

# Caregiving for a Loved One With Cancer

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Including Special Considerations for Patients Receiving Checkpoint-Inhibitor Therapy



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# INTRODUCTION

You are most likely reading this because you have taken on (or are about to take on) the role of a cancer caregiver. While it may not be a role you expected to take, it is a critical role in which you can make a big difference for your loved one with cancer. This guide is designed to assist you with the various aspects of caregiving, with a special focus on caring for a patient receiving checkpoint inhibitor therapy.

Some people who have provided support for a person with cancer see themselves as co-survivors. As one patient and advocate put it, “a person does not get cancer, a family does.” In fact, the caregiver often experiences many of the same stresses as the person with cancer but may not receive the same level of support. Therefore, in this handbook, we’ve also included services to support you and strategies to help you take care of yourself. Taking care of yourself is important, not only because you deserve it, but because if you do, you will be better able to take care of your loved one.

We hope you find this guide helpful in fulfilling your important role.

# WHAT DOES IT MEAN TO BE A CAREGIVER?

Approximately 2.8 million people report caring (unpaid) for a family member or friend whose primary diagnosis is cancer.[National Alliance for Caregiving 2016] The specific tasks may vary from caregiver to caregiver, but the general “job description” is the same: help with patient advocacy, daily activities, clinical care at home, emotional support, and so much more.

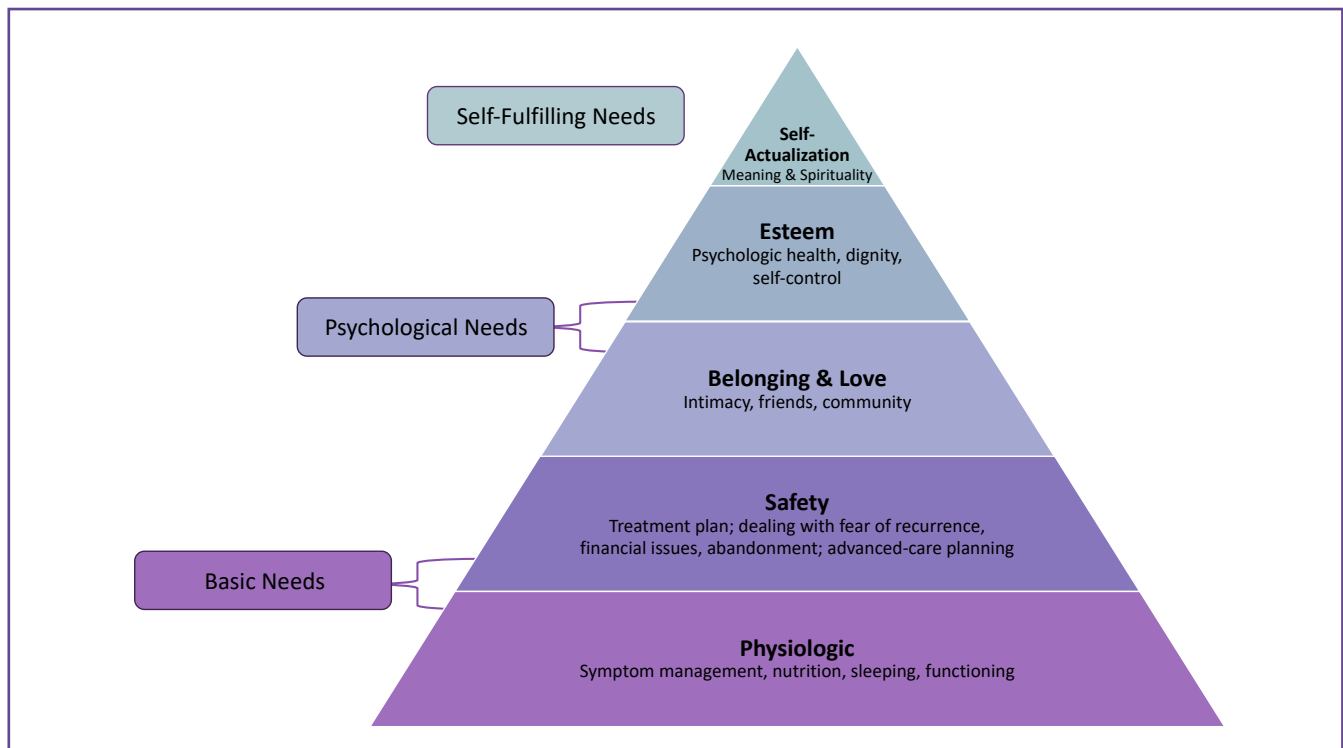
Please see Graphic 1, representing the Maslow’s Hierarchy of Needs Pyramid, which categorizes the needs of a patient with cancer. This handbook will discuss caregiving tasks based upon Maslow’s Pyramid. First we will discuss the caregiving tasks that are related to the Basic Needs of the patient, then the Psychological Needs, then the Self-Fulfilling Needs.

**Approximately 2.8 million people report caring (unpaid) for a family member or friend whose primary diagnosis is cancer.**

– [National Alliance for Caregiving 2016]

The Hierarchy of Needs Pyramid can also be applied to you, the caregiver. You have Basic Needs, Psychological Needs, and Self-Fulfilling Needs, just as the patient does, and this handbook will discuss a tweaked version of the pyramid as a guide to help you also care for yourself.

Graphic 1. Maslow’s hierarchy of needs pyramid as applied to the person with cancer. Adapted from Acute Leukemia Advocates Network 2020.

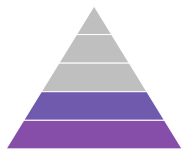


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### Caregiver Quotable:

**“We need educational programs specific to the needs of the cancer caregivers. They need to develop the knowledge and skills needed to care for the patients with cancer at home.”**

– *Massey Nematollahi, RN, MScN, OCN, CON®,  
Immuno-oncology Clinical Nurse Consultant.*




## ADDRESSING BASIC NEEDS

The first set of needs in the hierarchy are Basic Needs—those that are physiologic-and safety-related (the bottom two levels of the pyramid). And even though it rests on the second level of the pyramid, we’ll start our Basic Needs discussion with the caregiving tasks that accompany the need to make a treatment plan, because that is the first step the patient and caregiver need to take after diagnosis. Then we’ll move to caregiving tasks that support the treatment journey, everyday activities, finances, and future considerations.

### BASIC NEEDS: MAKING A TREATMENT PLAN

After a diagnosis of cancer, the patient must come to terms with that diagnosis and seek treatment. The caregiver often plays an essential role in helping the person with cancer seek out and select a treatment option. The caregiver can play a crucial role in making the treatment plan in the following ways.

#### Being the Eyes and the Ears of the Patient

 For the person with cancer, initial meetings with multiple specialists can be overwhelming. S/he may not absorb the information that is being presented. A cancer diagnosis (or a cancer recurrence) can be a very emotional experience, and patients can shut down emotionally. The caregiver can offer support by listening to the healthcare providers, taking notes, and asking questions.



## Being a Researcher

Every patient has a different style of decision making. Some people want a lot of information; others want to seek expert advice but aren't interested in delving into the data. For patients who seek a lot of information for decision making, caregivers can assist in the process of gathering information and doing research to support shared decision making. For patients who do not want to delve into data, the caregiver can take on that task and help frame the relevant questions to the rest of the healthcare team.

