

# **The Guiding Light Between Shorelines**

A Resource, Education, and Support Guide  
for Advanced Cancers  
Patients and Their Family Caregivers



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## Chapter 1

### INTRODUCTION

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*-“Anxiously you ask, ‘Is there a way to safety? Can someone guide me? The answer is a resounding yes. I counsel you: Look to the lighthouse. There is no fog so dense, no night so dark, no gale so strong, no mariner so lost but what its beacon light can aid. It beckons through the storms of life. It calls, ‘This way to safety; this way to home.’ – Thomas Monson*

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If you are reading this guide it is likely that a member of your oncology team has told you that you have been diagnosed with stage 4 cancer, advanced cancer, or, metastatic cancer. Though it may be called by different names, it means that you are dealing with a life threatening medical situation. While this is certainly a fearful discussion to have, we hope that you may find comfort in knowing the information in this book will help you navigate the unfamiliar and often times stormy waters of this disease and its management. Our goal is to provide a guiding light of wisdom during a time of feeling like you are lost at sea, which can answer questions you may already have, or you or your family likely may have in the future. It is our wish in writing this guide that you will learn how to maintain an active role in your healthcare decision making, that your wishes be known and honored, and that you feel empowered through use of the education and resources provided so that you remain in charge of your life’s decisions moving forward.

This guide provides trusted information alongside anecdotes from real people who have also traveled this same journey. Additionally, you will find information and resources that are interactive, so that you may begin developing a sense of self-awareness in order to better recognize your wishes regarding treatment planning, difficult conversations, and other milestones of importance that lie ahead. We encourage you to share what you discover in this guide with loved ones and members of your support team. Ultimately, however, it is up to you as to how you choose to use this guide. You will notice a recurring theme throughout:

YOU, the patient, are the one to be and remain in charge.

It will be helpful for you to watch this short animated video as you begin to learn more about your cancer and how to decide as well as plan for your treatments. This is part 1 of a 2 part video series:

<https://youtu.be/g1B4d4QQWHM> part 1

This guide give you an inside look at how oncologists are trained, too, in making decisions for and with their patients as well as ways they communicate this information. We hope by giving you such information you will be better equipped to remain in charge of your life going forward.

Some patients want to read this guide as soon as they learn they have advanced cancer; others prefer to wait until treatment options are diminishing. We recommend reading it sooner versus later so that you can begin by ensuring you are in good hands. There is also special content for your family caregivers too. So let's begin....

## Chapter 2

### THE PATIENT-CENTERED-CARE TEAM

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“In union there is strength.” Aesop

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A diagnosis of advanced cancer is probably the most difficult life crisis you and your loved ones will ever face. It is important to realize that you are not alone. During this journey there are and will be many people and professionals who will be working together as a team on your behalf, with you and for you, all with the unified goal of assisting in your care. Because of the desire to take care of you physically, emotionally, and beyond, you may find that your growing network of support is vast. Despite a broad network, we want you to remember this vital piece of information:

You are the most important member of your oncology team.

You are in control, and choosing where to receive services and selecting who will be a part of your care team is an important aspect of treatment planning. If you had been receiving cancer treatment previously, it would seem to make perfect sense to be taken care of by the oncology team who originally treated your disease. However, while this may be appropriate for some patients, a diagnosis of metastatic disease is more serious and complex, and often requires re-thinking this decision to ensure that you are going to be cared for by a team that specializes in the type and stage of disease that you now have. For patients like yourself, now dealing with metastatic disease, there are some specific elements you may want to be sure are available to you when selecting the facility and team for your care: These include:

Patient Empowerment ---You, the patient, are to be empowered with information so that you can directly participate in the decision making about your care.

Patient and Family Education – You and your family members (of your choosing) are provided educational information in an understandable form that helps you to confidently understand your disease and the treatment options you have to consider receiving.

Access to Clinical Trials – There are certainly some treatments that are standards of care for the type of cancer you now have however there also may likely be innovative treatments that are a part of a clinical trial that provides you additional treatment options.

Urgent Care Needs Met – So that in the event you develop a new serious symptom or side effect from treatment, you have easy access to your medical team to address your new medical problems that warrant rapid resolution.

Emotional Support—You and your loved ones will need emotional support throughout this journey, which includes receiving this support from specific healthcare team members trained in this role for you and your family.



