

# Caregiver Support Guide

A Comprehensive Guide Written  
by Caregivers for Caregivers



**MRF** MELANOMA  
RESEARCH  
FOUNDATION

## HAS A LOVED ONE BEEN DIAGNOSED WITH MELANOMA?

Get tips from other caregivers. Learn how to take care of yourself while also providing the best possible care to your loved one. Learn how to communicate with the melanoma treatment team, children and family members.

### CAREGIVER'S BILL OF RIGHTS

- I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.
- I have the right to seek help from others even though my loved one may object. I know the limits of my own endurance and strength.
- I have the right to maintain parts of my own life that do not include the person I care for just as if (s)he was healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.
- I have the right to get angry, be depressed and express difficult feelings once in a while.
- I have the right to reject any attempt by my loved one to make me do things out of guilt or anger.
- I have the right to get considerations, affection, forgiveness and acceptance for what I do for my loved one, as I offer these in return.
- I have the right to take pride in what I'm doing. And I have the right to applaud the courage it has taken to meet the needs of my loved one.
- I have the right to protect my individuality. I also have the right to a life that will sustain me when my loved one no longer needs my full-time help.



RESEARCH



EDUCATE



ADVOCATE

The Melanoma Research Foundation is the leading organization in advancing the goals of the melanoma community.

# Adjusting to Being a Caregiver

If you are reading this, you have likely received the news that someone you love has been diagnosed with melanoma. This responsibility may feel overwhelming, but it is important to know that you are not alone and you have support!

You have joined the ranks of the more than 60 million people in our communities who are informal, unpaid caregivers. Providing care for a loved one in need is a centuries-old act of kindness, love and loyalty. However, the demands of caregiving can be overwhelming, especially if you feel you have little control over the situation or that you're in over your head. It is very common to feel confusion and pressure at this time. After all, your new role may bring many stressors: changes in the family dynamic, household disruption, financial pressure and a tremendous amount of work.

The purpose of this guide is to focus on you and your needs. It feels natural to most caregivers to dedicate all of their time and energy to the loved one affected by illness, while putting their own feelings and needs aside. This will not work in the long-term.

Caregiving can take a heavy toll if you do not receive adequate support. By neglecting your own needs, you are putting yourself at risk for Caregiver Fatigue, which can have a serious impact on your physical and emotional health. So, remember: **You cannot take care of someone else if you do not take care of yourself.**





We understand that caregivers need information and support. In this guide, we'll talk about the tools you'll need to maintain some control over what is happening in your life, as well as provide you with tips on self-care.

## We encourage you to:

**Learn as much as you can about melanoma and the treatment options available.** The more you know, the more effective you'll be and the better you'll feel about your efforts.

### **Know your strengths and limitations.**

Be realistic about how much of your time and yourself you can give. Set clear limits. Make sure that those around you — doctors, family members and anyone else involved in your loved one's care — understand what those limits are so they can better support you.



**Accept your feelings.** You are probably riding a roller coaster of emotion right now. From day to day, difficult emotions may surface, such as anger, resentment, fear, guilt, helplessness and grief. These feelings are a normal response to the stress and the changes occurring in your life, so give yourself permission to feel them.

**Confide in others.** Talk to people about your feelings; don't keep your emotions bottled up. Caregiver support groups can be invaluable, but a trusted friend or family member with a willing ear can be helpful, too. You may also consider the benefits of seeing a therapist or counselor.

