Helping When The News is Not What Was Hoped For

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Caregiver to family

nbmtLINK
National Bone Marrow Transplant Link

Exercise

Grab a piece of paper and pen, write down the following

* Something you highly value about yourself -purpose, gift

* Your dream job

* A word you would us to describe your faith

* Your partners name or a word to describe the dream soulmate

* Write down a number for income a year to feel financially stable

* A physical feature you like or are most ok with about yourself

* Write down your children's names or someone in life that gives you a sense of purpose

* Write down a life goal or how you hope to spend your retirement years

Judy's Story

You might have experienced emotional tugs with this exercise. Let it provide a mini example of what your patients go through.

Take a moment to think about the multiple losses happening every step of the journey for your patients. Even a basic bad lab result can be given on a day where they feel their world is falling a part.

A key take away is to be present, supportive, truthful, but kind. As fast paced as healthcare is, we must slow down for these moments. Walk with them on the journey, never let them feel like you are leaving them alone.

Our patients experience complex levels of grief daily. We cannot always change the “weather in their world” but our presence should be like a cold drink on a hot day. We need to show authentic kindness and compassion.

Watch body language as you pace yourself with them, including your own.

1. Face them and give eye contact.

2. Lean in, nod as they speak, and listen to understand (not just to respond).
   Clarify what they understand and what you do as well. For example,
   "what I hear you say is you want a couple days to think about this".

3.Remove barriers while communicating. It is better to sit in a circle or living room style than at tables. It is much less sterile.

4. Don't talk too fast.

5. Carefully observing a patient's facial expressions and hand gestures (such as fidgeting) will allow you to shift the conversation, so the patient feels more at ease. For example, a patient who's exhibiting nervousness or confusion may need to have information about their medical results clarified. Taking a step back upon observing patients' reactions can put things in perspective and allow you to provide the best feedback at that moment. If you see body language that looks overwhelming, you can validate and stop a moment. You can say things like, " This is a lot to take in".

Have the team wrap around them as a village.

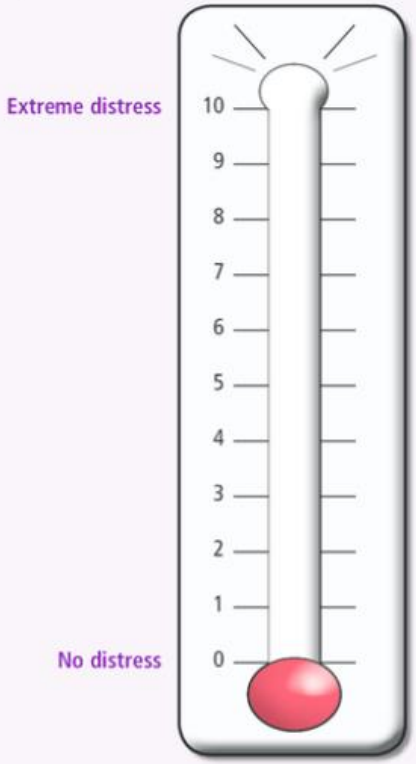
For example, doctors can consistently check in on symptom management and comfort.

Social workers can offer support and resources for practical needs and wishes.

Chaplains can assess spiritual needs and provide comfort in a way that is meaningful for them.

Check Ins could mimic the distress tools, even if done informally.

Instructions: First, please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.



Second, please indicate if any of the following has been a problem for you in the past week, including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
❒	❒	Child care
❒	❒	Housing
❒	❒	Insurance/financial
❒	❒	Transportation
❒	❒	Work/school
❒	❒	Treatment decisions

YES	NO	Family Problems
❒	❒	Dealing with children
❒	❒	Dealing with partner
❒	❒	Ability to have children
❒	❒	Family health issues

YES	NO	Emotional Problems
❒	❒	Depression
❒	❒	Fears
❒	❒	Nervousness
❒	❒	Sadness
❒	❒	Worry
❒	❒	Loss of interest in usual activities

