

| Coping with a cancer diagnosis



| Cancer Care & Research

Introduction

You or a loved one has just received a diagnosis of cancer.

Life has suddenly come to a standstill. The things that you planned for are placed on hold. Life is not going to be the same. You may feel overwhelmed with the diagnosis as well as the decisions and treatments to come.

This manual, developed with the wisdom of cancer survivors, is a guide to help you navigate some of the common emotions and concerns following a cancer diagnosis. It will help you gain a sense of control in your life as you gather information about treatment options. It will help you find ways to include the support and assistance of loved ones during this difficult journey. Funding for this booklet was provided by Marshfield Clinic Health System employees and donors who hope that it provides you with a few helpful “handles” to stabilize yourself as you move through the coming weeks and months.

This booklet uses the term “patient” to reflect the individual diagnosed with cancer. As the patient, it is important to remember that you are not alone with your cancer diagnosis. Each year approximately 1.7 million people in the United States are diagnosed with cancer. A tremendous amount of information is available on how to get through the challenges of cancer. We hope that you will use this booklet as a starting point.

Table of Contents

Challenges of an initial cancer diagnosis:	
Managing the panic.	1
Importance of effective self-advocacy	5
Considering the needs and concerns of family and friends	9
Palliative supportive care.	13
Path toward healthy survivorship.	14
Additional resources.	16

Challenges of an initial cancer diagnosis:

Managing the panic

Hearing the words “you have cancer” can be gut-wrenching. While everyone experiences emotion in different ways, some common emotions include:

- Shock
- Anger
- Powerlessness
- Fear
- Sadness
- Hopelessness
- Worry
- Despair

The questions often connected to these emotions are:

- Why did this happen?
- Will I survive?
- Who should I talk to about this?
- How will I tell my family, friends and co-workers?
- What about all of the commitments on my calendar?
- Will I be able to continue working?
- How will I care for my family?
- How will I pay for this?

The combination of these emotions and questions is often overwhelming and can lead to physical reactions including difficulty sleeping and fatigue.



While you may feel helpless, here are several things you can do to regain control in your life:

- Remember that right now, just after diagnosis, can be one of your most difficult times. These intense emotions usually decrease with time.
- Emotions tend to come in waves, intense and more frequent at first and less intense and less frequent as time passes and you adjust.
- Realize it is entirely normal to grieve in some manner for the losses that come with a health change.
- Allow yourself to experience your feelings. This helps them to ease with time.
- Look for balance in your life, including healthy activities, good nutrition, exercise, rest and time with family and friends.
- Express your feelings to family and trusted friends.
- Learn about your diagnosis.
- Ask questions of your treatment team and, if you do not understand, ask again.
- Remember that you have not become your diagnosis. You are still you.

Support is important and there are many helpful directions to turn for this. Some people notice that they prefer the comfort of family and friends for this support, while others may benefit from connections with those who have been through the cancer experience. Some may prefer the comforts of clergy or professional resources. Resources for support include:

- Family
- Friends
- Clergy
- Medical oncology team
- Cancer support groups
- Cancer survivors
- Professional counselors
- Oncology nurse navigator
- Online resources
- Oncology social worker
- Oncology survivorship coordinator





Importance of effective self-advocacy

Self-advocacy can help increase your sense of control during treatment. It includes:

- Taking an active role in your cancer treatment.
- Educating yourself about your diagnosis, the specific type of cancer you have, the treatment options and the effects of treatment.
- Communicating what you need with your treatment team, family and friends.
- Identifying your personal needs, establishing a plan and setting up goals to meet those immediate and long term needs.

How can I be a good self-advocate?

