



Living with Limited Time: Exploring Feelings

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You and your family are likely to experience all kinds of thoughts and feelings over the course of your illness.

None of the feelings described below will capture exactly what you are feeling. Everyone's experience will be unique. But, if you recognize just a bit of yourself here, you may feel better understood. You may also feel better equipped to respond to this challenging time of life.

Disbelief and denial

Receiving bad news about your health often leads to a sense of shock or disbelief. This feeling is like living a bad dream. Absorbing information becomes difficult. It's as if our whole system blocks things out.

Denial is our own human way of protecting ourselves from an attack on our reality. It's like wrapping ourselves up in cotton batten in order to absorb the blows. As we become more able to face what we are experiencing, we are able to peel away those layers and rely less on denial.

Since denial serves a purpose, it's not always helpful to try to "take away" someone's denial. Instead, families might consider trying to develop an understanding of each other and respect differences in how each person responds emotionally.

Denial sometimes requires a bit of a balancing act within families and with health caregivers. Never acknowledging that things are getting worse might lead to missed opportunities for important meaningful conversations or access to helpful care.

If you're not sure whether denial is becoming harmful, you may want to connect with a health care provider. This person can help you gain a perspective on your own emotional process and perhaps facilitate communication within your family or with the health care team.

Grief

We usually think of grief in terms of family members and friends who are struggling to carry on after the death of a loved one. However, grief can be felt even without a death. Where there is loss, there is grief.

From the moment of diagnosis – and probably earlier – there is a sense of loss. Physical changes can lead to an altered body image and an increasing loss of independence. Not being able to work can be a major loss. This is especially true for people whose identity is strongly connected to their jobs. All of these losses may lead to feelings of grief.

Loss of control is another type of loss. Loss of control becomes an overwhelming theme in advanced illness, as decisions about your life are made by others. Losing control can lead to anger, frustration, and at times, despair. While there are no easy answers for dealing with loss, talking about these feelings will at least give you a chance to vent and feel understood.

Another option to deal with loss of control is to explore ways to redefine our experience. As human beings we are amazingly resilient! Rather than just focusing on loss of control, it can be helpful to be

proactive by thinking of ways to take control where we can. A key consideration centers around "How do I want to use my energy?" Some things may not be worth the physical or emotional effort. You may want to save your energy for things that really matter to you.

Sometimes we continue placing demands on ourselves to keep going as if nothing has changed. Acknowledging and accepting the changes may save valuable energy.

Family members also experience grief in anticipation of the final days of someone's life.

- You may feel grief because the family functions differently. Changes in roles and responsibilities may lead to grief.
- You may feel grief because you recognize the losses felt by the person who is ill.
- You may feel grief for a future that will be different than you had imagined.

Adjusting as a family requires open and direct communication. Family members may have to be flexible in adapting to new roles. In addition, you may have to acknowledge and accept differences in the way individual family members respond to the situation.

Fear and anxiety

For someone living with advanced illness, fear can take many forms. A big part of dealing with fears is naming them. Fear of the unknown is a common theme. These are some common questions:

"What happens when I die?"
"What will I experience along the way?"
"Will I have pain?"
"Will I be treated with dignity?"
"Will I become a burden on my family?"

It's not easy to talk about your fears, especially when you're feeling vulnerable. Most often you will find that there is information and support available to help you. Reading about symptoms of illness such as pain and constipation, for example, may leave you feeling more confident about the care you will receive.

Probably one of the biggest sources of anxiety for families is the sense of uncertainty, often related to how the illness will progress and when death might occur. Unfortunately, this question is not easily answered. However, anxiety can be helped by knowing what to expect.

Another source of anxiety for families is the shift in roles and responsibilities that takes place when someone is ill. This is especially noticeable if a parent is affected by illness. The remaining parent experiences the demands of being a single parent.

Children may also feel anxious when dealing with the changes in the household. To reduce their anxiety, offer detailed information about who will take care of them and what changes they will see in their day to day routines.

See also: [Talking with Children and Youth about Serious Illness](#)

Anger

Living with a terminal illness brings many potential sources of anger:

- You might feel a sense of injustice, especially if your illness came after living a relatively healthy lifestyle.
- You might be angry at yourself if you feel you contributed in some way to your illness.
- You might be angry at the timing of the illness.
"I worked until retirement and now I'm sick."

- You may be angry at your increased dependency on others.
- You may be angry at the losses you're experiencing in life.
"I've lost my job, I've lost my ability to care for my family."
- You may be fearful, but express your fear as anger.
"The best defence is a good offence."
- You may feel anger toward health care providers or the health care system.
- You may be angry at a higher entity.

As with pretty well all emotions, the recurring theme is the importance of expressing feelings. Ideally, you will find someone who can listen, and accept you where you are at as opposed to trying to fix you.