YES	NO	Spiritual/Religious Concerns
❒	❒	

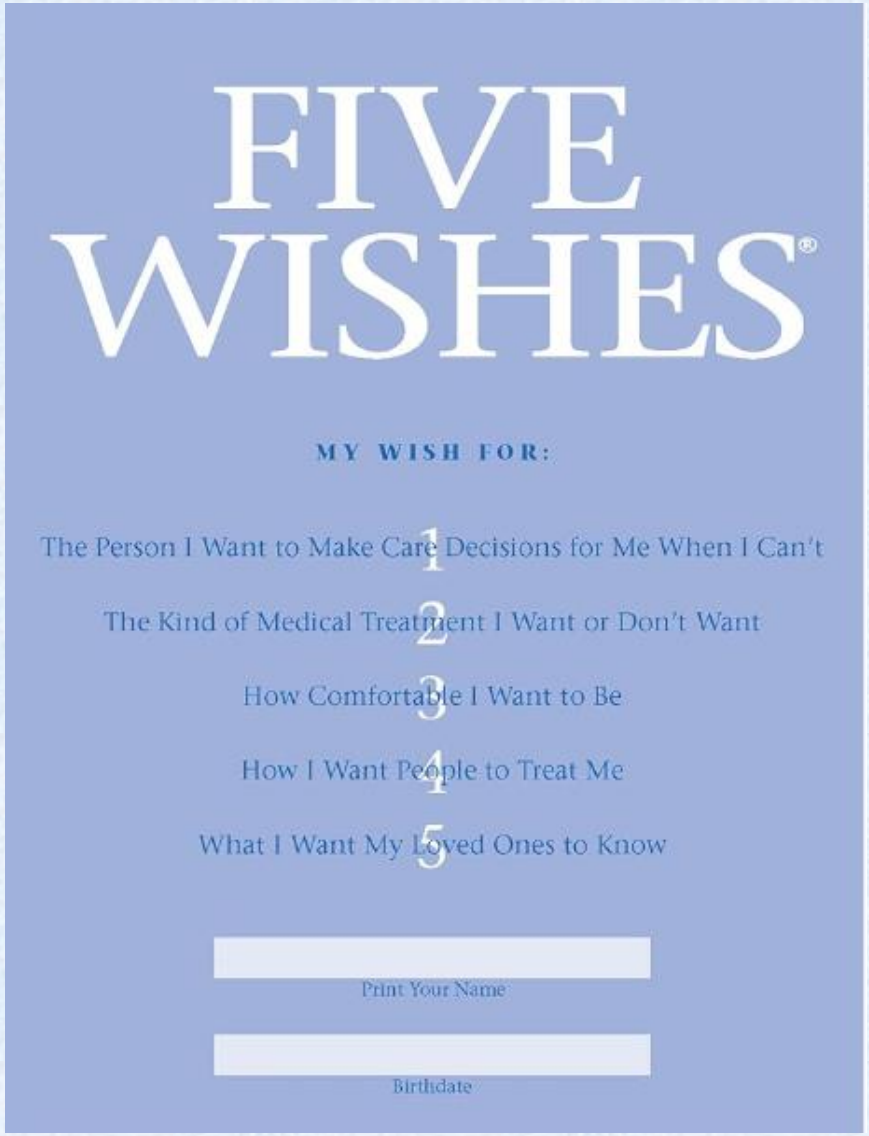
YES	NO	Physical Problems
❒	❒	Appearance
❒	❒	Bathing/dressing
❒	❒	Breathing
❒	❒	Changes in urination
❒	❒	Constipation
❒	❒	Diarrhea
❒	❒	Eating
❒	❒	Fatigue
❒	❒	Feeling swollen
❒	❒	Fevers
❒	❒	Getting around
❒	❒	Indigestion
❒	❒	Memory/concentration
❒	❒	Mouth sores
❒	❒	Nausea
❒	❒	Nose dry/congested
❒	❒	Pain
❒	❒	Sexual
❒	❒	Skin dry/itchy
❒	❒	Sleep
❒	❒	Substance abuse
❒	❒	Tingling in hands/feet

Other Problems: _____

_____

Distress Thermometer Screening Tool Note. Adapted with permission from the NCCN Clinical Practice

Ask questions on their needs but also can give examples. With everything that feels so out of control, look for ways to give them some control.



Can we recommend a counselor who has experience working with people with advanced cancer or prescribe medication to help? A support group? Peer mentor?

Do they need ideas on what can help with their grief?

Support involves asking individuals how they want to be cared for and **offering support to their familes and caregivers**. Individuals or their caregivers can choose where end-of-life care takes place. 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.**

Grief

from Cancer.net

Coping will be unique, just like their grief. Help them think about how they have coped with difficult situations in the past, and have them consider try similar things now. Here are some things they can try:

Let their feelings out. Grief hurts, but it is natural and healthy to grieve. Encourage them to experience their feelings, such as shock, sadness, anger, and loneliness without judgement. They can talk, journal, do art, or whatever helps them express what they are feeling.

Encourage self care. Grief can make you very tired, emotionally and physically. They need to take care of themselves.

Encourage connection with other loving family and friends. It is OK to get a break from grieving. 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 grieving.

Offer support groups if appropriate. Support groups give people the chance to talk with other people who are experiencing challenges. Group members can offer encouragement, comfort, advice, and practical suggestions. They can also show you that your experiences are normal.

Help Their Hope Transition

What you hope for changes with bad news.

Even if they are terminal,they can hope for other things such as comfort, peace, acceptance, meaningful moments with loved ones and even joy. Hoping can give a sense of
purpose and help them feel better.

Help give their mind a break from the heaviness of cancer. Here are some tips from others with advanced stage cancer:

- Help them look for things to enjoy each day. The nurses who gave their patient a manicure on the unit. Caregiver ideas.
- Encourage them to do what they can tolerate instead of just totally stepping back because of their cancer, even if it means only being able to partially do something. The baking story.
- Look for reasons to hope, while staying aware of what's at hand.
- Be mindful of making moments. Christmas ornament story.
- Focus on them as a person, don't make cancer a 24/7 experience.

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, or placing a hand on the shoulder

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.

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.

If they are going to hospice, these things can help with physical comfort.

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

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.

Resources

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

https://www.cancer.gov/publications/patient-education/advancedcancer.pdf

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

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