



## **Living with a Life-Limiting Illness**

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### ***Are you living with a life limiting illness?***

*This is a tender and challenging time, full of mixed emotions.*

*Living with a life limiting diagnosis brings many questions, fears and wonderings to the surface. May you find some of the following information helpful and reassuring to you. Take what is supportive, and leave behind what is not.*

*Most importantly of all, be kind and patient with yourself.*

## **Coping with a Life Limiting Illness**

There is no right or wrong way to feel when you hear bad news about your condition. You might feel numb at first, and unable to take in the news, or strangely calm and matter-of-fact. As time passes, you may experience a range of emotions. It's normal to feel some or all of the following:

- shock
- fear
- anger
- resentment
- denial
- helplessness
- sadness
- frustration
- relief
- acceptance

You may also feel isolated and alone, even if you have family and friends around you. You might not experience all of these feelings, and if you do they will not necessarily come in any particular order. Whatever you feel, you do not have to go through it alone.

### **When you hear the news**

Hearing that your illness cannot be cured can be a frightening experience. Many people will be unable to take everything in. If you are alone in the consultation, ask if you can bring a relative or friend in to hear everything the doctor has to say. You can also record your conversation on your phone. This may involve asking for a follow-up appointment so that someone can be with you. Ask the doctor what support is available to you. They may refer you for additional specialist palliative care alongside the care you are already receiving.

Your GP (General Practitioner or family doctor) will also know of any local sources of support. Get in touch with your GP to explain what has happened and ask what help is available near you. This may include information services about your illness, financial benefits you may be entitled to, support groups and counselling.

### **Find someone to talk to**

Not everyone wants to talk about what they are going through. Some people might not want to talk about it at all at first, and this is normal.

However, a terminal (sometimes called life-limiting or life threatening) diagnosis can bring up worries and fears, and it can help to talk about these so that they do not start to feel impossible to deal with.

You might want to talk to your partner, family, or friends, or to a doctor, nurse, counsellor, or chaplain.

People close to you will be dealing with their own feelings about your diagnosis. If you or they are finding it hard to talk about it, you might want to talk to someone less close to you. Your doctor or nurse can help you to find a counsellor.

You may also want to talk to other people who are in a similar situation. This can help if you are feeling alone or confused about how others deal with the news that they are dying.

You can ask your doctor or nurse about local support groups for people who are living with a life-limiting illness, or for people who have the same condition as you. You can also look on the internet.

Some people keep a blog or online diary about living with a terminal illness.

It can also be useful to have someone to talk to at night time. Liz Bryan, nurse practitioner at St Christopher's Hospice, London, says: "The night time can be particularly hard, lying in the dark and thinking about what it will be like to die. Make sure you have someone you can call, but also don't make yourself lie in the dark. Turn on the light, read a book, recognize that you don't have to keep on trying to sleep."

### **Living with uncertainty**

Knowing that you have a life-limiting condition inevitably leaves you living with uncertainty. You will probably have questions to which there are no definite answers, such as how and when your body is going to change, the effect this will have on your independence and your relationships, what will happen at work, and exactly how much time you have left.

Not knowing exactly what is going to happen to you can feel overwhelming and upsetting. It is normal to feel like this, and it is OK to talk to people about how you are feeling.

## **If you think you are depressed**

Everyone is unique and you will react in your own way to news that your condition is life-limiting. It is normal to feel shock, sadness, anger and helplessness.

However, for some people, the feeling that they are not able to cope with their situation does not go away, and they feel too low to be able to do any of the things they want to. If this happens to you and these feelings persist, it may be helpful to talk to your doctor.

Medication often helps and counselling or cognitive behavioural therapy (CBT) can make a difference to how you are coping.

## **Find out about benefits**

You may be entitled to benefits if you are ill and need treatment or care. You can ask your nurse or doctor to find out what benefits you are entitled to. You or your spouse may have a benefit package that will cover services, treatments or complementary therapies (massage, naturopath, acupuncture, Healing Touch etc).

## **Living with your diagnosis**

Penny Hansford, director of nursing at St Christopher's Hospice, offers the following suggestions, which you might find helpful. One step at a time...

What you are dealing with can feel overwhelming, but you may be able to make it feel less so by thinking about it as smaller "pieces".

"It's an old saying, but take one step at a time," says Penny. "Try to put life into bite-sized chunks, so take one day at a time, or one week at a time." Decide on some small, achievable goals, so that you gain confidence. This could be something like putting family photos into an album, or visiting a friend.

You can still think about bigger issues, such as where you would like to receive your care in the future, but don't feel that you have to tackle everything at once.

## **Write down your worries...**

Some people feel helpless and that everything is out of control. Writing down worries and questions can begin a process of deciding what is important to you and how to tackle it.

Penny says: "Start by thinking about what the important issues are for you, what things you want to do, what your feelings and worries are. Making that a bit more concrete by writing it down can help you put some structure around what may feel unmanageable and chaotic."

If you want, you can use what you have written to help you talk about things with your family, friends and care givers.

### **Look after yourself...**

Try to take some time to do things you enjoy. This is particularly important when you are feeling tired and weak.

