial be a problem?

Denial can be a problem if it hurts your ability to make decisions about your care or treatment. Denial may cause you to delay checking out symptoms or beginning treatments and in this way it could increase your medical problems. Denial may lead you to insist on continuing treatments that have proven ineffective in curing or slowing your illness. Denial is at work if you (or your family) claim that you have been cured while your illness grows visibly worse.

Hope and denial working together

Even if you want your medical team to be completely open with you about your health situation, you may later block out overwhelming information. When you talk with your friends and family about your diagnosis, treatment or prognosis, you may emphasize the positive aspects and not mention the more disturbing ones. These are signs that hope and denial are active within you, carrying on a discussion that helps you cope with your illness and the changes it has brought into your life.

How can I maintain hope?

You can promote hope during advanced illness in a variety of ways. No one way is right for everyone, but some of the following might be helpful.

Caring relationships

Knowing that others genuinely care about your well-being sustains hope. One or two of these suggestions may feel right for you.

Explore ways that you and your family can help each other through the changes the illness has brought into your life.

into your life.

- You may need to plan for changes in family roles and routines.
- You can look for opportunities to discuss the questions, thoughts and feelings that arise.
- You can arrange to do things together that you enjoy, preventing your illness from taking over your life completely.

Let your caregivers know how they can provide compassion and guidance in their care. For example:

- Discuss concerns you may have about your physical appearance, control of your symptoms, home care, changes in your physical abilities or mental state.
- Ask for a family conference with the health care providers to discuss decisions that need to be made about your care.
- Ask your health care providers for information you need and for explanations about things you don't understand.

Telling your story

Reminiscing and sharing your life story are hope-filled activities. When you tell stories from your life, you affirm the life you have lived. When others listen attentively to your life story, you know that you will continue to be remembered.

- Sometimes the sharing of simple interests, hobbies, or customs are ways to begin sharing your life story.
- Giving gifts, such as a favourite recipe or a special keepsake, can be an important way to pass on your heritage to future generations and create hope.

See also: [Sharing your Story](#)

Pain and symptom management

Managing pain and symptoms helps to maintain hope. Make sure you communicate your comfort level as clearly as possible to the health care team.

Emotional, spiritual or existential distress can make physical symptoms hard to treat successfully. Anxiety, for example, can influence shortness of breath as well as nausea. If you have difficulty accepting your illness and experiencing life satisfaction in the midst of your physical symptoms, make sure you tell your health care team about that too.

Humour and play

Laughter and play can change your perspective and inspire hope. Put humour and playfulness into your illness by:

- using humorous video or audio tapes
- telling jokes
- swapping amusing stories
- playing with pets.

Short-term goals

Setting short-term, flexible, realistic and measurable goals is necessary for hopefulness. Such goals help you maintain a sense of control over part of your life and strengthen your self-esteem.

- Make sure your family members and medical workers are aware of your goals and doing what they can to help you accomplish them.
- Be prepared to change your goals if your illness worsens.

Spirituality

Your personal spirituality and/or your connections to your faith community may offer you great comfort, strength, and hope. Your spiritual beliefs can give you a basis for courageous trusting in the midst of illness and in the face of death. Your spiritual practices and/or religious rituals can strengthen your sense of connection to a higher entity.

If you are experiencing spiritual pain or distress, spiritual care providers may be able to offer help through:

- meditation and relaxation exercises;
- spiritual (pastoral) counselling for the exploration of the meaning of illness and health;
- prayer for comfort and healing;
- readings (sacred scripture or other) addressing illness, healing, comfort, reconciliation;
- sacred touch, healing touch, therapeutic touch, Reiki;
- music (sacred or other);
- worship and/or ritual with members of your spiritual community;
- visits from leaders and members of your spiritual or faith community.

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