Physicians that Participate in Multidisciplinary Case Conferences—Most cancer centers today conduct weekly case conferences, sometimes referred to as tumor boards. These doctors present cases about specific patients they have seen or are currently treating to gain a group consensus from many other doctors who see and treat patients with your same type and stage of cancer. This provides what is known as a multi-disciplinary discussion of surgical oncologists, medical oncologists, radiation oncologists, radiologists, palliative care providers, pathologists, genetics experts, social workers, nurse practitioners, and nurse navigators to meet together weekly and provide their input and guidance on questions that arise related to treatment recommendations. Seeking services from a National Cancer Institute (NCI)–designated cancer center is usually a wise choice, since they require these services and expertise be in place at such institutions.<sup>i</sup>

It is important to note that all members of your care team should have open lines of communication, understand your goals (future hopeful life goals as well as goals of care), and respect your wishes, now and in the future. Many oncologists are naturally “patient-centered”, but some stories that patients share suggest that not all of them are. The term “patient-centered” refers to physicians who often display characteristics like empathy or tend to ask open-ended questions. They actively encourage their patient’s involvement in decision-making about treatment. In contrast, “doctor-centered” communication refers to physicians who tend to be more medically focused and use more controlling behaviors when meeting with their patient. Studies of physician behavior have generally shown patient-centered communication styles to be associated with greater patient satisfaction and a greater ability for their patients to recall the content of their discussions. (Back, 2006) These differences are highlighted in Table 1.

Table 1.

Characteristics of Patient-Centered vs. Doctor-Centered Approaches to Communication	
PATIENT-CENTERED	DOCTOR-CENTERED
Takes time to talk to you about your hopes and concerns when building a shared treatment agenda. ie. Takes a personalized approach to your treatment.	Dictates treatment agenda based on medical guidelines alone and does not take into account your thoughts and feelings. ie. Does not use a personalized approach.
Makes sure to specifically ask about your thoughts.	Assumes that if you wanted to share your thoughts would.
Encourages you to express your feelings.	Steers the conversation away from your personal thoughts and feelings.
Makes sure that you are involved with the decisions about your care.	Believes decisions should be made based solely on the doctor’s judgment.

## WHAT SHOULD YOU BE EXPECTING FROM YOUR ONCOLOGY SPECIALISTS

Based on survey data, this information provides insights into what patients want and expect:

Communication with Patients: This means listening, engaging patients by inviting questions, being honest with the information provided and sensitive by offering sincere empathy when talking about death and dying.

Emotional Support: This is perhaps more important in some situations to be provided to the family and loved ones of the patient, but also is considered important to the patient as well. Compassion, hope and comfort were key features identified by patients for this domain.

Accessibility and continuity: The infrastructure that is in place to be able to reach your oncology specialist as needed, especially urgently. Also the wait times to be seen and the number of interruptions that take place during a consultation. Feeling a sense of connectedness that the patient will not be abandoned. This will be very important to you.

Competence: Patients and their family members have high expectations when it comes to physician competence and less high expectations when it comes to nurses and social workers involved in their care. What was most important were the following: demonstrating knowledge, skill, and use of referrals as well as taking the patient's symptoms seriously. Also, another key trait was knowing when to stop treatment. (When we think about competence it makes perfect sense. You usually just have one opportunity of getting the right treatment in the right setting provided in the right method and at the right time. This is your life that they know they will lose. You don't have time to be trying to figure out if you are or aren't in good hands. Each day in the hands of what you believe is someone without these traits maybe days of time and life lost.)

Respect and Humility: Patients want to be treated as equals with us and not talked down to or treated like their opinion has no value. They also want us to admit our own shortcomings and to not view death as a personal failure.

Team Communication and Coordination: Though this is an important domain to the oncology team taking care of the patient it is also a priority to the patient and their family. When the oncology team member appears to be disjointed without evidence that they are communicating regularly, consistently and accurately with one another it can look to the patient that they frankly don't know what they are doing. This breeds distrust. You will also want to have one point person to go to who knows everything happening and is in touch with all the team members so communication for you is made easier.

Patient Education: Priority here is to provide educational information to the patient and their family that could be understood and also felt to be meaningful to their lives. It is a form of communication however was deemed important enough to be separated out of the communication category and listed separately as an important skill.

Personalization: This really means providing patient centered care. Not treating just the disease but really treating the patient. In order to accomplish this the oncologists must know you, their

patient, quite well. You are far more than your pathology and staging work up results. Patients are each unique individuals with concerns that are exclusive to them and deserve their treatment team member's time and energy in learning about and factoring into the care the doctors provide to them.

Pain and Symptom Management: This must include the treatment not just of pain and other physical symptoms but also treating and managing your anxiety, fear, frustration and depression. Oncologists must incorporate into their treatment planning your preferences as well. Pain and suffering are one of the greatest fears that patients worry about when thinking about end of life.