Complementary therapies, such as massage, energy therapies, acupuncture and aromatherapy, may help you feel better. You will probably have many concerns about the people close to you and it will help them if they know you are looking after yourself. There may be things that you can do together.

If friends and family offer help, try to accept this and give specific examples of support you need and would like. For example, someone might be able to help by taking you shopping, bringing you some meals to put in the freezer, or driving you to appointments.

(Excerpts from National Health Service [www.nhs.uk](http://www.nhs.uk))

## **Anticipatory Grief: Feeling Grief Before an Impending Loss**

Anticipatory grief acknowledges the many losses, changes and demands that people encounter during the course of a life limiting illness. Here is information about some of the struggles and stresses that may occur and ideas for dealing with them. Sometimes it is enough to know that what is happening is normal or to be expected. Other times, when the person with the illness and family members misunderstand what is happening for each other, more information and helpful suggestions can increase their tolerance and support for one another.

### **If you are living with a life limiting illness:**

As you deal with diagnosis, life-threatening illness and death, you grieve the many losses you face; past, present and future. In your grief you will experience a wide range of thoughts, feelings and responses in the struggle to come to terms with this reality. Due to the intensity of these reactions, you often feel frightened and overwhelmed. This is quite normal. It often helps to know what to expect and that these reactions are a necessary part of grief.

### **Social**

As you face changes in the roles and responsibilities you fulfill, this can result in feelings of self-consciousness and low self-esteem. Former activities and interests may no longer be available to you. Some people feel indifferent to social contact and withdraw; others need company, but find it difficult to ask. People around you may have unrealistic expectations about both your physical capabilities and emotional status.

### **Physical**

Adjusting to the continual changes in daily activities and the loss of your former lifestyle will likely increase your fatigue and sap already low levels of energy. It is important for you to pace yourself and save your energy for the activities that are most important to you. The loss of independence, both physical and personal, is difficult.

## **Emotional**

You will experience a wide variety of feelings which may occur as acute upsurges of emotion. Anger, sadness, depression, and guilt are common and natural to feel. You may be quite irritable, with low frustration and tolerance levels; current grief may resurrect old feelings, issues, or unresolved conflicts. You may experience anxiety or fear about yourself and others, as well as concern for the future well-being of your family.

## **Thoughts**

The stresses that you experience at this time may interfere with how well your mind functions; both concentration and memory can be poor and decision-making becomes difficult. At times you have a sense of unreality or of going crazy. Also, it is natural to fluctuate between denial and acceptance of the situation. You can be preoccupied with thoughts of how you will die, or thoughts about being a burden to your family.

## **Spiritual**

Attitude toward and perception of the changes that are occurring will affect how well you are able to cope. Hoping for miracles may change to looking for the hope in each day. People question their beliefs, search for the meaning in life or pursue spiritual peace. Mourning for hopes, dreams and unfulfilled expectations is a natural and important part of the grief process.

## **If someone you love is living with a life limiting illness**

During this time, you as family and caregivers will find that, you too, have a range of reactions and emotions. The many thoughts and feelings that arise may be intense and overwhelming and may recur with changes in your loved one's condition and care needs. Each member of the family will respond in their own way and it may help to know some of the typical healthy reactions to such a stressful time.

As changes occur:

- Helplessness and hopelessness may occur with increases in care needs
- Shock and numbness can accompany any sudden change in condition



- Yearning arises for things to be the way they were before
- As stresses increase anxiety and fear are common in three areas in particular:
  - Carrying on with the necessary tasks of living and caregiving
  - Ability to cope after death
  - Heightened awareness of your own mortality
- Loneliness increases as your family roles change and your loved one becomes more dependent on care.
- Edginess and irritability may arise in your relationships with other people.
- Fatigue is sometimes experienced as apathy or listlessness.

As emotions arise:

- Sadness is the most common feeling and may be expressed by crying and sighing.
- Anger is common and is usually caused by:
  - Frustration with the situation because there is nothing that can be done to prevent the progression of the illness
  - Anger, irrational or not, at your loved one for getting sick
- Guilt is a nagging feeling that is often accompanied by a need to review what has happened or what was neglected.
- Worrying about whether you are doing what is best is a part of normal caregiving

Adapted from: I. Warden, *Grief Counselling and Grief Therapy*. Springer, N. Y. 1982

## **How to Help**

A major loss experienced by all during this time is the loss of existing relationships. As the illness progresses and changes in condition occur, it can become increasingly difficult to maintain a mutually satisfying relationship. Loved ones may be withdrawing from those around them or may not have the energy to reach out. Families may be so exhausted by their own grief and the many tasks of caregiving that they have little left to offer. The following ideas are to help everyone to think about ways of supporting and communicating with each other.

## **Touch**

Touch can be one of the most comforting means of communication. A squeeze of the hand or an embrace can sometimes show love and caring more easily than words.

## **Smile & Laugh**

Continue to enjoy humorous incidents and stories. Illness should not put a ban on laughter.

## **Be Comfortable with Silence**

Understanding, caring and love often need no words. Silence can be as supportive as conversation.

## **Offer Truth**

When you/your loved one is doing poorly, don't deny it. Everyone, sick or healthy, should be treated with honesty and not deceit.

## **Know Your Limits**

It is impossible to solve all the problems or have all the answers; in fact, there may be no solution. Accept limitations and offer only what is possible. Ask for help!