- Self-advocacy is often promoted by patients themselves. Other times, a family member or friend may take the lead in advocating on your behalf. Bring someone you trust with you to appointments as it can be hard to absorb all of the details of your care when you are feeling overwhelmed.
- Self-advocacy involves active communication with your treatment team about your thoughts on treatment options and how your treatment team can best meet your needs through the process.
- Self-advocacy involves gaining a clear picture of all of the services available to you within the medical center to assist you during diagnosis, treatment and follow-up. This includes counseling, physical rehabilitation, nutritional services, community resource assistance and financial assistance.
- Self-advocacy may involve using brief, positive “self-talk” to coach you through this journey. For example, “My body has the capacity to heal,” “Focus on what you can control now,” and “One day at a time.”
- Self-advocacy may involve making connections with patients who have had cancer and are at other stages of survivorship.
- Learn more about self-advocacy at:
www.canceradvocacy.org/resources/publications/advocacy.pdf



How to communicate with your treatment team

- Have a conversation with your medical care team members about how to best communicate with you. Talk about how to best share information with you and how to best take care of you physically and emotionally.
- You will have many questions on your journey through treatment. Consider writing your questions on paper and bringing them with you to appointments.
- Before you come to your appointments, ask yourself, “What are the three things bothering me the most at this time?” This will help you to identify and communicate issues of priority for you.
- Remember that doctors and staff cannot read your mind. Do not assume that they know how you are feeling, what your concerns are or how your body is reacting to treatment. You will need to share this information with them.
- Take time to make sure that all of your questions are answered before you leave your appointment.

Considering the needs and concerns of family and friends

Many people report concerns and confusion about how to discuss their diagnosis with family and friends. What, and how much, should you tell them?

- There is no right way to share this difficult information with loved ones.
- Keep in mind that many family members and friends will want to know if you are facing a health crisis. Patients often worry that they will burden others and only cause worry and pain. Not only might it be difficult and stressful to keep your diagnosis a secret, but those close to you can often sense that something is different or wrong. In addition, you miss out on their support.
- Before disclosing your diagnosis, consider who you think can handle the information in a caring and supportive manner.
- Prior to telling your children, consider using professional, online and print material to help you find effective ways to discuss cancer with children of all ages. There are numerous resources to assist you with these discussions. A good starting point is www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-diagnosis.html.

Family and friends will react in many ways. Some common emotional reactions and behaviors that you might see in loved ones include:

- | | | | |
|-------------|-----------------------|------------|----------------|
| - Fear | - Anger | - Hovering | - Helplessness |
| - Sadness | - Uncertainty | - Grief | - Confusion |
| - Avoidance | - Feeling overwhelmed | | |



With any health crisis, people often face changes in roles and routines. Common changes that may occur for you and your family include:

- Responsibilities at home and work.
- Routines and schedules.
- Family interaction patterns and intimacy.
- The emotional needs of various family members.

Family and friends adjust in different ways and on different timelines. Some may jump quickly into active support while others may struggle in a more private way with the information. Some may feel uncomfortable finding a way to offer support to you and may avoid contact for a while. Open communication can often help you successfully get through these challenges. Your role will likely include educating and being assertive with loved ones about what you need and how they can help you.



How can family and friends help?

- Assist with advocacy in the medical setting.
- Manage the day-to-day tasks that treatment disrupts (for example: meal preparation, cleaning, errands, bill paying and child transportation).
- Assist with transportation to treatment.
- Provide comfort and company during chemotherapy.
- Provide emotional support and hope.
- Support you with setting limits with responsibilities.
- Help you to retain a sense of normalcy in your daily routine and relationships.
- Learn about programs for care coordination, often found through the Internet (for example: Share the Care, Caring Bridge and Lotsa Helping Hands.)

How can I help my family and friends?

- Communicate your needs as openly as possible.
- Discuss how to support you through this process.
- Listen to your family members' needs, concerns and feelings. Remember that they are struggling along with you.
- Let family and friends help you through treatment. This often reduces their sense of helplessness and assists you with conserving energy for treatment.
- Educate family and friends about your condition and treatment.
- Encourage family to obtain support for themselves.



