Guide for Individuals Supporting a Cancer Journey



By: University of Pittsburgh
Occupational Therapy
Doctorate Students





Sarah Kargbo, Morgan Krantz, Helena Krejsa, & Rhea Roy Pitt Faculty Mentor: Avital Isenberg, CScD, OTR/L

This guide was created to support the supporters.

"Supporters" refers to anyone involved in the emotional or physical care of someone who is currently experiencing, or has previously experienced, symptoms related to a cancer diagnosis and treatment. This can include teachers, friends, care partners, and others in a supportive role.

Taking on the role of a supporter, especially for someone with cancer, can be an emotionally and physically demanding journey. This guide aims to provide insights, practical tips, and emotional support strategies to help you navigate the complexities of caregiving while taking care of your own well-being.

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MODULE 1

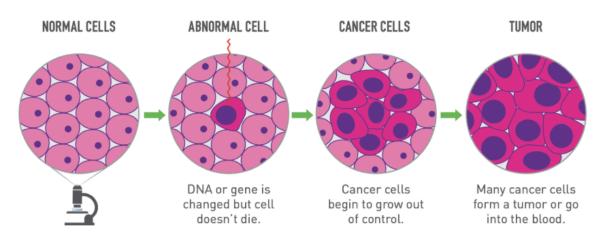
Understanding Cancer and Symptom Management

This module covers...

- Understanding cancer
- Stages of cancer
- Cancer treatment
- Symptom management
- Reminders on keeping your loved one safe
- Questions to ask the doctor
- Post cancer treatment (Remission)
- When treatment is ongoing
- Final tips for supporters

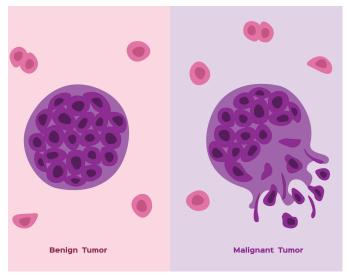
Understanding Cancer

When your loved one is diagnosed with cancer, it may be helpful to understand their disease



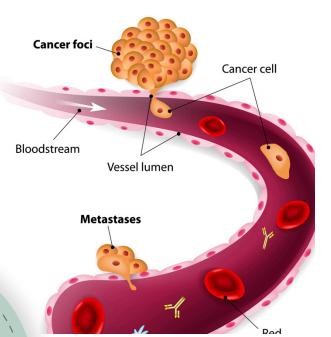
Cancer is when abnormal cells in the body grow out of control through this process:

- Normal cells become abnormal cells when the DNA or gene is changed. The cause of damaged genes is unknown, but it can be due to inherited damaged genes or environmental factors
- Abnormal cells become cancer cells when they grow out of control and make new cells that have the same damaged genes. Normal cells can repair damaged genes, or the cell will die but these cancer cells cannot repair themselves and they don't die so they replicate
- In some cancers, like breast, prostate, and lung cancer, the cancer cells continue to replicate until they form a tumor. In other cancers, like leukemia, the cells do not form a tumor, but instead, circulate through the bloodstream.



Not all tumors are cancer cells. Benign tumors are a noncancerous collection of cells. Because they are not cancerous, they cannot invade other tissues or spread. However, they may press on healthy organs and tissues and therefore need to be removed

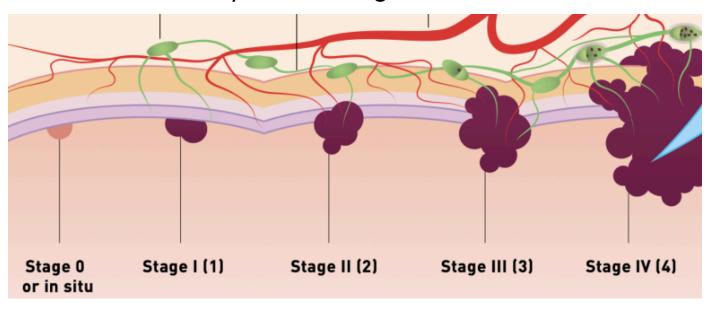
Metastasis occurs when the cancer cells travel to other parts of the body through the bloodstream lymph vessels and form new tumors in other areas of the body.



Cancer can look different depending on the type and stage of cancer. Each cancer grows at different rates and responds to different treatment

Stages of Cancer

When your loved one is diagnosed the doctor will often tell you the stage of the cancer



Abnormal cells. that have not spread

The tumor has grown larger and possibly spread out of the original site

The tumor is small and contained in one area, so it has not spread out of the original site

The cancer has spread outside of the original site to other areas of the body

The tumor has grown deeper into surrounding tissue and has potentially spread out of the original site

Cancer Treatment

Below provides a summary of the types of treatment your loved one may be receiving, has received, or will receive

Surgery

Used to	Side Effects
 Detect cancer Biopsy: taking out a small piece of tissue to check for cancer cells Staging: Determining the stage of the cancer Treat cancer Removing all the cancer Remove some of the cancer Treat problems caused by the cancer Remove organs or tissues that are at a high risk for developing cancer 	 Bleeding Pain Infection Blood clots Nerve damage Scar tissue buildup

Chemotherapy

Medication given via intravenously (IV), oral medication, or injection

Used to	Side Effects
 Kill cancer cells Keep the cancer from spreading Make the cancer grow slower Used with other treatments May be used to shrink tumors before surgery or radiation. May be used after surgery or radiation to help kill any cancer cells that are left. 	 Nausea and vomiting Hair loss Mouth changes Skin changes Sexual function changes Memory changes Emotional changes

Radiation

High energy beams directed at cancer cells

Types include...

- External beam radiation therapy: In a clinical setting, a big machine sends high-energy beams to the tumor and some of the area around the tumor
- Internal radiation therapy: A sealed radioactive source is placed in or near the tumor using a minimally invasive approach
- Systemic radiation: An unsealed radioactive source that's given in an IV or as a pill you swallow

Purpose	Side Effects
 Kill cancer cells Slow the cancer's growth Used with surgery, chemo, or other treatments 	FatigueSkin changesEatingproblems

Targeted Drug Therapy

Purpose	Side Effects
 Specialized medications given to attack the specific type of cancer cells that are present May be given via oral medication and IV 	 Skin changes Changes in hair growth or color High blood pressure Bleeding problems Blood clots Heart problems Swelling in the face, feet, legs or hands

Immunology

Purpose	Side Effects
 Allows the person's immune system to identify and destroy cancer cells May be given via an IV, injection or oral medication 	 Skin rashes or itchiness Diarrhea Fatigue Cough Nausea Muscle and joint pain

Hormone Therapy

Purpose...

Side Effects...

- Block or change hormones to slow or stop certain types of cancer that rely on hormones to grow (ex. breast, prostate, adrenal, and uterus cancer)
- May be given via injection or oral medication

- Hot flashes
- Night sweats
- Feeling tired
- Bone problems
- Sexual interest changes

(!)

Important



Symptoms can be the result of treatment or the cancer itself.

The above information includes common side effects for each treatment, but each person can experience different symptoms

Symptom Management

The following are symptoms of the cancer itself and/or side of effects of treatment and ways you can assist as a supporter

Fatigue

Fatigue is extreme tiredness that does not get better with rest

To help your loved one manage fatigue...

- Plan daily activities for times when they are most refreshed
- Encourage regular exercise because it can reduce fatigue. It is important to start small and build up each day
- Limit naps to 30 minutes so they can sleep at bedtime
- Meet with a registered dietitian to learn about nutrients that keeps energy levels up

Pain

Pain is a symptom that can occur with or without obvious cause

To help your loved one manage pain...

- Work with the care team to treat pain with medications. It may work best to align medication intake with the times of the day that pain is the highest
- Keep a pain diary to log times of day your loved one is in pain and track medication intake
- Ask the care team to assist in creating a pain control plan with the goal of staying ahead of the pain
- Prepare to describe pain to the care team on a scale of 0-10
- Provide warm baths, washcloths or hot water bottles for your loved one
- Encourage stretching and exercise to reduce pain and increase energy levels

Edema

Swelling caused by a buildup of fluid in tissue

To help your loved one manage edema...

- Ask your care team whether specialized compression garments can be provided. This helps improve blood flow and can reduce the swelling
- Have your loved one avoid wearing tight clothes, shoes and jewelry because as this can exacerbate swelling
- Have your loved one elevate their feet to reduce swelling. This can be as simple as putting pillows under their feet or getting them a footstool when they sit or lie down.
- Avoid cooking with high sodium foods, such as chips, bacon, ham and canned soup, can help
- Ask your loved one's healthcare provider about diuretics. This medication helps your body get rid of fluid to reduce swelling

Nausea and Vomiting

Nausea is often a result of treatment, and it may last a few days after treatment but call the doctor if your loved one has been vomiting for more than 1 day

To help your loved one manage nausea and vomiting...

- Have your loved one take anti-nausea medicine on a regular schedule
 - Take it a half hour before meals and before and after receiving chemotherapy, or per doctor recommendations
- Serve cold or room temperature meals so nausea isn't triggered by the aroma of the warm food cooking
- If food aromas are bothersome, use a crock pot to cook outside or in a garage
- Have your loved one eat a small, light snack 3-4 hours before treatment (check with the care team first to determine if it is acceptable)
- Have your loved one use plastic utensils to eat if metal utensils cause a bitter taste
- Serve smaller meals with snacks in place of three large meals
- If vomiting is happening, make sure your loved one drinks enough liquids to prevent dehydration
- Have your loved one go outside for fresh air
- Lead your loved one through deep breathing exercises to relax and distract them

Diarrhea or Constipation

Treatment and medication can also lead to diarrhea and/or constipation

To help your loved one manage diarrhea...

- Have your loved one avoid foods that are high in fiber (ex. Breads, cereals, unpeeled fresh fruits and vegetables, beans and nuts) and eat foods high in potassium (bananas, mashed or baked potatoes without the skin) and high in sodium (soups, crackers, pretzels)
- Use a mattress pad or towels on the bed if diarrhea is occurring at night
- Consult with the care team about a prescription medication

To help your loved one manage constipation...

- Prepare high fiber foods (ex. Breads, cereals, unpeeled fresh fruits and vegetables, beans and nuts)
- Encourage your loved one to drink plenty of liquids, tea and coffee
- Encourage activity on a daily basis to stimulate the bowels to move
- Consult with the care team about daily stool softeners and laxatives

Oral Side Effects

Cancer treatment can cause sores in the mouth and throat

To help your loved one manage oral side effects...

- Ensure your loved one brushes their teeth and gums after each meal
- Have your loved one rinse their mouth regularly especially before and after meals and at bedtime
 - A homemade mouth rinse can be made by mixing 4 cups of water, 1 tsp of salt and 1 tsp of baking soda
- Have your loved one use a soft bristled toothbrush or soften bristles by soaking in hot water prior to brushing
- Check your loved one's mouth for mouth sores twice per day using a small flashlight
- If eating becomes painful due to mouth sores
 - Coat their mouth with numbing gels before meals
 - Mash or puree foods in blender
 - Avoid dry crackers, toast, and hard rolls
 - Avoid fresh fruit and vegetables unless they are ripe and soft
 - Avoid citrus, like oranges and grapefruit
- Encourage your loved one to drink plenty of fluids
- Avoid alcohol, tobacco products and carbonated drinks because these can aggrevate mouth sores

Changes in Apperance

Changes in appearance may include hair loss, skin or weight changes, limb loss, or other physical changes

To help your loved one manage appearance changes:

- Ask your loved one how you can provide support during this challenging time
- Ask your loved one's cancer care team for
 - o Tips on taking care of their hair and scalp during chemotherapy
 - Appropriate treatment for skin changes
 - Ways to monitor skin, weight, and body changes
- Encourage skin care
 - Keep the skin clean and dry to prevent infections
 - Protect skin from the sun
 - Moisturize skin
- Encourage your loved one to find ways to embrace their new appearance
 - Shop for things they like and can feel good in. For example, clothing and shoes, in addition to having them find caps, scarves, turbans or wigs
- Allow your loved one to mourn their changes, as they are real

Appetite Loss or Gain



Your loved one's appetite may change due to nausea and changes in their body

To help your loved one manage appetite changes...