# WHAT DOES A MELANOMA DIAGNOSIS MEAN?

STAGING CLASSIFICATIONS		
STAGE	WHAT IT MEANS	TREATMENT OPTION
0	The tumor is confined to the epidermis and has not entered the dermis, a deeper layer of the skin. This stage of melanoma is also called melanoma <i>in situ</i> .	The tumor and some surrounding tissue are removed surgically. Usually no further treatment is necessary; however, continued skin examination to evaluate for a new melanoma or other skin cancer will continue.
IA	<b>WHAT IT MEANS</b> The tumor is less than 1 millimeter thick. The outer layer of skin does not look cracked or scraped (ulcerated). It has not spread to any lymph nodes or other organs.	<b>TREATMENT OPTION</b> The tumor and some surrounding tissue are removed surgically. Usually no further treatment is necessary.
IB	<b>WHAT IT MEANS</b> The tumor is either less than 1 millimeter thick and ulcerated, or 1–2 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.	<b>TREATMENT OPTION</b> The tumor and some surrounding tissue are removed surgically. Usually no further treatment is necessary.
IIA	<b>WHAT IT MEANS</b> The tumor is either 1–2 millimeters thick and ulcerated, or 2–4 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.	<b>TREATMENT OPTION</b> The tumor and some surrounding tissue are removed surgically. Usually no further treatment is necessary.
IIB	<b>WHAT IT MEANS</b> The tumor is either 2–4 millimeters thick and ulcerated, or more than 4 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.	<b>TREATMENT OPTION</b> The tumor and some surrounding tissue are removed surgically. Additional treatment(s) may be recommended.
IIC	<b>WHAT IT MEANS</b> The tumor is more than 4 millimeters thick and is ulcerated. These are aggressive tumors that are more likely to spread.	<b>TREATMENT OPTION</b> The tumor and some surrounding tissue are removed surgically. Additional treatment(s) may be recommended.
IIIA IIIB IIIC	<b>WHAT IT MEANS</b> The tumor may be of any thickness. It may or may not be ulcerated. The cancer cells have spread either to a few nearby lymph nodes, or to some tissue just outside the tumor, but not to the lymph nodes.	<b>TREATMENT OPTION</b> The tumor and lymph nodes that have cancer cells are removed surgically. Additional treatment(s) may be recommended.
IV	<b>WHAT IT MEANS</b> The cancer cells have spread to the lymph nodes, other organs in the body, or areas far from the original site of the tumor. This is called metastatic melanoma.	<b>TREATMENT OPTION</b> The tumor and lymph nodes that have cancer cells are removed surgically. Additional treatment(s) may be recommended.

Note: 1 millimeter = 1/25 of an inch

# Doctor's Visits and Medical Care

Choosing the right doctor can be difficult. The best advice you can give when helping your loved one choose a doctor is to encourage them to see a doctor who they are comfortable with and who has a lot of experience treating melanoma.

**Dermatologist** — A dermatologist takes care of diseases, in the broadest sense, and some cosmetic problems of the skin, scalp, hair and nails. Seek a dermatologist who specializes in melanoma.

**Pathologist** — A specialist in pathology who interprets and diagnoses the changes caused by disease in tissues and body fluids.

**Surgical Oncologist** — A doctor who performs biopsies and other surgical procedures in cancer patients.

**Plastic Surgeon** — A surgeon who specializes in reducing scarring or disfigurement that may occur as a result of accidents, birth defects or treatment for diseases.

**Medical Oncologist** — A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy and targeted therapy. A medical oncologist is often the main healthcare provider for someone who has cancer. A medical oncologist also gives supportive care and may coordinate treatment given by other specialists.

**Radiation Oncologist** — A doctor who specializes in the treatment of cancer patients using radiation therapy as the main modality of treatment.

**Oncology Nurse** — A nurse who specializes in treating and caring for people who have cancer.

**Oncology Social Worker/Counselor** — A person with a master's degree in social work who works with cancer patients. The oncology social worker/counselor provides counseling and assistance.

**Patient Navigator** — A healthcare professional whose primary focus is to assist cancer patients, caregivers and families in "bridging the gaps" within the healthcare system and decreasing barriers to care by utilizing resources.

**Psychiatrist** — A physician who specializes in the diagnosis and treatment of mental disorders.

**Psychologist** — Someone who studies the mind and behavior of humans and other animals.

## **PREPARING FOR APPOINTMENTS**

- Plan your travel arrangements ahead of time.
- Take someone else with you and the patient when going to the doctor. It is helpful to have another set of ears and someone to help take notes. It is a lot to take in.
- Don't be afraid to challenge the doctors. Advocating for what your loved one needs is one of the most helpful things you can do.
- Keep a notebook where everything can be recorded — doctors, medications (new and old), x-rays, scans, pathology reports, etc. Pain levels, moods, naps and eating habits also can be noted.
- Keep an appointment calendar.