## **Accept and Acknowledge Feelings Expressed**

Don't pretend that everything is alright; be sensitive to changing feelings. You or your loved one may need to express your emotions and some encouragement may be helpful! Questions such as "What are you feeling?" or "Tell me what is happening to you" may be helpful.

## **Spend Time Together**

Talking, listening to music, watching television and playing cards or games can help fill lonely or frightening hours with shared companionship.

## **Be Respectful**

Respect privacy, confidentiality and opinions.

## **Communicate in New Ways**

Sometimes people talk about their dying in symbolic ways: e.g. going on a trip, meeting with family who have already died, seeing visions. Rather than treating this as confusion, listen closely and encourage discussion of feelings.

Adapted from: Earl A. Grollman

## **Tasks for the family of a loved one living with a life limiting illness**

Caring for a terminally ill family member can be confusing and difficult, especially trying to balance the needs of the person who is ill with those of the family. On the one hand you are attending to the care of the ill family member and maintaining involvement with them. On the other hand, you are grieving your own losses and beginning to prepare for life after the person has died. There is never enough time or energy to attend to these opposing needs.

The steps taken to cope with all of this are called **“tasks”** and they are part of an ongoing process. You will likely find that you are engaged in all of these tasks to varying degrees at the same time. There is no set procedure or need for completion; different ones will be more important at different times. Looking at each of these separately will help you to understand more exactly the demands of the situation and help you make the best use of time, energy and resources to deal with them.

### **Fluctuating from denial to acceptance of the illness and death**

Some denial of reality is healthy and necessary in order to function. It allows information to be taken in at a more tolerable pace, and gives you a break from the emotional stress of a situation. Acceptance of what is happening will not necessarily bring peace.

### **Establishing a relationship with health professionals**

It may be necessary to learn how to be constructively assertive, as well as find a way to deal with frustration. Family and caregiver conferences can help to reduce anxiety by opening communication lines and providing direct information. It may help to write concerns down before meeting with caregivers.

### **Meeting the needs of the dying person**

As their illness progresses, their physical and emotional needs will change. The task here is to help in the best way possible without taking away the person's control or independence. Don't make assumptions about what they need or feel; ask before you act.

### **Maintaining a functional family unit**

When someone is sick, it means that everyone in the family must take on new roles and responsibilities. At the same time, it is really important to maintain some normal family routines, as this provides some security in the midst of chaos.

### **Living with the emotions of grief**

During this time everyone experiences intense swings in emotion. Having information about these feelings and being aware of reactions will help everyone begin to cope. It is important for family to let each other know how they are feeling and what they need. There may also be things that people prefer to discuss with someone outside the family unit.

### **Dealing with people outside the family**

There may be little energy for outside relationships and commitments at this time. Often, other people's reactions may be unpredictable and difficult. Some friends or helpers may be too involved or too cheerful; others may avoid talking about the illness or even visiting the person who is ill. Many people don't understand what family members are going through and it is hard not to resent others' stability and good fortune.

### **Anticipating the family's new reality after the death**

It is impossible to imagine the future. However, estate planning, funeral planning, dealing with different kinds of unfinished business and building in supports are things that can help family members to prepare. The important thing is to do the best you can.

### **Finding appropriate hope**

What everyone hopes for throughout this time will change. Long term plans need to be replaced by short term plans; treatment aimed at cure may be given up for that which relieves symptoms. Accepting the goal of comfort rather than of cure is a step toward acceptance of the inevitability of death.

### **Allowing the dying person to be at risk**

Refusal to take medications or accept personal help may be very difficult to deal with, but it is important to recognize your loved one's right to choose activities that may put him or her at risk. However, these choices should not put family members at risk.

### **Making decisions for the dying person**

There may come a time when the dying person is unable to make decisions for him or herself. Prior discussions, an advance directive or living will and knowledge about the person will help you respect and represent his or her best interests.

### **Self-care**

When caring for someone else, it is hard to have energy for yourself and to see this as important. Building in time for your self-care is crucial, e.g. sleep, nutrition, exercise, relaxation. Recognize that all members of the family have needs... physically, emotionally and spiritually. Also, family strength and good health makes it possible for everyone to support and care for the person who is ill.

Adapted from: T. Rando, Grief, Dying & Death.

## **Helping Yourself Live When You Are Dying**

You have learned that you are dying. Life limiting illness presents human beings with an exceedingly difficult and contradictory challenge; you are dying, you know you are dying, yet it is your nature to want to live. The thoughts in this handout are intended to help you deal with this tension and to continue to live even though you are dying.

### **Acknowledge You Are Dying**

Acknowledging you are dying is the first step to living the rest of your life. If the onset of your illness was sudden or unexpected, you will likely feel shock and numbness at first. This is a natural and necessary response to painful news.

You can only cope with this new reality in doses. You will first come to understand it with your head, and only over time will you come to understand it with your heart.

To acknowledge you are dying is to let go of the future. It is to live only in the present. There is no easy way to do this, and you will probably struggle with this task every day until you die. Know that if you work at acknowledging the reality of your coming death, however, instead of denying it, you will open your heart and mind to the possibility of a new, rich way of living.

