

TOPIC 5:

What do people with a life-limiting illness want?



WHAT YOU NEED TO KNOW

People who are sick and weak and who are struggling to help themselves, have the same priorities as you do. They want for themselves what you want for yourself:

- To maintain a sense of dignity and privacy, as much as possible;
- To maintain a sense of control, as much as possible;
- To be treated with respect, sensitivity and an awareness of their feelings; and
- To avoid being a burden to their family and friends, as much as possible.

The essence of your role as a caregiver is to do the very best that you can to honour these priorities.

There is no magic formula for caregiving; each caregiver will do the best that they can. But, by giving attention to these four priorities and by adopting a problem-solving approach, you too can be an effective caregiver.

How to Use a Problem-Solving Approach

Adopting a problem-solving mind-set and approach will help to decrease the feelings that you may have of being overwhelmed. It can feel like putting the pieces of a puzzle together; but, if you follow these key steps, you can work out most problems that you are faced with as a caregiver.

01

Gather information by observing any changes in the person's needs or abilities and any reasons that you can think of for those changes.

02

Gather resources if possible that address the issue that you are facing.

03

Make a plan of action based on what is realistic and manageable.

04

Choose what action you will take, share them with the person; and then act!

05

Evaluate the changes, results and outcomes with the person that you are caring for.

Create a Plan to Live Well Now

You could suggest to the person that you are caring for that you work together on a legacy gift for friends and families. A legacy gift can take many forms. It can be a final trip you all take together, a handwritten letter, some hand written notes, a journal, a narrated or captioned photo album, a video, an audio recording. Take some time and help the person that you are caring for to create a legacy gift for their loved ones. It can be satisfying to make and wonderful to share.

“Carve your name on hearts, not tombstones. A legacy is etched into the minds of others and the stories they share about you.” ~ Shannon I. Alder

What to write or talk about?

- Relationships
- Family history
- Highlights of your life
- Trips you took
- Favourite music, sports teams, heroes
- Your favourite saying

- Hopes and dreams for your family and friends
- Favorite books, poems, songs
- Favorite places in the world

“Your story is the greatest legacy that you will leave to your friends. It’s the longest-lasting legacy you will leave to your heirs.” ~ Steve Saint

Be a Friend

A young woman named Courtney Strain died of brain cancer in June 2010 at the age of 25. In the months before she died, she said that when she was diagnosed with brain cancer she sometimes felt like an outcast. People didn't know what to say to her, so they said nothing at all. So, with a friend's help she wrote a simple guide called “What You Can Do When a Friend (Like Me) Faces the End of Life.”

Here are some of the things she wanted people to know:

- **Hallmark doesn't fix it all.** ... Write a letter or send an email. ... [Talk to me when] I'm strong enough to sit and laugh or cry with you.
- **Don't pretend that everything is going to be OK.**
- **Don't abandon me at my most vulnerable time.** ... Sit and pray with me. Don't just pray for me.
- **Don't treat me like a child — even a well-loved child.** ... Include me in decisions that affect our family or social group.
- **Instead of asking, “What can I do for you?” Offer some concrete suggestions** — like bringing a meal or treat, or running errands.
- **Respect my decisions about my health care** — my doctors, my medications and my treatments — and about my end-of-life plans.
- **Just because I'm dying doesn't mean I'm any less capable of being your friend.** Dying isn't my whole identity.

(“What You Can Do When A Friend (Like Me) Faces the End of Life,” BJC Palliative Home Care and Hospice)

WALK IN THESE SHOES



1. Think again about the four priorities of people who are ill:

People who are sick and weak and who are struggling to help themselves want what you want:

- To maintain a sense of dignity and privacy, as much as possible;
- To maintain a sense of control, as much as possible;
- To be treated with respect, sensitivity and an awareness of their feelings; and
- To avoid being a burden to their family and friends, as much as possible.