But such information gathering can be an overwhelming task. Some of the strongest voices on the internet about cancer therapies are often the most unreliable. You want information that is well-vetted by experts in their fields, which is based on well-designed studies, and that is up to date. To find such information, it's important to seek credible sources. Some of these reliable sources include national cancer organizations that develop materials for people with cancer and their caregivers. These include The American Cancer Society, Cancer.Net, Cancer Support Community, the National Comprehensive Cancer Centers, and the US Centers for Disease Control and Prevention. There are also reliable disease-specific organizations such as AIM at Melanoma Foundation, Go2Foundation for Lung Cancer, and the Bladder Cancer Advocacy Network. In the area of immunotherapy, patient materials can be found on [AIMwithImmunotherapy.org](http://AIMwithImmunotherapy.org) and on [SITCancer.org](http://SITCancer.org).

### Caregiver Quotable:

**"When it comes to melanoma information online, some of it is related to old statistics, before patients were able to take immunotherapy. That's where you need to clearly communicate with your oncologist. Bring your doctors what you're finding, and they'll discern it for you. I found emailing our doctor with questions was a great way to verify what I was reading."**

*– Celeste M, caregiver for a patient with melanoma.*



## Supporting Decision Making

A lot of different decisions need to be made, and rather quickly, when a patient is diagnosed with cancer. Should the patient be treated in the community or at an academic center? Should s/he seek a second opinion? What should be the treatment approach? How should the patient weigh all of the factors of each treatment, such as how the drugs are given, the convenience of the regimens, financial considerations, and family planning (if applicable)?

Sometimes a second opinion is warranted, particularly for a challenging case. The caregiver can be helpful in securing that second opinion at the beginning of the treatment journey or later, as needed.

### Caregiver Quotable:

**"When I was diagnosed with a nail matrix melanoma, my dermatologist set up a referral for me in a city 70 miles away to get specialized surgery. My husband called around and found out that a well-respected dermatologic surgeon who had the capacity to do the surgery had just moved to our town. So my husband really helped out—I was just too overwhelmed to think about getting a second opinion."**

*– Lisa R, melanoma patient*



Examples of decision-support tools that can be used to help guide patients in their decision-making process are shown here:

**AIM at Melanoma Stage III and Stage IV Decision Support Tools**

### **Streamlining Tip:**

Start a binder for caregiving to keep receipts, insurance information, and other key papers. Drop a notebook in there as well, so you can take notes at appointments. You may also want to consider an emergency room plan in case you need to go urgently. See [Caregiver\\_Worksheet\\_1\\_ER\\_2019.pdf \(lls.org\)](#)



### **Being an Advocate**

The caregiver's role in advocating for the patient begins at diagnosis and is especially critical while making the treatment plan. To advocate for your loved one, you may:

- Assist with scheduling appointments
- Accompany your loved one to appointments, take notes, and ask questions
- Be a conduit for medical information for your family. If you'll have this role, your loved one should sign a release for you to receive medical information. See <https://www.ncbi.nlm.nih.gov/books/NBK396411/> for a discussion of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) policies. It's important, however, to have a conversation with the person with cancer early in the process to make sure the communication pathway is what s/he wants
- Keep track of appointments and provide or arrange transportation
- Coordinate care among various healthcare providers
- Assist with or oversee financial issues, health insurance claims, etc.
- Address any disability or legal issues

**It's also helpful to ask questions. Examples of questions to ask after diagnosis and during immunotherapy can be found here:**

**About Stage II Melanoma**

**About Stage III Melanoma**

**About Stage IV Melanoma**

**About Immunotherapy for Use in Different Disease States**

**Patient Action Plans AIM with Immunotherapy Immuno-Oncology Essential**

# BASIC NEEDS: SUPPORTING TREATMENT

Once your loved one has decided upon a treatment plan, your role will shift to supporting your loved one through that treatment plan. For many, it's a long journey. All of the tasks mentioned in the above discussion about making a treatment plan—being an advocate, supporting decision making, etc.—will also be part of the treatment journey. And so much more.

A large part of your caregiving will likely relate to helping your loved one through symptoms, side effects, and immune-related adverse events (irAEs).

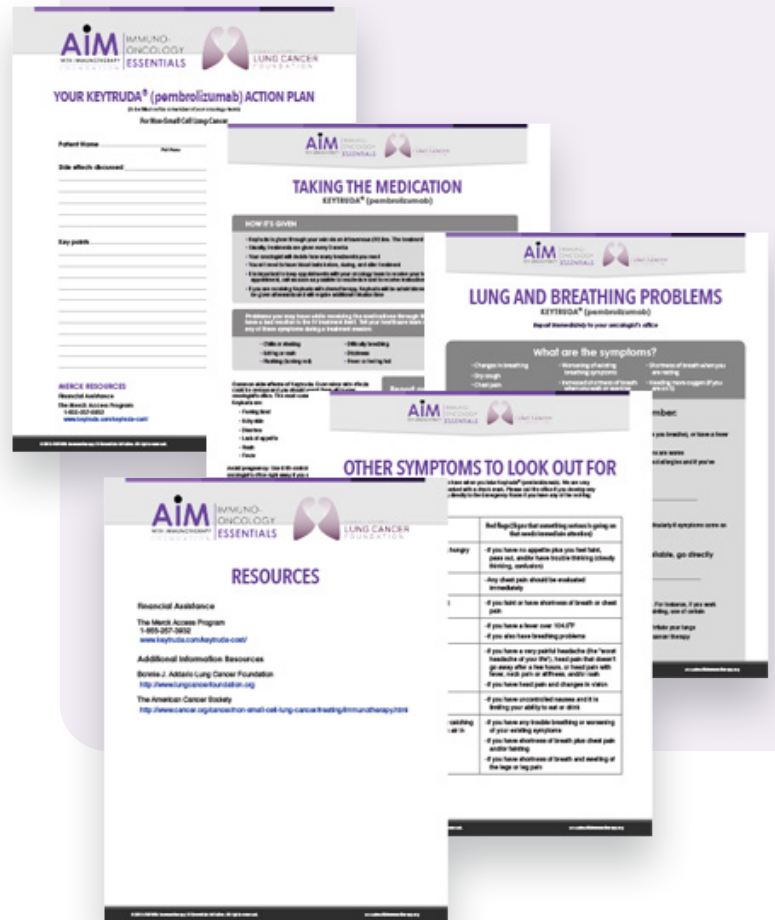
Supporting your loved one through treatment is easier when you have some information about what to expect during treatment. But not all patients and caregivers are aware of the intricacies of cancer treatment, particularly of immunotherapy since it is a relatively new form of treatment. A 2016 survey showed that most participants knew very little about how immunotherapy differed from chemotherapy. This study revealed that detailed educational content about the side effects of immunotherapy was especially desired. For example, which side effects should be reported immediately to the healthcare team? Which side effects would cause the patient to be removed from treatment? Which drugs, vaccines, or treatments that can and cannot be used by cancer patients on immunotherapy? [Saxton 2017]

Because issues such as these are paramount for both patient and caregiver, we encourage you to peruse the AIM with Immunotherapy Patient Action Plans for your loved one's particular disease state. As shown in Graphic 2, these Action Plans provide relevant, much-needed information. To review these action plans, see <https://aimwithimmunotherapy.org/patient-action-plans/>