### **Questioning the Meaning of Life**

Discovering that you are dying naturally makes you take inventory of your life. You have a right to have questions, fears and hopes. Illness establishes new directions and often causes some questioning of old directions. New thoughts, feelings and action patterns will emerge. The unknown invites you to question and search for the meaning of your life, in the past, present and future.

### **Accept Your Response to the Illness**

Each person responds to news of terminal illness in his or her unique way. You, too, will have your own response, be it fear, excitement, anger, loss, grief, denial, hope or any combination of emotions.

Becoming aware of how you respond right now is to discover how you will live with your terminal illness. Don't let others prescribe how you feel; find people who encourage you to teach them how you feel. After all, there is no right or wrong way for you to think and feel.

### **Respect Your Own Need for Talk, for Silence**

You may find that you don't want to talk about your illness at all. Or you may find that you want to talk about it with some people, but not with others. In general, open and honest communications is a good idea. When you make your thoughts and feelings known, you are more likely to receive the kind of care and companionship you feel will be most helpful to you.

But if you don't want to talk about your illness, don't force yourself. Perhaps you will be able to open up more later on, after you have lived with the reality of your illness for a time.

### **Telling Your Family and Friends You Are Dying**

Your family and closest friends deserve to know that you are dying. Tell them when you feel able to. If you simply cannot bring yourself to tell them, find a compassionate person with whom you can entrust this important task.

Be aware that everyone will react differently to your news, just as each terminally ill person reacts differently to his or her own illness. Many will be shocked. Many will cry. Some will refuse to believe it. Some will spring into helpful action by running errands for you, offering to clean your house, etc.

Many will not know how to respond. Because they don't know what to say or do, or because your illness may arouse their own fears of mortality, they may even avoid you altogether. Know that their apparent abandonment does not mean they don't love you.

Even children deserve to be told. As with all people, children can cope with what they know. They cannot cope with what they don't know. Be honest with them as you explain the situation in language they will understand. Don't over explain, but do answer any questions they may have.

## **Be an Active Participant in Your Medical Care**

Many people are taught as “patients” to be passive recipients of the care provided by medical experts. But don’t forget this - this is your body; your life. Don’t fail to ask questions that are important to your emotional and physical well-being out of fear that you will be “taking up someone’s time.”

Learn about your illness. Visit your local library and consult the medical reference books. Request information from educational associations, such as the National Cancer Institute or the American Heart Association. Ask your doctor, nurses and other caregivers whenever you have a question.

If you educate yourself about the illness and its probable course, you will better understand what is happening to you. You will be better equipped to advocate for personalized, compassionate care. You may not be in control of your illness, but you can and should be in control of your care.

## **Be Tolerant of Your Physical and Emotional Limits**

Your illness will almost surely leave you feeling fatigued. Your ability to think clearly and make decisions may be impaired. And your low energy level may naturally slow you down. Respect what your body and mind are telling you. Nurture yourself. Get enough rest. Eat balanced meals. Lighten your schedule as much as possible.

## **Say Good-bye**

Knowing you will die offers you a special privilege: saying good-bye to those you love. When you feel you are ready, consider how you will say good-bye. You might set aside a time to talk to each person individually. Or, if you are physically up for it, you might have a gathering for friends and family. Other ways of saying good-bye include writing letters, creating videotapes and passing along keepsakes. Your survivors will cherish forever your heartfelt good-byes.

## **Find Hope**

When people are seriously ill, we tend to get caught up in statistics and averages; How soon will the illness progress? How long do I have left? These can be helpful to know, but they don’t always provide spiritual and emotional comfort.



Even if you are certain to die from this illness, you can find hope in your tomorrows, your next visit from someone loved, your spirituality. At bottom, hope means finding meaning in life, whether that life will last five more days, five more months or five years.

### **Embrace Your Spirituality**

If faith is part of your life, express it in ways that seem appropriate to you. You may find comfort and hope in reading spiritual texts, attending religious services or praying. Allow yourself to be around people who understand and support your beliefs. If you are angry at God because of your illness, realize that this is a normal and natural response. Find someone to talk to who won't be critical of whatever thoughts and feelings you need to explore.

### **Reach Out for Support**

Many of us grew up believing, "Do it on your own so you don't have to depend on anyone else." But confronting a terminal illness cannot and should not be done alone. As difficult as it may be for you, you must reach out to your fellow human beings. Most of us know whom we feel comfortable turning to when we are under stress. Whom do you turn to? Give yourself permission to reach out for prayers, support and practical assistance.

Hospices are an indispensable resource for you. They are well staffed and trained to help both the dying person and the dying person's family. Their mission is to help the dying die with comfort, dignity, and love, and to help survivors cope both before and after the death. They often offer support groups for people with life threatening illness. You might also consider seeing a counselor one-on-one.

Whatever you do, don't isolate yourself and withdraw from people who love you.

By Dr. Alan Wolfelt

## How to Tell People You're Dying

Having to tell people that you're dying can feel like an incredible burden, and you may worry about causing distress to those closest to you. There's no single right way to tell someone you're dying, and while some people prefer a face-to-face conversation, you may decide instead to write a letter.

Your approach might vary greatly, depending on who you need to inform. For example, talking to a child about death is very different compared to talking to an adult.