Palliative supportive care

Palliative care aims to relieve suffering and improve quality of life for patients (and their loved ones) facing a serious or life-threatening illness. Problems might include physical symptoms (for example, pain or shortness of breath), emotional stress, spiritual concerns, or challenges with communication or decision making.

Palliative care is available alongside (or in conjunction with) all other appropriate medical treatments. It is not just offered when treatments are no longer working. Though palliative care may include hospice and end-of-life care, it is sometimes most helpful early in the course of illness when the goals of treatment include trying to cure the cancer.

Palliative care team members become part of your cancer care team. In outpatient care, patients see a specialist physician or allied provider. In the hospital setting, there may be additional involvement from a chaplain, dietician, music therapist, nurse and/or pharmacist.

Path toward healthy survivorship

“Cancer survivorship” is a phrase you will hear as you learn about your cancer diagnosis. “Cancer survivors” are individuals who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends and caregivers (Source: Centers for Disease Control and Prevention).

Medical advances in both early detection and the treatment of cancer have resulted in people living many years following a diagnosis. It is estimated that there are nearly 15.5 million cancer survivors in the U.S., with the number of cancer survivors to increase to more than 20 million in the coming years.

Many cancer survivors experience long-term remission of the disease while others may experience cancer as a chronic disease requiring periodic treatments. Many will go on to lead normal lives (often described as a “new normal”) with few negative side effects from treatment. Treatment for cancer can also have lasting physical, social and emotional effects that alter life for years to come. Many cancer survivors report that recovery from the emotional experience of a life-threatening illness lingers significantly beyond the completion of actual treatment.

We are focused on meeting your needs through cancer treatment and beyond. With the guidance of individuals who have experienced cancer treatment, we have developed a comprehensive survivorship program to help you with your adjustment and to put you on the path to wellness and recovery. Our goal is to provide you with resources to support your move into healthy survivorship, including linking you to a wide range of assistance on a community, state and national level. You can access more information about this program and cancer care at Marshfield Clinic Health System through our website www.marshfieldclinic.org/survivorship or by calling a Marshfield Clinic Health System Cancer Center closest to you and asking for the cancer survivorship team member.

We Inspire, Nurture and Give Support (WINGS)

The WINGS Advisory Council provides inspiration and guidance to our cancer survivorship program. It includes cancer survivors and “co-survivors” – family members and friends whose lives have been impacted by the diagnosis.

Locations

Marshfield Medical Center- Eau Claire

2200 Craig Rd
Eau Claire, WI 54701
715-858-6767

Marshfield Clinic Cancer Center- Stevens Point

4100 State Highway 66
Stevens Point, WI 54482
715-343-7722

Marshfield Medical Center

1000 North Oak Avenue
Marshfield, WI 54449
1-800-782-8581

Marshfield Clinic Minocqua Center

9601 Townline Road
Minocqua, WI 54548
1-800-347-0673

Marshfield Medical Center- Rice Lake

1700 West Stout Street
Rice Lake, WI 54868
1-800-442-4268

Marshfield Clinic Wausau Center

2727 Plaza Drive
Wausau, WI 54401
1-888-782-8581

Marshfield Clinic Weston Center

3501 Cranberry Boulevard
Weston, WI 54476
1-888-782-8581



Additional resources

Survivorship Coordinator
www.marshfieldclinic.org/survivorship
800-782-8581

American Cancer Society
www.cancer.org
800-227-2345

National Cancer Institute
www.cancer.gov
800-4-CANCER

National Coalition for Cancer Survivorship
www.canceradvocacy.org
888-650-9127 or
877-622-7937

LIVESTRONG (Lance Armstrong Foundation)
www.livestrong.org
866-673-7205

Cancer Net
www.cancer.net
888-651-3038

Cancer Care
www.cancercare.org
800-813-HOPE (4673)

Association of Cancer Online Resources
www.acor.org

Cancer Information Resources
www.fda.gov/oashi/cancer/links.html

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