- Encourage new foods
 - "What to Eat During Cancer Treatment" by the American Cancer Society is an amazing resource that has recipes based on the symptoms your loved one is experiencing. Click on the hyperlink above to purchase it.
 - For more resources on nutrition, go to page 148

Emotional Changes

The impact of cancer and its treatment on daily life and personal relationships can lead to emotional changes

To help your loved one manage emotional changes...

- Encourage your loved one to participate in counseling or a support group
- Socialize with people that provide guidance, reassurance, and emotional connections
- Ask your loved one about how they are feeling and what support you can provide

Intimacy & Sexuality

Cancer treatment may affect your loved one's desire for intimacy, which can lead to changes in your sexual relationship

To help your loved one manage sex life changes:

- If you are in a romantic relationship with your loved one with cancer, have a conversation about their need for intimacy
 - Some may find that intimacy during treatment is beneficial for staying close during a difficult time
 - Others may be limited by fatigue or feel uncomfortable due to body changes
- Ask the cancer care team about precautions that need to be taken to maintain partner safety
 - Condoms may be needed to prevent excessive fluid exchange in bodily fluids containing chemotherapy medications

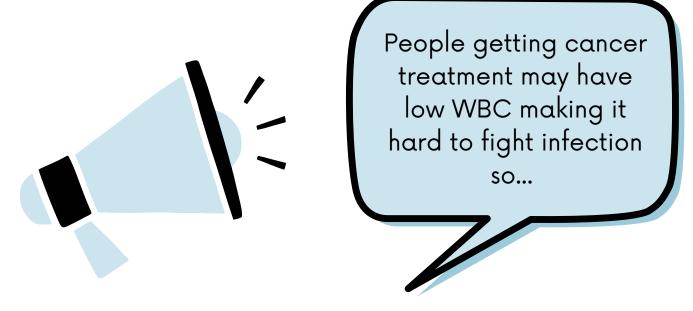
Cognitive Changes

Cancer treatment may impact your loved one's memory and thinking abilities, a side effect often referred to as "chemo brain" or "chemo fog"

To help your loved one manage memory changes

- Talk to the care team to see if they recommend occupational therapy to work on cognition for daily tasks
- Be patient with your loved one
 - You need to approach your loved one's memory loss in a way that doesn't frustrate them, but rather helps maintain their independence and safety. To find that balance of independence and safety...
 - Break down the task into smaller steps
 - Supervise them when there is an element of safety
 - Do tasks with them to guide them
 - Ensure they are focusing on only one task at a time
- Encourage healthy habits
 - Sleep, nutrition, movement
- Encourage "exercise" of the brain
 - o Crossword puzzles, sudoku, puzzles, reading, coloring
- Introduce memory tactics such as...
 - Written reminders, verbal reminders, phone reminders
- · Assist your loved one with medication management if needed. Some strategies that can be used are...
 - Use a paper form to track medications, a pill organizer box, or smart phone apps.

Reminders on Keeping Your Loved One Safe



- If you are sick, have someone else take over as supporter or wear a disposable mask
- You and your loved one should wash your hands frequently
- Ask people with colds or illnesses not to visit until recovered
- Avoid raw, unwashed fruits and vegetables, raw eggs, and food handled by others
- Arrange for someone else to manage your pet's feces because it has a lot of bacteria
- Encourage good dental hygiene to keep mouth clear of bacteria
- Check your loved one's temperature regularly as a fever may be a sign there is a problem with the WBC count
- Consult with the care team about other recommended precautions

Call the doctor if your loved one has....

- A 100.5 fever or higher
- A fever that lasts more than 24 hours or goes away and comes back within 24 hours,
- Shaking chills that last 20 minutes or longer,
- A new cough, sore throat, shortness of breath, frequent, painful urination, pus or yellowish discharge from an injury or other location
- Redness from an incision site

IMPORTANT!

If your loved one has fever symptoms, ensure they are staying hydrated and be sure to alert the medical team

Questions to Ask the Doctor

If you have a question about...

- Your loved one's treatment plan
- Preparation for treatment
- Managing your loved one's symptoms or side effects
- Insurance and money concerns

Then use the American Cancer Society guide below...

As a loved one of someone with cancer, it can be overwhelming because there is so much uncertainty, so this list of questions is great because it provides a good start on getting some answers from the medical team



Post-Cancer Treatment (Remission)

Assisting with Changes in Emotions

Physical and emotional challenges persist in remission, making it difficult to return to typical routines

Common emotions that YOU or your loved one may experience...

- Fear of recurrence
- Stress
- Anxiety
- Depressive symptoms
- Self-consciousness
- Loneliness

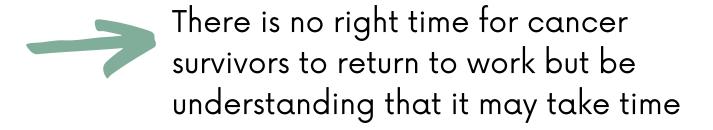
These emotions may result from your loved one feeling like nobody understands what they went through. Spending less time with the care team is also difficult because they were once an element of support in their life

As a supporter, encourage your loved one to join a post cancer support groups or counseling services

Research has shown that supporters sometimes experience higher levels of fear of the cancer returning than cancer survivors, so do not forget to take care of yourself, and seek professional counseling if needed

Returning to Routines

People often do not realize the time it takes for someone post cancer treatment to return to their prior level of function



- As a loved one, continue to provide physical assistance as needed for tasks that require high levels of energy and strength
- As a loved one, continue to provide emotional assistance by asking them how they are feeling and what support you can provide
- At the same time, encourage your loved one to gradually participate in their own tasks

When Treatment is Ongoing



For some people, cancer treatment lasts longer than expected, and cancer is treated as a chronic illness

Some may be able to go back to work during long term treatment but still need additional assistance immediatley after treatment

As a supporter...

- Assist with home responsibilities, family needs, and bills
- Adjust your schedule to keep up with the treatment plan

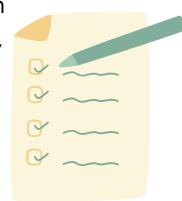
Emotional support may be needed for you and your loved one with cancer such as a...

- Caregiver support group for you as a loved one
- Cancer support group for your loved one

Additional Tips for Supporters



Advocate for your loved one to obtain resources like palliative care, hospice, occupational therapy, physical therapy and mental health assistance if needed



- Palliative care: provides medical care to reduce pain and other symptoms of a serious illness, including cancer
 - It can be provided at ANY point after diagnosis
- Hospice: provides ways to enhance comfort in the time a person has left
- Occupational therapy: provides interventions to improve performance and participation in daily tasks
- Physical therapy: provides interventions to improve strength, endurance, and balance
- Mental health: provides mental/emotional support



Assist in following the treatment plan closely. For example, remind your loved one of upcoming doctor appointments



Both you and your loved one are now living with uncertainty so it's important to support each other and ask the care team questions to clarify uncertain points



Allow your loved one to mourn any permanent changes and take their time in modifying their routine to accommodate their limitations

(American Cancer Society, 2023)

Please remember...



Although you play a large role in providing assistance and care for your loved one, please remember to take care of yourself and your own physical and emotional symptoms.

Please remember to continue to take care of your own body by eating healthy, engaging in physical activity and completing relaxation techniques.

MODULE 2

Emotional & Psychological Support

This module covers...

- Understanding changing roles.
- Managing supporter distress and unmet needs.
- Understanding and managing your own emotions and offering emotional support.
- Anticipatory grief and tips on how to handle it.
- Good communication skills including problemsolving communication, talking with friends and family, and talking with children.
- The importance of self-care for the supporter.

Understanding Changing Roles

When a loved one faces a serious illness, your relationship with them may shift. While stepping into a new role can feel overwhelming, it can also bring a deeper sense of connection as you support them through their journey. You might find yourself in unfamiliar roles that feel more intense or demanding. This change can lead to emotional struggles and confusion, making the relationship feel unbalanced. It's common to experience mixed emotions—grieving the nature of your past relationship while also feeling gratitude for being able to support them now.

Tips:

Communicate **Openly:**

Establish a foundation of mutual respect and understanding. Regularly check in with each other to discuss feelings and concerns.

Find a Support System:

Seek out friends, family, or support groups to help you adjust to this new normal. A strong support network can boost your mood and resilience.

Prioritize Self-Care:

Remember, the supporter is often at a higher risk for depression. Make time for yourself and recognize when you need rest or support.



Managing Supporter Distress & Unmet Needs

Supporting can be accompanied by significant emotional distress, often fueled by fears like the cancer returning. Recognizing and addressing these fears is crucial.

Common Scenarios:

- Balancing caregiving with job responsibilities or other family obligations.
- Managing your own emotional distress, such as anger, anxiety, or fear.
- Navigating the changing dynamics (i.e., if the person you care for prefers only you, or struggles with relying on others.)

Tips:

Seek Information:

Understanding your loved one's condition can reduce anxiety. Stay informed about treatments and prognosis.

Develop Coping Strategies:

Consider stress-relief techniques like meditation, journaling, or speaking with a counselor. See page 52-53 for journaling prompts.

Use a Checklist:

A caregiver distress checklist can help you identify and manage the stressors in your life. Click here to be taken to the checklist or see page 50-51 for the list.

Challenges Faced by **Supporters**

Supporting a loved one through cancer can be deeply meaningful, but it may also bring challenges that affect a supporter's physical, emotional, and financial health. The term "supporter burden" describes the stress that can arise when caregiving demands exceed available resources. Recognizing signs such as fatigue, anxiety, or feeling overwhelmed is an important first step in seeking support and maintaining personal well-being

Signs & Symptoms:

- Emotional & physical exhaustion
- Withdrawal from friends, family, & other loved ones.
- Loss of interest in activities previously enjoyed
- Feeling hopeless & helpless
- Changes in appetite or weight
- Changes in sleep patterns
- Unable to concentrate
- Irritability, frustration, or anger towards others.

Management & Treatment:

- Talk to a healthcare provider
- Make time for yourself
- Ask for help
- Find local resources (i.e., Cancer Bridges, Hillman Cancer Center)



Understanding Your Own Emotions

Emotions are often confused with feelings and moods, but these three concepts are not interchangeable. According to the American Psychological Association (APA), emotion is defined as "a complex reaction pattern, involving experiential, behavioral, and psychological elements."

Emotional Experiences has 3 Key Components:

Subjective Experience:

All emotions begin with a subjective experience, also known as a stimulus. The way emotions are triggered varies from person to person.

Physiological Response:

These are bodily reactions, often involuntary, such as increased heart rate, sweating, or the activation of the flight-or-flight response.

Behavioral or Expressive Response:

This includes outward expressions such as smiling, frowning, laughing, or sighing, which help communicates how someone is feeling.



Emotional Intelligence

Emotional intelligence is the ability to manage both your own emotions and understand the emotions of others.

The 5 Key Elements of Emotional Intelligence are:

Self-Awareness

Recognizing and understanding your own emotions.

Self-Regulation

Managing your emotions in a healthy way.

Motivation

Using emotions to achieve personal and caregiving goals.

Empathy

Understanding and sharing the emotions of others.

Social Skills

Navigating interpersonal relationships effectively.



Managing Your Own Emotions

Supporters often experience a range of emotions. It's normal to feel good and bad emotions. There's a magnitude of emotions you may feel, but they could include:

Sadness

Gratitude

Grief

Guilt

Loneliness

Relief

Tips:

Tune Into Your Feelings:

Pay attention to how different situations affect your emotions and acknowledge them.

Rate the Intensity of Your Feelings:

Understanding the strength of your emotions can help in managing them.

Sharing your feelings with

Express Your

Emotions:

teelings with trusted individuals can provide relief and clarity.









