

“Psychology Works” Fact Sheet: End of Life

Psychological Distress and Coping with Serious Incurable Illness

When people become seriously ill, they are often immersed in an intense process of medical testing and treatments. They may be overwhelmed with navigating a complex health pathway and unfamiliar medical language.

Understandably, this unfamiliar illness pathway affects different parts of people’s physical, emotional, social, and spiritual lives. It can have a profound psychological impact. For example, medical testing may be a time of real worry, as one prepares for the possibility that the illness is very serious. After diagnosis, there may be a period of shock, as well as anxiety, fear, and for some, anger.

Medical treatments may bring about troubling side effects, perhaps with no certainty of a cure. People may experience several changes over time that increases psychological stress. These include declining physical function, changes in family and social roles, increasing dependence on the health-care system, and the potential threat of death.

People use different coping strategies during these stressful times. Coping styles may range from trying to avoid reminders of the illness to thinking about it all the time.

People who adopt more active coping strategies, such as seeking support from others, constructive problem-solving, and finding positive meaning, tend to show the best adjustment.

Most people who are told that they have an incurable illness experience some periods of anxiety, sadness, and grief. As their health declines, they may experience many emotions, in anticipation of their own death. These can all be considered part of a normal coping process, albeit a very difficult one.

For many seriously ill people, however, these emotions can become quite overwhelming. For example, it has been estimated that about 1 out of 4 people with incurable cancer will develop depression or anxiety disorders.

These problems are important to recognize and treat, as they are very distressing. They also make it more difficult to manage physical symptoms and to face the wide range of concerns involved in preparing for the end of life.

Occasional, passing wishes for death are relatively common among individuals who are living with incurable illnesses. For some, requests for end-of-life measures are consistent, and are associated with physical and emotional suffering.

For some, considering a hastened death in a hypothetical way, might be comforting if the symptoms of their illness become unbearable. For others, dying brings about a great level of despair, and psychological support can help manage this despair. Some, who are ready for death, have prepared themselves for it as best they are able, and are ready to discuss end of life options with their medical team. Medical options

for end of life could include ceasing treatment, do not resuscitate orders, or Medical Assistance in Dying, which became legal in Canada in 2016.

Quality Health Care at the End of Life

What do people want from the health-care system at this stage? First and foremost, patients say that they want adequate treatment for their pain and other symptoms.

They want to take part in treatment decisions to maintain a sense of control and to be treated as a 'whole person' by professionals. Most people want truthful information, given in a way that is respectful of their hopes and fears.

They also want to be prepared for their own death, having achieved a sense of completion in their lives.

They want their families to have a decreased burden of care. Wherever possible, they would like to resolve any conflicts and be able to say goodbye, hoping that their families and other significant relationships will be okay.

How can Psychologists Help?

The care of people with serious incurable illness is complex. It often requires contributions from several different kinds of health professionals working together in a team, each bringing special skills. Psychologists can be involved in the following ways:

Stress Management

Different types of relaxation therapies may help people calm down, sleep better, and separate themselves from the stress of physical symptoms.

Problem-Solving

People with incurable illness have issues with declining health. They also have practical concerns, such as managing finances, keeping their households running, and supporting others who also must cope. Some psychological interventions involve help in setting priorities, breaking problems down into manageable parts, and finding solutions.

Counselling Support

Counselling can provide people with a non-judgmental, confidential relationship. They can speak openly about any personal issues that may be troubling them. These may include fear, anger, and guilt, as well as distress around changes in appearance or function, or concerns about family members.

Family Therapy

Families handle stress in different ways. For some, there may be a history of conflict. Others may have a general style of avoiding the expression of deep emotion. Within a family, members may not all come to a place of acceptance of a person's illness at the same time. Family therapy could help all members face their challenges together by opening genuine communication.

Psychotherapy

Different types of psychotherapy can be helpful for people with incurable illness.

Supportive-expressive psychotherapy encourages people to express and explore their deep-seated worries and concerns. It helps them identify personal ways of dealing with illness and acknowledges efforts to live meaningfully in the time remaining. This is often done in a support-group format with other people with incurable illness.

Cognitive-behavioural psychotherapy helps people to be realistic in their judgement of situations. It challenges them to think differently when their negative thoughts start to become a major cause of distress. It also encourages people to stay engaged in pleasurable activities as long as they are able. Achieving small goals can contribute to an ongoing sense of fulfillment.

Supportive therapy. In addition to supportive-expressive and cognitive-behavioural psychotherapy, there are other supportive approaches that can be helpful.

Meaning-centered therapy: The view of a 'good death' is very personal and can vary from one person to the next. For some people, a 'good death' means that symptoms are well controlled and that important psychological, social, and spiritual concerns have been addressed at the end of life.

People want to feel that their lives have made a difference. They want to know that they have touched others in meaningful ways, and that they will leave a legacy that lasts beyond their physical presence.

Hope-focused therapy enables people to identify and enhance hope in their lives, without denying the reality of the severity of their illness. Different strategies can be used to help with recalling special memories, leaving a legacy, finding positive viewpoints, dealing with uncertainty, maintaining hopeful relationships, and motivating people to find meaning in life.

Creative Arts

The creative arts can be used to help people share their emotions, find meaning in their suffering, and create a legacy, when words are not enough.

Life Review

Through thoughtful discussion and life review, people can be helped to conduct a "summing up," find meaning in the experience, and reflect on the important contributions that they have made in their lives.

Dignity therapy: One type of life review is Dignity Therapy. This interview approach may be used to help people identify and come to terms with their life accomplishments. It can also be used to create a legacy document for sharing words of wisdom and special memories.

End of Life Decision Making

Physicians or nurse practitioners provide treatment options and conduct the assessment for eligibility for Medical Assistance in Dying. Psychologists can work with individuals and/or families to work through the thinking, emotions, and possible social (e.g., burden, isolation) concerns of those who are contemplating end of life treatment options.

Where do I go for more information?

- The Emotional Facts of Life with Cancer, 4th edition (2012). Canadian Association of Psychosocial Oncology at <http://www.capo.ca>.
- Advanced Cancer (2015). Canadian Cancer Society at <http://www.cancer.ca/en/support-and-services/resources/publications> (Copies are also available through the Canadian Cancer Society's Information Service: Toll-free at 1-888-939-3333)
- Canadian Virtual Hospice at <http://www.virtualhospice.ca>.
- Medical Assistance in Dying: Overview at <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>

You can consult with a registered psychologist to find out if psychological interventions might be of help to you. Provincial, territorial and some municipal associations of psychology often maintain referral services. For the names and coordinates of provincial and territorial associations of psychology, go to <https://cpa.ca/public/whatisapsychologist/PTassociations/>.

This fact sheet was originally prepared for the Canadian Psychological Association in cooperation with the Canadian Coalition on Seniors Mental Health by Dr. Keith Wilson. At the time of the original publication, Dr. Wilson was a staff psychologist at the Rehabilitation Centre of the Ottawa Hospital and Associate Professor of Medicine and Psychology at the University of Ottawa.

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Your opinion matters! Please contact us with any questions or comments about any of the *Psychology Works* Fact Sheets: factsheets@cpa.ca

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