When it comes to informing wider social circles, some people use blogs or social media pages to talk openly with their loved ones, but when it comes to close family and friends, sitting down one-on-one is often the best way to talk about it.

### **Telling friends and family in person**

Find somewhere calm and peaceful to break the news. This might be at home, in a coffee shop or in a park sitting on a bench. Choose somewhere you feel comfortable where it's not too noisy. It's best if the person is sitting down. A hot beverage can be comforting and may be a welcome distraction during the conversation.

### **Don't wait for the right moment**

Be straightforward with them. It's likely they'll sense you have something to say, so don't try to make small talk or wait for a pause in the natural flow of conversation, as this may never come. It's ok to start the conversation by saying, 'I wanted to talk to you about something.' Start with the facts. Tell them what the doctors have told you, and be specific. For example, you could say, 'The doctor said I have X months left.' Be honest, and don't try to pretend everything's okay, as this will only lead to more hurt in the long run. With some people you might want to talk about your relationship with them, expressing your love. For others, it might be appropriate to just talk about the diagnosis, in a very straightforward manner.

### **Be ready for any kind of reaction**

Don't have too many expectations for how they will respond; tears, silence and shock are all common. They may be in disbelief at first or think you are joking, in

which case talk about the illness, using specific details. Talking about it is bound to be emotional for them and you, so it's good to have some tissues to hand. Give them time to respond. They might need a couple of days to think the news through.

### **Tell them how they can help**

Many people feel uncomfortable around the subject of death, and struggle with what to say or do. Remove any doubt – tell them what you need from them and how best to support you through this journey. Let them ask questions and leave room in the conversation for them to speak. You may well find that involving your loved ones in the process of planning your funeral while you still can, makes the process of arranging the funeral a lot easier on your loved ones after you're gone.

## Life-Threatening Illness: What to Tell Family, Friends

### Saying Good-bye

One of the hardest things about learning you have a life-threatening or terminal illness is figuring out how to tell the people you love.

What do you say? When do you tell them? And how do you talk about tough topics – your wishes for removal of life support, for example, or whether you want to be buried or cremated?

You may worry about how loved ones will feel and want to protect them from the harsh truth. But, say the experts at Capital Caring, which daily serves more than 1,000 people living with advanced illness in the Washington, D.C. area, your family and closest friends deserve to know. And many people also find that telling others about their diagnosis brings a sense of relief.

So how do you go about sharing the news? There's no one right way. You can:

- Tell one very trusted family member or friend and ask that person to spread the word among your loved ones
- Meet with family members and friends individually to talk about your condition
- Hold a 'family meeting' to explain the news
- Ask a doctor, nurse, or social worker to talk to your family or to be with you when you do

You can't predict how family members and other loved ones will react. Some will cry; some will become numb; and some will be eager to jump in and be the 'go-to helper' person.

Many people will ask what they can do to help. If you know what that is, it's a good idea to tell them, or they will come up with their own ideas of how to help, which may or may not be what you need. You might want:

- Someone to sit with you and hold your hand during times of day that are particularly tough for you
- To talk a lot about your diagnosis and condition
- To talk about anything but your diagnosis and condition

- People to help you get out and participate in activities you enjoy
- Friends to help you with mundane daily activities, or with caring for children or pets

## **Talking to Children**

What if you have to share the news of a life-threatening illness with your child or grandchild? Many people fear talking about death or the possibility of death with children and try to hide the information. But that can be unhealthy.

Even a child of three or four is old enough to know in simple terms what's happening. And talking about it creates the opportunity to have some closure -- both for the child and the person who is dying. When talking to a young child, it's important to not give too much information. And what you do say should always be age appropriate.

For example, you might tell your young child, "Grandma's very sick. She's trying to get better and her doctors have been helping her, but it looks like she is probably going to die."

Once a child has been told this news, expect him or her to have questions -- but not necessarily right away. Sometimes, a child may say nothing and turn right back to playing, only to ask about Grandma dying while driving home from school the next day or the next week. Here are some tips to help you with these conversations:

- Let children know it's OK to ask questions whenever they have them. You might say, "You're probably going to wonder about what's happening to Grandma, and it's OK to keep asking me when you have questions."
- If your child says that she feels sad or scared, let her know that it's OK. Tell children that you have feelings like that too. If they catch you crying, there's nothing wrong with telling them that you're feeling sad or scared.
- Let the child's primary caregivers at school, day care, or church know what he or she is going through, and make sure children know who they can talk to at school.
- Give them the opportunity to express their feelings through writing or drawing.

- Depending on how old the child is, you can explain the treatments the person that is dying is going through.
- Don't ever compare sleep and death ("Grandma will just go to sleep") -- that can make a child afraid of going to sleep.

This is another area in which your palliative care team can be a very important resource. The team has the expertise to tell a 6- or 7-year-old or older child what is going on.

### **Sharing Your Last Wishes**

At some point, there may come a time when you will want to share with your loved ones how you would like things to go at the end of your life: what kind of treatments you do and do not want and how you would like things handled once you have died. Actually, these are conversations that people should be having with their families even when they are healthy, but many do not.

You can express your wishes using advance directives such as a living will or a medical power of attorney, but it's also important to talk directly with your closest loved ones about what you want.