**“I have learned as a caregiver to arm myself with information because the doctors don’t always tell you everything you need to know to make an informed decision.”**

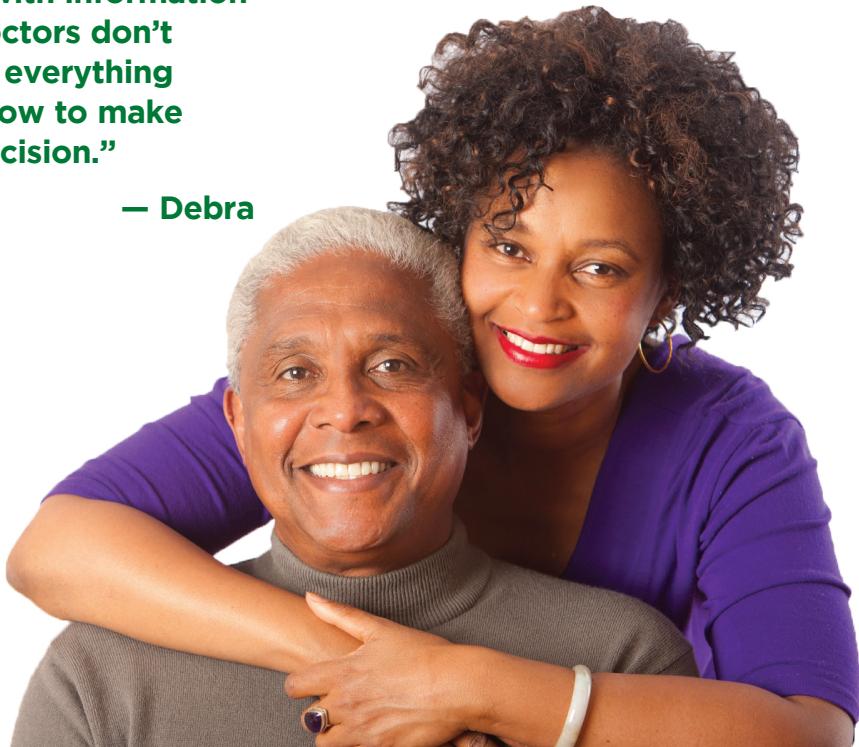
**— Debra**

- Write down a list of questions you want to ask... and then write down the answers.
- Don't be afraid to ask the same question twice if you don't understand the answer.
- Find out about side effects of treatment so you know what to expect and can make the best decisions possible.

## **SECOND OPINIONS**

Some people worry that doctors will be offended if they ask for a second opinion. However, most doctors welcome a second opinion and many health insurance companies will even pay for them.

**A second opinion may provide you and your loved one with more information and perhaps a greater sense of control.**



## **EDUCATE YOURSELF**

Understanding the diagnosis, treatment and prognosis can make you feel more confident. Educating yourself will help you and your loved one become more comfortable making the difficult decisions throughout this journey. Research shows that patients have better outcomes when they are well informed and supported. Be sure to use only trusted resources when doing research for your loved one's condition.

### **The Melanoma Patients Information Page**

(MPIP) is the oldest and largest community of people affected by melanoma and can be found on the MRF website at [www.mpip.org](http://www.mpip.org). This forum is designed to provide support and information to caregivers, patients, family and friends. Once you have been touched by melanoma — either as a patient or as a caregiver — you become part of a community. It is not a community anyone is anxious to join, but you will find no better source for support and information during your journey with this disease.

## **Questions to Ask Your Melanoma Treatment Team:**

- Do I need a biopsy?
- Will I have a scar?
- When will I know the results?
- Have you checked my body for other possible lesions?
- How will we determine if the cancer has spread?
- Has the cancer spread to my lymph nodes?
- Do you know what stage of melanoma I have?
- What are my treatment options?
- Which treatment plan do you recommend?
- Will I be able to continue my normal daily life?
- Should I continue to see a dermatologist?
- Will I develop a new melanoma?
- Should I get a second opinion?
- Do I need a sentinel lymph node biopsy?
- Do I need chemotherapy or immunotherapy?
- What are the risks and side effects?
- What is this process like?
- What type of follow-up care will I need?
- Do I need regular scans or a brain scan?
- Should I begin looking at clinical trials?
- Do you know what my Breslow Measurement is?

# Taking Care of You

**Make time for yourself to relax.** Give your mind a break from the demands of caregiving, even if it's just for a few minutes. Read a book, take a nap, see a movie, take a drive, keep up with a hobby, watch television, listen to music or talk on the phone with a friend.