Offering Emotional Support

Providing emotional support to your loved one is just as important as offering physical care. Emotions can be overwhelming for both the supporter and the patient, so creating a nurturing and understanding environment is essential.

How to Offer Emotional Support:

Listen Actively: Sometimes, simply listening without trying to solve the problem can be the most valuable support.

Validate Their Feelings: Let them know their emotions are normal and that it's okay to express them.

Encourage Expression: Allow them to talk about their fears, hopes, and uncertainties without judgment.

Be Present: Small gestures like holding their hand, sitting quietly together, or offering a comforting word can make a big difference.

Respect Their Wishes: Some individuals may not want to discuss their illness in depth; respect their boundaries while ensuring they know you are available.

Scan & Waiting Room Anxiety

Waiting for scan results or being in a waiting room can be one of the most stressful parts of the cancer journey—for both patients and supporters. The uncertainty, the "what ifs," and the long waits can take an emotional toll.

Tips:

Try to schedule scans early in the morning to reduce stress day of the appointment.

Discuss and plan with your care team of when and how results will be given.

Use relaxation techniques, such as deep breathing, stretching, or meditation.

See page 55 for Deep Breathing exercises.

Do calming activities as you wait including listening to music, reading, cross word puzzles, etc.

Talk to family and friends about how you are feeling.

Anticipatory Grief

Anticipatory grief is the emotional distress supporters and loved ones experience before an actual loss occurs. This type of grief can bring up many complex emotions, including sadness, anger, guilt, and anxiety.

Signs of Anticipatory Grief:

Experiencing mood swings, ranging from sadness to frustration.

Feeling helpless or overwhelmed by the uncertainty of the future.

Having difficulty concentrating or sleeping.

Withdrawing from social interactions or daily activities.

A sense of emotional numbness or detachment.

Coping Strategies

Acknowledge Your Feelings: Allow yourself to experience grief without judgment. It's natural to feel a mix of emotions.

Seek Support: Speak with a counselor, join a support group, or confide in a trusted friend or family member.

Create Meaningful Moments: Spend quality time with your loved one, reminiscing, sharing stories, or creating new memories.

Practice Self-Compassion: Understand that it's okay to grieve while still being present for your loved one.

Prepare for the Future: Discuss wishes, legal matters, and other practical concerns ahead of time to ease later stress.

Good Communication

Effective communication is essential in supporting, as you interact with medical professionals, family members, and the person receiving care.

Constructive communication fosters understanding and strengthens relationships.

Tips:

Be Clear and Assertive: Express your needs and concerns without being aggressive.

Encourage Open Dialogue: Foster conversations where both parties feel heard and valued.

Validate Feelings: Acknowledge emotions without dismissing or minimizing them.

Use "I" Statements: Express your thoughts in a non-confrontational way (e.g., "I feel concerned when...").

Practice Active Listening: Repeat what you hear to ensure understanding and show engagement.

Stay Patient and Organized: Keep notes of important discussions and appointments.

Problem-Solving Communication

Effective communication is an ongoing process, especially in supporting situations where emotions and stress levels are high. Using structured problem-solving strategies can help facilitate more productive conversations. See page 54 for a problem-solving worksheet.

3 Steps to Problem-Solving Communication:

Define the Problem Clearly:

Stick to the facts and avoid making assumptions about other's emotions. Use "I" statements to explain your perspective without blaming others (e.g., "I feel overwhelmed when..."

2

Brainstorm Solutions Together:

Allow all involved parties to share their ideas without immediate rejection. Consider the pros and cons of each option before making a decision. Reiterate what the other person has said to ensure mutual understanding.

3

Choose the Best Solution

Select the option that best fits everyone's needs and is most likely to be successful. Be open to revising solutions if new challenges arise. Maintain a respectful and constructive tone throughout the discussion.

Talking with Family & Friends

As a supporter, you may find that talking to friends and family about your loved one's condition can be challenging. You might struggle to find the right words, feel overwhelmed by emotions, or worry about how others will react. Some people may not understand the realities of supporting, while others may unintentionally offer unhelpful advice or avoid the conversation altogether.

Tips:

Be Honest and Clear.

Use clear and direct language to express your needs and concerns.

Set Boundaries.

You do not need to share everything- only share what you are comfortable with. It is okay to steer conversations in another direction.

Ask for Specific Help.

Give family & friends specific ways they can support you, such as running errands, providing respite care, or simply being there to listen.

Stay Patient and Open-Minded.

Some people may need time to process what you are saying.

Be open to different reactions, but do not feel obligated to
justify your role or decisions.



Talking with Children

Explaining a loved one's illness or condition to a child can be one of the most difficult parts of being a supporter. Children may have questions you don't know how to answer, struggle to understand complex emotions, or feel scared and uncertain about changes in their routine. It's natural to want to protect them, but open and honest conversations—at an age-appropriate level—can help them feel secure and included.

Common Reactions can Include:

- Feeling confused, angry, lonely, guilty, or overwhelmed.
- Acting scared or unsure about how to interact with the loved one.
- Seeking extra attention or becoming clingy.
- Struggling with eating, sleeping, schoolwork, or friendships.

Talking with Children Tips:

Be Honest:

Explain the situation in an age-appropriate way.

Listen Actively:

Ask them how they feel and what they are worried about.

Validate their Feelings:

Let them express their emotions and reassure them that their feelings are normal.

Provide Reassurance:

Offer love, hope, and stability.

Stay Involved:

Keep routines as normal as possible and make time for fun and connection.



Age-Appropriate Conversations

Preschoolers:

Keep the conversation brief, give basic information and don't go into much detail. They may notice side effects of cancer so you may need to discuss what the side effects are.

Young-aged School Children:

They may ask a lot of "why" questions. Answer simply, and don't be afraid to say "I don't know". Give plenty of reassurance to your child.

Older-aged School Children (pre-teen):

These children may need more information. Try to be straight-forward, open, and honest. Provide them with as much detail as they ask for, such as the name of the cancer and treatment plans.

Teenagers:

Talk to them like adults. Provide facts about the diagnosis, treatments, and expected outcomes. Let them know it's okay to ask questions and try asking them open-ended questions about how they are feeling.

Self-Care for the Supporters

Supporters often focus so much on others that they neglect their own well-being. Caring for your own needs, hopes, and desires is essential to being able to care for someone else effectively.

Tips:



Daily Relaxation: Dedicate 15-30 minutes each day to something you enjoy, such as reading, meditation, or a hobby.

See page 55 for Deep Breathing exercises.

Stay Connected: Keep in touch with friends and family to avoid isolation and maintain emotional support.

Ask for Help: Don't hesitate to reach out when you need support from others, whether it's family, friends, or professional home aide's

Recognize Burnout: Pay attention to signs of emotional and physical exhaustion, and take proactive steps to address them.

Caring for Your Body

Prioritize Sleep: Aim for 7-9 hours of quality sleep each night to recharge your body and mind.

Eat Nutritious Meals: Maintain a well-balanced diet rich in fruits, vegetables, whole grains, and lean proteins to fuel your body.

Stay Active: Engage in regular physical activity, such as walking, stretching, or yoga to improve overall well-being and reduce stress.

Monitor Your Health: Stay up to date with medical check-ups, vaccinations, and screenings to maintain your own physical health.

Hydrate and Manage Stress: Drink enough water daily and practice stress-relief techniques such as deep breathing or mindfulness.

Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

Had trouble keeping my mind on what I was doing	Yes Yes	N8 N8	13. Had back pain □Yes □No 14. Felt ill (headaches, stomach
2. Felt that I couldn't leave my relative alone			problems or common cold) \square Yes \square No
3. Had difficulty making decisions			15. Been satisfied with the support my family has given
4. Felt completely overwhelmed	Yes	No	me
Felt useful and Reeded 6. Felt lonely	Yes Yes	No No	16. Found my relative's living situation to be inconvenient or a barrier to care □Yes □No
			17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful,"
7. Been upset that my relative has changed so much from his/her former self	Yes	No	please rate your current level of stress.
8. Felt a loss of privacy and/or personal time	Yes	No	18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate
9. Been edgey or irritable	Yes	No	your current health compared to what it was this time last year.
10. Had sleep disturbed because of caring for my relative	Yes	□No	Comments: (Please feel free to comment or pr ovide feedback.)
11. Had a crying spell(s)	Yes	□No	leeuback.j
12. Felt strained between work and family responsibilities	Yes	□No	





Trusted Information. Better Care.

Self-Evaluation	Local resources and contacts:
To determine the score:	
1. Reverse score questions 5 and 15.	
For example, a "No" response should be counted	
"Yes" and a "Yes" response should be counted as	a
"No."	
2. Total the number of "yes" responses.	
To interpret the score	-
Chances are that you are experiencing a high degree o distress if any of the below is true:	f
☐ If you answered "Yes" to either or both	
questions 4 and 11	
☐ If your total "Yes" scores = 10 or more	
☐ If your score on question 17 is 6 or higher	
☐ If your score on question 18 is 6 or higher	
Next Steps	
☐ Consider seeing a doctor for a check-up for	
yourself	
☐ Consider having some relief from caregiving	
(Discuss with your healthcare provider or a social	
worker the resources available in your community.)
☐ Consider joining a support group	
Valuable resources for caregivers	
HealthinAging.org	
(800) 563-4916 www.healthinaging.org	
Caregiver Action Network	
(202) 454-3970 www.caregiveraction.org	
Eldercare Locator	
(a national directory of community services)	
(800) 677-1116 <u>www.eldercare.gov</u>	
Family Caregiver Alliance	
(800) 445-8106 <u>www.caregiver.org</u>	
Medicare Hotline	
(800) 633-4227 www.medicare.gov	
National Alliance for Caregiving	
(301) 718-8444 www.caregiving.org	

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AGS/HiAF 7.24.2014

Gratitude Weekly Reflection

WHAT INSPIRED ME THIS WEEK?				
A MOMENT THAT MADE ME SMILE:	SOMETHING I DID WELL:			
WHAT AM I LOOKING FORWARD TO N	EXT WEEK?			
10 THINGS I AM GRATEFUL FOR THIS	WEEK:			
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

Other Prompts:

- LIST 5 GOOD THINGS ABOUT TODAY.
- WHAT IS ONE LONG-TERM GOAL YOU WOULD LIKE TO WORK TOWARDS?
- WAS TODAY A DIFFICULT DAY? IF SO, WHAT MADE IT DIFFICULT AND WHAT CAN YOU DO TO PREVENT DAYS LIKE THIS FROM HAPPENING IN THE FUTURE?
- ARE YOU TAKING TIME TO CARE FOR YOURSELF?
- REFLECT ON THE STRENGTHS THAT WILL HELP OR HAVE HELPED WHILE BEING A CAREGIVER.
- WHEN THINGS ARE CHALLENGING, I WANT TO REMEMBER...
- TODAY MY VICTORIES WERE...
- WHAT DID I HAVE DIFFICULTY COPING WITH TODAY?
- WHAT WENT WELL TODAY?
- WHAT MEMORIES BRING ME JOY?
- WHAT IS SOMETHING I AM PROUD OF IN MY ROLE AS A CARETAKER?
- WHAT IS ONE THING I WISH OTHERS UNDERSTOOD ABOUT MY CAREGIVING EXPERIENCE?
- HOW DO I EXPRESS MY NEEDS AND SET BOUNDARIES IN MY CAREGIVING ROLE?
- WHAT IS SOMETHING MY CARE RECIPIENT SAID OR DID THAT MADE ME SMILE?
- HOW HAS CAREGIVING CHANGED MY PERSPECTIVE ON LIFE AND RELATIONSHIPS?
- IF I COULD ASK FOR HELP IN ONE SPECIFIC WAY, WHAT WOULD IT BE?

Communication/Problem Solving Worksheet

Let's talk about communication in your family. Kids, what do you feel are causes for communication breaking down at home?