People, though, are often afraid to say anything about these matters, and family members often don't want to be the first one to bring them up. That's where a doctor or counselor can help; to ask the hard questions in a gentle way.

So if you're thinking about these things and struggling with how to talk about them, ask your doctor, counselor or other support person for help.

### **Saying Good-bye**

When you know that death is near, just how do you say good-bye?

Some people hold big parties or gatherings, or have their families host them. Often the gatherings occur around holidays, and the significance of the gathering, even if not stated, is implicitly understood.

Other people prefer more intimate good-byes. You may want to set aside time to speak with each of your closest family members and friends individually, or give them a gift or letter. Or you may prefer to be more informal and just ask loved ones to visit more often, and be sure to say "I love you" more frequently at each visit.

You may also want to leave something behind for your loved ones: a video, a scrapbook, letters, or photos. Ask your hospital, hospice, or palliative care program if they have volunteers who can work on putting something together with you.

When people are very near death, they are often no longer able to speak or communicate with those around them. That's why it's important to make sure that you've said your good-byes and had any other conversations you want to have with the people you love sooner, rather than later.

WebMD Medical Reference Reviewed by Carol DerSarkissian on September 11, 2017

## Things to Remember After Others Learn the News

1. One or two people - probably family members - will make enormous personal sacrifices to help you. If you are married, your spouse is likely to do this, but don't be surprised if others - a daughter, a brother-in-law, or even a friend, step forward to offer extraordinary help. Be grateful, and accept help, from whatever source, graciously.
2. Some family members, but especially friends, will treat you differently. Even before you show signs of serious illness, people will have a different look in their eyes as they talk with you. You might consider this patronizing or overbearing. It may be difficult, but it is best to ignore their attitudes and treat them as you always have. They will come around to their normal selves when they get over the shock.
3. Happily accept all gifts from family and friends. It makes them feel better and you might receive something you really like and appreciate.
4. Don't be afraid to ask to be alone. We need time to be by ourselves. Some family and friends may feel driven to fill your every waking moment with activities; perhaps they are trying to "take your mind off" your prognosis, but they may also be doing the same thing for themselves.
5. Be your own counsel. No one, including your physician, religious/spiritual counselor, spouse, or friends can understand 100% what you want and need. It surprised me that some people seemed to "bully" me with advice when they learned that I was terminally ill. We should remember Immanuel Kant's advice to avoid accepting someone else's authority in place of our own powers of reason. We are the ones who should be considering alternatives and making choices. We can, and should, ask for advice. Make telephone calls and read books - but ultimately, we should decide.
6. Slow down and ask your family and friends to slow down. There may not be a lot of time, but there is sufficient time in all but the most extreme cases to think, plan, prepare.

(Excerpts from "A Dying Person's Guide To Dying" by Roger C. Bone, M.D.)



## **Cancer Diagnosis: 11 Tips for Coping**

Learning that you have cancer is a difficult experience. After your cancer diagnosis, you may feel anxious, afraid or overwhelmed and wonder how you can cope during the days ahead. Here are 11 suggestions for coping with a cancer diagnosis.

### **Get the facts about your cancer diagnosis**

Try to obtain as much basic, useful information as possible about your cancer diagnosis. Consider bringing a family member or friend with you to your first few doctor appointments. Write down your questions and concerns beforehand and bring them with you. Consider asking:

- What kind of cancer do I have?
- Where is the cancer?
- Has it spread?
- Can my cancer be treated?
- What is the chance that my cancer can be cured?
- What other tests or procedures do I need?
- What are my treatment options?
- How will the treatment benefit me?
- What can I expect during treatment?
- What are the side effects of the treatment?
- When should I call the doctor?
- What can I do to prevent my cancer from recurring?
- How likely are my children or other family members to get cancer?

### **Keep the lines of communication open**

Maintain honest, two-way communication with your loved ones, doctors and others after your cancer diagnosis. You may feel particularly isolated if people try to protect you from bad news or if you try to put up a strong front. If you and others express your emotions honestly, you can all gain strength from each other.

## **Anticipate possible physical changes**

Now — after your cancer diagnosis and before you begin treatment — is the best time to plan for changes. Prepare yourself now so that you'll be better able to cope later. Ask your doctor what changes you should anticipate. If drugs cause hair loss, advice from image experts about clothing, makeup, wigs and hairpieces may help you feel more comfortable and attractive. Insurance often helps pay for wigs, prostheses and other adaptive devices. Members of cancer support groups may be particularly helpful in this area and can provide tips that have helped them and others.

## **Maintain a healthy lifestyle**

This can improve your energy level. Eating a healthy diet consisting of a variety of foods and getting adequate rest may help you manage the stress and fatigue of the cancer and its treatment. Exercise and participating in enjoyable activities also may help. Recent data suggest that people who maintain some physical exercise during treatment not only cope better, but may also live longer.

## **Let friends and family help you**

Often friends and family can run errands, provide transportation, prepare meals and help you with household chores. Learn to accept their help. Accepting help gives those who care about you a sense of making a contribution at a difficult time. Also encourage your family to accept help if it's needed. A cancer diagnosis affects the entire family and adds stress, especially to the primary caregivers. Accepting help with meals or chores from neighbors or friends can go a long way in preventing caregiver burnout.