Inclusion and Recognition of the Family: Family members must be incorporated into their communication and education. They are family caregivers. They are also the people who will be losing a loved one and need preparation from the oncology team how to prepare for this, what to expect will happen going forward, and need support during as well as after their loved one has passed.

Attention to the patient's values: Oncologists and other medical professionals must all respect their patient's beliefs even if they don't match to their own. These include but may not be limited to spirituality, religion, alternative medicine, and lifestyles. Drug use and cigarette smoking for example are not things that should be the focus for any discussion at this time. There is no value in discussing blame, meaning pointing out to a patient what may have directly contributed to them developing cancer. If they inquire then a discussion may ensue but pointing out lifestyle behaviors that contribute to getting cancer is a moot point and one not to be given discussion time.

Support of Patient Decision Making: Oncologist must make their patients' informed wishes become the center of decision making about their medical care at end of life. After all this is the patient's life; not the doctor's. (Patients do however need to tell their oncology team to what degree do they want to participate in the shared decision making process [Samant,Aivas, Bourque 2010].)

People in general believe it is better to be alive than dead. At least they think so, perhaps due to life after death being an unknown for some or perhaps many. This can depend on their spiritual hope and upbringing as well. What doctors do know is that patients will embark on toxic treatments for a tiny benefit which suggests that those facing a serious illness have different values from those doctors who do not and never have. Clinicians must be very aware of this in order to guide their patients in a direction that is appropriate and desired for them with a full understanding of the tradeoffs of treatment with challenging side effects versus not receiving additional treatment [Smith 2000]. This may sound obvious but your doctor also needs to know what you are living for. Are you believing you will experience a miracle or are you holding onto life to witness a specific milestone in your or your family's lives?

Patient story—Here come the brides

*Last year there was a man with end stage metastatic cancer on television, which later appeared on YouTube. It was very touching. He had hoped to be able to still be here in the coming years to*



*walk his daughters down the aisle on their wedding days. He realized that this hope was not possible yet he realized he could still fulfill this hope in an alternative way. So he arranged with the help of others to be brought to their church and he walked each of his daughters down the aisle with just immediate family present. There was no groom waiting at the end of that aisle. Such people were not yet in the lives of either of his daughters. But he wanted to still walk them down the aisle and tell them what he hoped for their future as a young bride one day. It was perfect.*

Of course your personal preferences are most important when choosing your oncologist, however the quality of communication and ease of exchanging information is important to consider. If you do not feel like you are receiving the support you need and deserve, it may be worthwhile to have a discussion with your doctor and other team members about how your care can be improved by communicating better with one another. Sometimes patients decide to seek a second opinion elsewhere too, evaluating other treatment options as well as potentially a different team for their actual care going forward. This relationship needs to be a partnership that works for everyone. Sometimes however a patient may be seeking a different oncologist to take care of them hoping they will get a different answer regarding their treatment options or even how long they will live. It is important for the relationship you have with your oncologists to be an honest and open one. Give thought to questions such as—How much do you know about your cancer? How much do you want to know about your cancer? Who among your family members do you want to also know about your cancer and its treatment? These types of questions are important to bring up with your doctor if the doctor doesn't initiate asking them of your first.

Remember, too, you are more than your cancer. You are a person with a life and the care team needs to know the details of who you are. You may be a 5<sup>th</sup> grade math teacher, whose husband left her for another woman a year ago, and is raising a 9 year old son with autism, and has a mother who has been showing signs of early dementia AND has now been also diagnosed with stage IV breast cancer. All of the elements, these details, need to be known to your treatment team because at various points in time they will play a role in your decision making about how you want to approach your care.

Now that we have placed an emphasis on receiving specialized care that places you at the center of your care and provides you and your loved ones with empowering information to guide your healthcare decisions, it may be helpful to have a clear understanding of the roles of each healthcare professionals you who may be joining your oncology healthcare team. You may notice that people participating in your care come from various specializations and unique knowledge, experience and skills in order to best provide you with the comprehensive and personalized care you need.

Keep in mind, there is a possibility that not all of the following team members will be appropriate to utilize in your specific circumstance, or you may need the services of additional

professionals. What is important is that the proper team is assembled to address and support your individual needs.

### TREATMENT SPECIALISTS

Treatment is primarily led and coordinated by one or more oncologists, depending on your specific needs. Oncologists are doctors who have extensive education and training in the diagnosis, treatment, and management of cancer. Different types of oncologists may be a part of your treatment team.