If it works we can consider _

	Causes of Communication Breakdown
	I don't feel like my opinions matter.
	Parents (or others) don't wait for me to finish.
	Parents (or others) think they are always right.
	Parents (or others) get emotional, and that makes me emotional.
	I am not being spoken to like an adult.
	Other:
about a prob want to talk real disagre Write a sta	rksheet to use this plan to solve a problem. For each step fill in how you would talk plem. You can make-up an example just to practice, or you can plan out how you about a real problem later, or kids and parents can use these steps to go through a ement right now together. tement describing the facts you are concerned about:
	rned about
	tement showing how you feel:
	tement proposing a solution:
	do you have? (Answer)
Write a sta	tement proposing a solution:
• Ith	nk this solution might work becausebut I am concerned it
Wo	n't work because What are your thoughts?"
• I th	nk this solution might work becausebut I am concerned it
	n't work because What are your thoughts?"
	nk this solution might work becausebut I am concerned it n't work because What are your thoughts?"
Write a pla	
Let's first t	y54
Write a pla	n to review, revise, and reward:

(Mayo Clinic, n.d.)

Breathing Toolkit

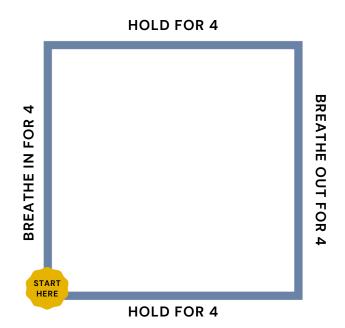


TRIANGLE BREATHING



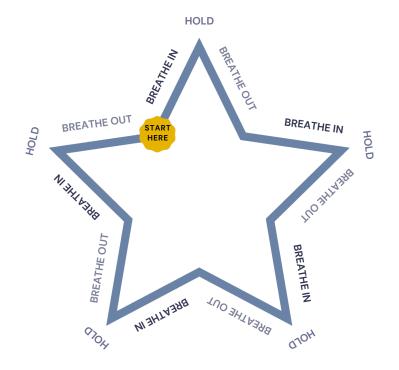
Imagine a triangle. Inhale as you ascend one side, hold for 3 counts at the peak, exhale along the bottom. Repeat for calmness.

BOX BREATHING



Begin at the bottom left of the square. Inhale as you ascend one side, holding for 4 counts on the second side. Exhale as you descend to the other side. Hold for 4 counts along the bottom. Repeat.

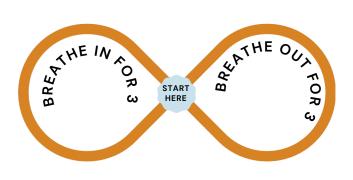
STAR BREATHING



Ascend one side of the star with your inhale, reaching the point.

Exhale as you descend the other side. Repeat until you've traced the entire star.

INFINITY BREATHING



Inhale as you trace the left side, exhale as you trace the right side of the figure-eight. Repeat.

Home Modifications and Adaptive Equipment

This module covers...

- Energy conservation
- Cancer Related Fatigue
- Energy Conservation Principles
- Impact of Independence
- Common home modifications
- Adaptive equipment use

Through this module, you will learn about energy conservation techniques, home modifications and adaptive equipment use.

The information in this section can be beneficial for both you as a supporter and your loved one. Resources such as the AARP HomeFit guide and organizations such as the Inglis Innovation Center will be great additions for you to refer to along with this module





AARP HomeFit Guide





Energy Conservation

Energy conservation is the intentional management of an individuals personal energy to prevent depletion

 The goal is to balance rest and activity, especially when fatigue is high, so you can still do the things that matter to you.

Strategies to assist with energy conservation efforts:

- Taking more rest breaks.
 - While rest is helpful, it's also important to find ways to keep up with daily tasks. It is important to balance rest with activity
- Physical activity and exercise
 - Short walks can ease fatigue and help you feel better.
 - A combination of aerobic exercise and resistance training have shown to aide managing fatigue
- The 4 Principles of energy conservation
 - Pacing, Prioritization, Plan, Position

Since everyone experiences fatigue differently, it's important to adjust your daily routine and use energy-saving strategies that work best for you. There is no one-size-fits-all approach!

Cancer Related Fatigue (CRF)

Common symptoms

- Extreme tiredness or exhaustion
- Feeling weak or drained
- Difficulty concentrating or thinking clearly
- Reduced physical activity and endurance
- · Loss of interest in activities once enjoyed
- Sleep disturbances
- Emotional distress, such as anxiety or depression

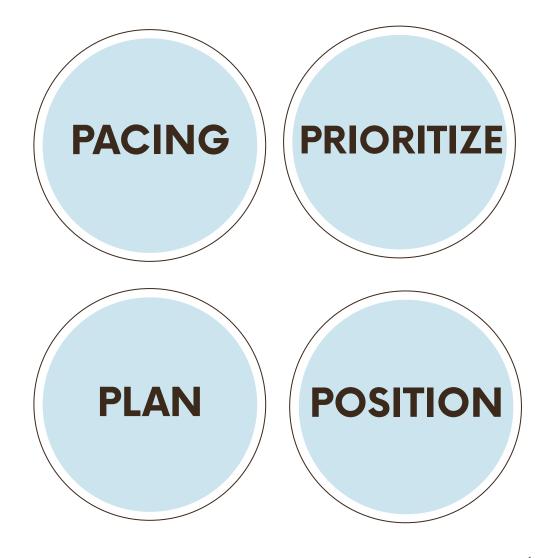
Cancer-related fatigue (CRF) can greatly impact quality of life. Fatigue is one of the most common symptoms of cancer and its treatment. This can affect daily life and participation in preferred activities while loved ones are experiencing the common symptoms. Studies show that <u>exercise</u>, <u>diet and lowering stress</u>, along with following <u>energy conservation techniques</u>, are effective ways to manage CRF.

4 Ps of Energy Conservation

The 4 P's of energy conservation allow one to manage their energy effectively, reducing fatigue and allowing them to participate in daily activities that are meaningful to them.

Encourage your loved one to follow these principles to conserve energy throughout the day—these strategies not only support their independence and well-being but also help ease the role of supporter and reduce overall stress.

The 4 P's are:



PACING

Sometimes, individuals experiencing cancer related fatigue may feel like rushing to complete tasks quickly and get them out of the way. However, hurrying to complete tasks quickly can result in exhaustion and make it difficult to complete activities later in the day.

- To avoid excess fatigue:
 - Break tasks into smaller steps with rest periods in between.
 - When tidying up, focus on small areas of a room rather than the whole and take breaks in between
- Plan to rest before you feel fatigued rather than pushing to the limit.
 - Use a timer or schedule short breaks to prevent overexertion.
- Avoid prolonged standing or excessive movement:
 - Sit whenever possible to reduce energy expenditure.
 - While cooking, take seated breaks nearby when able



PRIORITZATION

Encourage your loved one to prioritize their daily tasks by identifying what truly needs to be done today and what can be scheduled for another time. Remind them that not everything has to be completed in one day—this can help them conserve energy and reduce fatigue.

- Identify important tasks that need to be completed ahead of time
 - Based on importance and need, schedule them at a time of high energy
- Guide decision making around what needs to be done immediately vs what can wait
 - For example, going to a doctor's appointment may take priority over dusting the living room.
- Assign specific days for different high energy tasks
 - E.g., Monday for laundry, Tuesday for vacuuming,
 Wednesday for grocery shopping



PLAN

It is important assist your loved one to be prepared PRIOR TO COMPLETING ACTIVITIES in order to decrease unnecessary movement in an effort to reduce fatigue.

- Gather supplies ahead of time to avoid extra trips.
 - For example, before taking a shower, have your towel, clean clothes, and toiletries ready in the bathroom.
- If you have a social event or appointment, adjust your daily routine to conserve energy beforehand.
 - This can look like sitting on a couch with your family pet and reading a book for 1-2 hours before
- Plan alternating tasks
 - Switch between heavy and light activities to balance workload and recovery time.
- Schedule a dedicated rest period each day to recharge and prevent exhaustion.

POSITION



Your posture and positioning play a significant role in energy conservation. Avoiding excess bending, reaching, and awkward positions can reduce unnecessary fatigue.

- Modify your environment to make tasks easier
 - Keep everyday items at waist level to reduce bending and reaching.
- Use adaptive equipment to assist with daily activities, if needed:
 - A reacher can be used to grab items from low or high places
 - Elastic shoelaces can be used to eliminate the need for bending when putting on shoes.
 - A sock aid can help your loved one put on socks or compression stockings more easily and with less effort.
- Support your breathing
 - Good posture allows for better lung expansion, increasing oxygen intake and preventing shortness of breath.

4 P's of Energy Conservation

By incorporating these strategies, you can conserve energy, reduce strain on your body, and continue participating in the activities that matter most to you. Small adjustments can make a significant impact on maintaining independence and improving quality of life.



Impact of Independence in Daily Activites

According to a study, about half of adults with cancer have difficulty or require assistance to perform some aspect of their day-to-day activities. The most frequently affected activities they identified were: personal hygiene, walking and transfers, housework, and shopping and transportation.

<u>Activities of Daily Living (ADL's)</u> are essential tasks that support basic functioning and independence. These tasks include personal hygiene, eating, mobility, and other daily self-care activities.

<u>Instrumental Activities of Daily Living (IADL's)</u> include more complex activities related to the ability to live independently in the community. These include shopping, housekeeping, managing finances, meal preparation, and transportation.

Cancer treatments like chemotherapy and radiation can limit movement/activity, cause fatigue, and affect memory and decision-making. These challenges can make people less independent, increasing dependency on supporters. Encouraging your loved one to increase their participation in their chosen activities will aide them in decreasing their reliance on others and help build confidence, independence, and a sense of autonomy during recovery.

Modifications You Can Make to Your Home

Home modifications and using adaptive equipment can help people do tasks more easily and safely. Modifying one's living space can help your loved one stay independent, which also benefits you, as the supporter.

Simple ways to make your home easier to navigate



THE LIVING ROOM

Make sure you have bright lights and clear pathways so your loved one can navigate around the home with ease.

Use technology such as Alexa or google home to help you manage activities such as controlling lights, TV and other applications, create shopping lists, listen to music, etc.

Make sure all cords and wires are secured and tape down to prevent a fall.

Use chairs with arm rests to assist with sitting up/down.



THE KITCHEN

Have a chair/stool nearby in the kitchen to encourage your loved one to take frequent rest breaks

Promote the use of reachers to grab items from higher cabinets or from the floor.

Place heavy items such as pots/pans on the counter or low-level cabinets and frequently used items on the counter.

Keep handwashing and hygiene supplies nearby to promote infection control and safety during meal preparation.



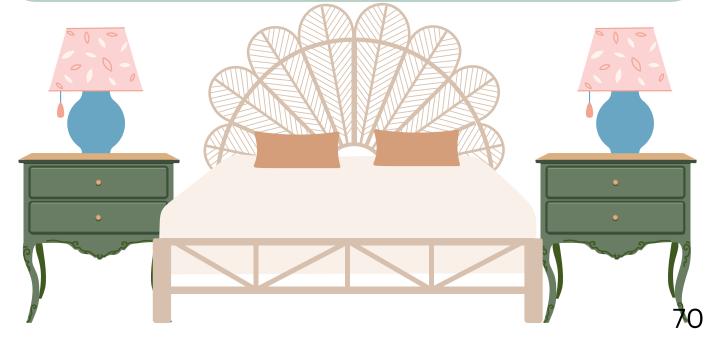
THE BEDROOM

You can install and use voice activated lights so your loved one can control the lights without having to ask or get up.

Encourage your loved one to place commonly used items on the bedside. This could include water bottles, tissues, remote controls and cellphones so your loved one can call you for help

If your loved one is experiencing cognitive changes or if they lose their balance because of medication side effects, you might want to consider connecting a motion sensor to detect falls.

Treatment can cause neuropathy, which may increase your loved one's risk of tripping. To help prevent falls, avoid using thick rugs, as they can be hazardous.

