



Amaranth Foundation

But I Don't Know What to Say...

Though words often fail us when friends or family face a terminal illness, they're often all we have left.

Fran Johns

Strange as it sounds, the terminal diagnosis is often the "easy" part. After the diagnosis comes breaking the news to friends and family, dealing with colleagues and neighbors, finding new ways to speak about the unspeakable.

"Somehow it seems a little unfair," says one 55-year-old woman suffering from metastasized breast cancer. "I weigh my words to avoid burdening my friends, and they stay away because they think they don't know what words to use."

Don't let a concern for saying the "wrong thing" keep you away from a friend or loved one who's facing death. The best solution is often to say nothing at all, simply to be present. Or, if you are a close friend, to say, "I love you" and let it go at that. "I love you," according to the woman above, "is sort of a generic OK expression in the case of those who are dying."

Simple expressions of concern are what most of us, living or dying, welcome, especially if the expression comes from a good listener. Critical to talking with someone who is dying is practicing the art of listening: be present and wait; or ask a question and wait. Try to avoid offering instant solutions or pleasantries, instead saying, "That must be awful/ gratifying/ painful/ frustrating/ wonderful," or whatever single word fits.

One man uses this effective greeting with a close friend who is dying, pausing quietly between phrases: "How are you doing physically?"... "How are you doing emotionally?"... "How are you doing spiritually?"

"It's important to differentiate between 'spiritual' and 'religious,'" says Sara, another woman in her fifties with cancer now defying intervention. "People willing to share their thoughts on the possibilities of

something more than this mortal life have been really helpful to me. But I know others who want to dump their own religious certainties on me and that can be terribly offensive." The "just listen" admonition may be particularly appropriate here.

Talk about ...the day at hand...Or we talk about small successes past. Recognizing and acknowledging the impact for good that one leaves behind, thanks to some deed or interaction, can be a comfort in the waning days of life. (Do you remember the time...? I was just thinking about ...)

With casual friends, neighbors and colleagues, questions, sincerely meant and sincerely asked, are often welcome and useful. The traditional "How are you?" can evoke the traditional "Fine" and end the exchange. (Which is sometimes all that's intended.) But a thoughtful question--"Do you want to talk about..". or "Will you help me find a way to be useful to you?" can establish a small connection which other connections can be built.

Enjoying the moment is something you learn when moments are quickly disappearing; it's also a gift the dying make to the living.

Here are some easy words to say out loud: I'm sorry. I want to help if I can. You're a wonderful friend. I love you.

<http://www.beliefnet.com/Love-Family/2003/07/But-I-Dont-Know-What-To-Say.aspx>

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Loss & Grief

Grief is a multi-faceted response to loss, particularly to the loss of someone or something to which a bond was formed. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioural, social, and philosophical dimensions. While the terms are often used interchangeably, bereavement refers to the state of loss, and grief is the reaction to loss
<http://en.wikipedia.org/wiki/Grief>

You may associate grief with the death of a loved one—which is often the cause of the most intense type of grief—but any loss can cause grief, including:

- Divorce or relationship breakup
- Loss of health
- Loss of financial stability
- A miscarriage
- Retirement
- Death of a pet
- Loss of a cherished dream

- A loved one's serious illness
- Loss of a friendship
- Loss of safety after a trauma
- Selling the family home

The more significant the loss, the more intense the grief. However, even subtle losses can lead to grief. For example, you might experience grief after moving away from home, graduating from college, changing jobs, selling your family home, or retiring from a career you loved.

http://www.helpguide.org/mental/grief_loss.htm



Grief is a journey made without a map.