**Join a support group or talk to a counselor.** Find the format that works for you. Is it over the phone, on the Internet or meeting face to face? Is it easier to open up to a health professional, a spiritual leader or a group of other caregivers?

**Write in a journal.** Research shows that writing can help relieve negative thoughts and feelings.

**Look for the positive.** Once a day, think about something that you found rewarding. This could be in your role as a caregiver, something that made you laugh, or even something as simple as a beautiful sunset.

**Keep up with your own medical needs.**

Keep current on all checkups, screenings and medications.

**Eat healthy meals.** Eating well will help you keep up your strength.

**Get enough rest.** Get enough sleep at night, take short naps if needed, and talk to your doctor if lack of sleep becomes a problem.

**Exercise.** Any kind of exercise can help keep your body healthy. Aim for 30 minutes a day on most days of the week.

## STAGES OF GRIEF

Developed by Elizabeth Kübler-Ross and introduced in her 1969 book "On Death and Dying," the five stages of grief were designed to give us a framework for dealing with grief and/or the loss of a loved one. Not everyone will go through each of these stages and the stages may not be experienced in order. You may jump back and forth between stages before moving on to the next, or you may never experience one or more of the stages. There is no right or wrong way to deal with grief. It may be most helpful to look at these stages simply as a guide in the grieving process.

**DENIAL:** The first reaction to learning of the terminal illness or loss of a loved one may be denial. Denial and shock help us cope and survive. As you accept the reality of your loss, you are beginning the healing process.

**ANGER:** Anger can be directed at anyone and anything. The anger may not seem rational but is caused by the intense emotion of your feelings. Do not hide your anger. Instead, feel your anger and help yourself begin the healing process.

**BARGAINING:** Sometimes bargaining is accompanied by guilt. You may keep asking yourself "what if." You may even bargain with the pain you're feeling. These are natural reactions and feelings as you make the attempt to regain control of your feelings and your life.

**DEPRESSION:** Depression is an appropriate reaction — the loss of a loved one is depressing. This does not mean you have a mental illness. Sadness, regret and worry may also accompany depression.

**ACCEPTANCE:** Not everyone reaches the stage of acceptance. Acceptance is not being "all right" with what has happened. It is more about recognizing that your loved one is permanently gone and that this new reality is a permanent reality.



## CONSIDER YOUR STRENGTHS AND LIMITATIONS

Many caregivers say that, looking back, they took too much on themselves. They often say they wish they had asked for help sooner. Take an honest look at what you can do, and what you can't do. Ask yourself, what things am I good at? What do I need to take care of myself? What can I ask others to help with? Be willing to let go of the things that aren't essential for you to do. Focus your energy on the things you can control. This could mean:

- Helping schedule doctor visits
- Maintaining a record of all medical appointments (scans, blood tests, etc.)
- Learning more about melanoma and treatment options
- Maintaining a list of your household's weekly tasks and activities

## ASK FOR HELP

Accepting help from others isn't always easy. But, as your loved one goes through treatment, and more challenges are added to your plate, it is important to remember that accepting help

for yourself also will help your loved one. People want to help, but many don't know what you need or how to offer it. Ask for what you need and for those things that would be most helpful to you.

### Lotsa Helping Hands

([www.lotsahelpinghands.com](http://www.lotsahelpinghands.com))

is a free service that provides families with an organized means of answering the question "What can I do to help?" Your private online community can help you:

- Organize meal deliveries, rides to appointments and visits from friends and family members
- Arrange for help with household chores such as cooking, cleaning, shopping, yard work, dog walking and childcare
- Easily communicate and share updates using announcements, message boards and photos

### CaringBridge ([www.caringbridge.org](http://www.caringbridge.org))

is another free service that allows families to stay connected by providing free personalized patient websites.

**"Let people come and give you a break. Also, take meals that are made for you. You will never know when you won't be in the mood to cook. Tell people the foods your family likes... it's okay to be specific!"**

— Sarah

# What Is Caregiver Fatigue?

We cannot stress enough the importance of taking care of yourself while you take care of your loved one. People often underestimate how physically and emotionally exhausting caregiving can be, especially if the responsibility falls to one person. Caregiver Fatigue (or "burnout") can be dangerous to you and your loved one. Feeling extreme stress over extended periods of time will affect your health, motivation, attitude and mood, as well as your ability to cope with your daily responsibilities.



