



Caregiving after treatment

a guide for caregivers of survivors

MD Anderson
Cancer Center

Making Cancer History®



Have you cared for someone treated for cancer?

There are many types of caregivers.

- Some are family and friends living in the home, assisting the patient with daily living and offering care.
- Some are neighbors and friends who run errands, cook dinner, get the oil changed and listen.
- Others are long-distance caregivers who offer emotional support through phone calls, cards and email messages.

This booklet reflects the experience of caregivers. They share their challenges and ways they moved forward beyond cancer treatment. Each caregiver's experience is individual and intimate. We hope this helps you on your path as a caregiver.



Table of Contents

Survivorship	3
A Caregiver's Bill of Rights.....	5
Self-Care: Taking Care of the Caregiver	6
Emotions.....	7
Body	9
Mind.....	11
Spirit	12
Community	13
Finances and Legal Matters.....	15
Conclusion	16
Caregiver Resources	16

Survivorship

A person is considered a cancer survivor from the time of diagnosis, throughout the remaining years of his or her life. Family members, friends and caregivers are also part of the survivorship experience. There are three stages of survivorship: living with cancer, living through cancer, and living beyond cancer. In this guide, “survivor” refers to people who have completed active cancer treatment.

Your New Normal

Active cancer treatment is finished. You and your loved one are ready to move to the next phase of survivorship. Life may return to what it was like before cancer. Or, it may be completely different. Everyone has their unique story.

Next Steps

Your loved one may choose to have follow-up care with a doctor in the community or continue care at MD Anderson. That care may look different than active treatment as survivorship clinics help patients develop a plan for

“How do we reconstruct our life no longer centered on cancer?”

Bill and Suzanne, survivors of her melanoma cancer

their ongoing health care. If your loved one chooses care at MD Anderson, care will be provided through MD Anderson's Survivorship Clinics. A new care team will work closely with specialized health care providers to monitor and manage late effects related to cancer and its therapies. The clinic will help with physical and psychosocial care. Your survivorship clinic will:

- Review recent medical history and perform a physical examination
- Conduct a complete assessment to detect cancer recurrence or progression
- Identify and help manage side effects of cancer and treatment
- Develop a treatment summary and follow-up care plan
- Provide education and referrals related to:
 - Cancer screening examinations
 - Health behaviors that reduce cancer risk
 - MD Anderson or community survivorship resources

The survivorship health care team will include physicians, advanced practice nurses and patient service coordinators, who work closely with the other specialized doctors and nurses who treated you at MD Anderson. Non-cancer doctor visits should be continued with a primary doctor in the community.

A Caregiver's Bill of Rights

To have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she was healthy.
- I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed and express other difficult feelings occasionally.
- To reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt, anger or depression.

"I am so proud of my loved one who faced this cancer, but I forgot to be proud of me, too."

Bea, partner of prostate cancer survivor

- To receive consideration, affection, forgiveness and acceptance for what I do from my loved one as long as I offer these qualities in return.
- To take pride in what I accomplish and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- To expect and demand that, as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

Add your own statements of rights to the list. Read it to yourself every day.

Reprinted from "Caregiving: Helping An Aging Loved One," a book by Jo Horne.

Self-Care: Taking Care of the Caregiver

As you and your loved one move forward beyond cancer, it is important you take care of yourself. Give yourself permission to focus on your needs. During treatment, you may have put your needs aside. Some caregivers feel guilty. Some do not even notice they have neglected themselves. You have the right and responsibility to take care of yourself. This is not being selfish. It is self-care!

Cancer changes life. It may impact daily living, relationships with others and how you view the world. Some changes start the day of diagnosis. Others show up years later and some last a lifetime. Some changes seem more difficult than others, but there are solutions. These changes are opportunities to explore new things along the cancer journey. Millions of caregivers and survivors find ways to thrive while surviving. What can you do today? What will make a difference for you?

Emotions

It is normal and okay to experience a wide variety of feelings. Feelings may, and will likely, range from uncertainty to hope. As your loved one transitions from active patient to survivor, you too will experience change. Embrace your feelings. Talk with a counselor, support group or friend. Your feelings matter.

Recurrence: Concern about cancer coming back is common. Certain events can trigger worry and anxiety. The anniversary date of the cancer diagnosis; ending care with a trusted physician, or beginning follow-up in another clinic

“I still don’t have time to take care of myself. Even if I did, I forgot what I used to know, where to go, or what to do.”