## **Review your goals and priorities**

Determine what's really important in your life. Find time for the activities that are most important to you and give you the most meaning. If needed, try to find a new openness with loved ones. Share your thoughts and feelings with them. Cancer affects all of your relationships. Communication can help reduce the anxiety and fear that cancer can cause.

## **Try to maintain your normal lifestyle**

Maintain your normal lifestyle, but be open to modifying it as necessary. Take one day at a time. It's easy to overlook this simple strategy during stressful times. When the future is uncertain, organizing and planning may suddenly seem overwhelming.

## **Talk to other people with cancer**

Sometimes it will feel as if people who haven't experienced a cancer diagnosis can't fully understand how you're feeling. It may help to talk to people who have been in your situation. Other cancer survivors can share their experiences and give you insight into what you can expect during treatment.

You may have a friend or family member who has had cancer. Or you can connect with other cancer survivors through support groups. Ask your doctor about support groups in your area or contact your local chapter of the American Cancer Society. Online message boards also bring cancer survivors together. Start with the American Cancer Society's Cancer Survivors Network.

## **Fight stigmas**

Some old stigmas associated with cancer still exist. Your friends may wonder if your cancer is contagious. Co-workers may doubt you're healthy enough to do your job, and some may withdraw for fear of saying the wrong thing. Many people will have questions and concerns. Determine how you'll deal with others' behaviors toward you. By and large, others will take their cues from you. Remind friends that even if cancer has been a frightening part of your life, it shouldn't make them afraid to be around you.

## **Develop your own coping strategy**

Just as each person's cancer treatment is individualized, so is the coping strategy you use. Ideas to try:

- Practice relaxation techniques.
- Share your feelings honestly with family, friends, a spiritual adviser or a counselor.
- Keep a journal to help organize your thoughts.

- When faced with a difficult decision, list the pros and cons for each choice.
- Find a source of spiritual support.
- Set aside time to be alone.
- Remain involved with work and leisure activities as much as you can.

What comforted you through rough times before your cancer was diagnosed is likely to help ease your worries now, whether that's a close friend, religious leader or a favorite activity that recharges you. Turn to these comforts now, but also be open to trying new coping strategies.

By Mayo Clinic staff

## Creating Meaningful Experiences at the End of Life

It can be difficult for people to talk about dying and death, our own as well as the deaths for those we love. Yet we know we will all die. This is the natural order of life.

Some people feel that talking about dying is akin to a death wish. It is seen as bad luck, giving up, calling upon death to come more quickly. Or it means that there is not the will to live, not enough love; that death is a failure. It can be terrifying. We don't want to feel this emotional pain, this fear or cause this grief to others. We hope to skip over the difficult and painful parts by avoiding them. It feels too hard.

Although deeply painful, and with a path that is not clear, if we can gather the courage to reframe how we see the end of our lives, we can open our hearts and souls to living fully, loving fully and being more fully ourselves. All this pain, all this grief, can be a doorway to healing and beauty.

*"The truth is, once you learn how to die, you learn how to live."*

*Mitch Albom, Tuesdays with Morrie*

If your death is imminent, or you have a life limiting condition that has invited you to face your own mortality, there are things you can do. In your own unique way, you can make this last part of your life meaningful and create a gift that cannot be destroyed by death.

**Have personal visits** with those you love and speak with them from your heart. Mend old hurts, say what needs to be said, share your love for them. Allow people a space to be sad.

**Create** a video for your children, write a letter to friend, send a message to someone, clear up any unfinished business.

**Have a gathering** with your loved ones, giving opportunities for people to speak with you, hug you, say good bye, to give their love and receive yours.

**Have a ceremony**, a living funeral, a ritual with your loved ones that honours the richness and intensity of being alive, as well as the journey into death.

**Talk about your beliefs** about what happens after someone dies. What you believe will happen to you after you die.

**Plan your celebration of life**, memorial, funeral, party, whatever you would like to happen after you pass away.

**Follow your heart** to find ways to connect with those you love, to say those things that are still unsaid. I'm sorry. Please forgive me. I forgive you. Thank you. I love you.

Your loved ones will find great comfort and take solace in these gifts for the rest of their lives.

## How to Bring More Meaning to Dying

Most of us don't like to talk about our own death. And when we refer to other people's deaths, we often say things like "Her health is failing" or "He failed treatment." These common sentiments make it sound like death is an option or that we can prevent it somehow—if only we ate more kale or walked 10,000 steps a day.



But guess what? Death isn't optional.

Death is as much a part of our life as birth. And, just like a birth, it goes better when we are prepared for it. Not that we can control all outcomes or make it pain-free—but there is a lot we can do to help make it easier and more meaningful.

In our new book, *A Beginner's Guide to the End*, we talk about all of the ways people can prepare themselves and their family members for the inevitable. Some of our book focuses on basic practicalities—like how to talk to doctors if you have a chronic illness, how to make treatment decisions, what documents to have in place for your end-of-life care, and how to create wills and trusts. We try to provide a comprehensive list of resources and detailed advice about how to manage this part of dying.

But, while many people think to prepare for the practical aspects of dying, too often they give short shrift to the *emotional* side of dying—meaning, what to do so that your death has more meaning and is less emotionally trying for yourself and those left behind.