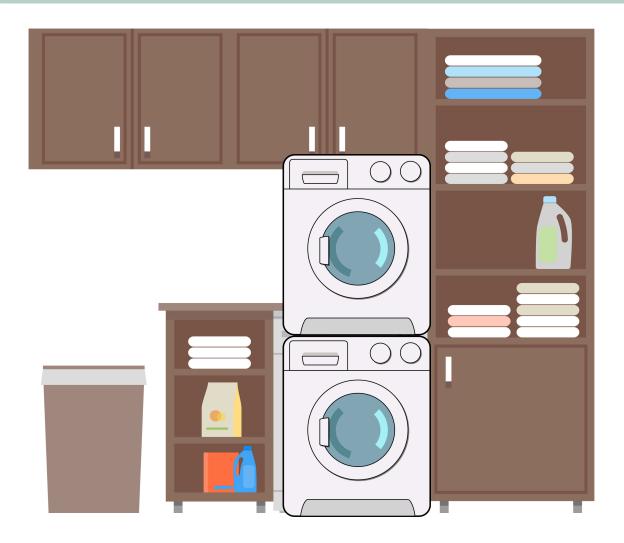


THE LAUNDRY ROOM

Use a table-top to place laundry baskets on to minimize the need to repetitively bend and reach.

Using a reacher or stackable machines can prevent the need to bend and reach excessively. This would allow your loved one to complete the task without increasing fatigue.

Reduce the load size while doing laundry to decrease weight of items your loved on is carrying



Adaptive Equipment

Easy-to-use tools that help you support your loved one with daily activities.



Helps you pick up items from the floor or cabinets that are too high or too low,

providing assistance when items are out of reach.

As discussed in Module 1, while undergoing cancer treatment your loved one can experience symptoms such as fatigue, pain, memory changes, and more. The following tools can be used by your loved one to complete their daily activities independently



Weighted Utensils

Great to use when
experiencing tremors. They
also provide an increase grip
assistance and are useful
when one is experiencing fine
motor deficits



Easy Hold

Helps hold onto glasses or bottles that do not have handles. Provides assistance when experiencing weakness or fatigue



Pull Tab Can Opener

Help you lift up pull tabs on cans.
Provides assistance when
experiencing difficulty with fine
motor skills



Vegetable Cutter (mandoline)

A mandoline slicer allows for quick, uniform slicing of vegetables with minimal hand movement. It saves time and energy in meal prep, reducing strain on the hands and arms.



Hand Chopper

It uses a push-down or twist mechanism to chop food without a knife. It reduces the effort and coordination required, making meal prep more energy-efficient.



Adaptive Cutting Board

Designed with non-slip surfaces, corner guards, or stabilizing pegs to hold food in place. It reduces the need for hand strength and coordination.



Adaptive Knife

Has a curved blade that allows users to cut food using a rocking motion. This minimizes wrist strain and requires less effort and accommodating limited hand strength or dexterity.



Dycem

Non-slip material is used to stabilize objects like dishes or cutting boards during tasks. It helps conserve energy by minimizing the need for gripping or holding items in place.



Door Handle Extension

It attaches to door knobs to allow for more ergonomic use, best when one is having difficulty rotating door knobs due to decrease in hand strength or grip



Chair Lift Stand Assist Device

A frame that can be placed inside your couch to assist with sitting up independently, aiding in fall prevention. It's also known as a universal stand assist.



Walker Tray

It attaches to a walker allowing users to carry items hands-free. This promotes your loved one's independence and reduces the need for multiple trips or awkward lifting.



Adaptive Bottle Opener
It provides a large, easy-to-grip
handle that helps open twist-off
caps and jars with less hand
strength. It conserves energy by
reducing strain and preventing
fatigue during repetitive tasks.



Easy Key Turner
It attaches to a standard key and provides a larger grip surface, making it easier to turn locks. It reduces wrist strain and conserves energy by improving leverage and grip.



Pill Puncher

It's used to easily remove pills from blister packs without excessive hand pressure. It saves energy and reduces hand strain



Digital Pillbox

A digital pill box have alarms or reminders to cue medication times, reducing the mental load of remembering doses. It simplifies routines and promotes your loved one's independence.

Activities of Daily Living

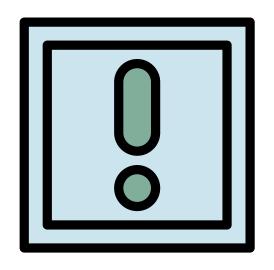
This module covers...

- Assisting your loved one with bed mobility
- Assisting your loved one with dressing
- Assisting your loved one with toileting
- Assisting your loved one with bathing

Assisting with Bed Mobility

Tips

- Encourage your loved one to utilize adaptive equipment and safe transfer techniques to mitigate fall risk.
- Addressing bed mobility helps your loved one gain autonomy and promotes safety.



The following pages describe the use of adaptive equipment and ergonomic techniques you and your loved one can use to complete bed transfers independently. By utilizing these techniques, you can keep yourself safe from injury and allow your loved one to access their bedroom safely, conserve energy, and maintain greater independence in daily routines.

Safety Considerations for Bed Mobility

- 1. It is important to make sure any equipment is installed as stated on the equipment manual.
- 2. Make sure your equipment is compatible with your materials.
- 3. If your loved one is prone to falling from the bed, consider placing a cushioned pad on the floor to prevent your loved one from getting injured.
- 4. While physically assisting your loved one with transfers, make sure you use proper body mechanics (see page 84) to prevent an injury.

Process for an Assisted Bed Transfer - Log Roll

- Plan ahead. Clear the area and have needed equipment in reach.
- If there are any lines/tubes or catheter, ensure they would not interfere with the performed activity by moving them away.
- Decide which side of the bed your loved one is going. This should be based on their strength, comfort, and ease of transferring to a chair.
- Position yourself to that side of the bed. Your loved one would roll toward you.
- If the bed has rails lower the rail on that side.
- Place your hands on your loved one's hip and behind their shoulder facing upwards and roll them towards you.

See page 86 for a tutorial video on independent log rolling and page 87 for a tutorial video on assisting with log rolling

Process for an Assisted Bed Transfer- Seated Position

- After completing a log roll, have your loved one swing their legs off the edge of the bed.
- Have them assist by asking your loved one to push up off the bed. You should place your hand on your loved one's hip (facing upwards) and behind their shoulder (on the bed).
- Assist your loved one by scooting them to the edge of the bed. Make sure their feet are flat on the ground.
 - Communicate with your loved one as much as possible, ask them to help you as much as they can, and give clear directions.

See page 85 for a tutorial on assisting with a sit to stand transfer, which can be used to stand from a bed or any surface



Proper Body Mechanics

- If able to, adjust bed height to approximately waist-height.
- You should be able to stand comfortably with your back straight. Do not bend with your back when attempting to transfer your loved one.
- Be as close to your loved you as you can while assisting them with transfers.
- Communicate with your loved one to allow them to assist if able.
- Keep your feet shoulder-width apart.
- Bend your knees and lift with your leg muscles, not your back.
- Do not twist your back as you lift. When lifting, pivot your feet to turn.

Sit to Stand Transfer



Here is a tutorial on how to do a sit- to-stand transfer.



Independent Log Roll Transfer



Here is a tutorial on how to do an independent log roll.



Assisted Bed Transfer



Here is a tutorial on how to help your loved one go from lying down to standing up.

Make sure to communicate with your loved one and adhere to safe body mechanics.



Adaptive Equipment and Durable Medical Equipment

Using adaptive equipment (AE) and durable medical equipment (DME) can support both you and your loved one during bed mobility activities. By incorporating these tools, your loved one may be able to participate in daily activities with greater ease.



Adaptive Equipment and Durable Medical Equipment: How to use it!



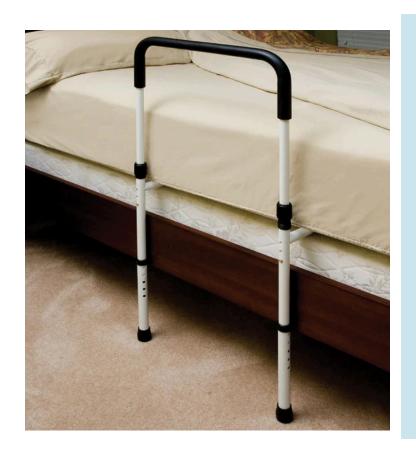
Leg Lifter: A leg lifter is a long strap with a stiff, reinforced loop at one end that helps lift and reposition a leg.

- Place the loop around your foot or ankle.
- Use the handle end to lift or guide your leg onto or off the bed, or to reposition it while lying down.
- Helpful for individuals with limited leg strength or flexibility.



Bed Ladder: A bed ladder is a set of sturdy straps or rope "rungs" that attach to the foot of the bed, allowing a person to pull themselves up to a sitting position.

- Secure the ladder to the footboard or bed frame.
- While lying down, reach for the nearest rung and pull yourself up, one rung at a time.
- Promotes independence with sitting up



Adjustable Bed
Rails: Bed rails are
metal bars that
attach to the side of
the bed. Some
models can be
folded down or
adjusted in height
and length.

- Use the rail for support when getting in and out of bed or when rolling over.
- Provides stability and safety, reducing the risk of falls.
- Insure proper installation instructions are followed to prevent any injuries.



Bed Wedge Pillow: A wedge pillow is a firm, triangular-shaped pillow that supports the upper body or legs.

- Place it under the upper back and head to elevate the torso, making breathing or digestion easier.
- Alternatively, place it under the legs to reduce pressure and improve circulation.
- Useful for positioning, comfort, and reducing the need to reposition frequently.



Overhead Trapeze:

A metal triangle attached to an overhead frame or bed mount that hangs above the bed.

- Grasp the triangle to assist with repositioning in bed or to help transition from lying down to sitting.
- Encourages upper body strengthening and promotes independence with bed mobility.

Bed Ladder Use



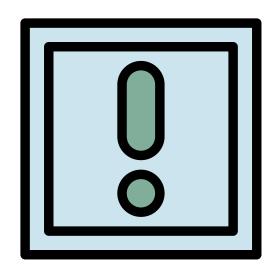
Here is a tutorial on how to use a bed ladder at home.



Assisting with Dressing

Tips

- Encourage your loved one to dress themselves as much as possible, and provide help when needed.
- Provide a chair for your loved one to accommodate for fatigue and limited balance.



The following pages describe tips for assisting your loved one with dressing.

It is important to allow your loved one to complete as much of the task independently and then assist as needed.

Upper Body Dressing



If your loved one's cancer or treatment has impacted one side of the body more than the other (ex., surgery on one side, weakness on one side), dress this side first.

If your loved one needs help with one aspect of dressing (ex., closing small buttons), allow them to help with the parts of dressing that are easier for them (ex., putting their arms in the sleeves).

Lower Body Dressing

If your loved one's cancer or treatment has impacted one side of the body more than the other (ex. surgery on one side, weakness on one), dress this side first, similar to upper body dressing.

If standing is challenging, your loved one can thread their legs through the underwear and pants from a seated position, and then stand and pull them up together.

Footwear

Encourage your loved one to use the figure 4, which involves crossing one leg over the thigh of the other leg.

This technique allows your loved one to put on socks/shoes without bending or limits the bending YOU need to do if helping them put on their socks/shoes.





Adaptive Equipment for Dressing

To increase independence of your loved one in dressing, consider purchasing adaptive equipment

Dressing Stick

S shaped hook

C shaped hook

Purpose & Use

- The S shaped hook is used to unhook clothes from a hanger, pull clothes on without bending down, and take clothes off without bending down.
- The C shaped hook is used to pull zippers up and down.