Sometimes family and friends feel helpless when they hear what you are expressing. A normal response is to try to make things better. While their intention is to be supportive, these encouraging words may make you feel as though you're not being heard or understood. You may begin to feel isolated. If that's the case, you might consider contacting a health care provider or spiritual care provider. These people are trained to help you work on your own process to find a way to deal with what has been thrown at you.

Families may have different sources of anger:

- You may feel the need to blame someone for what is happening.
- You may feel an overwhelming sense of helplessness.
- You may be afraid. You may be fearful about increasing demands on you. You may be fearful about an unknown future.
- You may feel guilty for not being able to provide the care you would like to provide.
- You may be frustrated with the way the ill person lived. You may be frustrated with a long-standing conflicted relationship.

All of the above emotions may come out as anger. The source of the anger may not be obvious to anyone, even the person who is angry.

In the case of difficult relationships, for some people there may be an opportunity to talk about the difficulties before death occurs. You may want to call on professional help, but it's equally important to be realistic about expectations.

Guilt

Knowing that time is limited tends to make people reflect on the past. Sometimes, reflecting on the past exposes regrets for past actions. Or, regrets may be connected to what hasn't been done or said.

Sorting out what needs to be expressed and what needs to be let go is emotional work. Sometimes this means exploring thoughts and feelings in a deeper way.

For family members, guilt can be related to feeling somehow responsible for the situation. Guilt might be expressed this way: *"I should have taken him to the doctor sooner,"* or *"I feel like I've made her life more stressful."* Although these thoughts are very real to the person expressing them, they are not factors in causing illness.

Feelings of guilt can also stem from conflicted relationships or ones where there are mixed feelings. The uncertainty in the relationship or intensity of feeling can lead you to feel regret or second guess past choices.

A sense of *"wishing it were all over"* is not an uncommon feeling and does not reflect a lack of caring or love. Instead, wishing for the end likely comes from a feeling of being overwhelmed. These thoughts are completely understandable. Expressing these feelings to someone who can listen in a non-judgmental way can be very supportive.

Hope

Feeling a sense of hope when life is cut short can be challenging. Living with a terminal illness means redefining hope, even though none of us realistically hope to live forever. There is always potential for hope, but sometimes the challenge is finding it.

Hope tends to shift as illness progresses. Hope for a cure may change to hope to be able to live as long as you can. Hope often centers on personal goals. For example, *"I want to live long enough to see a new grandchild or attend a family reunion."* As one person who lived with a neurological disease which made her unable to move any limbs, when asked what she hoped for, said: *"I hope to see a beautiful sunrise tomorrow morning."*

Within families, hope can be seen as something to maintain at all cost. There is a fear that if hope is taken away the person will give up and die more quickly. Sometimes well-meaning family members try to restrict information about the illness in order to maintain hope. While the intention is totally understandable, the people living with the illness most often are aware of changes in their own bodies and are sensitive to other people's reactions around them. The biggest drawback in holding back difficult information is that the person who is ill may become more isolated and have nowhere to go to express fears and questions. The risk of isolating the patient far outweighs any benefit of the protective behavior.

See also: [Hope and Denial](#)

Need for closeness and intimacy

Touch and intimacy are essential human needs that affect all of us regardless of age, gender, and nature of the relationship. Couples who have less opportunity to hold each other may miss that physical closeness. Children also need the opportunity for close physical contact.

Sometimes the healthy partner in a relationship may miss sexual contact and feel guilty for feeling desire when the ill partner is suffering. Such desire is normal. While intimacy may play out in a different fashion in the context of palliative care, any form of closeness between couples often provides an opportunity for expressions of affection, devotion and love. Gentle stroking of any part of the body that promotes good feelings is a great gift that the patient can receive from their partner, and perhaps give in return.

Time alone to explore intimacy is an important aspect of end-of-life care. Finding ways to ensure privacy should be a consideration in any setting.

Emotional exhaustion

There is no road map showing how the last months of life for a person with advanced illness will unfold. Typically, there are many ups and downs. The unpredictability of illness can be emotionally draining as everyone wonders what to expect next. Many have described this time as being on an emotional roller coaster.

Coping as a family is aided by taking a practical and proactive approach.

- Being practical means asking questions like this.
"What's going to make this work?"
- Proactive means pausing before responding and asking this question:
"Is this how we want to use our emotional energy?"

Often we feel we don't have choices and we pile a lot of "shoulds" on ourselves. We feel we need to be strong and not break down. While it's important to respect that everyone has their own way of coping, acting as if you are always in control takes a lot of energy. Similarly, there are many benefits to maintaining a positive attitude, but that doesn't mean that you cannot also express upsetting thoughts and feelings.

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Living in this challenging time often forces us to examine our expectations. We need to recognize that the rules of the game have changed. As caregivers, we have a tendency to keep going without fully recognizing the demands of the situation require a different approach. We need to give ourselves permission to take care of ourselves.

See also: [Caring for Yourself](#) and [CaregiversCAN](#)

For more information about grief, before and after a loss or death, and how you can support others visit [MyGrief.ca](#).

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