**Medical oncologist.** A doctor who specializes in treating cancers with medicines; these medicines can be chemotherapy, targeted biologic therapies, immune-therapies and other cancer-fighting-drug treatments. They are often the ones who lead the multidisciplinary treatment team for patients like yourself with a diagnosis of an advanced cancer. There are medical oncologists who specialize in specific types of cancers, and you will want such a doctor who specializes in yours and takes care of large numbers of patients with this type of cancer that is in an advanced stage.

**Surgical oncologist.** A doctor who specializes in treating cancer with surgery. You may have previously had such a doctor take care of you if your cancer was originally diagnosed as stage 0, 1, 2 or 3 and now has progressed to stage 4. There are also circumstances where you may need some type of surgery again, that focuses on where the cancer has spread. Just as is the case for a medical oncologist, if surgery of some type is needed, you will want a surgical oncologist very experienced in doing this type of surgery with prior patients like yourself.

**Radiation oncologist.** A doctor who specializes in treating cancer using radiation. Again, you may have had prior radiation if your cancer was previously diagnosed at an earlier stage. Radiation therapy treatments, if recommended for you, would likely be for pain management, shrinking a metastatic lesion that is pressing on a nerve which is causing localized pain such as back pain, hip pain, or other symptoms. As is the case with the other oncologists, you will want someone very experienced in the type of care you need.

### NURSING SPECIALISTS

Nurses bring a remarkable amount of knowledge, care, and clinical skill to the bedside. While they collaborate with doctors and other members of your team in delivering care, they are uniquely trained in educating patients and their families, providing one-on-one support, and facilitating patient care throughout the treatment processes. Nurses are often the ones who you will experience the most contact with during your treatment.<sup>iv</sup>

**Clinical oncology nurse.** A health care professional who is a registered nurse who cares for a person with cancer by providing bedside care, preparing and administering treatments such as chemotherapy, providing supportive care, and educating the patient and their family about their cancer, treatments, and side effects. You may find these clinical nurses in both an inpatient and outpatient setting, as well as just before and after surgery.<sup>vii</sup>

**Advance Practice Nurse.** This is a registered nurse with advanced training to serve as an extension of the doctors she works with. She is able to see patients independently without a doctor present and also is able to prescribe medicines, such as treatments to diminish side effects caused by treatment.

### DIAGNOSTIC SPECIALISTS

Often working behind-the-scenes, members of the diagnostic team are professionals who use information from blood tests, imaging, and other specialized tests to identify the type and location of cancer, as well as determining the stage (extent) of the disease.<sup>ii</sup>

**Pathologist.** A pathologist is a doctor that identifies and classifies different types of cancer by studying the appearance of cells and tissue. Some pathologists specialize in looking for genetic abnormalities that are associated with certain diseases or cancers. Pathology results are critical in determining the precise stage (extent) of disease or cancer.**Error! Bookmark not defined.** They also are able to determine some specific features of the tumor, known as prognostic factors, that directly influence decisions about treatment options.

**Radiologist.** A radiologist is a doctor who uses medical imaging technology, such as x-rays, CT, PET scans, MRI, or ultrasound, to examine internal organs and other structures inside the body. Radiologists interpret information from imaging tests to help make an accurate diagnosis and the extent of the disease for many types of cancer.<sup>ii</sup> In some cases they also perform biopsies using imaging technology as their guide.

### SUPPORT CARE SPECIALISTS

It is very important that you request to add the following healthcare professionals to your team, as these individuals are able to further address the unique physical, emotional, and spiritual challenges patients with metastatic disease face. You will likely find that utilizing these experts will aid in increasing comfort and reducing anxiety while creating a network of care that is more comprehensive.

**Oncology Nurse Navigator.** These clinically trained registered nurses are professionals specifically trained in providing personalized assistance to cancer patients, families, and caregivers to help overcome barriers to your care and treatment you may be experiencing or