Grieving is a personal and highly individual experience. How you grieve depends on many factors, including your personality and coping style, your life experience, your faith, and the nature of the loss. The grieving process takes time. Healing happens gradually; it can't be forced or hurried—and there is no “normal” timetable for grieving. Some people start to feel better in weeks or months. For others, the grieving process is measured in years. Whatever your grief experience, it's important to be patient with yourself and allow the process to naturally unfold.

http://www.helpguide.org/mental/grief_loss.htm

“...there is not a typical response to loss, as there is no typical loss. Our grieving is as individual as our lives.”
Elisabeth Kübler-Ross

We might ...think of the grieving process as a roller coaster, full of ups and downs, highs and lows. Like many roller coasters, the ride tends to be rougher in the beginning, the lows may be deeper and longer. The difficult periods should become less intense and shorter as time goes by, but it takes time to work through a loss. Even years after a loss, especially at special events such as a family wedding or the birth of a child, we may still experience a strong sense of grief.
Source: Hospice Foundation of America

There is no right or wrong way to grieve. Normal emotions associated with grief include anger, anxiety, confusion, sadness, depression, fear, guilt, shock and relief. Ways of coping may include looking after your physical health, spending time with family or time alone, counselling, meditation and memorials to a loved one.

Generally, there are two broad styles of grieving, but most people experience a combination of both. They are:

- The intuitive approach – people seek out social support and tend to focus on the emotional aspects of their loss and managing their feelings
- The instrumental approach – people tend to focus on the cognitive (thinking) aspects of their loss. They may grieve through activities and problem solving. This style tends to be more solitary and private, focusing on managing the thoughts that arise.

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Grief_explained



Terminal Illness—The Tricky Questions

What is a Terminal Illness?

A terminal illness is one that despite any treatments there may be to slow the progress of the illness, the illness can't be cured. It will, in time, result in death.

What is the difference between Palliative care and Hospice care?

Many people confuse palliative care and hospice care. Medical professionals who practice palliative care focus on relief of pain, stress and other symptoms of debilitating illness. Hospice is for the terminally ill only. No one knows how long someone has, however typically they expect death in under 6 months.

(<http://www.ask.com/question/what-is-a-terminal-illness>)

Time seems to freeze when you learn that someone you love has a life-threatening illness. Maybe you instinctively pushed the news away. Or perhaps you cried, or swung into action. No matter what happened that day, time and life go on after the diagnosis is made—regardless of whether you feel ready to cope. You and your loved one may have pursued promising treatments and perhaps enjoyed a respite from encroaching illness. At some point, however, the illness may become terminal, and gradually the end draws closer. Once further treatments are unlikely to be successful, there is a great deal you can do to muster support for both of you.

Some of the support you need is emotional. The fears and

feelings that surface now are better aired than ignored. Some of the support you need concerns practical details. End-of-life care needs to be arranged and funeral plans need to be considered. Legal and financial matters must be addressed now or in the days after the death.

Not everyone who is terminally ill is ready to talk about death. So how will you know when to talk and what to say? Below are some words that may help you. Your task in this difficult time is merely to open the door to this conversation and promise to stay for it if the person you care for wishes to talk.

Look for openings. A sermon or song you heard, a book you read, or the way someone else's illness and death unfolded can be an opportunity for remarks that open the door. By commenting, you signal that you're ready to talk and needn't be protected.

Broach the topic gently. Maybe start with the simplest question: "How sick are you?" While you may be too close to reasonably make that inquiry, there are other questions you can ask:

- What do you worry about?
- How can I help?
- Is there anything you want to talk about?

Try not to rebuff tentatively expressed fears with hearty assurances. It might help instead to ask specific questions. Depending on your loved one's comfort level and receptiveness to the topics, questions you could ask include:

- What are you thinking about?
- What would be a good death?

http://www.helpguide.org/harvard/dealing_serious_illness.htm

Questions to ask your doctor

If you have been diagnosed with a serious illness, you will face some important and life changing decisions about your medical care. Will you decide to try every treatment available to cure your disease? Or will you choose to treat your illness more conservatively? Maybe you'll decide to focus on comfort, or palliative care. Determining your goals of care will start you on the right path.

When considering any treatment options, whether they're considered curative or palliative, there are some essential questions you will want to ask your doctor.