Kaye, wife of colon cancer survivor

may make you worry. For some, receiving an appointment letter or reading about cancer in the newspaper is uncomfortable. It is okay to worry. However, don't let your worries be greater than your reasons to celebrate. Share your concerns with the doctor. Set new goals with your loved one and for yourself. What plans were on hold? What new plans will you make?

Depression: Depression is common for cancer survivors and their caregivers. About 70% experience depression. It can occur during treatment or years after. Depression is a medical condition. It is not a sign of weakness or failure, and it affects every person differently. Symptoms of depression may include:

- Feeling sad, blue, or crying a lot for no reason
- Feeling guilty, unworthy, helpless, and lacking self-confidence
- Seeing life as meaningless or feeling like nothing good will ever happen again
- Losing interest in hobbies or activities once enjoyed (i.e., music, sports, being with friends, going out)

“It’s hard to be hopeful about the future when I don’t know what may happen to “my survivor” or to me.”

Minal, wife of husband with lung cancer

- Wanting to be left alone most of the time
- Having difficulty making decisions, remembering things, or trouble concentrating
- Being irritable often, getting mad over little things, and over-reacting
- Having difficulty falling asleep or sleeping too much
- Awakening earlier or later than normal
- Eating too much or too little (loss of appetite)
- Loosing or gaining weight
- Feeling restless and tired most of the time
- Thinking about death or suicide

It is very important to get help. If you would like to speak with someone about your feelings, call the Social Work Department at 713-792-6195. If you or someone you know is having suicidal thoughts, get help right away.

Body

Too often, caregivers forget about their own health while caring for their loved one. Remember, you can't be much help if you are not feeling well. Check with your doctor, but here are basic suggestions.

“Survivorship is not a sprint but rather a marathon”.

Martin Raber,
physician and survivor

- **Get a physical exam** at least every year (eye exam, dental exam, hearing test, etc.)
- If needed, **see a specialist**, a doctor who works on specific diseases or body parts (a cardiologist for your heart, endocrinologist for diabetes, etc.)
- **Get screened for cancer** (prostate screening, mammogram, colonoscopy, etc.). This is very important if you have a family history of cancer. Finding cancer early increases the risk of survival.
- **Adopt a healthy lifestyle.** Get physically active. Exercise regularly. Avoid tobacco products. Eat well. This means eating more fruits and vegetables and less red meat. Limit alcohol, salt and sugary foods. Find positive ways to manage stress.
- **Move.** Physical activity relieves tension and helps the body work better. Try stretching, walking 10 minutes a day, enjoying a swim or playing tennis. Explore alternative and complementary medicine like yoga, Pilates, or dance.

- **Sleep.** Sleep in a bed for 6-8 hours a night. When you feel fatigued during the day, take a walk or lie down for a few minutes.
- **Drink.** Drink plenty of water — 6-8 glasses a day.
- **Treat yourself.** Look for little ways to honor your body. Maybe a manicure or massage. A special dinner. New earrings. New haircut. New ball cap. Walk on the beach.

For more information on cancer screening and healthy living, visit the Cancer Prevention Center or go to <http://bit.ly/LsJi8P>.

Mind

Cancer can be mindboggling. There is a lot to learn, and a lot to process. There are often many decisions to make. All of this is in addition to day to day life. Here are some tips to help calm your mind or manage your thoughts.

- **Journal.** Some people enjoy writing in a journal as a good way to sort thoughts and feelings. It can be a soothing process to empty the mind of stress.

“I couldn’t stop thinking about everything we experienced. The kids would ask me “Mom, are you listening to me”. I wasn’t. I was in my head and not with my family. I want it to stop.”

Rose, wife of
testicular cancer
survivor

“There was a change in me and it is hard to explain to others. My priorities changed. My values shifted. I am a new person and I like the change.”

Jan, sister of
breast cancer survivor

- **Scrapbook.** Creating a book about the journey can put things in perspective.
- **Support groups.** Caregivers sharing with others is a safe place to sort out thoughts and feelings, balance one’s perception and to learn new ways to regain your own strength.
- **Read.** Explore something that always interested you but you never had time to learn about.
- **Meditate.** Simply defined as quiet reflective thought, meditation can reduce stress and positively affect the body.

Spirit

Spirituality has many meanings. For some people it means finding a purpose. Why am I here? Spirituality also could be connecting to nature. Others may relate it to formal organized religion. Spirituality is personal.