might have to deal with in the future. They have access to resources for eliminating these barriers such as free transportation, discounted drug costs, food, and even help with day care in some incidences. Their mission is to not have anything interfere with you getting the care you need when you need it and where you need it. They also help with getting timely access specialists you may need. Another role for the navigator is helping you and your loved ones with psychosocial care through all phases of the cancer experience.<sup>iii</sup> The patient spends time with their navigator at key points across the continuum of their care— commonly beginning at the time of diagnosis to the completion of their treatment or end of life. Consider her your advocate, and your voice when you need members of your treatment team to know what you are thinking about or particularly worried about. You may have had a nurse navigator involved in your care before if you were diagnosed with an earlier stage in the past. You may still have the same navigator or there may be a specific navigator who navigates patients with advanced cancer. <sup>iv</sup> Something very important for you to share with the navigator who in turn discusses with the treatment team is what are your life goals. We don't always think about life goals very often, but this is a time to do this type of thinking. So think about the milestones you have been looking forward to achieving in the future, before you learned of your current cancer diagnosis. Some of those goals you may be able to still achieve but others may not be as realistic. It is important that the navigator, or other medical professional, talk with you about each one of them and how to strategize how they might be accomplished, whether you are here or not. Also, if there are special events coming up that carry significance to you, such as your daughter's wedding in six weeks, then it is important that the treatment team know it so that your treatments can be worked around it. You and they will want to preserve your wellbeing so that you can enjoy that day even if it means changing your treatment schedule. This is an example of a significant life goal— being present for your daughter's wedding. Your life goals should be incorporated into the treatment planning process to ensure that measures are taken on your behalf to preserve your life goals whenever possible.<sup>v</sup> There will be further discussions later in this guide regarding steps to take to accomplish life goals that aren't due to happen for some time from now.

**Palliative Care Physician.** This is a medical oncologist who specializes in symptom management for patients with serious life threatening illnesses. While a detailed discussion of palliative care exists later in this guide, it is absolutely essential to understand that palliative care is not limited to, or only intended to be provided as part of end-of-life care. It is about comfort and living well at any stage of a serious disease. Palliative care doctors concentrate on preventing and alleviating suffering, improving your quality of life, and helping you and your loved ones cope with the stress and burden of your illness.<sup>vi</sup> You will find in speaking with a palliative care doctor that this can be done in many creative and fulfilling ways. Palliative care should be offered to cancer patients at the time of diagnosis through survivorship or end of care.<sup>ix</sup> Palliative care is intended to preserve your quality of life or restore your quality of life.

**Oncology Social Worker.** Oncology social workers are professionals who counsel people affected by cancer and help them access practical assistance. They can provide individual counseling, support groups, locate services that help with obtaining healthcare coverage, home care and guide people through the process of applying for Social Security disability or other forms of assistance.<sup>vii</sup>

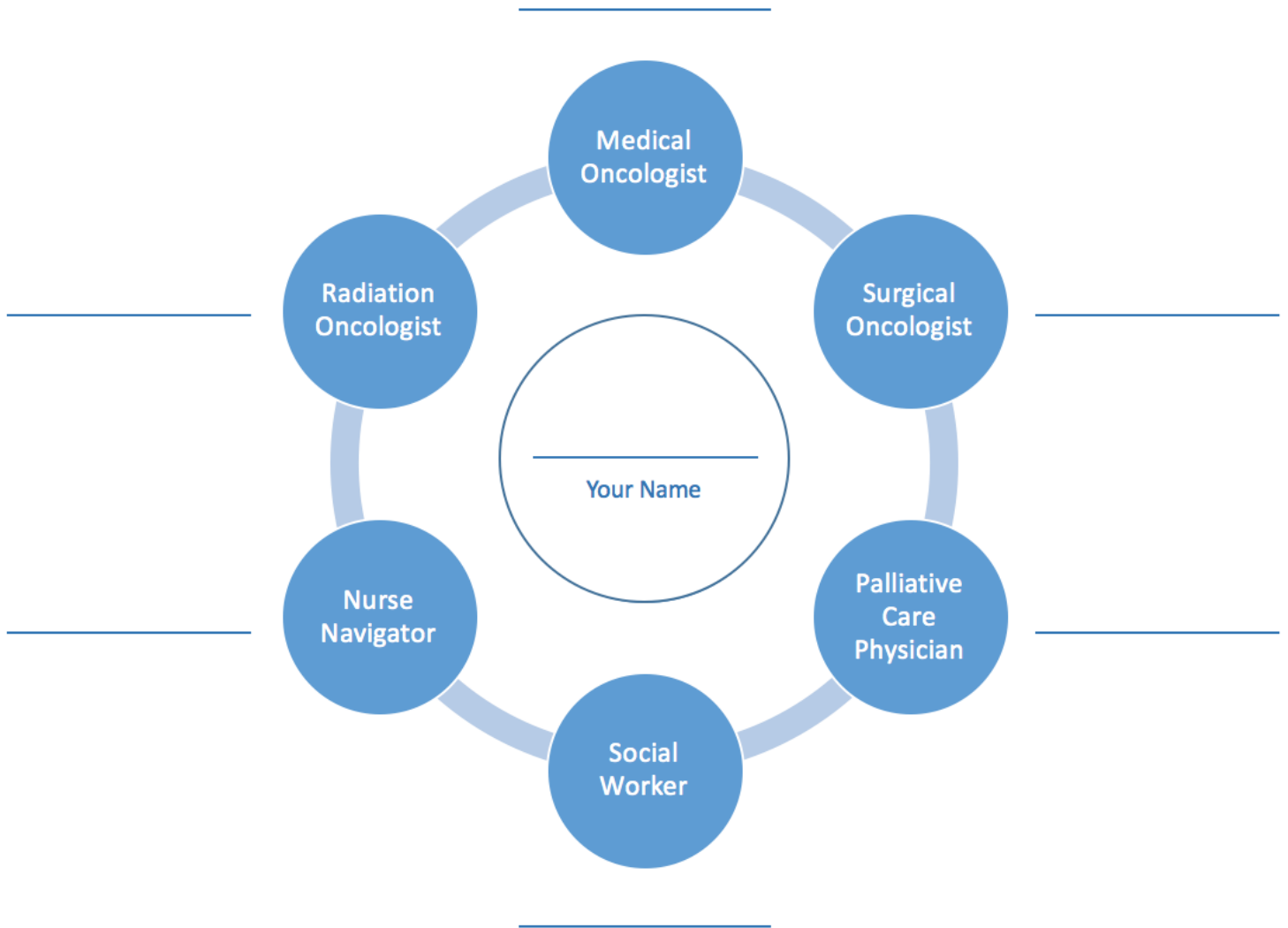
**Dietician/Nutritionist.** A dietician or nutritionist are specially trained healthcare professionals who can help you with difficulties eating as well as select for you the right foods to eat. Patients with certain types of cancer — such as head and neck cancer, stomach cancer, or pancreatic cancer — may have dietary limitations during or after treatment. Additionally, nutrition can be an important part of a cancer patient's overall health and well-being. You will need to maintain a healthy weight as well as have the physical strength to receive certain types of treatments as well as enjoy time spent with family and friends. You and your loved ones also socialize over food. Nutritionists can provide valuable consultation.<sup>viii</sup>