1. What treatments are available for my illness?

Your doctor should tell you what treatments are standard for your illness. Your doctor will not always share the option of palliative care or hospice without being asked directly. If you are interested in finding out how palliative care or hospice can help you, be sure to ask.

2. What are the chances that a particular treatment will be effective?

Some treatments are standard and very effective. If you have tried treatments before that have lost their effectiveness or haven't worked at all, ask your doctor about less standard and experimental treatments. Knowing what the chances are that a treatment will provide relief will help you determine if the benefits of the treatment are worth any risks.

3. Will this treatment prolong my life?

Some treatments will target symptoms of an illness without extending life. You will want to know whether the treatment you're considering will extend your life and based on your

goals of care, you can decide if that indeed what you want.

4. What are the risks of a particular treatment?

This may be the most important question to ask. Just about every treatment has some sort of undesired consequence or side effect. Depending on your goals of care, a particular risk may not be worth the potential benefit. For example, if the treatment will likely make you feel sick, weak, and tired but not cure your illness, you might decide to forgo it to focus on quality of life.

5. How will this treatment affect my other medical conditions and treatments?

Some treatments have unintended effects on other medical conditions or treatments. For example, a patient with lung disease, heart disease, and kidney disease may take steroids to control lung disease, which can lead to increased water retention making their heart disease worse. Then, taking diuretics to control water retention and swelling can lead to worsening kidney failure. Finding out how potential side effects will affect any other illnesses will help you decide if the treatment is worth it.

6. If this treatment doesn't work, what is our next step?

You will want to know where you're heading if things don't go as hoped. Having a plan in place will make any new decision easier to make. Armed with the right information, you are empowered to make your own informed decisions about your treatment.

<http://dying.about.com/od/ethicsandchoices/a/6-questions.htm>

“HOW PEOPLE *Live* MATTERS”

... it really does.

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Advanced Care Plan

Planning for your future

- what if you had an accident or became so unwell that you were unable to speak for yourself?
- What sort of medical care would you want?
- Who would you want to make decisions for you?
- Have you spoken to your family or doctor about this?

An **Advanced Care Plan** is a written document that reflects what you would like done if you became unable to speak for yourself. This is prepared so that your wishes are known and respected. It might include appointing a substitute decision maker and may also include recording which treatments you would or would not wish to receive in the future. An Advanced Care Plan also allows you to write down other non-medical wishes.

Advanced Care Planning can make it easier for your loved ones to make difficult decisions about your health care in stressful and emotional times when you are unable to make these decisions for yourself.

“Don't cry because it's over, smile because it happened.”
Dr. Seuss

Recipe: Inca Inchi Protein Bars

Ingredients

2 cups almond meal
4 tablespoons Inca Inchi Protein Powder
½ cup unsweetened shredded coconut
½ teaspoon Seaweed salt
½ cup Coconut oil
2-4 tablespoons of Honey or Rapadura Sugar Syrup (add more if you like it sweeter)
1 Vanilla bean, scraped

Cacao Topping

½ cup Cacao wafers
2 tablespoons Coconut oil
2 tablespoons Honey or Rapadura Sugar Syrup (add more if you like it sweeter)
Pinch of Seaweed salt
½ cup activated almonds, chopped



Method

1. Mix almond meal, shredded coconut, inca inchi protein powder and salt together
2. In a small sauce pan, melt coconut oil over very low heat
3. Remove coconut oil from stove, add the honey or rapadura syrup and vanilla into oil
4. Add coconut oil mixture to dry ingredients until a coarse mixture forms
5. Press mixture into a lined baking tray and chill
6. In the meantime, (In the same sauce pan) melt cacao, coconut oil, honey or rapadura syrup and seaweed salt over low heat
7. Once completely melted, spread cacao mix on top of the base and sprinkle with almonds, return to fridge until chocolate hardens

Remove from refrigerator, cut into bars, serve, eat and enjoy!

<http://www.changingabits.com.au/recipes-1/inca-inchi-protein-bars-topped-with-cacao>