Changing the Sails on the Cancer Journey

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Caregiver to family

“I can’t change the direction of the wind, but I can adjust my sails to always reach my destination.”

nbmtLINK
National Bone Marrow Transplant Link
Its okay to grieve as you enter this step in the journey
All emotions are normal with advanced cancer. You may feel things you do not expect.

It is important to let yourself feel these emotions and grieve for what you are losing. You might feel some or all of the following emotions:

Grief  Anger  Resentment  Fear  Regret  Sadness  Relief  Calm  Acceptance

Your health care team can help you cope with them. They may be able to recommend a counselor who has experience working with people with advanced cancer or prescribe medication to help. Many people also find that talking about their feelings/concerns with family and friends is comforting. Some people may join support groups specifically for advanced cancer. Some may blog, write letters, and look for ways to show appreciation for those they love.
Treatment and care of end stage AML
When treatment stops being effective and/or people choose to discontinue treatment, doctors may offer individuals end-of-life care.

End-of-life care aims to support the individual and their families and enhance their quality of life as much as possible, including providing comfort and managing pain.

Support involves asking individuals how they want to be cared for and offering support to their families and caregivers. Individuals or their caregivers can choose where end-of-life care takes place and where they want to die. They can get palliative care, home care, respite care, supportive care, and hospice care. They can choose to stay at home or go to a hospice, nursing home, or the hospital.

Support looks at the needs for both the patient and caregiver/family. This includes physical, emotional, mental, spiritual, social, practical and legal.
Physical care is about comfort and pain management. It also is choosing where you want your final days.

The ultimate goal in end stage care is to make people as comfortable as possible. The following may help provide comfort:

- ensuring cushions, beds and chairs are comfortable
- observing proper turning schedules to prevent bedsores
- serving small frequent meals
- elevating the person’s position slightly to help with breathing
- using blankets to provide warmth

Keep their mouth moist, offer sips of liquid through a straw or from a spoon if they can swallow. If appropriate, ice chips are an option or swab water with a sponge.

- putting a damp cloth over closed eyes to ease dryness
- gently holding or rubbing the person’s hands and feet, offering massages if the person finds them comforting
- applying lip balm or glycerin swabs on dry lips and mouth
- gently applying alcohol-free lotion on dry skin
Emotional/Spiritual Needs
For family and relatives who want to offer their support, any peaceful presence is enough. They can help reduce the feelings of uncertainty, anxiety, and loneliness by:

- holding hands
- sitting beside them
- talking to them
- listening to their stories
- Playing music they enjoy

Counseling/medication

Meeting a person’s spiritual needs. Many people find courage and peace through their faith, and reading texts and playing spiritual music may help bring comfort to the individual. Ask what rituals or ceremonies are important to them now and when their life is celebrated.

Remembering happy memories and sharing how the person has impacted people’s lives may also fulfill their spiritual needs, including living a purposeful life.
Hope
You can feel a sense of hope, despite your cancer. But what you hope for changes with time.
You can hope for other things such as comfort, peace, acceptance, meaningful moments with loved ones and even joy. Hoping may give you a sense of purpose and help you feel better.
To build a sense of hope, set goals to look forward to each day. Plan something to get your mind off the cancer. Here are some tips from others with advanced stage cancer:
■ Plan something to look forward to each day
■ Don’t stop doing the things you like to do just because you have cancer, even try to part of it if you can’t fully do it.
■ Plan for the future
■ Look for reasons to hope, while staying aware of what’s at hand.
■ Be mindful of making moments
Stories can be a gift to the people you leave behind. As you review your life, you may want to write down or record your memories. Or you can ask someone else to write or record as you talk. Sharing your wishes and dreams for loved ones may help ease your regrets about leaving them. It can also help them connect with you at important times in their lives. For young children, consider making them videos and photo albums that remind them of your love and connection.
Some people may also take comfort in knowing that, even towards the end of life, they are giving those who care about them an opportunity to follow a path of least regret. Every experience, conversation, disclosure, or time shared together with loved ones creates lasting memories and shapes the grief that will soon follow. Even when words are no longer possible, your presence offers those within your circle a place to gather and begin mourning; a place to comfort and support one another as they contemplate how to move forward in their lives without you. Whatever your final path towards death, know that it will imprint those who grieve your passing and how they face the end when their time comes. That is something you will shape, until you take your final breath.

-Harvey Max Chochinov, MD

Joe’s Story
My words to him
His words to us
Special surprises
Spiritual Needs
The spiritual needs of patients receiving hospice or palliative care can include: Connecting with the faith and practices of their religion. Understanding what gives their life meaning. Exploring how they wish to be remembered.

Everyone, whether religious or not, have spiritual needs such as:
the need to love and be loved.
the need for meaning and purpose.
the need for support and hope.
the need for dignity and respect.

This could involve rituals, spiritual leaders, devotions, spiritual reading, prayer, meditation, community and more.
Social

Support Online

**CancerCare** offers about 100 online groups for people with cancer and their loved ones. The groups are led by oncology social workers who give support and guidance.

**Cancer Connect** combines current cancer treatment news and educational content with a moderated social community for patients and caregivers. Cancer Connect is used by some cancer centers, allowing patients to interact with others receiving treatment at those centers and creating a destination to seek information, support, and inspiration.