**Financial Counselor.** Financial counselors work closely with you to discuss your insurance benefits, out-of-pocket cost obligations, and, for patients in need, the resources available to assist them in reducing their personal out-of-pocket cost of care.<sup>ix</sup>

**Clergy/Chaplain.** Prayer, spiritual counseling, and a strong sense of spirituality helps many people face difficult challenges with courage and hope.<sup>vii</sup> Full-time chaplains, community clergy and lay people can provide patients, their families, and friends of all faiths pastoral and spiritual care, sacramental ministries, help with advance directives (which will be discussed later), and other spiritual support.<sup>x</sup> Sometimes patients are interested in connecting with a chaplain early on and others choose to not have them involved until much later in their care. It is a personal choice. You may have some family members that want to speak with clergy even though you personally don't feel this need to do the same at this time.

**Mental Health Professional /Therapist.** A diagnosis of advanced cancer can be very frightening. It is not uncommon to begin experiencing difficult emotions like anxiety, depression, or other unpleasant thoughts about the future. Individual, family, and couples counselors are available; some existing with special training to support the needs of patients with cancer. These professionals can help you better understand and come to terms with your diagnosis. They can also help with any difficulties you experience between you and your spouse or family members. These professionals may fall under many names, such as a psychologist, counselor, therapist, or other titles. Note that a psychiatrist is a medical doctor who has special training with psychological conditions, and – if necessary - is also able to prescribe medication to treat anxiety, depression, insomnia, and other psychological conditions.

**You may find it helpful to fill in the following spaces with the names of the professionals involved in your care.**





**Other Members of My Care Team Include:**

	<b>Name</b>	<b>Role</b>
1	<i>Example: John Smith, AFC</i>	<i>Financial Counselor 410-555-1234</i>
2		
3		
4		
5		

## Chapter 3

### COMMUNICATING WITH YOUR ONCOLOGY TEAM AND YOUR FAMILY

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“When you give yourself permission to communicate what matters to you in every situation you will have peace despite rejection or disapproval. Putting a voice to your soul helps you let go of the negative energy of fear and regret.” – Shannon L. Alder

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Communication will undoubtedly be important throughout your journey with advanced cancer. What we say, how we say it, and what we mean by it are extremely important, and whether or not your values and intentions are understood can alter the course of your treatment as well as your relationships. The quality of communication with professionals as well as family members has been proven to be fundamental to the quality of life of patients with advanced cancer. Further, ineffective communication was found to be one of the most significant barriers to good care. (Shockney L. , 2014)

The importance of being clearly understood as well as your understanding of information provided to you can directly impact discussing your options for treatment, and even the current status of your disease. It is very important to have clear and effective communication with your treatment team as you embark on what may be difficult discussions on topics like when you want to stop treatment. Again, you need to be in charge. You need to decide how you will determine when treatment is no longer benefitting you in the way you had hoped. Treatment for treatment’s sake is bad care. There is a tendency for oncologists to want to keep offering treatments, though the treatments’ real benefit may be questionable at some point. They don’t want to have you feel like they are giving up on you. However as treatments stop working and other treatments begin (referred to as line of therapy—first line, second line, third line, etc.) you will need to determine if doing more treatments that get increasingly toxic and impact quality of life, are worth it to you.