These Patient Action Plans contain:

- Side effect management sheets, including information about how to triage and when to contact the healthcare team vs going directly to the emergency room
- Specific information about vaccines and other aspects of health maintenance
- Disease-specific resources

Graphic 2. Immunotherapy action plan, representative pages



[Take me to the Patient Action Plans](https://aimwithimmunotherapy.org/patient-action-plans/)



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## Overview of Immunotherapy (How it Works)

irAEs are caused by the effects of the drugs on the immune system. They can appear at any time, even after therapy is discontinued. Here are some key principles for managing irAEs that are helpful for you to know:

- It's important to report any change in how your loved one is feeling. Sometimes the changes can be subtle. As a caregiver, you can help recognize these subtle changes
- These side effects are easier to manage when they are caught early
- Your loved one should not fear reporting symptoms. It's better to address them early
- Your loved one should keep a wallet card on the checkpoint inhibitor s/he is taking. This information should be presented anytime s/he seeks medical care outside of the oncology office
- You should have the phone number of the healthcare provider's office handy at all times. Know what to do after hours and understand under what circumstances you should take your loved one directly to the emergency department. However, it's always a good idea to call the healthcare provider's office to let them know you are taking your loved one directly to the hospital. The office may be able to call ahead.

You may be asked to help your healthcare providers grade the severity of irAEs. Although you are not expected to become a triage nurse, it's helpful for you to understand how the clinicians think through the grading of these side effects. This way, you can understand what to expect and how to recognize the symptoms earlier when they are easier to treat. Often the oncology team will look for the severity of the symptoms based on specific criteria, but much of the grading is based on the impact of the symptoms on the patient's function. Later in this document, we will explain how you can gauge how your loved one is functioning by looking at his/her ability to perform more complex and simpler tasks. By keeping an eye out for functional changes, you can actually help identify these irAEs earlier, when they are more treatable.

In general, the way the irAEs are graded is as follows:

- Grade 1: Mild or only slight symptoms, often diagnosed because of changes in laboratory values
- Grade 2: Moderate symptoms or laboratory changes. In this case, your loved one can still take care of him or herself but has difficulty with higher level tasks like cleaning the house because, for example, s/he is too short of breath. In many cases, the checkpoint inhibitor therapy will need to be held and corticosteroids may be used to calm the immune system
- Grade 3 or Grade 4: Severe or life-threatening symptoms. In this case, your loved one is very sick and is unlikely to even perform self-care. For example, your loved one is unable to walk to the bathroom because of joint pain. In these situations, the checkpoint inhibitor therapy is likely to be permanently discontinued. Your loved one is most likely going to require corticosteroids or other therapies to calm the immune system. S/he may need to be hospitalized if the irAE is significant.

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## Caregiving for Patients Receiving Corticosteroids

Corticosteroids given by mouth are tricky. As a caregiver you will need to watch for specific symptoms. Your healthcare team will need to stay in close contact with either the patient or you during the period that the corticosteroids are given. Corticosteroids can cause stomach problems, and the doctor may want to prescribe something to protect the stomach. They can cause mood changes, increased appetite, interrupted sleep, or fluid retention. They also can put the patient at risk for oral yeast infections. Because the corticosteroids can suppress the immune system, your loved one may need to receive

drugs to prevent infections. If the patient is on corticosteroids for a long time, they may affect the liver or cause bone loss. The patient will need to be careful using drugs or alcohol. It may take time for the oncology team to find the dose to control the irAE, so don't be surprised if it takes multiple appointments to modify the dose. They will also need to taper the steroid dose carefully once they have the irAE under control. See a video produced by Dr Eric Whitman about the intricacies of use of corticosteroids for irAEs. <https://aimwithimmunotherapy.org/patient-videos/>

### Caregiver Quotable:

**“When my mom was receiving high-dose corticosteroids, she called me at 3 am to tell me she had just made a cake and to come on over for a piece and some coffee. She was totally amped up and couldn't sleep. We made a quick call to the physician the next morning to report this and to see if she needed a dosage adjustment.”**

– Rose R, caregiver for a lung-cancer patient.

## BASIC NEEDS: SUPPORTING EVERYDAY ACTIVITIES

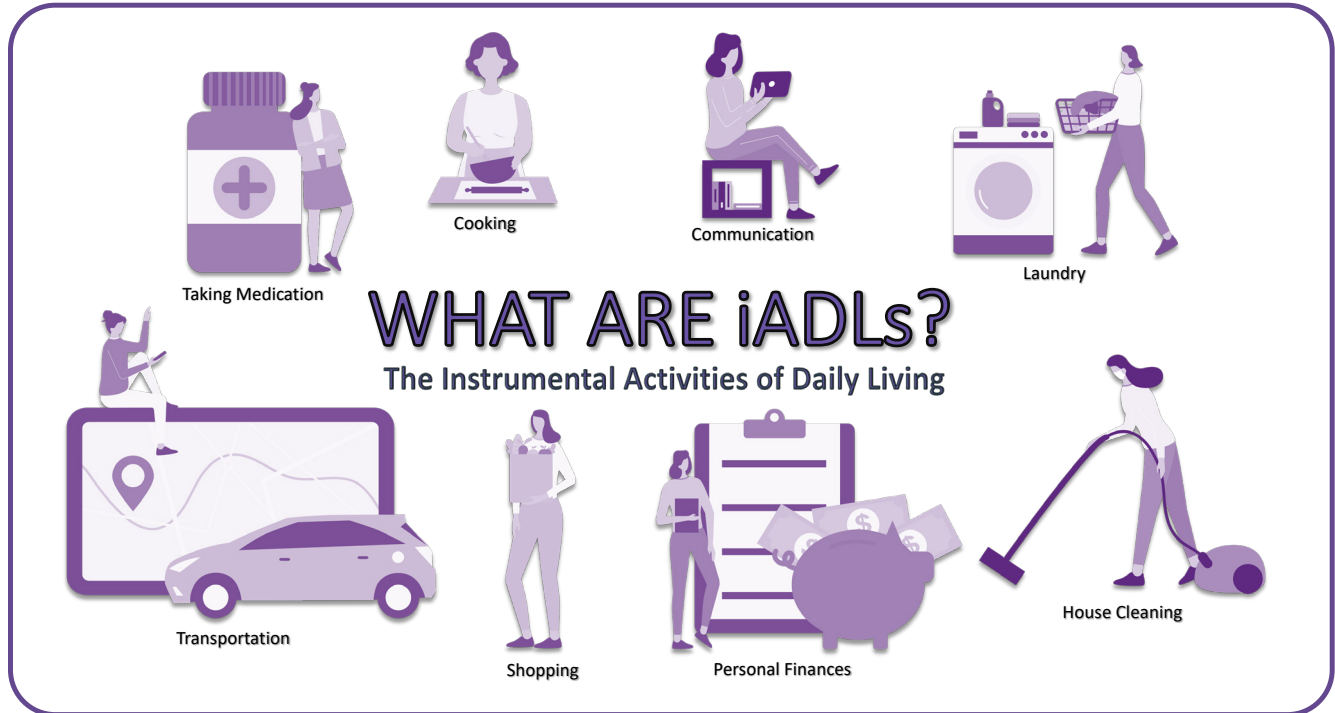
Beyond addressing your loved one's needs in dealing with the cancer treatments, you will most likely have to provide a lot of support for daily activities if s/he is sick or experiencing side effects from therapy. Your loved one may have been able to perform many of these activities independently before, and as mentioned, it's important for you to note the differences in what s/he was able to do previously vs now. So it's useful to assess how much help your loved one needs to accomplish daily activities. This way you can communicate effectively with the healthcare team about how your loved one is doing overall and help catch irAEs at an early stage, when they are most manageable.