## CAREGIVER FATIGUE IS A RESULT OF:

- Not asking for help
- Having unreasonably high expectations of yourself
- Having difficulty saying "no"
- Consistently sacrificing yourself and your needs for the benefit of others
- Feeling like you are the only person capable of providing care

## COMMON PHYSICAL SYMPTOMS:

- Insomnia or restless sleep
- Headaches and backaches
- Feeling physically "drained"
- Lingering colds
- Changes in your weight
- High blood pressure

## COMMON EMOTIONAL SYMPTOMS:

- Becoming easily frustrated and irritable
- Having a short temper
- Feeling overwhelmed or profound loneliness
- Decreased self-esteem
- Depression
- Anxiety
- Feeling like you have nothing else to give

Caregiver Fatigue can be avoided. You should not feel guilty for nurturing yourself. Taking time to recharge your mind, body and spirit can help you be a better caregiver.

## COPING WITH YOUR FEELINGS

Recognize that your feelings exist and that feeling them is normal. It may help to know that other caregivers have felt the same way you do. You may relate to all of the feelings listed below, or just a few. Give yourself time to understand and work through your range of emotions.

**Grief** — You may experience grief for losing your loved one's health or the life you had before the melanoma diagnosis. Give yourself permission to grieve those losses and take time to work through and accept the changes in your life.

**Loneliness** — You may feel alone in your role as a caregiver, even if you are surrounded by people. You may feel like no one understands you and that you are in this alone. Support groups may help you connect with others in a similar situation.

**Anger** — It is common to feel angry, whether it is aimed at yourself, your family or your loved one. However, anger can be healthy if you handle it the right way. It may help motivate you, but if the feelings persist, speak with a health professional.

**Anxiety/Depression** — Are you having a difficult time relaxing or are you having panic attacks? Are you worried about insurance, medical bills or how this is affecting the family? If you experience persistent sadness or depression that lasts more than a couple of weeks, speak with your healthcare provider.

**Guilt** — Feeling guilty is a common reaction for caregivers. You may feel guilty that you are healthy, that you aren't helping enough or even for not acting cheerful enough.

**Hopelessness** — Throughout your loved one's treatment, you may feel different levels of hope. You may hope for a cure, for peace, for comfort or even for acceptance. But if you develop feelings of hopelessness and they don't pass, speak with your healthcare provider.

**"I met with a psychiatrist. I have issues! But, he understood them. He was able to describe what I have been feeling so darned well that I feel relieved just knowing someone understands."**

**— Anonymous**

# Communication Is Key

## BRING UP THE HARD TOPICS

Some things are really difficult to talk about and initiating those conversations can be emotionally draining. You and your loved one are facing decisions that include a broad array of choices. They may be practical, emotional, spiritual, legal, existential or medical in nature. For example, you may have a strong opinion that differs from the patient's concerning a treatment approach. Or, perhaps your loved one is struggling with feelings of loss of independence and doesn't want to burden you. It is important to keep in mind that we all express our emotions differently. With some practice, you can find ways to communicate with your loved one that work for both of you.

### Keep in mind:

- Your loved one may not want to hear what you have to say.
- Speak from your heart.
- Be clear in your intentions.
- Things will not likely be resolved after one conversation.
- Sometimes just listening is the most valuable thing you can offer. Let your loved one process their thoughts and fears in their own time and in their own way.
- It's your loved one's life, and it's their cancer. As a caregiver, you must accept that you cannot fix everything, no matter how much you want to, and some decisions must be made by the patient.

## BE OPEN ABOUT STRESS

Sometimes just acknowledging the stress of the situation can be helpful.

## LEARN ABOUT ADVANCE DIRECTIVES

Advance Directives are legal papers that let your loved one decide important issues relating to their treatment and care. These can include specifics such as how much treatment to receive, and who should make decisions if he or she cannot. Having an advance directive helps ensure that patients get the treatment that they want. It will also make it a lot easier for caregivers to make treatment decisions if they understand their loved one's wishes. Advance Directives include:

**Living will:** This document outlines what kind of medical care patients want if they are unable to speak for themselves.