There are many ways that you can improve the experience of dying if you plan for it and communicate your wishes to your loved ones. Here are some of the ideas we recommend in our book.

## **Don't leave a mess**

Many people don't realize that the stuff they've been saving may not be of much value to those they leave behind. Therefore, it's important to take time while you are still alive to clean out those closets and attics. Doing a big purge serves a dual purpose: It will make you feel lighter and also lighten the load on loved ones when you're not around to help sort through your belongings.

It's important to ask yourself why you're keeping so much stuff. It is because you still use it and it brings you pleasure? Or does keeping it push away thoughts of dying? Or are you overwhelmed by the task of going through it all?

It can be cathartic to set aside time to go through your possessions, reflecting on what they mean to you, then letting them go. In some cases, you may want to save family heirlooms that have special value and make a plan to talk to your heirs about keeping them after you die. But it will have more meaning for them if you explain why you'd like them to have the item and what it means to you.

## **Clean out your emotional attic**

Cleaning out your emotional attic is important, too. This may include sharing old secrets that you have kept from loved ones that are likely to be discovered after your death. Especially in this age of popular DNA testing, it's important not to leave important things unsaid, though it requires sensitivity in the delivery.

If your secrets are just too damaging to reveal, consider enlisting someone to "scrub down" your life after you die. This can be a close friend who goes through your medicine cabinet, electronic files, and nightstand to rid them of old medications, personal diaries, sex toys, and other unmentionables. If you are happier knowing that these parts of your personal life won't be exposed after you're gone, we are not here to shame you! Just take care to make it a choice.

## **Mend important relationships**

When people die, they don't regret not having worked harder; they regret not having worked on their relationships. It's important to mend old wounds before it's too late. Even if you meet resistance from loved ones, keep pushing for more conversations, making sure you say what you want to say to them now.

In Ira Byock's book, [The Four Things That Matter Most](#), the pioneering palliative care physician talks about what most people long to hear that can help mend even long-fractured relationships:



Please forgive me.

I forgive you.

Thank you.

I love you.

Why these four phrases? True apologies and forgiveness, while helpful to consider at any stage of life, can go a long way toward making someone's death more peaceful. Gratitude and love are what most people tend to need at the end of life. Closure is a human construct, rather than an act of nature, and a very useful one at that. This framework offers a recipe.

When we asked Dr. Byock if he would add anything to this list, 14 years after publishing that book, he said, "It's useful for a parent to say to their child, 'I'm so proud to be your mother, I'm proud to be your father.'" He's met many men in their 60s who still yearn to hear that from a father who's long gone.

## **Leave a mark**

*Legacy* can be a loaded word. But most dying people want to know they mattered in some way, and they want to leave a mark. While for some this will mean using assets to fund a scholarship or a trust for their kids, others will have fewer material—but no less valuable—things to leave behind.

In a survey of baby boomers, only 10 percent thought it "very important" to inherit financial assets from parents, while 77 percent said that receiving and providing "values and life lessons" is very important. This means that money is not the only thing of value you can leave behind, and you may want to start thinking about what you want to pass down.

Here are some ideas that we've found helpful to those who wonder what to leave.

### **1. Leave your story.**

Telling the story of your life and leaving a record of experiences, people, and ideas that mattered to you gives those who love you a feeling of continuity from one generation to the next. While you may assume that no one will care, imagine this: What would it be like to have the story of your great-great-grandmother in your hands? Wouldn't that be amazing?

If you're still daunted by this idea, you may want to enlist the services of a friend. Or you could create a family tree. Fun for you, important for those you leave

behind, and research suggests doing so may help improve your and your caregiver's well-being at the end of life.

## **2. Leave a letter.**

Writing a letter can be a good way to put into words things that may be difficult to say in person. You might want to express how much you love someone, how proud you are of them, what they mean to you, your hopes for their future.

## **3. Leave an ethical will.**

An ethical will is a way of transferring immaterial things to your loved ones: your life lessons and values. It's not a replacement for a regular will, but a complement to it, and research suggests it reduces your suffering by taking care of "unfinished business" and bringing a deeper sense of purpose to the life you still have.

An ethical will can explain why you made certain choices in your legal will—e.g., why you left your car to your youngest daughter instead of all of your children—or tell a story about where you came from and what you value. Barry Baines, a hospice medical director who wrote a book called *Ethical Wills*, found that 77 percent of his patients felt their emotional well-being improve and 85 percent felt their physical well-being improve after completing an ethical will.

Of course, there are many other ways people can make the experience of saying goodbye less fraught. Few folks will get to every last detail before the end comes; as ever, do the best with what you have, while you can, and forgive yourself and others the rest. By taking care of emotional needs and focusing on what you hope to leave behind, you can bring more meaning to the experience and ease the burden on loved ones in the process. In other words, bring the same dignity and care to death that you bring to life.



*Compassionate end-of-life and grief support for Yukoners*

Hospice Yukon offers grief support for individuals and families, including children and teens. Our services include counselling (in person, by telephone, or online), Healing Touch, a variety of grief groups, educational workshops, and a lending library.

Please contact us for information about current offerings.

**Hospice Yukon is open**

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