We'll look at everyday activities in two categories: instrumental activities of daily living (higher level activities; those your loved one may need help with first) and activities of daily living (basic level activities; those your loved one may need help with if s/he gets sicker). Below are lists (and visuals) of activities you might have to help with.

## Instrumental Activities of Daily Living (Higher Level Functions)

Instrumental activities of daily living are complex tasks that allow an individual to live independently. These tasks are the first types of activities your loved one is likely to need help with. The instrumental activities of daily living (iADLs) are shown in Graphic 3.

Graphic 3. Instrumental activities of daily living (iADLs).



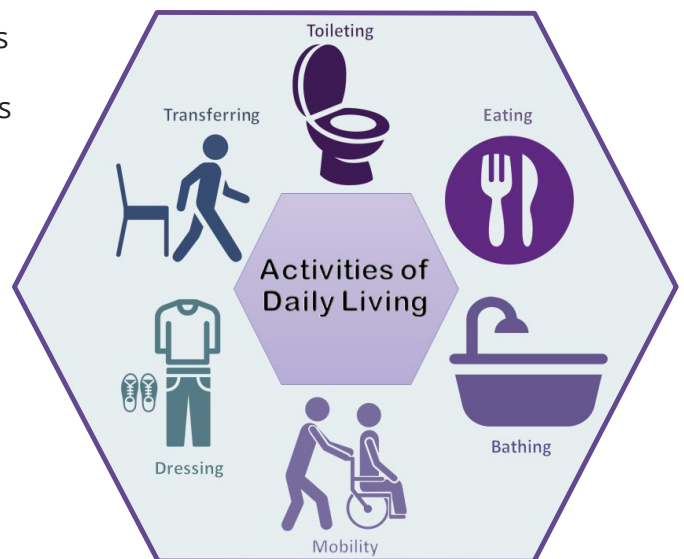
## Activities of Daily Living (Basic Level Activities)

Activities of daily living are those skills one uses to manage one's basic physical needs. But sometimes cancer patients may be too ill to take care of themselves and their basic physical needs. Below is a list of the self-care activities that your loved one may have difficulty performing if s/he is ill. These activities of daily living are shown in Graphic 4.

- Dressing
- Eating
- Mobility
- Toileting
- Bathing
- Transferring

[Click here for more details](#)

Graphic 4. Activities of daily living.



## BASIC NEEDS: FINANCES

Make no mistake about it—cancer will most likely have a negative impact on the family's finances. In fact, the term *financial toxicity* is often used to describe cancer's effect on a family's finances. See the **FINANCIAL RESOURCES** section at the end of this document for helpful financial information, particularly for treatment involving checkpoint inhibitors.

Immunotherapy medications can be expensive. Patients need to be aware of the total costs of the medications, which can differ depending on insurance situations. As a caregiver you can help navigate these issues.

- For patients with commercial insurances: if the patient has commercial insurance, s/he generally can receive co-pay assistance from the drug manufacturer. Financial assistance information for immunotherapy from the manufacturers is shown at the end of this handbook under **FINANCIAL RESOURCES**
- For patients with coverage from a federal/state program (such as Medicare, Medicaid, or Tricare): If the patient has insurance through a federal/state insurance program, s/he can't receive financial assistance from the drug manufacturer, but s/he may be eligible for co-pay assistance from an independent charitable foundation. Again, see the **FINANCIAL RESOURCES** section
- If the patient is not insured, s/he may be eligible for free medications through drug manufacturers, charitable organizations, or designated hospitals, depending on income. See the specific information from the manufacturers listed and other resources listed under **FINANCIAL RESOURCES**. If for any reason, you have difficulty accessing testing or therapies or need assistance with travel or housing, please see the Other Helpful Organizations page on the AIM at Melanoma webpage: <https://www.aimatmelanoma.org/support-resources/helpful-organizations/>

### Where can I find a caregiver?

You may need to delegate some of the caregiving tasks. You might have a team of friends and family members to help you with specific tasks, such as shopping, driving, help with keeping track of finances, etc. But at some point, you might want to consider paid help. For detailed discussion on finding the right help, financing it, and addressing the employment and legal aspects, see resources from the Family Caregiver Alliance (<https://www.caregiver.org/resource/hiring-home-help/>).

The loss of your loved one's contributions to the family's daily functioning can also be a challenge. Your loved one may be too busy with appointments or may not have the energy to contribute as s/he used to. Further, if you, the caregiver, also cannot perform your usual family duties because you are caring for your loved one, there may be a lot of household tasks and responsibilities that need to be assigned to extended family, friends, or paid help. For example, who will care for other family members? Who will assist with housework and prepare meals? These are real considerations for the functioning of the family that you, the caregiver, can help address.

### CAREGIVING TIP:

**It's ok to get help. In a 2016 study, 41% of caregivers for patients with cancer reported receiving paid help from aides, housekeepers, and other helpers. [National Alliance for Caregiving 2016]**

## It's Not Just About the Medications

The patient may need to miss work for medical appointments or treatment, and, as the caregiver, you may want or need to accompany the patient, which may require you to miss work. Ask yourselves the following questions: Will missing work be necessary in order to receive infusions? What happens when there are side effects? Does your or your loved one's work require travel? Can you or your loved one switch to a flexible schedule? Concerns about ability to work and keeping one's job—both the patient and the caregiver—can lead to financial stress and affect the entire family.

### CAREGIVING TIP:

Both the patient and the caregiver may have legal protections against job loss under the Family and Medical Leave Act. The Patient Advocate Foundation at <https://www.patientadvocate.org> or (800.532.5274) can assist in this process.

## BASIC NEEDS: REASSURANCE OF NOT BEING ABANDONED AND ADVANCED CARE PLANNING

For cancer patients, the future can feel uncertain. This uncertainty can include fears of being abandoned and concerns about advanced care. As the caregiver, you will most likely need to broach these subjects after your loved one has started on a treatment path.

For some people with cancer, fear of abandonment is a main concern. If patients perceive that their personal support system is inadequate, they are likely to experience more emotional problems and more physical symptoms. Some patients worry that their physicians and caregivers will abandon them if they stop active treatment. It's best if the oncology team has what is termed compassionate presence, which means the team is able to compassionately support your loved one through his or her choices during the treatment journey and even if the patient chooses to stop treatment. As a caregiver, you can get a sense of the oncology team and make sure that there is someone in that team that can provide this support, ideally the medical oncologist. You may also be able to help this dynamic by being another voice of compassionate support. It is also important that you reassure your loved one that you are in it together and that you encourage other members of your loved one's social support to stay involved.

