Anticipatory Grief

When someone you care about is seriously ill and may even die, it is natural to think about what your life would be like without that person. You may also experience feelings of loss and grief, even though the seriously ill person is still alive. This is called anticipatory grief. It is a normal process of trying to prepare yourself for the death of your friend or family member.

Some reactions you may have

- Feelings of anxiety/avoidance of spending time with a seriously ill friend or family member
- Depression — feeling heavy, lethargic and like nothing seems to matter
- Feelings of being alone and that nobody understands what you are experiencing
- Change in sleeping and eating patterns
- Loss of interest in school/work
- Lack of concentration
- Sadness and tears
- Disbelief that this is really happening
- Anxiety – like you can’t stop moving, thinking or worrying
- Anger
- Fear of other people becoming sick
- Thoughts about hopes and dreams that may not happen
- Guilt
- Worry about what life will be like without your friend or family member
- Frustration about disruptions in your daily life
  - Not being able to spend time with your friends because you are needed at home
  - Missing special social events, such as a dance, club or sporting event
  - Visits by a nurse or hospice staff in your home
  - Seeing and hearing medical equipment in your home, such as an oxygen tank

Some challenges you may experience

A change in family roles

For Teens:
- May need to help take care of the sick family member
- May need to help take care of younger siblings
- May need to have more responsibilities such as meal planning, laundry, or outdoor chores

For Adults:
- May need to balance work and caregiving responsibility
- May need to take on new household responsibilities such as grocery shopping, meal preparation, or car maintenance
- May need to take responsibility for financial desires and bill paying
- May need to assist aging parent/family member

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(218) 786-4402. GriefCenter@essentiahealth.org
In decision making regarding safety concerns such as driving and living independently

- May need to advocate for seriously ill person at medical appointments
- May need to assist seriously ill person in end of life decision making/Hospice options
- May need to assist seriously ill person with medication management/setting up weekly pill box
- May need to be gatekeeper for encouraging or regulating visitors
- May need to update family/friends on patients condition via phone calls, email, Facebook, or Caringbridge.org website

Changes in the family routine since your loved one has become ill

- Your daily schedule may change.
- You may not be able to sit down to a meal together as often as a family.
- Other family members may be stressed, exhausted, worried and not readily available

Some ways to help you get through this

- Request information about your loved one’s illness.
- Identify support systems, such as family, friends, church, or grief support counselor.
- Identify someone you can confide in who is outside your family.
- Decide how you want to communicate with your loved one in person, via e-mail, or by telephone.
- If hospice is involved, ask the hospice team members for support. They can
  - Find more help for the family
  - Lead a family meeting where everyone airs feelings
  - Listen to your concerns
  - Help you find information and answer your questions about your loved one’s illness
- For more resources for youth – call St. Mary’s Grief Support Services at 218-786-4402 or email griefcenter@essentialhealth.org for information regarding “Kids Can Cope” groups for youth and “Helping Children & Teens When A Family Member is ill packet

Some ways you can express your thoughts and feelings with your seriously ill friend or family member

- Express what you need to say through writing (journal, letter, poem, song), music or art
- Create a photo album or memory book together
- Create a special music CD by downloading music that you can enjoy together
- Create a family Web site like Caringbridge.org
- Put together a photo CD
- Tape record or video tape conversations or stories with your friend/family member
Some ways you can manage the stress of caregiving

- Take breaks as needed without feeling guilty
- Ask for help when you need it
- Practice slow Belly Breathing – slowly in through your nose to the count of 5 and gently out through your mouth to the count of 5
- Tend to your physical needs: adequate water, nutrition, sleep, exercise (walking)
- Avoid excess caffeine which can contribute to anxiety
- Limit/avoid alcohol which can contribute to depressive symptoms and dehydration
- Avoid worrying about what is beyond your control. Focus on taking charge of what is within your control
- Take time for activities which help you feel more relaxed – time with a pet, reading, soothing music, warm bath, gardening
- Take time for your spiritual needs: prayer, meditation, coloring mandalas, refection in nature
- Visualize a safe/calm place with Belly Breathing – imagine laying on a beach, in a tree house, etc.

What can you say to a dying person?

- Meet the person where they are at in that moment. Some days they may want to talk about their grief and other times may focus on the here and now
- It’s important to keep in mind that the person that is dying knows they are dying and it is something you don’t have to avoid or force.
- Don’t forget to say “I Love You” – the book The Four Things That Matter Most, by Dr. Ira Byock, writes that dying people typically want to hear (and to say) four things: “Please forgive me,” “I forgive you,” “Thank you,” and “I love you.”
- Talk about how they are feeling (and listen) - Listening to your loved one is the first step to understanding what they truly need most. Ask them what they’re thinking about, what they may need – and if they need help with something, do the best you can, whether they ask for help with household chores or simply your company.
- Encourage them to share memories and Goals - Everyone is going to approach their death differently; some will find it most important to mend relationships with friends or family, while others will prefer to focus on remembering accomplishments or discussing old regrets. Either way, it’s important to give your loved one a chance to open up and talk about what they have experienced, and what is to come. Have conversations about the things they’ve learned, the legacies they’ve left, the memories you have of them. Help them feel like they are important.
- Be truthful, but kind - You don’t have to avoid talking about the fact that your friend/family member is dying. It is very okay to say you don’t have answers to the big questions, or that you don’t know how to respond to some expressed need. Always be truthful, but don’t clobber them with the truth. Most of all, you’ll want to let your loved one guide the situation. It’s not so much the exact words you say as it is maintaining the openness of the conversation.
- Don’t be afraid of tears – yours or the dying individuals. Tears may help that person express their death in a healthy way with you. Be present to give warmth and love. You don’t have to fix or heal their pain. Just be there.