Reacher/Grabber

Purpose & Use

- Reach for clothing or other items
- Pick up clothing or other items from the floor
- Pull up pants and undergarments



See pages 64, 69, and 71 for additional ways to use a reacher

Sock Aid

Purpose & Use

- Used to pull up socks over feet without bending down
- Steps: 1) Place sock on the sock aid until there is no loose sock hanging
 2) Put foot in 3) Pull on strings



Button Hook and Zip Puller

Purpose & Use

- Used to help with buttoning and zippering clothing
- The diamond shape is for buttoning.
 Loop it through the hole, then clasp on to the button and pull it through
- The c shape is for zipping: Attach it to the zipper and pull up

Diamond shaped button side



C shaped zipper side

Long Handled Shoe Horn

Purpose & Use

 Allows the person to put on shoes with limited bending

See pages 101-103 for tutorials on using adaptive equipment for dressing and ensuring safe body mechanics





Adaptive Equipment for Upper Body Dressing



Here is a tutorial on using a button hook for upper body dressing.



Adaptive Equipment for Lower Body Dressing



Here is a tutorial on using lower body dressing adaptive equipment, including a reacher, sock aid, and long-handled shoe horn.



Body Mechanics when Assisting Your Loved One with Dressing



Here is a tutorial on how to assist your loved one with lower body dressing using proper body mechanics.



Optimal Clothing Choice

Wear clothes that are easy to put on and take off such as...

Pants with an elastic waistband

Shirts that fasten in the front i.e., zip up or button up shirt

Dresses or skirts

Velcro or slip on shoes

It may be helpful to rearrange the closet so the items easier to wear are more accessible.

Dressing for Treatment

Clothing recommendations for during or post cancer treatment include...

Chemotherapy port access
Wear loose clothing Special chemotherapy port access shirts with zippers at the top are available for purchase (Amazon)
Layers Some treatments, like chemotherapy, can lead to body heat fluctuations. Recommend your loved one dresses in layers that are easy to remove.
Keep cozy
What you wear affects your mindset! 105

Assisting with Toileting

Tips

- Safety for you and your loved one are of utmost importance.
- You should encourage your loved one to do as much as possible on their own to preserve their independence.
- Avoid lifting them or having them pull on you as this can increase the risk of injury for both of you.
- Follow proper body mechanics when lifting.
 See page 84 for tips.



The next few pages will describe the process of assisting your loved on with the toileting process, assistive devices, and safety considerations.

Toileting Safety



- Walk slowly and together to/from the toilet. Once there, have your loved one reach back for grab bars, raised armrests, or a stable and secure surface (ex: wall; counter).
- Instruct your loved one to slowly lower themselves to a seated position. If you are providing assistance have your hands on their waist/hips and bend with your knees as you help them lower themselves in a controlled manner.
- If your loved one finds it challenging to complete perineal hygiene, there are assistive devices that can help increase your loved one's independence.
- Once your loved one is finished, have them position their hands on a stable surface (e.g., grab bars, raised arm rests, or counter), and push themselves up. If you are assisting, position your hands on their waist or hips and lift from your legs.

Safety Considerations for Toileting

- Anti-cancer treatment medication remains in bodily fluids (e.g., urine, stool, vomit, semen/vaginal fluid) for 48 to 72 hours after the treatment ends.
- Your loved one may use the toilet as usual, but close the lid and flush twice after use.
- Be sure to wash hands well with soap and water.
- If a bedpan, urinal, or commode is used, wear gloves when emptying it. Rinse it well with soap and water at least once per day. The same applies to basins for vomiting.
- When installing grab bars, consult a home health occupational therapist for optimal positioning.

• If using equipment, ensure your loved one's weight is within the specified limits.

Adaptive Equipment for Toileting





Raised Toilet Seat:

A detachable seat that adds height to a standard toilet, making it easier for people with limited mobility to sit down and stand up.

How to Use:

To use it, simply place it securely on the toilet bowl and ensure it is locked or fastened before sitting.



Commode:

A portable toilet chair with a built-in seat and removable bucket, designed for people who have difficulty accessing a regular bathroom.

How to Use:

To use it, position the commode near the bed or where needed, ensure the bucket is in place, and sit down carefully like on a regular chair.

Adaptive Equipment for Toileting



Toilet Aid:

a long-handled device designed to help individuals with limited mobility or flexibility clean themselves after using the toilet.

See page 111 for a tutorial on using a toilet aid

How to Use:

To use, extend the wand and insert toilet paper into the top of the aid by pushing into the bottom piece. Once used, push into bottom of the piece to release toilet paper into the toilet.



Grab Bars:

Sturdy metal or plastic bars installed to provide support and stability for people when sitting, standing, or moving.

How to Use:

To use, contact a home health occupational therapist for optimal positioning in your home. You may ask for a referral to occupational therapy from your loved one's physician.

Toilet Aid



Here is a tutorial on how to safely use a toilet aid.



Assisting with Bathing

 Bathing is a personal task that your loved one may need help with.





Reminder: Let your loved one do as much as they can before stepping in.

If your loved one experiences fatigue during bathing, implementing adaptive strategies or investing in assistive equipment may benefit them and you, as their supporter. The following pages describe how to assist your loved one in entering and exiting the shower. It also provides helpful tips to make the bathing process easier for your loved one.

Adaptive Equipment for Bathing

Shower Tub Bench





Purpose & Use:

A <u>tub transfer bench</u> is a bath seat that goes in the bathtub to help you or the person you care for enter and exit the shower with ease. A portion of the tub transfer bench has legs that sit outside of the tub and the other half sits inside of the tub. To use it, you sit on the edge of the bench, scoot your hips along the bench, and swing your legs into the tub. This allows you to avoid having to step over the bathtub's threshold and improves overall bath safety.

Purpose & Use:

The hand-held shower head allows for better control over the water by directing it precisely where needed. These shower systems can be easily installed in existing showers without the need for extensive modifications.

Shower Chair



Here is a tutorial on how to safely use a shower chair.



Adaptive Equipment for Bathing



Grab Bars:

Purpose & Use: Grab bars are installed metal wall supports that help increase stability and lessen fatigue while showering. While entering, exiting, standing or sitting grab onto the bars while transfering in or our of the tub.



Non-slip Adhesive:

Purpose & Use: Non-slip adhesives are placed on the back of bath rugs to prevent rugs from moving when stepping on them.

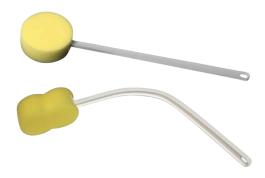


Bath Mitt:

Purpose & Use: Placed over the hand, cloth bath mitts enable washing if hand/finger grasp is reduced.

Long Handled Sponge:

Purpose & Use: These extended handles increase reach and enable the washing of the legs, feet, and back.



Bathing While Standing

As your loved one enters and exits the shower while standing, you may need to stand by and provide assistance as they side step one foot at a time over the edge of the shower/tub.

See pages 117-118 for a tutorial on side stepping in to and out of the shower

- Stand beside your loved one and provide safe physical support.
- Bend your knees and have a wide stance.

 Make sure you have firm footing as your loved one exits the shower.

Note: If your loved one is using a walker as they enter the shower, you can assist them by stabilizing the walker. Place your hands evenly on the front and side with slight pressure.

Getting in the Shower



Here is a tutorial on how to safely enter the shower.



Getting out of the Shower



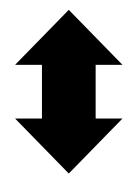
Here is a tutorial on how to safely exit the shower.



Bathing While Sitting



- Get as close to the chair/bench as possible.
 - <u>Tip:</u> If your loved one is using a walker, approach the shower and slowly turn keeping the walker with them at all times.
- Once they have hold of a stable surface, instruct them to lower themselves to a seated position in a controlled manner.
- Once sitting, they should shift their legs into the shower or lift them over the edge of the tub.
- Once your loved one is finished bathing, their hands should be positioned on a stable surface of the seat to push themselves up.



Cancer Supporter

- If you are providing assistance, have your hands on their waist or hips and bend with your knees as you slowly help lower/lift your loved one.
- Assist them in shifting their legs if needed
 - <u>Tip:</u> Avoid lifting or bending with your back.

Safety Considerations

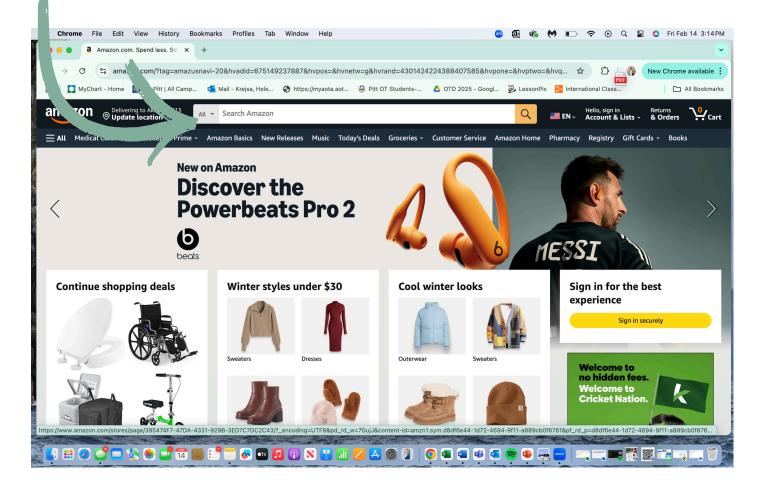
- 1. When transferring in or out of the shower make sure the water is turned off to avoid risk of slipping. Be aware of wet surfaces.
- Avoid wall suction grab bars as they can become unstable due to applied pressure. Grab bars should always be mounted through proper installation methods.

3. Have all needed items close by and in reach for your loved one to conserve energy: including towels, bathing products, hair products, toothbrush/toothpaste, etc.



Amazon

In the search bar type in the item you are searching for (e.g., commode, grab bars, grabber, etc..)



Here is a link & QR code to all adaptive equipment mentioned throughout our guide: <u>Amazon Store Front.</u>

https://www.amazon.com/hz/wishlist/ls/3KBI5TEL6THKG?



ADL & Transfer Videos

Use the link & QR code below to access the ADL and transfer videos.



You will find videos of University of Pittsburgh
Occupational Therapy Doctorate students
demonstrating the use of adaptive equipment and
tips when assisting your loved one in activities of
daily living.

Community Resources

This module covers...

- Processing cancer and accepting your loved one's cancer diagnosis
- Community resources to receive emotional support
- How to move forward with cancer and learn more about cancer stages and side effects
- How to find facilities and providers in the Pittsburgh area
- Questions to ask the treatment team and discharge team
- How to create a comprehensive cancer care plan
- Overview of available home health, organizational, financial, and nutritional options to address the effects of cancer

As a community resource, Cancer Bridges is here for you

Learning that a loved one has cancer can be life-changing. It's normal to feel uncertain, overwhelmed, or unsure of how best to support them—and yourself.

This module will help you navigate this new reality by offering guidance, reassurance, and practical ways to support both your loved one and your own well-being throughout the cancer journey.

Processing Cancer

The initial shock of a cancer diagnosis is often overlooked. Everyone's process of accepting cancer looks different. Throughout the journey you may need to:

- Cry
- Scream
- Talk feelings out with someone
- Receive a hug
- Participate in anger relief rooms
- Sit in silence

Regardless of your method of processing, accepting <u>your</u> <u>new normal</u> and your new role as a supporter is part of <u>your</u> <u>recovery process</u>.

Quick Tips:

Pause, take a step back, and breathe. See page 126 for box breathing instructions.

Participate in <u>active</u>
reflection: reflecting
specific life changes in the
moment on a consistent
basis.

Exercise: Box Breathing



Box breathing is a simple yet powerful breathing technique designed to reduce stress and promote mental clarity. This method involves a rhythmic pattern of inhaling, holding, exhaling, and holding again—each for four seconds. By focusing on your breath and the steady rhythm, box breathing can help you feel more grounded and centered. You can do this exercise independently or follow the guided meditation below.