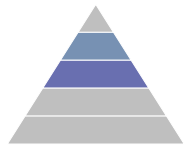
While the oncology team is working to achieve the best outcome from therapy, it's impossible to predict if, and when, things may not go as hoped. Your loved one may want to discuss different scenarios to make sure his/her wishes are met as much as possible during the cancer journey. Advanced planning can include everything from choosing the healthcare proxy, to making an advanced directive, to addressing a will, to assessing under what circumstances your loved one would want to withdraw care and move on to hospice. It's important to encourage your loved one to do this planning when s/he is feeling well. This subject can be touchy, particularly if the caregiver is in the will. However, if this type of planning is delayed, your loved one may not be well enough to make the decisions thoughtfully. If your loved one doesn't have a chance to do any planning at all, there can be unnecessary additional stress and confusion for everyone involved. A resource from the American Society of Clinical Oncology (ASCO) on advanced planning is included in the **GENERAL RESOURCES** section at the end of this document.



### Caregiver Quotable:

**“When my wife was diagnosed with cancer, people warned me our marriage might not survive this journey. I was committed to seeing her through this, and I told her that. I think it was important to reassure her.”**

– Gavin S, caregiver for a patient with cancer.



## ADDRESSING PSYCHOLOGICAL NEEDS

The next set of needs in the hierarchy are the Psychological Needs—those relating to both a patient’s external relationships and internal state of being. We’ll discuss belonging and love needs first and then move to esteem needs.

### PSYCHOLOGICAL NEEDS: BELONGING & LOVE

Patients with cancer may be concerned about their role in their family, their intimate relationship, and where they fit in. They may also be worried about how their family is going to function while they are unwell or if they die. As a caregiver you will likely help your loved one deal with these concerns, and you may have similar concerns of your own.

#### Family Dynamics

Some strategies have been found to be helpful for families dealing with cancer:

- Getting the family together in a family conference mediated by a health professional
- Sharing care support roles among family members. Sharing support roles help ensure the person with cancer receives the necessary emotional and logistical support without overlooking a particular family member, which, in turn, can reassure the person with cancer. Consider using an app for this organization, such as [Lotsahelpinghands.com](https://lotsahelpinghands.com)
- Sharing information among family members openly and in a timely manner. There are communication tools to help with this process, such as CaringBridge Personal Health Journals for Any Condition <https://www.caringbridge.org/>

### Caregiver Quotable:

**“My husband did not want to talk about his cancer. And I did. I wanted to get all the information I could on it.”**

– Celeste M, caregiver for a patient with melanoma.

Family Dynamics (continue next page)



## Family Dynamics (continuation)

Each family has its own family and relationship dynamics as well as communication strategies and roles. It's important to understand that these dynamics, strategies, and roles may shift with the cancer diagnosis. As you develop things such as new communication strategies, keep in mind that the patient, yourself, and other family members may have personal preferences or cultural expectations about sharing information and talking about the disease. Or the person with cancer may not want to cause more stress for the remainder of the family by talking about the disease. However, no matter what the communication strategy is, your loved one should never be left out of communications with the healthcare team. If you, as a caregiver, have something to share with the oncology team, it's best to bring it up with the patient there. In fact, the patient should guide the level of your involvement. If your loved one does not feel like s/he has a say, it can lead to a lot of unnecessary frustration and a break down in the relationship with the oncology team.

## Sense of Belonging

It's important for patients with cancer to feel like they are still part of the family. Your loved one should be reassured that s/he is still a contributor and should be involved with normal family activities as much as possible. Roles may need to shift at different stages of the cancer journey; however, it is important to make sure the person with cancer still feels valued. Some members of the family will feel the need to be protective of the cancer patient and may have guilt about asking anything from the patient. But being able to contribute to the family, even in a reduced capacity, can be helpful for a cancer patient's sense of self-esteem. Doing loving things for their family members can give cancer patients a sense of control and make them feel more like themselves. It's important to let them fulfill those roles.

## What Can I Do With a Difficult Patient?

Cancer can be a roller coaster ride, and emotions run high. As a caregiver, you may reach a point where you want to quit if your loved one is inadvertently driving you crazy.

Some general principles that help when dealing with a difficult person include[Macaraeg 2020]

- Accept that it's not you
- Don't take it personally
- Redirect the person
- Acknowledge the person's concern
- Get help from the healthcare provider
- Get support for yourself in your caregiving role
- Find outlets for the person to connect
- Stand up for yourself (you love this person, but you will not tolerate bad behavior)

## Caregiver Quotable:

**"When I was visiting my mom who was ill with lung cancer, she looked at my jacket and noticed I had a loose button. She asked to fix it. I brought her the sewing kit, and she sat in the chair and fixed it. It was good for her to feel useful, and it was nice to see my mom... being my mom."**

*– Lisa R, long-distance caregiver.*

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## Intimacy Needs

Cancer can affect intimate relationships for a number of reasons. Cancer surgery can leave scars that can be disfiguring. If radiation therapy is involved, it can also leave unattractive sores. The cancer treatments themselves can have sexual side effects. In the case of immunotherapy, the fatigue and potential hormonal impact can pose a challenge to intimacy. Other irAEs such as skin toxicities or neurologic effects can also make intimacy challenging. In addition, the emotional aspects of the cancer journey can affect both partners in a relationship. If you are a caregiver who is also the intimate partner of the patient, it is worthwhile addressing these concerns directly and with open communication. For more information about addressing the effect of cancer on intimate relationships, see <https://www.cancer.net/navigating-cancer-care/dating-sex-and-reproduction>

Another important intimacy consideration is the safety aspects of pregnancy and family planning during cancer treatment. For patients receiving checkpoint inhibitors, there are specific requirements for avoiding pregnancy during treatment and for a period of time thereafter. These timeframes may differ depending on the specific drug(s) taken, but generally speaking, it's best to wait six months before considering pregnancy after the last dose of checkpoint inhibitor therapy. Little is known about the impact of checkpoint inhibitors on fertility. The impact is likely to be complex because of the potential of long-term effects on the immune system from these drugs in both men and women. Side effects could occur (including hormonal changes such as pituitary or thyroid problems) that may require additional hormonal supplementation, thus affecting fertility. If you are the caregiver who is also the intimate partner of the patient, these considerations are important for both of you as you navigate cancer and family planning.

It's important for the person with cancer to have a frank conversation with the oncology team about family planning issues prior to starting treatment. The patient might also want to consider seeing a fertility specialist who is familiar with these issues in cancer patients to discuss egg or sperm freezing. As the caregiver, you can help the patient broach these topics as part of the planning process.

## Social Needs

Sometimes the social needs of the patient extend beyond the partner, family, and friend support systems. For patients with cancer, there can be a large benefit in talking with other patients with the same cancer type. Patients with cancer should be informed about options for support groups or peer-to-peer connections. While not everyone feels comfortable with these support models, patients should know about the option. It's always a good idea to suggest to your loved one that s/he at least considers trying a session or two to see if the s/he finds benefit. These support groups can fulfill several roles for people with cancer:

- Educating people and families about the disease
- Sharing the illness experience
- Providing strength and hope
- Raising public awareness about the disease
- Fundraising for research into the disease

The support groups may also provide a means for people with cancer to give back when they are further along in their journey. This ability to give back can be helpful in the healing process and in finding meaning with the cancer experience, which we will describe later in this handbook.