**Durable medical power of attorney:** This document names a person to make medical decisions for a patient if he or she can no longer make decisions. This person, chosen by the patient, is called a "healthcare proxy."

# Things to Remember...

## WHEN YOUR PARTNER IS THE PATIENT

Some relationships get stronger during a cancer treatment, while others are weakened. During this time, it is almost certain that you will feel more stress in the relationship than usual. After a cancer diagnosis, couples often feel stressed about:

- Knowing how to best support each other
- Making decisions
- Changing roles
- Figuring out how to communicate — especially about difficult topics
- Intimacy issues
- Caring for children
- Dealing with new emotions
- Financial burdens

### Become a team when it comes to decision making.

You and your partner may need to be a team now more than ever. Discuss which decisions should be made as a couple and which decisions each of you should make alone. How can you help each other?

**Find ways to say “thanks.”** During a crisis, it may be difficult to notice the small things your partner is doing to get through each day. When you can, try to look for these things and thank your partner for doing them. Showing a little gratitude can make both of you feel better.

**Make dates.** In the process of just getting through the daily grind, it’s easy to forget how important it is to make time for each other. Set time aside on a regular basis, even if it just means sharing a meal together or watching a movie.

**Find ways to be intimate.** Sex might not feel like a priority right now, but it’s important to consider the emotional and physical value of remaining intimate with your partner. Redefine what intimacy means to you. Talk about it with your partner. Make space for each other, as a couple.



# Things to Remember...

## WHEN YOUR PARENT IS THE PATIENT

Although you will always be “the child” in the eyes of your parents, sometimes it becomes necessary for your roles to change. Finances, insurance, nursing homes and home health care are just a few of the difficult topics that will need to be discussed. Another area of concern is the ability, or lack thereof, of the parent to maintain independence. Whether it is regarding driving, shopping, living alone or decision making, the parent will likely feel angry and as if their rights are being taken away. Don’t take this anger personally. Try not to argue with your parent — or humor him, either. Simply acknowledge his feelings: “I’m sorry you are feeling that way...”. The parent may also be overcome with guilt as they watch their children become their caregivers. Facing a life-limiting illness can be a lonely process. Reassure your parent that he/she is not alone, and that you will be a solid source of support throughout this process.

## WHEN THE PATIENT IS YOUR CHILD

Everyone agrees that parents are not supposed to outlive their children. Nothing will erase the pain and anguish that a parent will experience while caring for their child with cancer. Anger and

guilt may overwhelm you at times so it will be important to share your feelings with your partner, your loved ones and maybe even a mental health professional. The dual role of being a parent and a caregiver can be physically and emotionally draining, so take all the help you can get during this time. Sharing stories, looking through old photos and simply spending time together may help ease some of the pain you are experiencing.

Encourage honest communication about the disease process, how your child is handling their diagnosis, and how it has affected his/her life. Oftentimes, the patient will try to protect their parent/caregiver by stifling their thoughts and feelings. They may make statements, ask questions, or display behavior that indirectly reflects how they are feeling. Look for these cues, and try to create a safe and loving space for honest dialogue. Allow them to grieve for their losses.

## WHEN THE PATIENT HAS A YOUNG CHILD

For some families, talking about serious issues is very difficult. However, avoiding the subject with your children can make a bad situation worse. Experts say that telling the truth about cancer is better than letting them imagine the worst. Don’t be afraid to let your children know how you are



feeling and don't assume they know what you are thinking. It is also important to find out what they are thinking and feeling.

You may want to first talk to your children about what melanoma (or cancer) is. This could help them understand that they did not cause the melanoma, that they are not responsible for fixing the problem and that you cannot "catch" melanoma from another person. Let them know that it is okay to be upset, angry, scared or sad and that it is completely normal to have these feelings. Assure them that no matter what, they will always be taken care of and be okay.

Younger children may prefer to draw a picture or play with a doll to express themselves. Teens may ask difficult questions or questions for which you don't have answers. It is important to be honest with them and keep the lines of communication open at all times. Be prepared for questions and concerns about death from your children. Even if the prognosis is good, children may still worry. Tell them the truth, don't guarantee a certain outcome, correct misinformation and reassure them that you will tell them if their loved one starts to get better or worse. Conclude by reiterating the fact that they will be taken care of no matter what happens.