**Cancer Support Community** is an international nonprofit dedicated to providing support, education, and hope to people affected by cancer. They provide support services through a network of professionally-led community-based centers, hospitals, community oncology practices, and online.
Resources

Memories Live
Contact: 646-245-1698
Population Served:
Individuals in the US with a terminal illness or end-stage disease

Mission
To help people with life-limiting illnesses preserve their images, stories, and wisdom by creating personalized movies to pass on to their loved ones.

Creates unique legacy movies at no cost to families. The final product is an edited movie saved on a USB drive and mailed to the family.
**CaringInfo**  
**Contact:** 800-658-8898 or email caringinfo@nhpco.org  
**Population Served:** People in the U.S. seeking information about hospice and end-of-life care  
**Mission**  
CaringInfo is a program of the National Hospice and Palliative Care Organization that provides free resources to educate and empower patients and caregiver to make decisions about serious illness and end-of-life care and services.  
• Offers free resources and information in multiple languages to help people understand curative, palliative, hospice, comfort, and bereavement care topics and on tools, guides, and resources on decisions about end-of-life care  
• Free, downloadable, state specific templates for advanced health care directives and other resources

**Compassion & Choices**  
**Contact:** Website  
**Population Served:** People with life-threatening illness  
**Mission**  
To improve care, expand options and empower patients to chart their end-of-life journey.  
Offers a variety of programs, tools and resources (including in Spanish) to help people with life-threatening illnesses find the support, opportunity and courage to live their remaining time on their own terms.
Legal- Advance Directives, Wills, and more...

**Triage Cancer**
Contact: 424-258-4628 or info@TriageCancer.org
Population Served:
Cancer patients, survivors, caregivers, advocates, and health professionals

**Mission**
To help navigate cancer survivorship from the point of diagnosis throughout life, by providing education on all types of cancer survivorship topics

Offers free in-person and online educational events, a speakers bureau, and online educational materials and tools. Resources cover a wide array of topics including guides on reasonable accommodations, chemo brain, insurance, employment, finances, etc.
You or your family should find and organize important legal and financial papers. These may include:

Your will

Marriage and birth certificates

Social Security card

Insurance policies, bank statements, and investment summaries

Account passwords

If your finances are complicated, consider talking with a financial advisor. If you are concerned about leaving your family with high medical bills or debts, a medical social worker can help. They can work with you to create a plan that reduces stress on you and your family. Your health care team can help you find a medical social worker.
What are the different ways to cope with grief?

Your ways of coping will be unique, just like your grief. Think about how you have coped with difficult situations in the past, and try similar things now. Here are some things to try:

**Let your feelings out.** Grief hurts, but it is natural and healthy to grieve. Let yourself experience your feelings, such as shock, sadness, anger, and loneliness. Don't judge yourself for any feelings, even if you think you should not have them. You might feel guilty or feel pressure to "get over it" from others. Let yourself react, even if it means crying or screaming.

**You might want to spend some time alone each day to process and release your feelings.** This might be especially helpful if it is hard to show your feelings around others.

**Be patient. Let your grief happen at its own pace.** Do not judge yourself or compare yourself to others. Everyone grieves differently.
Find ways to be creative. Playing music or creating art can help you express your feelings. This can be done on your own or with the help of a music therapist or art therapist. Or, write your thoughts, feelings, and memories in a journal. Looking back through your journal may allow you to see how your grief changes over time.

Be physically active. Walking, running, riding a bicycle, or other forms of physical activity can help you release stress and cope with feelings. You can try hitting a punching bag or hitting golf balls at a driving range as a healthy outlet for any frustration or anger you feel.

Forgive yourself. Be kind to yourself if you are thinking about things you regret about your time with your loved one. This can help you focus more on good memories.
Take care of yourself. It is important to take care of yourself before and after someone dies. Grief can make you very tired, emotionally and physically. Try to get enough sleep at night, eat a healthy diet, and exercise regularly. Talk to your doctor or nurse if you need advice on healthy lifestyle choices or experience problems, such as sleep disturbances.

Keep up your routine. Having a daily routine helps you know what to do with your time. It also keeps you connected to familiar people and places. You might want to avoid any major changes, such as getting a new job or moving, soon after a loss. Keeping your routine can help you feel more normal and secure, and less stressed.

Stay connected with your person. You can stay connected to your loved one in many ways. These could be looking at photos, watching videos, remembering their advice to you, or thinking about your times together.
How can family and friends support you when you are grieving?

You don’t have to grieve alone. Ask for help and support from your family and friends. Here are some things you can try to feel less alone while you are grieving:

**Talk with other loved ones.** Talking about your loss and sadness may help you deal with your feelings and let them go. Tell family and friends that it helps you to talk. Make sure they know you do not need them to give you answers. You just need them to listen.

**Stay connected with other loving family and friends.** It is OK to give yourself a break from grieving. Spending time with people you enjoy can help you heal after you lose a loved one. Part of coping with loss is being able to go back and forth between grieving and participating in everyday life. It is OK to laugh and feel happy moments, even when you are losing or have lost someone.

**Join a support group.** Support groups give you the chance to talk with other people who are experiencing loss. Group members can offer encouragement, comfort, advice, and practical suggestions. They can also show you that your experiences are normal. You might want to join a support group for people who have lost a family member or friend. Or you might want a group of people in your specific situation, such as losing a spouse to cancer.
Resources

https://www.cancer.net/navigating-cancer-care/advanced-cancer/completing-your-life


https://www.medicalnewstoday.com/articles/signs-of-dying-from-aml

https://www.lls.org/managing-your-cancer/end-life-care