Cancer support groups are available for all of the cancer organizations and are listed in the **RESOURCES** section of the Patient Action Plans.

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## PSYCHOLOGICAL NEEDS: ESTEEM

As mentioned, the diagnosis of cancer and the cancer journey can have a profound impact on the emotional status of the patient. And, emotional status can affect how your loved one fares overall. In fact, when emotional issues are not addressed, they can reduce the patient's quality of life, impair social relationships, increase the rehabilitation time, and affect adherence to treatment. These problems are common—about 50% of patients with cancer experience psychiatric problems, including severe emotional distress.[Grassi 2020] Unfortunately, many psychiatric issues in cancer patients go unrecognized or untreated. While there is increased emphasis on psycho-oncology as a mandatory component of comprehensive cancer care, as the caregiver you can assist the healthcare team in identifying signs of psychological distress and making sure the issues are addressed. Be as proactive as possible in communicating concerning issues to the oncology team. They will have options to help directly, or they may bring in experts to help.

**About 50% of patients with cancer experience psychiatric problems. These can include severe emotional distress. Many of these conditions go unrecognized or untreated.**

– [Grassi 2020]

Some signs of more serious distress in the patient are outlined by the American Cancer Society and include:

- Feeling overwhelmed or panicky
- Being overcome with dread
- Feeling sad to the point where the person with cancer thinks s/he no longer can go on with treatment
- Acting unusually irritable or angry
- Being unable to cope with pain, tiredness, and nausea
- Fuzzy thinking, poor concentration, memory issues
- Difficulty making decisions, even about small things
- Feeling a sense of hopelessness
- Thinking about cancer and/or death constantly
- Experiencing trouble sleeping or getting less than 4 or 5 hours of sleep a night
- Having trouble eating for a few weeks
- Family conflicts and issues that seem impossible to resolve
- Questioning faith and beliefs that once gave you comfort
- Feeling worthless, useless, and like a burden to others

If your loved one appears to be experiencing any of the above, make sure you share this information with his or her oncology team and seek professional help.

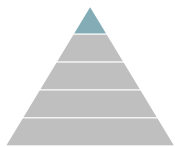
**PSYCHOLOGICAL NEEDS: ESTEEM (continue next page)**

## PSYCHOLOGICAL NEEDS: ESTEEM (continuation)

Beyond seeking professional help, patients with cancer can benefit from lifestyle changes that can reduce stress. In fact, usually a combination of approaches is most beneficial. But in general, the approaches are similar to those strategies we can all use for stress relief:

- Practice a breathing method
- Try medication or yoga
- Make sure to get enough sleep
- Start an exercise routine
- Explore hobbies
- Eat well during treatment
- Seek light and humorous experiences
- Be social

By remaining actively engaged in life and exerting control over the things they can control, your loved one can hopefully achieve greater peace of mind and can enhance self-esteem. As the caregiver, you can help encourage lifestyle changes that reduce stress and enhance self-esteem.



# ADDRESSING SELF-FULFILLING NEEDS

The top level of patient needs in the hierarchy are Self-Fulfilling Needs. These needs are related to self-actualization, and caregivers can play an important role in helping their loved ones in this area, too.

## SELF-FULFILLING NEEDS: SELF-ACTUALIZATION

Like all of us, patients with cancer need to feel self-actualized, which means becoming the best version of one's self. For people with cancer, this might mean establishing new goals and working to achieve them. Or it might mean seeking to make meaning of their cancer experience or coming to terms with it.

How can someone come to terms with cancer, and how can a caregiver help? In a recent study of people who survived mouth or gastrointestinal cancer, about half reported that they wanted to find meaning in their experience of illness.[Moye 2020] Serious illnesses can cause an existential crisis as well as spiritual distress. How people deal with this distress varies based on faith and cultural traditions. For some people, spirituality equates to religion and will be governed by a specific set of beliefs and practices, usually in the context of an organized religious group. For other people, spirituality is more related to an individual's sense of peace, purpose, connection to other people, and beliefs about life's meaning. So people can be spiritual, religious, or both, and these beliefs or faith can help a cancer patient make meaning of their journey. As the caregiver, your support of your loved one's attempts to make meaning will be helpful.

**SELF-FULFILLING NEEDS: SELF-ACTUALIZATION** (Continue next page)

## SELF-FULFILLING NEEDS: SELF-ACTUALIZATION (Continuation)

Spirituality can be a very important aspect of cancer care. When spiritual needs are not met, the person with cancer can experience poor outcomes and a reduced quality of life. [Puchalski 2019] As mentioned previously, the oncology team should serve as a compassionate presence during every stage of the patient's journey. This presence can lead to healing by finding meaning, hope, or a sense of coherence even in the midst of the illness. In addition, the healthcare team that is checked into spiritual needs might be able to provide some basic support and may also bring in resources from trained professionals as needed (for example, referring to chaplains as spiritual care specialists). Caregivers can also help the clinical team address these issues. On the personal side, caregivers are often in a good position to help connect their loved ones to their established spiritual support systems or to new resources as needed.

Spirituality can help provide perspective, hope, and peace during the process. For many patients surviving cancer, there is a potential upside to the cancer journey. Some cancer survivors can experience enhanced meaning through relationships, experiences, resilience, and goal-orientation. There are stories about people learning to appreciate the small things in life after a cancer diagnosis. However, for other people, the cancer experience can lead to a loss of meaning in their lives.[van der Spek 2013] Therefore, it's important for patients, when they are ready, to explore the existential aspects of the cancer experience. For those patients who will, unfortunately, not have a good outcome, the spiritual aspects may be particularly important as they grapple with mortality, the experience of suffering, and leaving a legacy for their loved ones. As your loved one explores these heavy subjects, your support will be critical.

Finally, making meaning from the cancer experience can lead some cancer survivors to become advocates, peer-supporters, and resources for other patients going through the journey. In fact, some of the events that survivors choose to participate in, such as for-cause physical activities, serve a dual purpose of helping others while giving the survivors an opportunity for more regular physical activity and improved quality of life.[Umstattd Meyer 2018] There are many avenues for patients living with cancer to help others and "pay it forward," and as a caregiver, you may be able to help research the appropriate avenues for your loved one.