2. Read each scenario below then problem solve the situation by honouring these priorities.

SCENARIO #1

John needs to use the toilet or commode. There is a minimal risk of him being injured if left unattended. So what

should you do to allow John to maintain a sense of dignity and privacy?

ANSWER?

Leave the room. If there is a minimal risk of John being injured if left unattended and if you are dedicated to helping John maintain a sense of privacy and dignity then the answer is clear. Leave him alone when he is using the toilet or commode. If you are worried, close the door and stand right behind it. Provide John with toilet paper prior to leaving him.

SCENARIO #2

Diane isn't hungry at lunch time. She simply doesn't want to eat. What should you do to help Diane to maintain a sense of independence and control?

ANSWER?

Ask her what she might like for lunch when she is hungry. Ask her to tell you when she is hungry and then prepare what you have talked about together. Give the person choices in the food provided, and offer reassurance. By doing so, you will help her maintain a sense of independence and control. Remember: very ill or dying people don't feel hunger like well people do. Do not force food. She may enjoy only one spoonful of her favourite treat. Do not make big plates of food. Smaller, more frequent snacks are often better tolerated and accepted.

SCENARIO #3

Natsu needs to have access to some special equipment that represent "sick rooms" including a commode, wound care dressings and adult incontinence garments or briefs. What can you do to be sensitive and respectful of Natsu's feelings?

ANSWER?

Remove these items when they aren't in use. Store them in a nearby closet or drawers. If you are ill, you don't need to be constantly reminded of your medical needs. Being sensitive to a person's feelings often means treating them as you would like to be treated. Cover a commode with a throw rug when not in use if you have nowhere to store it. Do not refer to adult incontinence garments as "diapers" as such a term can be very demeaning.

ADDITIONAL RESOURCES



Print these Tips for Caregivers and keep them handy.

Tips for Caregivers

- 1. Make time to care for yourself. (see Topic #3)** You will be of no use to the person you are caring for if you don't take the time to care for yourself.
- 2. Listen to the person** and empathize with their concerns. Avoid saying "I know how you feel" or "Try to cheer up" or "Pull yourself together." Rather, use empathetic statements such as "This is obviously a horrible time for you."
- 3. Take your cues from your loved one** but acknowledge how you are feeling too. Keeping a daily journal may help.
- 4. Answer the person's questions as best you can.** If you don't know, say so. Try to find out what you don't know. Always be truthful; everyone, whether sick or well, should be treated with honesty.

5. **Reinforce the person's dignity at all times.** Respect the person's privacy and allow as much control as you can about decisions over care and activities.
6. **Support the person's sense of independence and control.** Help the person do what they can for themselves and give them choices whenever possible. Help maintain their normal routines and rituals.
7. **Respect the person's right to choose.** Go easy on giving advice and be open to it being ignored.
8. **Support the person's sense of hope.** Hope can change over time. If a person is diagnosed with a life-limiting illness what they hope for when first diagnosed may change over time. That is okay. Be the person that supports a person's sense of hope. Ask the person, "What are you hoping for today?" It could be as simple as having no pain, sitting outside, seeing a friend, etc. Once you know what they hope for, you can perhaps help it happen.
9. **Maintain family relationships.** Create a place where family members feel welcome. Encourage people to visit and to share some of their time. Include your loved one in family activities whenever possible.
10. **Reminisce** about your life together, the good and not so good.
11. **Spend time together** talking, listening to music, watching television, playing cards or games. Share your laughter and your tears. Work on that legacy gift and that bucket list.
12. **Resolve any unfinished business** as best you can even if this means involving a third person.
13. **Help identify unmet spiritual or psychosocial needs.** If a person you are caring for feels anxiety or fear, ask if they would like to talk to a priest, a clergyman, a spiritual leader, or counsellor. Help your loved one put affairs in order.
14. **Build in time for the person to rest** and let visitors know when that is.

(Adapted from Canadian Hospice Palliative Care resources)