Cancer can change thoughts about spirituality. There may be a shift in priorities, or values may in a variety of ways change. What was thought to be important before may now seem less important. Take time to

define what spirituality means for you. Renew your spirit.

Do I have spiritual peace? Balance?

MD Anderson chaplains are available 24 hours a day/7 days a week. If you would like to speak with a chaplain for spiritual support or questions call 713-792-7184. For a list of support groups or to submit an online prayer request, click on the Spiritual Support link on www.mdanderson.org/chaplaincy.

Community

Returning to social and professional life can be overwhelming. Who do you tell? What do you share? What is comfortable for you? You may decide to keep your work life separate from your personal life. Or, you may tell all or a few of your coworkers. You have control over what you decide to share about the experience of you and your loved ones. Do what makes you comfortable.

The same is true among your friends. Do what makes you comfortable. People may not know what to say or

“Sometimes, I just have to get away. Some days I just don’t want to talk about cancer.”

San, mother of son surviving thyroid cancer

if they should act a certain way. If there is something that you need, share that need. For instance you may not be as social. You could say “I need a little space right now.” Or, maybe you want to get your mind off of health issues. You say something like, “I just need to do something different, let’s go for a walk.”

Just as it may take time to settle into this new phase of survivorship, allow time for your relationships. If your spouse or significant other is the survivor, intimacy and sex may have changed since the diagnosis. Communicate your concerns, but be patient. If there are physical and/or emotional challenges speak with the health care team.

Some relationships may change as other members of the family or friend may be impacted in different ways during survivorship. For example you may or may not be able to ease some of the concerns of overprotective siblings, or an anxious parent.

Be mindful of children and teens. They may not share their feelings. So pay special attention to mood or behavioral changes. Give them opportunities to express themselves. Contact the Social Work department for programs and community resources at 713-792-6195.



Finances and Legal Matters

Money issues often have a major impact on survivors and their families. There may have been little or no income received during treatment, and insurance coverage may have changed or been lost. Families can be left paying for some or most of the treatment related costs for several months after treatment. Needing financial help after cancer treatment is normal.

For questions about the cost of care received or a bill, talk to your care team.

Legal issues are also important to survivors and their loved ones.

A history of caring for someone with cancer can affect your employment and insurance coverage. You are encouraged to know your rights and survivor's rights.

Survivors and caregivers should plan for the future. It is never too soon to make financial and legal plans. Proper planning will make sure your wishes are followed and ease stress. Advance directives are legal documents that clearly tell your medical choices to your family and medical team.

These documents are free. You do not need a lawyer or notary public. For more information or copies of these forms go to <http://bit.ly/1invpoL> or call 713-792-6195.

Conclusion

A cancer diagnosis may have a lasting impact on a person's life. It is okay to worry. It is okay to enjoy yourself, to have fun, and even smile. Every person's and family's survivorship experience is different. Tomorrow is the start of new possibilities. Life is more than cancer.

Caregiver Resources

MD Anderson's Resources:

myCancerConnection

1-800-345-6324

www.mdanderson.org/mycancerconnection

- Matching caregiver to caregiver
- Annual week long celebration for caregivers.
Includes educational programs, resources, social networking and more.
- Annual Survivorship Conference for patients, caregivers and survivors.

Spiritual Care and Education

713-792-7184

www.mdanderson.org/SpiritualSupport

Provides spiritual care to patients and caregivers

Integrative Medicine Center

713-794-4700

www.mdanderson.org/integrativemed

Provides services and programs that work together with conventional cancer care and focus on physical, mind-spirit, and social health.

The Learning Center

713-745-8063

www.mdanderson.org/learningcenter

Provides the latest information about health, cancer and cancer prevention.

Social Work

713-792-6195

www.mdanderson.org/socialwork

Offers counseling, support groups, referrals to community resources.

Other Helpful Resources:

Caregiver Action Network

202-454-3970

<http://caregiveraction.org>

Educates, supports and empowers caregivers.

Family Caregiver Alliance

1-800-445-8106

www.caregiver.org

Offers a variety of materials to support family caregivers, ranging from booklets and tip sheets to webcasts and conference materials.

Well Spouse Association

1-800-838-0879

www.wellspouse.org

A place for caregivers to receive emotional support as well as tips to building a new life once caregiving ends

*“I need to remember
it was hard so I can
appreciate today”.*

Asabi, wife of throat
cancer survivor