### Caregiver Quotable:

**When my wife was some time out from her treatment, she began helping out other patients on a cancer journey through a young survivor's network. At times, this got emotional for her, particularly if someone was not doing well. I questioned whether it was worth it in those instances. But for the most part, I think she benefitted from helping other people on a similar journey."**

*– Gavin S, caregiver for a patient with cancer.*

## TAKING CARE OF YOURSELF

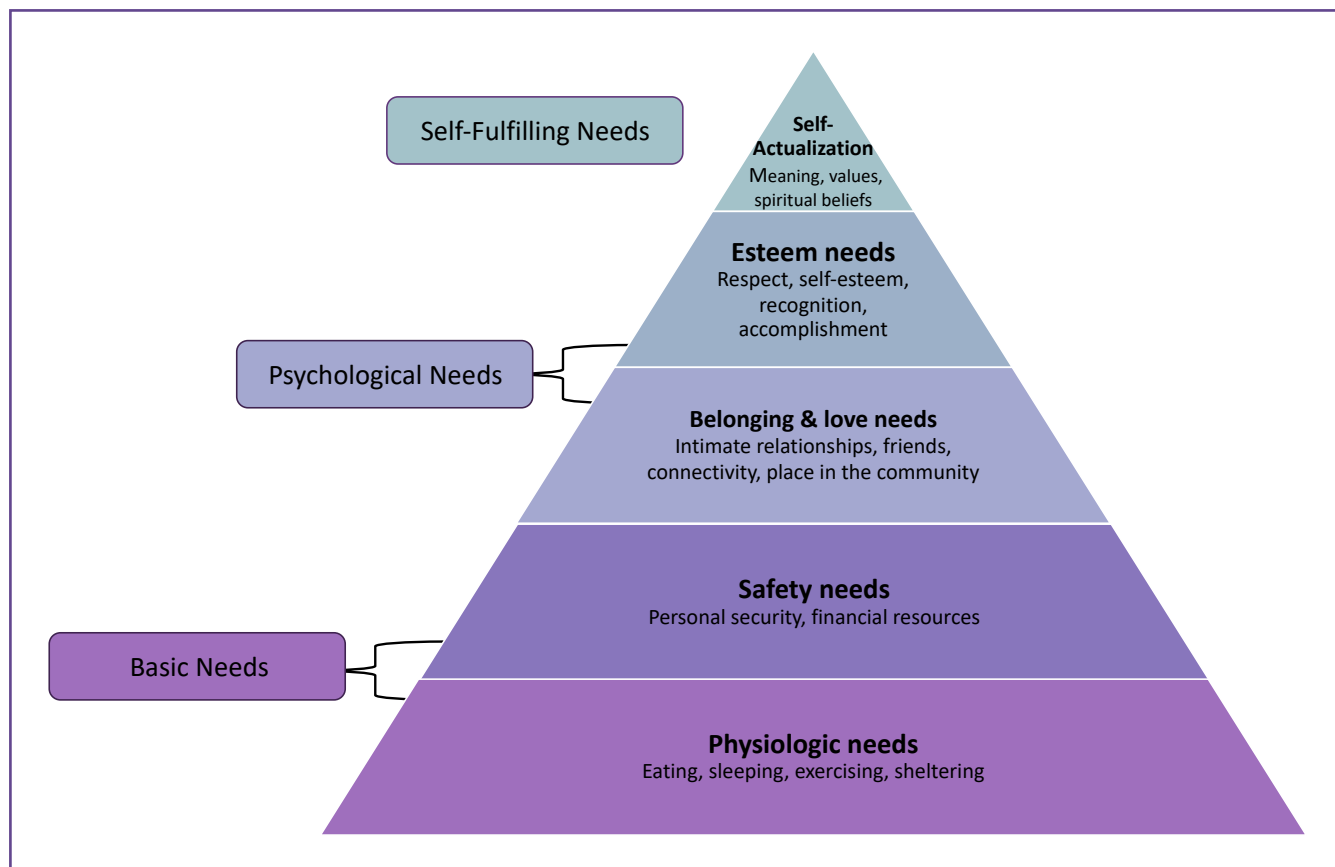
Until now, we've discussed your important role as the caregiver in helping your loved one with cancer meet his/her needs. And yet, what about you? We will now discuss your needs as the cancer caregiver and strategies for meeting them using a similar pyramid of needs, as shown in Graphic 5.

### Caregiver Quotable:

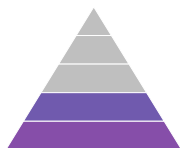
**“One of the most important—but often forgotten—tasks for caregivers is caring for themselves. A caregiver’s physical, emotional, and mental health is vital to the well-being of the person who has cancer. To be a good caregiver, you must be good to yourself.”**

– [Cancer.Net 2019]

Graphic 5. Maslow's Hierarchy of Needs as Applied to the Caregiver.







# ADDRESSING BASIC NEEDS

Your most basic physiologic needs include eating, sleeping, and exercising. Are you being intentional about taking care of your health? Having your world turned upside down overnight and being forced in a journey you can't avoid can be terribly hard on your body and your mind. Beyond that, you may be hesitant to focus on your own needs because of guilt or feeling overwhelmed. But you need to take care of yourself, or you won't be able to take care of your loved one. You are in a battle, and you must be conditioned. It is really important, even if you don't feel like it, to practice good health hygiene. This includes:

- Eating healthy foods
- Staying hydrated
- Getting enough sleep
- Being on guard for unhealthy habits such as smoking, drinking too much alcohol, or abusing prescription medications. It is easy to slip into unhealthy habits under the stress of caregiving
- Being proactive about addressing your own healthcare needs. See your primary care physician and get on a plan to address your own health needs. Some oncology practices will also offer checkups for the caregiver as well—it's a good idea to ask early what the oncology practice can do to support you.
- Moving on to safety needs, as a caregiver, you may feel like things are out of control in terms of running the household, maintaining financial oversight, and dealing with your loved one's illness. Make sure you share information about what you are going through with people who are able to help you. People may be able to offer direct support or suggest resources
- Talk with your employer about what is happening (if applicable). S/he may be able to offer flexible working arrangements
- Consider paid help, if needed
- Mobilize your support network to get help with the everyday tasks of running the household or taking care of other tasks that can be delegated
- Learn what you can about the Family and Medical Leave Act, which is described in the **GENERAL RESOURCES**.

## Caregiver quotable:

**"It's so easy to get caught up in what they have going on. You have to remember to take care of yourself, too."**

*– Celeste M, caregiver for a patient with melanoma.*



# ADDRESSING PSYCHOLOGICAL NEEDS

In terms of loving and belonging needs, all humans are social creatures. We need to interact with others, family, friends, and groups. It is important not to turn away from the contact and support from those who care, love, and help us. So make time. Some specific recommendations include:

- Enlist the support structure you share with your loved one in providing care. You can work together to take care of your loved one, but you can also help support each other
- Maintain the rituals and traditions you have with your loved one, as much as possible. By engaging in these activities, you can keep the relationship strong and perhaps maintain some sense of normalcy
- Plan social activities that build you up and that keep you connected with your own friends. If you put these items on the calendar at regular intervals, you can be assured that they happen and also have something to look forward to
- Consider caregiver support groups. These groups fulfill many of the same functions we described for patient support groups. For caregivers, they can provide a safe place to share emotional experience without guilt. And hearing from those who have been there can be helpful. See the **GENERAL RESOURCES** for caregiver support groups.

ADDRESSING PSYCHOLOGICAL NEEDS (Continue next page)

## Caregiver Quotable:

**“Speaking to other people with melanoma who have had similar experiences was incredibly helpful to deal with the anxiety. In the beginning, there’s so much anxiety around the unknown. It helped ground me in. I’m still in communication with those people and will continue to talk to them as a sounding board.”**

– Celeste M, caregiver for a patient with melanoma.

## Caregiver Quotable:

**“When my wife was in the middle of her treatment, she arranged for me to go to a Blues Traveler concert with my friends. Before she was sick, I would never go to something like that without her. I felt incredibly guilty about going, but she insisted, and I had a good time with my friends. It was a very loving thing for her to do. So we both benefited.”**

– Gavin S, caregiver for a patient with cancer.