Don't underestimate your child's capacity to understand. Children are capable of understanding more than we often give them credit for. Children can cope with what they know. Follow their lead as you create an open dialogue about melanoma and how it is affecting their life. They will ask for what they need. Try not to over-explain things out of your own anxiety.

Create normalcy for your child, as much as you can. When a family member is facing a melanoma diagnosis, it's easy for the focus to shift entirely onto that person. Be mindful of this, and ensure that your child's emotional needs are being met.

## WHEN COMMUNICATING WITH OTHER FAMILY MEMBERS AND FRIENDS

You, or someone else, may be the main person updating friends and family about how the patient is doing. Ask the patient what information he wants to share, and with whom. Emails, websites and blogs are simple and quick ways to connect with people if you don't want to make phone calls.

Sometimes close family members and friends may not agree on what should be done. Everyone brings their own set of beliefs and values to the table and may disagree on what they think is best. Holding a family meeting is one way to keep everyone involved. You can even ask a social worker or counselor to be there to mediate. It is important to remember that everyone is trying to do what they think is best for your loved one.

# Hospice

For most people, the term “hospice” equates to “death,” but that is not always the case. Hospice care is for people with a life-limiting illness who can no longer benefit from traditional medical care and are interested in care that keeps them as free from pain as possible. The focus is on comfort and quality of life rather than treatment. Each person must decide whether (and when) hospice is the right choice for them.

Hospice is a Medicare benefit. To qualify, a doctor must certify that his/her patient has six months or fewer to live. Of course, no one will be kicked off of hospice at the end of that six-month period as long as they still qualify, and the patient can decide at any time to discontinue hospice services and seek aggressive/curative treatments. Hospice care depends on doctors, nurses and social workers to help people with fatal illnesses live the best life possible *right now*. The focus is on freedom from pain, maintaining mental awareness and enjoying time spent with family.

While those who have not experienced hospice care may equate it with giving up on their loved one, many report that hospice provided critical

emotional, physical and logistical support when it was needed the most. Several studies have shown that hospice patients suffered less, were able to interact with others and were more physically capable for longer periods of time. Studies have also shown no significant difference in survival time with hospice and non-hospice patients, and in some situations the hospice patients actually lived longer than the non-hospice patients. In addition, it was found that family members of hospice patients were less likely to experience major depression in the following months after their loved one’s death.

Studies have also indicated that those who had previous discussions about their end-of-life preferences were more likely to die in peace, feeling in control of their situation, while experiencing less suffering. The Hospice Foundation of America can provide you with more information on how hospice works, and can assist you in locating hospices in your area.

Visit [www.hospicefoundation.org](http://www.hospicefoundation.org) for more information.

“One of the most difficult phases was knowing and helping my parents accept the need to move to hospice. It is a very emotional transition to make...I wish there were more educational resources and more doctors who would advocate hospice to families. I am so grateful beyond words for the care and comfort my dad received through hospice care. It made a huge difference to the whole family.”

— Kelly

“Please listen to your loved one and let them make their own decisions in what’s happening... it is so important for them. Know how important their last rights are and respect them no matter what.”

— B.D.

“When the time comes, do not be reluctant to have a reputable hospice program help with care. I was not aware how valuable hospice can be when treatment is no longer an option. They not only care for the patient, but the entire family as well, with understanding, resources and compassion.”

— Tina

“Hospice...some are better than others. They offer different services — both to the patient and to the family...What works best for the patient? It’s all about their wishes.”

— Leni



The MRF would like to thank all of the caregivers on MPIP, Facebook and Twitter who contributed their thoughts and helped make this caregiver guide a reality.

**Visit [www.melanoma.org](http://www.melanoma.org) for more information about prevention, diagnosis and treatment options, and to find the largest community of melanoma patients online.**



## MELANOMA RESEARCH FOUNDATION

1411 K Street NW, Suite 800

Washington, DC 20005

T 202.347.9675 or 1.800.MRF.1290

F 202.347.9678

E [info@melanoma.org](mailto:info@melanoma.org)

[www.melanoma.org](http://www.melanoma.org)

[www.facebook.com/Melanoma.Research.Foundation](https://www.facebook.com/Melanoma.Research.Foundation)

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