Each doctor’s appointment, each conversation with a loved one, is an opportunity to express your values and to make sure that your voice is heard and fully understood. Effective communication with others may seem simple, but the reality is that our interactions with others are often more complex than we realize. In addition, the depth and difficulty of conversations that take place during your journey may cause repeated situations for misunderstandings or even cause a lack of

trust. It will take an active approach to make sure your message is understood and to make sure you understand the reasoning of others.

Certain principles such as honesty, open-mindedness, and respect are central to achieving peaceful resolutions and mutual understanding with whoever we interact with. Certain techniques like active listening will also broadly improve our communications. We realize, however, that the dynamics between you and your physician are not the same dynamics that exist between you and your family members. Therefore, we will outline advice to coincide with your roles as a patient, family member, and also touch on appropriate communications between the family and members of your treatment team.

By using some of the advice outlined in this guide, we are confident you will discover improvements in your relationships and feel more confident and in control of your care.

## COMMUNICATION WITH YOUR DOCTOR

The doctor's office can be an understandably intimidating place. Research has shown that patients often have a strong desire to participate in shared decision making with their doctors, but that various obstacles often get in the way. You as a patient may feel that you should let your doctor dictate to you what your treatments should be and not ask questions about such decisions. Some patients see their doctor as the person to be in charge rather than they (the patient) being in charge. You might be worried that if you ask too many questions you will be labeled as a "difficult" patient. (Back, 2006) Under normal circumstances when you were diagnosed with an earlier stage of cancer, you may have felt comfortable being assertive for yourself. Now that you are in a more serious situation, you may feel more vulnerable and frightened and decide to defer treatment decisions to the doctors. Some patients worry if they disagree with their doctor or raise too many questions, it may actually impact the care they receive from that doctor, or even the multidisciplinary team. This unfortunately results in patients often holding back from asking questions or sharing opinions, and they end up less involved than they could be in making their own medical decisions. (Weir, 2012)

These perceptions can further lead to unfortunate gaps between what information patients would like to receive and what they actually do receive. In a survey of patients with breast cancer or melanoma, 57% wanted to talk about prognosis, yet only 27% actually did; likewise, 63% wanted to talk about the effects of the cancer on other aspects of their life, yet only 35% did. (Butow PN, 1996) In another study of patients with advanced cancer, a research nurse used a checklist to obtain from the patient his/her concerns after a visit with the medical oncologist. Patients were found to have numerous concerns they had not disclosed to their oncologists. A larger number of concerns were sadly associated with the patient's inability to effectively cope with their illness. (Maguire, 1999) This data suggests oncologists have room to improve in practicing effective communication, specifically in soliciting the various concerns that you, as

their patient, may have.. The good news is that research in the field of the patient-physician dialogue is growing, and while some of this data may initially cast oncologists in a bad light, the overwhelming majority of these physicians care immensely about their patients and are aiming to improve their own communication skills.

It is important to have the concerns you have about your cancer and its impact on your life be acknowledged as valid concerns and deserving of an empathetic ear. It is also important to know that even the most caring and patient-centered oncologist may forget to mention aspects of your care that are important to you. The patient-physician relationship is a partnership; one that is very dependent on effective two-way communication. While your doctors are attempting to improve their communication skills, do not be afraid to take charge of the conversation. Our hope is that you will take ownership of your values, concerns, and uncertainties when walking into your doctor's office; knowing you deserve to be listened to. Do not be afraid to ask tough questions. And ask your nurse navigator to accompany you to your appointments. Additionally, if you need, she can speak on your behalf or provide prompters for you as you engage in a discussion with your physician. Be assertive in your desire to be heard and place your values at the beginning of each conversation – whatever they may be. Remember that throughout your partnership with your physician and the treatment team, ultimately one thing must remain true:

The patient is in charge.

Remember that, when in the doctor's office, there is no one in the room more important than you. Coming to your visit prepared, ready to ask questions, and openly discussing your values and concerns can go a long way in getting the most out of your visits with your doctor.

