

Living with Change and Loss

Living with a life threatening illness can create painful feelings for patients and families associated with change and impending loss. Physical care concerns are combined with the difficult emotions experienced. Adjusting to these changes can be challenging.

What causes the feelings of loss and grieving?

Fear of losing the present family structure, such as the head of household, the family matriarch, or traditional family relationships

- Fear of the future, of not knowing what will happen
- Fears related to life without the loved one
- Loss of social life and activities that have brought happiness and meaning
- Loss of companionship, relationship changes, loneliness
- Loss of independence
- Change in “role,” inability to work, outside jobs and home chores and responsibilities
- Loss of control, such as, being able to care for themselves or their loved one

Reactions to Change and Loss

- Guilt, regret, resentment, anger
- Sadness and depression, anxiety, tearfulness
- Longing for life to be different
- Withdrawal from others, loneliness, isolation
- Irritability, frustration
- Feeling overwhelmed
- Feeling hopeless, helpless
- Changes in appetite, sleep patterns
- Forgetfulness, difficulty concentration

Steps for Coping with Change and Loss - What Helps? Recognize and respect feelings

Encourage patients and families to take time to honor the losses they have had and the sadness they feel. Trying to avoid feelings by trying to escape them will not make them go away. The body, mind and spirit suffer when feelings are not expressed in some way. Allow time to reflect, rest and feel. It may help to remember special times, reminisce with others, cry or laugh whenever they can. They may find that feelings will come up and then pass more easily when the person doesn't spend energy resisting them.

Find a way to express feelings Good friends, religious or spiritual care providers or family members can be a good source of support. Reaching out to others will help reduce feelings of isolation. Any activity that helps the person express what they feel can help them learn to cope with loss. Drawing, painting, listening to music, singing, writing or talking - communicating feelings of sadness is the most effective and healthy way to deal with them.

Join a support group Support groups are simply people coming together to share a common experience. Many people find support groups help them feel less isolated and offer a chance to learn from others and share happiness and sadness. Finding friendship in a group of people who understand or relate to their situation promotes hope. If they are unable to leave the house, encourage them to join a group by telephone or on the internet. Local organizations often provide support groups that they can attend in person.

Write feelings down If you enjoy writing, it can be a wonderful way to express feelings of loss and grief. It doesn't matter what you write or how you spell – the process of putting your feelings down on paper is what's most important, not what the end result looks like.

Read a book on coping with grief There are many books available on the issues of caregiving, self-help, grieving, and loss. Many people benefit from reading inspirational books.

Take time to remember Make an effort to remember happy times. Creating a memory book with photos and mementos of special events, holiday celebrations, or travels may help bring back memories of better days. Making a video diary to honor a person's life or can be a wonderful gift.

Take Care It is easy for the physical health of a bereaved person to suffer. Remind them to pay attention to the basics: eat healthy foods, get some exercise, rest when they can, consciously relax and take plenty of deep breaths. Encourage them to give their body the time and energy it needs to adjust to emotional stress and worries.

Seek Help When Needed

Caregivers may need to be encouraged to get help. Support sources can include:

Hospice Remind caregivers that the hospice interdisciplinary team is there to help them as well as the patient. Volunteer support as well as hospice nursing aide assistance can provide important respite reinforcement.

Family and Friends Help caregivers be prepared with suggestions for the time when family and friends ask “what can we do to help?” Running errands, shopping, cooking, or walking the dog – being relieved of everyday chores can provide caregivers time to focus on their loved one or get some needed rest.

Community Resources Community organizations are a great resource for various types of help. Faith communities and groups such as Cancer, Lung, or Alzheimers Support can help. Hospital, long term care and other health care providers may have support groups. The Agency on Aging (AoA) has many resources for caregivers.

Help can be hired privately. They may want to ask friends for recommendations or check the internet for local homemaker/companion or home health aide services.

Schedule Time to Recharge Everyone rests and recovers in their own way. For some people that may mean time spent with friends, family members or a group. Others may need time alone. There are still others who need to spend time doing something like gardening, going to a movie, or taking a walk. Encourage them to do whatever it takes to re-strengthen so they can continue doing the things that are most important.

Nurture the Spirit Grief and loss often bring up painful questions and doubts about our most basic spiritual beliefs. People often feel lost, abandoned and vulnerable. Prayer, meditation, sacred or spiritually meaningful reading or attending religious services can bring comfort and reassurance. Sharing feelings and questions of faith with a spiritual care provider can be helpful. Fundamental questions about the meaning of life are common in all cultures and peoples at times of suffering.

Keep Hope Along this journey, there are good days and bad days. As time passes, the pain and loss of today will be balanced by experiencing the kindness and compassion of others, and by eventually finding the path to enjoy life in new ways. People often find hope in small accomplishments by setting small goals.