- Step 1. Start by breathing in and out 4 repetitions of normal breathing
 - Guided Meditation: "Close your eyes if comfortable; now begin this exercise by breathing normal."
- Step 2: Acknowledge any emotion that you are feeling currently 4
 repetitions of normal breathing
 - Guided meditation: "Now, every breath cycle, acknowledge a new emotion. Breath in that emotion then breath out that emotion. Ex. If you' are tired, sad, calm, neutral; acknowledge it, then breathe it out as if you are releasing that emotion."
- Step 3: Begin Box Breathing 4 repetitions of box-breathing.
 - Guided meditation: "Now begin box-breathing. Breath in for 4 seconds, hold for 4 seconds, breathe out for 4 seconds, hold for 4 seconds. Focus solely on your breathing and count internally."
- Step 4: Breath Normally
 - Guided meditation: "Now relax and resume breathing normally again."

Promoting Acceptance

Oftentimes a cancer journey is not linear, therefore the process of accepting cancer must be continual. Here are 4 helpful tips to aid this process.

Helpful Tips:

- Find your support system.
 - Quick Tip: A lack of a support system could lead to compounding stress. However, being alone or scheduling me time could be beneficial for your processing. Avoid too much self isolation and find the best balance for you.
- Find activities that have personal meaning to foster positive memories with your loved one.
 - Identify parts of your life that are still in your control.
 - Talk to a professional about your feelings and concerns.

Cancer Bridges

Cancer Bridges offers cancerfocused, short-term counseling for caregivers, family, and friends.

A Caregiver Support Group is also available for connection and shared experience.

For more information, call 412-338-1919 or email cbteam@cancerbridges.org.

Because of high demand, there may be a waitlist for counseling services. If so, please consider alternative options.

IMPORTANT!

Hilman Cancer Center

Second Tuesday of the month and the fourth Wednesday of the month from 1 to 2 p.m. at UPMC Hillman Cancer Center – Gumberg Family Resource Center in Pittsburgh, Pa.

For more information visit: Website:

https://hillman.upmc.com/patients/commu nity-support/caring-for-the-caregiver Call:

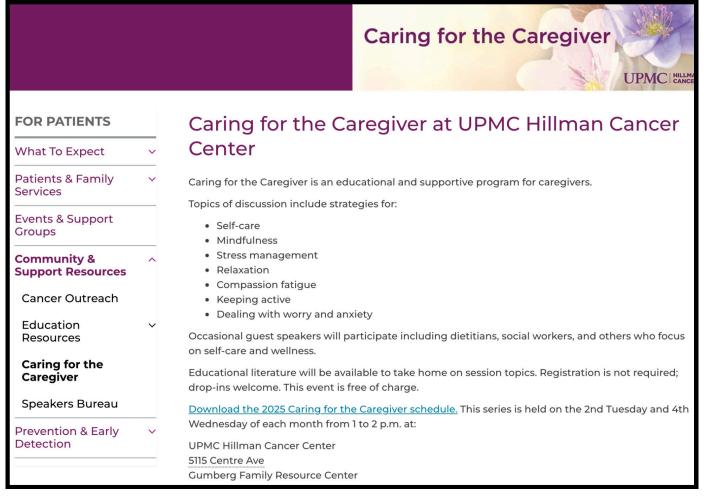
412-864-6659

Email:

Melissa Potter: pottermc@upmc.edu.

Topics Include:

- Strategies for self care
- Mindfulness & relaxation
- Keeping active
- Stress, worry, anxiety, compassion, and fatigue management



CanCare

CanCare is a national non-profit organization that provides numerous emotional support resources including one-on-one emotional support services. Their mission is to provide hope and healing to individuals living with cancer and their caregivers, ensuring they have a survivor by their side to lean on during a cancer journey. To learn more, visit the CanCare web link below.

Web Link: https://www.cancare.org/cancer-caregiver-support

Emotional Support for Cancer Caregivers

Our Cancer Caregiver Support Page

Home > Cancer Caregiver Support

One-on-One Support for Cancer Caregivers

As the loved one of someone living with cancer, your life looks different now. As a husband, wife, partner, mother, father, brother, sister, son, daughter or friend – you now have your own cancer journey, that of supporting someone with cancer. At CanCare, we offer help for caregivers of cancer patients by providing emotional support to the cancer patient's family and friends as well as the cancer patient.

CanCare is a non-profit organization dedicated to providing hope and healing to those impacted by cancer by ensuring they have someone who has shared a similar experience by their side. **Our extensive network of volunteers offer hope to cancer patients and their caregivers nationwide through personalized support.**



Resources for Cancer Caregivers

Building a support network is an important part of cancer support. We recommend starting to build your cancer support community by **requesting a Caregiver match** with CanCare.

Family Caregiver Alliance

The mission of Family Caregiver Alliance is to improve the quality of the life for family caregivers and the people who receive their care.

800-445-8106

Visit Website >

Caregiver Action Network

Non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

855-227-3640

Visit Website >

Well Spouse Association

Offers peer support & educates healthcare professionals and the general public about the special challenges and unique issues "well" spouses face every day.

732-577-8899

Visit Website >

CanCare Application Process

How the application process works:

1

Sign Up

Select "client".
Enter your email.
Check email for
form link.

2

Fill Out Form

Share details about yourself to help us match you with a volunteer.

3

Confirmation

Submit form.

Get confirmation
email.

Matching process
begins.

4

Welcome to CanCare

Once matched, we'll email you. Your volunteer will reach out in 24-48 hours.

Additional Emotional Support Resources

How to Find a Counselor - LIVESTRONG

- About LIVESTRONG: This resource provides information about the types of counseling, potential costs, and tips on how to find a counselor.
- Web Link: https://livestrong.org/resources/finding-acounselor/

• 10 Tips for Cancer Caregivers - Cancer Support Community

About Cancer Support Community: This resource provides
 10 tips to help find balance, support, and connection
 during your loved one's cancer journey.

• Web Link:

https://www.cancersupportcommunity.org/blog/10-tips-caregivers

• Caregivers and Family Page – American Cancer Society

 About American Cancer Society: This resource includes video series, explanation of what cancer caregivers do, how family and friends can assist or encourage care, caregiver guide, and more.

• Web Link:

https://www.cancer.org/cancer/caregivers.html

Call: 800-227-2345

Moving Forward with Cancer

How to get started:

Cancer Support Community provides information on becoming a caregiver. The Caregiver Role and Cancer Treatment page explains how to navigate the practical challenges of caregiving as well as provides ways that friends and family can be involved. To learn more, visit the Cancer Support Community website below.

Web Link: https://www.cancersupportcommunity.org/caregivers#thecaregiver-role-&-cancer-treatment

Caregivers Let us help you find what you need. Are you here for yourself or a loved one? If you've already saved your personalized content, login. Myself My Loved One



Becoming a Caregiver

The ripples of a cancer diagnosis extend to spouses, partners, siblings, children, and friends. Many of these family members will find they now need to take on the role of caregiver — something they have never done before.

Your main job will be to support and encourage your loved one as they learn about their cancer and make decisions about — and then start — their cancer treatments. What will this involve? Not all caregivers do all of the same things, but a survey of 66 caregivers who are part of our <u>Cancer Experience Registry</u>® found:

- 98% provided emotional support
- 96% went with their loved one to medical appointments
- 82% helped with decision-making
- 79% coordinated medical care
- 80% provided transportation
- 74% helped manage finances

Becoming a caregiver may seem scary or overwhelming. Know that you are not alone: The Caregiver Action Network estimates that, during any given year, more than 65 million people in the United States spend about 20 hours each week caring for an ill, disabled, or aged family member or friend.

National Cancer Institute

How to Learn More:

The National Cancer Institute provides information about causes and risk factors, symptoms, how cancer is diagnosed, and treatment options. To learn more, visit the National Cancer Institute website below:

Web Link: https://www.cancer.gov/



NCI is the nation's trusted source for cancer

Find a Cancer Type

Treatment

Side Effects

Causes & Prevention

Diagnosis & Staging

Find a Clinical Trial

IMPORTANT!

You and your loved one can learn about cancer types and stages together.

Finding Health Care Facilities & Providers

- UPMC Hillman Cancer Canter: Services for Cancer Patients & Families
 - About UPMC Hilman Cancer Center: This resource provides information and services on Nutrition support, pain management, palliative/support care, sleep studies pharmacy, second opinions, etc.
 - Web Link: https://hillman.upmc.com/patients/support-services
- UPMC Integrative Medicine Services
 - About UPMC Integrative Medicine Services: This resource provides
 information on health care services outside of cancer related treatment
 such as massage therapy, decongestive therapy, and many more offered
 services.
 - Web Link: https://www.upmc.com/services/integrative-medicine/services
 - Call for general information or for appointment booking at 412-623-3023

• AHN Cancer Navigation Team

- About AHN Cancer Navigation Team: This resource provides information on AHN interdiscipline care team and the services they offer.
- Web Link: https://www.ahn.org/services/cancer/departments/navigationteam#ourTeam
 - For resources outside of central Pittsburgh, these facilities could possibly connect you to branch locations for certain aspects of care.
- *<u>Ouick Tip:</u> If comfortable, talk with other Cancer Bridges Supporters
 and staff about their helpful experiences with oncology providers
 and facilities.

Questions to Ask the Health Care Team

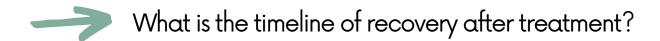
To feel more confident in the care that is being provided to your loved one, it may be beneficial to ask questions. Being clear and direct during questioning can help build rapport with the care team and provide you and your loved one with more control of their health outcomes. Please refer to page 25 for more questions to ask a health professional.



- What are the benefits/risks of each type of treatment?
- What would you recommend to one of your loved ones?
- How can I support my loved one in managing the side effects of their treatment?

Questions to Ask the Discharge Team

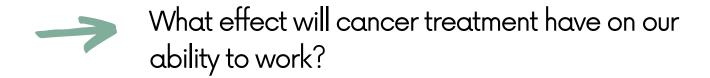
Before leaving the clinic, it is essential to receive as much information as possible about post cancer care before returning home. This will set you and your loved one up for success. To guide this process, here are examples of questions you or your loved one can ask the care team at discharge.



- When should we call the physician if a problem develops?
- What is the proper technique for changing dressings or handling other medical equipment? What supplies are needed?
- Are there any post treatment activity restrictions that my loved one should follow?
- Who should my loved one follow up with for their care? When should this happen?
- Are there any environments my loved one should avoid?
- Will there be potential diet changes following treatment?

Questions to Ask Yourself

As you are navigating through your loved ones' cancer journey it is essential to recognize and address your own thoughts and feelings. To guide this process, here are examples of questions you can ask yourself.



How will cancer treatment affect other friends and family?

What would be the best way to address my concerns?

*Ouick Tip: Keep a note pad or an electronic note app on hand to write down questions and/or comments.



Creating a Care Plan

- Try to stay organized by:
 - Writing down all appointments in a notebook or paper calendar or input them in an electronic calendar with automatic reminder alarms
 - Keep all important documents in the same place
- Prepare for Good Days and Bad Days
 - A cancer journey can look different everyday, thus setting up a plan ahead for your loved ones "rainy days" could be useful within the care plan.
 - Quick Tips:
 - Try finding "Easy and Quick" meal recipes that can help save time, money, and energy
 - Example: Visit the Memorial Sloan Kettering Cancer Center website for quick recipes that are suited for cancer related diet changes.
 - Web link: https://www.mskcc.org/experience/patient-support/nutrition-cancer/recipes#sort=relevancy
 - Have a nanny or additional care partner on call if needed
 - Example: Visit Care.com for local caregivers
 - Web Link: https://www.care.com/

Addressing Burnout

With the all the responsibilities that come with supporting your loved one, experiencing burnout is normal. To guide the process of addressing burnout, here are examples of solutions you could consider.

1

Don't be afraid to set boundaries

- Quick Tip: Schedule time for self care ahead of time
 - <u>Example</u>: Schedule alone time from 3-4 pm except for emergencies only
- 2

Consider establishing a takeout day to replace home cooking

- Example: "Takeout-Tuesdays"
- 3

Consider finding a new hobby and/or consider recommending a hobby to your loved one

 <u>Example</u>: LIVESTRONG at Greater Pittsburgh YMCA, see page 141 for more information

"People talk about a caregiver, but you don't really know what a caregiver is until you're really in that role...I learned that a caregiver wears many hats: listener, observer, protector, planner, anticipator, the backup brain to the patient, the organizer, the strong one, the levelheaded one...I quickly realized that I could not do it all and that I needed help."