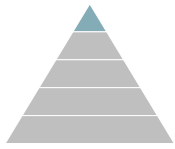
When we move on to the emotional needs of cancer caregiver, it's helpful to remember that caregivers, like others who face cancer, are often woefully unprepared for that battle. Caregivers may face depression, anxiety, frustration over lack of information about the disease and treatment, and guilt for not attending to family during the treatments for the disease. Fear can be very real—fear of loss of control, inability to function, and of death. It is easy for caregivers to burn out and become overwhelmed with stress. Here are some important actions to consider in order to preserve your emotional health:

- Make time for activities that de-stress you—whether that's exercising, gardening, or other activities that normally bring you joy. These activities are helpful, particularly when they force a break from the caregiving routine or involve a change of venue. You may need to force yourself to do them at first, but consider them investments in your health so that you can come back to caregiving with energy and compassion
- Look for signs that you are distressed (as previously described for the patient). You may want to have a close friend looking out for these signs or enlist the help of your healthcare provider to monitor for any issues
- Consider seeking professional help if things are not going well. Finding a trusted mental health professional can be key during this journey
- Find the humor in things—many studies have shown that laughter is therapeutic for people dealing with chronic challenges. If you and your loved one can find ways to laugh together, it can be de-stressing for both of you.

**Caregiver Quotable:**

**“When my wife was diagnosed with cancer, I was still coaching golf at my school. Those times outside exercising were a real outlet for me, particularly as a place to expel anger.”**

*– Gavin S, caregiver for a patient with cancer.*



# ADDRESSING SELF-FULFILLING NEEDS

Finally, we can move up to the self-actualization needs. You may feel completely lost as an individual in this fight against cancer. Once again, it's important to take an inventory of your needs and how they are being met.

Are you still pursuing any of your own goals? Have you given up all your creative outlets? It's important to still be you and have your own identity. Find time for your creative pursuits and your commitment to being the best version of yourself.

Are you attending to your own spiritual needs? We've talked about taking care of your body and mind; you also need to think about your soul. Whatever that means for you, it's important to pursue it.

Finally, when we discussed the self-actualization needs of the person with cancer, we talked about making meaning of their experiences. The caregiver needs to make meaning of the experience as well. Has your role changed you? Caregivers are human, and they may struggle with their tasks and roles. As humans, they will fail, succeed, hope, and despair. Sometimes, being a caregiver is like a roller coaster ride in the dark, and it can change a person. How so? The caregiver is also a survivor. According to the National Coalition for Cancer Survivorship: "As a caregiver it is easy to be overwhelmed by caring for a cancer survivor. An important point to remember is that you, a caregiver, are also a survivor because you are surviving the challenges, responsibilities, and life-changing effects of the disease and treatment." (National Coalition for Cancer Survivorship)

## Caregiver Quotable:

**"When my wife was sick, I was still writing plays at my school. I wrote a play that semester and it was very light and funny. That's not usually my style, but writing that play helped me. It was just what I needed."**

*– Gavin S, caregiver for a patient with cancer.*

## CONCLUSION

As you begin—or continue—your journey as a cancer caregiver, ensure that you keep both your loved one's and your own needs in mind. It may feel like you are on an uncharted path, and it is paramount that you prioritize basic, psychological, and self-fulfilling needs in conjunction with the treatment goals. You may find it difficult to even consider addressing your personal needs but remember that a healthier and happier you can act as a better caregiver for your loved one. You, as a caregiver, are a trusted source of support and reassurance for your loved one, but you are not alone in your experience. Be sure to make use of the range of resources available to support you in your role. We hope you find this handout and related resources helpful to you on this journey.

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# GENERAL RESOURCES

## **Imerman Angels**

Provides one-on-one peer support among cancer fighters, survivors, and caregivers.  
<http://www.imermanangels.org/>

## **4th Angel**

Matches patients and caregivers with trained volunteer mentors.  
<https://4thangel.ccf.org>

## **Cancer Hope Network**

Provides one-on-one support to people undergoing treatment for cancer and to their families through training individuals who have recovered from cancer and matching them with cancer patients currently undergoing a similar experience.  
<http://www.cancerhopenetwork.org/>

## **Friend for Life Cancer Support Network**

To help persons recently diagnosed with cancer and their care partners navigate the path through diagnosis, treatment, and recovery by pairing them with a trained survivor of a similar experience.  
<https://www.friend4life.org>

## **PATIENT AND CAREGIVER PEER SUPPORT/ MENTORING PROGRAMS**

<https://www.oncolink.org/support/caregivers>

ASCO® Answers. Advanced Cancer Planning: A Decision-Making Guide for Patients and Families Facing Serious Illness from the American Society of Clinical Oncology. Available at <https://www.cancer.net/navigating-cancer-care/advanced-cancer>

Canadian Cancer Society Family Life.

<https://cancer.ca/en/living-with-cancer/coping-with-changes/family-life>

## **DISEASE-SPECIFIC CAREGIVER MATERIALS**

AIM at Melanoma Foundation

<https://www.aimatmelanoma.org/support-resources/caregiving/>

Bladder Cancer Advocacy Network

<https://bcan.org/tips-for-caregivers-printed-version/>

GO2 Foundation for Lung Cancer

<https://go2foundation.org/blog/caregiver-award-winner-on-learning-to-appreciate-each-day/>

Leukemia & Lymphoma Society

<https://www.lls.org/support-resources/caregiver-support>



# FINANCIAL RESOURCES

## MANUFACTURER SPECIFIC RESOURCES

### AMGEN

AMGEN ASSIST 360™

<https://www.amgenassist360.com/>

TEL: 1-888-4ASSIST (1-888-427-7478)

FAX: 1-888-407-9787

### ASTRAZENECA

ACCESS 360™ REIMBURSEMENT COUNSELOR

<http://www.myaccess360.com/patient/imfinzi-durvalumab.html>

1-844-275-2360

### BRISTOL MYERS SQUIBB

BMS Access Support; BMS Oncology Co-Pay Assistance Program

<https://www.bmsaccesssupport.com>

[bmscustomerconnect.com/patient](https://www.bmscustomerconnect.com/patient)

1-800-861-0048

### CLINIGEN

Proleukin Support Hotline

<https://proleukin.com/>

1-877-PROLEUKIN (776-5385)

### GENENTECH ACCESS SOLUTIONS

Provides coverage and reimbursement support, patient assistance, and information resources.

<https://www.genentech-access.com/patient.html>

Phone: (866) 422-2377 or (866) 4 ACCESS

### GENENTECH PATIENT FOUNDATION

For eligible patients who are uninsured or who have been rendered uninsured because they have been denied coverage by their insurance company.

Phone: (888) 941-3331

### MERCK

The Merck Access Program

1-855-257-3932

### Regeneron Sanofi-Genzyme Resources

Libtayo Surround Program

1-877-542-8296

<https://www.libtayo.com/nsclc/libtayo-surround>

(lung-cancer specific; support for other disease states can be found by selecting another cancer type)

## GENERAL FINANCIAL RESOURCES

### GROWING FAMILY BENEFITS

This organization provides guidance on getting cancer treatment without health insurance.

<https://www.growingfamilybenefits.com/cancer-without-insurance/>

### PAN FOUNDATION

This organization helps federally and commercially insured people living with life-threatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications. <http://www.panfoundation.org/>