-Sheri; Former cancer caregiver for a close friend

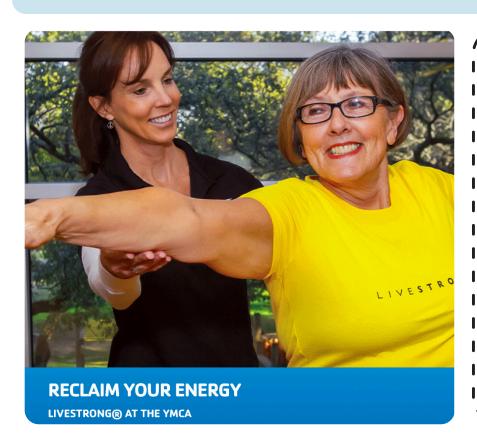
LIVESTRONG at Greater Pittsburgh YMCA

LIVESTRONG is a nonprofit cancer organization that has collaborated with YMCAs all over the country. The Greater Pittsburgh YMCA offers a 12- week program for adult cancer survivors that meets twice a week and provides facility access to the survivor's household free of charge. To learn more visit the YMCA web link below:

How to register:

Contact: Jennifer Werley, CPT, Healthy Living Director Sampson Family YMCA

Phone/Email: 412 744 1179 | jwerley@ymcapgh.org § 2200 Golden Mile Hwy, Pittsburgh PA 15239 Web Link: https://www.pittsburghymca.org/ylivestrong



*Space is limited for each session to allow for a low instructor-to-participant ratio.

Survivors are limited to participating once, in order to accommodate others.

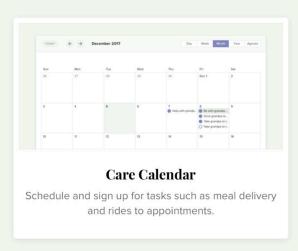
Lotsa Helping Hands

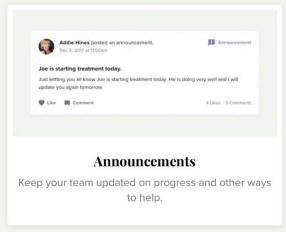
How to get started:

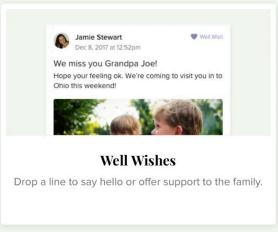
Lotsa helping hands is an online resource where you can create a care community to coordinate and community care for your loved ones. The platform has numerous features such as creating a care calendar to input doctor appointments or assign tasks, posting announcements, and sending photos or well wished, to family/friends. To learn more visit Lotsa Helping Hands website below.

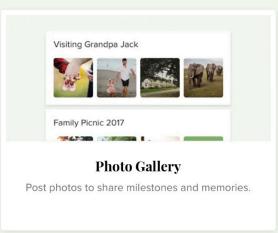
Web Link: https://lotsahelpinghands.com/#body-top

Lotsa Features









Lotsa Helping Hands

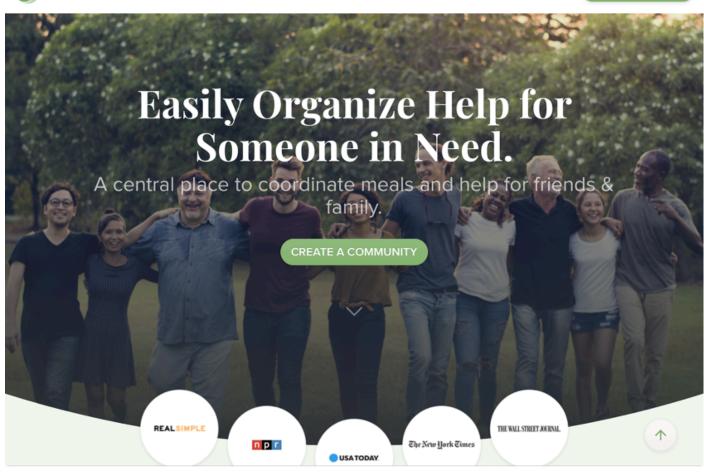


Support

Log In

Join a Care Team

CREATE A COMMUNITY



Who Uses Lotsa?



Caregivers

You need help organizing care for a loved one or family member.



Friends & Family

You know someone caring for others and want to help.



Volunteers

You want to help people in your neighborhood.



New Parents

You want to let family know how they can help.

Considering Home Health

What is it?

What it might look like?

Home Health is medical, therapeutic, and/or personal services provided in a client's home to support recovery, manage a condition, or maintain independence.

 Care can be provided by aides, nurses, occupational and physical therapists or other health professionals.

- Receiving full/part time assistance with physical, emotional, or mental care.
- May include wound care, medication management, rehabilitation, assistance with daily activities, and education for patients and caregivers.
- Assistance with providing transportation, grocery shopping, or general supervision/companionship.



Important



Receiving home health is NOT solely for terminal illnesses. You and your loved one can receive help during any time of a cancer journey and recovery process.

It is possible that your loved one is uncomfortable with having additional help in the home. If this is the case, it may be beneficial to include your loved one in the decsion making process when selecting a carer and establishing the amount of care needed.

Home Health Resources

*Note: It is important to know that this resource page is not a comprehensive list. We recommend visiting the website and calling to determine the agency that will fit best for you.

• Care.com Home Care Agencies Pittsburgh

- About Care.com: Care.com matches your with highly rated local home care agencies near you and compare
 the agency options to find the best fit.
- Web Link: https://www.care.com/home-care-agencies/pittsburgh-pa

Life Pittsburgh

- About Life Pittsburgh: LIFE Pittsburgh is an all-inclusive program for people whose health issues interfere with
 their daily lives but, are capable of living safely and independently in the community. Coordinated plan of
 care includes medical, social, and daily living support.
- Web Link: https://www.lifepittsburgh.org/

UPMC Home Health Care

- About UPMC Home Health Care: Provides nursing, rehabilitation, community support, and medical equipment services for the Pittsburgh, Erie, Altoona areas and more of Western PA
- Web Link: https://www.upmc.com/services/home-health-care

Freedom Care

- About Freedom Care: Medicaid Home care program where a child, relative, or friend could be paid to care
 for their loved one in need if eligible.
- Web Link: https://freedomcare.com/pennsylvania/?
 utm_source=Google&utm_medium=CPC&utm_campaign=21781102734&utm_keyword=in%20home%20car
 e%20pittsburgh&gad_source=1&gbraid=0AAAAADb7ny&vVkoU0o9UFd13NOUgXXnyi&gclid=CjwKCAiAqrG
 9BhAVEiwAaPu5zkuSKkdfj2a7gUvuGw-7SuGUg2dUzSxsTalSKCuea34txGWd8_FbNBoC_wcQAvD_BwE

• Comfort Keepers.com

- Comfort Keeprers: offers older adult care services such as: hospital home recovery care, personal care, dementia care, 24 hour care, end of life care, and companionship
- Web Link: https://www.comfortkeepers.com/offices/pennsylvania/pittsburgh-city/

CLASS: Good Use Program

- <u>About CLASS</u>: The Good Use Program gives both durable medical equipment (DME) and AT a second life at
 no cost to participants. There are no age requirements to participate.
- Web Link: https://www.classcommunity.org/services/adult/good-use-program

• AARP HomeFit Guide:

- <u>About AARP HomeFit Guide</u>: This resource was created to help individuals and families make their current or future residence safer via age-friendly designs and modifications.
- Web Link: https://www.aarp.org/content/dam/aarp/livablecommunities/housing/2020/homefit/AARP%20HomeFit%20Guide-singles-062022.pdf

Life Organization Resources

Caring Bridge

- o About Caring Bridge: Online care community network
- Web Link: https://www.caringbridge.org

Organizing and Keeping Important records - LIVESTRONG

- <u>About LIVESTRONG</u>: Provides helpful tips on how to manage your important documents.
- Web Link: https://livestrong.org/resources/organizing-andkeeping-important-records

Job Accommodation Network

- About Job Accommodation Network: If your loved one is returning to work during or after treatment and is in need of accommodations, this could be a beneficial resource.
- Web Link: https://askjan.org/info-by-role.cfm#for-individuals

• Magee-Women's Hospital of UPMC Cancer Supportive Services

- About Magee-Women's Hospital Cancer Supportive Services:
 Although there may be a waitlist for their counseling services,
 they have several additional services such as financial
 counseling, a sexual health clinic, and more.
- Web Link: https://www.caregiving.pitt.edu/magee-womens-hospital-upmc-cancer-supportive-services

Financial Resources

*Note: It is important to know that this resource page is not a comprehensive list. We recommend visiting the website or calling to determine which financial resource will fit best for you.

• Magee-Womens Hospital of UPMC Cancer Supportive Services

- <u>About Magee Womens Hospital</u>: Financial counselors are available to help patients with co-pay concerns and insurance questions.
- To speak with a financial counselor, call 412-623-5888.

• Finding Transportation Services - LIVESTRONG

- <u>About LIVESTRONG</u>: This resource discusses helpful tops to find transportation and other cancer support services.
- Web Link: https://livestrong.org/resources/transportation-and-other-cancersupport-services/

CancerCare Co-Payment Assistance Foundation

- About CancerCare: This resource helps people with cancer overcome financial access
 and treatment barriers by assisting them with co-payments for their prescribed
 treatments. They offer easy-to-access, same-day approval over the phone and online.
- Web Link: https://www.cancercare.org/copayfoundation#!covered-diagnoses

Navigating Financial Planning Guide

- About Financial Planning Guide: This guide will cover common issues you may
 encounter as a caregiver regarding financial and legal matters and offer key
 information, insights, and strategies to assist you and your loved one.
- Web Link: https://www.caregiving.pitt.edu/sites/default/files/CaregiverGuide_NavingatingFinancialPlanning.pdf

American Life Fund.com

- About American Life Fund: Provides financial assistance through organizing many financial resources to access in one place. Whether it is mortgage/rent, prescriptions, health insurance, and more.
- Web: Link: https://www.americanlifefund.com/cancer/financial-assistance/

Food Nutrition Resources

Nutrition Basics for Patients and Caregivers.pdf

- About Nutrition Basics: Strengthening the immune system, managing side effects, grocery shopping tips, and more are discussed in this guide to increase nutrition during treatment recovery.
- Web Link: https://www.mdanderson.org/documents/Departments-and-Divisions/Clinical-Nutrition/Nutrition-Basics-for-Patients-and-Caregivers.pdf

Greater Pittsburgh Food Bank

- <u>About Greater Pittsburgh Food Bank:</u> The food bank is committed to ensuring Pittsburgh neighborhoods have access to food. Services include food distributions, grocery deliver programs, food assistance programs, and more.
- Web Link: https://pittsburghfoodbank.org/find-food/get-help/

Winter and Spring 2025 Food Distribution Calendar PDF:

 Web Link: https://pittsburghfoodbank.org/wpcontent/uploads/2024/12/Winter-Spring-2025-Distro-Calendar-Digital-Version-1-INNOV-529-2024-1.pdf

MealTrain.com

- About MealTrain: By creating a Meal Train page, friends, family, and neighbors can sign up to provide meals for a loved one.
- Web Link: https://www.mealtrain.com/

• Meals On Wheels America

- About Meals on Wheels America: Meals on Wheels service provides nutritious meal, companionship and a watchful eye on the health and safety of older adults. Visit the web link to find your local program.
- Web Link: https://www.mealsonwheelsamerica.org/find-meals
- Quick Tip: Consider food shopping & delivery services
 - Ex. Instacart
 - Web link: https://www.instacart.com/

APPENDIX

References

• All references used to complete this guide are included in this section.

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