Dr. Craig Hildreth, MD, a practicing medical oncologist and frequent writer for Cancer Network, compiled the following tips to help you get the most out of your visit with your doctor (Hildreth, n.d.). We supplemented his explanations to be more fitting for this guide.

### **1. Don't come to appointments alone.**

- a. While we understand that not everyone has a readily available support system to join them, we know that being alone while waiting to hear results of the unknown can be highly anxiety provoking. Having a trusted friend or a group of family members join you in the room provides you with additional advocates and an extra set of ears to help you remember everything that was said. Dr. Hildreth goes on to say, "Do you know what oncologists first think when they walk into a room full of people? 'This patient is loved,' followed by 'I had better do my best.' I believe that inviting supporters to the consultation fosters patient empowerment and all its advantages." Now, if you don't feel like you have friends or family members that you can count on to join you, an experienced nurse navigator can usually accompany you serving as your patient advocate and would surely love to be by your side.

**2. Bring copies of the key parts of your medical records.**

- a. This not only applies to your first visit with your oncologist, but also if you are going to another facility to seek a second-opinion. It is very helpful to call before your appointment and ask if you should bring CDs of your scans or copies of pathology reports for your doctor to review. There are times when this information is already scanned and uploaded into the new hospital or clinic's computer system, but many times it's not, or it may be incomplete. This is especially true if you are starting to receive care from a different institution. After your care is established and an ongoing partnership is formed, this may no longer be necessary unless certain changes occur (Eg. receiving new imaging or pathology reports from an outside hospital or clinic, or if certain medications are changed by your primary care physician). You don't have to bring your whole chart with you every time, but it may be helpful to ask if there is anything the office or doctor might need to review. Keeping this line of communication open can save you the burden of getting to your appointment and realizing that you and your doctor don't have all of the information necessary to make a decision about moving forward with treatment.

**3. Gather up your questions, write them down, and ask them.**

- a. As Dr. Hildreth puts it, "When your life is on the line, there is no such thing as a silly question. You owe it to yourself to ensure that when you leave the office all your concerns have been addressed. Questions tend to appear magically at all hours of the day, so this is why you should record them and remember to bring your list." With that being said, he goes on to explain that there are times when your oncologist may not know the answer to some of your questions. In fact, "I don't know" is frequently the correct answer to a question, so don't be discouraged if you hear it or mistake it for a lack of competency or caring. As long as you feel that everything you have to ask is being addressed with a reasonable and empathetic explanation, you are likely on the right track with your provider.

**4. Don't be afraid to ask for a favor.**

- a. It is not uncommon for patients to ask to record the audio of their conversation, or to ask permission to dial in friends and relatives on video applications like Skype or FaceTime. Remember, your future and the quality of your life is at stake – don't be shy. Dr. Hildreth says, "I personally don't care if a patient employs the speakerphone, FaceTime, Skype, Bat phone, or Ouija board. One of our principal obligations is to communicate with family, no matter where they are." Other favors may include asking your oncologist to further help you understand the often complex topics of disease and treatment to you. This could be done by

asking him or her to simply repeat what they said, or by having them illustrate what they are talking about on a piece of paper for you to take home. Do not forget that you are the most important person in the room and that your oncologist has a responsibility to do what it takes to make sure you and your support system understand what is going on.

**5. Get any treatment recommendations in writing.**

- a. This is similar to the advice given above, but having your treatment plan recommendations in writing will prove to be extremely helpful to you and those in your support system. With the myriad of new cancer drugs, complex and often similar spellings and similar sounding names, it will be difficult to investigate your curiosities on the topic once you get home without the exact plan written down on paper. If you or someone else is in the room taking notes, don't be afraid to ask your doctor if you are spelling things correctly. Have them take a look at what you wrote down to make sure you have the recommended treatments and their timelines down correctly. Or, as we discussed, don't be afraid to ask them for a favor and have them write it down themselves! Additionally, having your written treatment plan, along with any drug information, can be especially helpful when getting a second opinion. Dr. Hildreth notes, "Remember, what makes a second opinion useful is when it is compared to the first. If no one can remember what the first opinion was, it might be a bit challenging to compare the two."

**6. Keep an open mind.**

- a. When hearing your oncologist's treatment recommendations for the first time, try asking for specific reasons why they feel it is the best option for you. Dr. Hildreth says, "As we explain why we want you to consider taking a particular treatment, don't dismiss it without learning all the facts." The vast majority of oncologists follow evidence-based national guidelines when recommending treatment; treatments that have been supported by gold-standard, randomized controlled trials. With that being said, each treatment carries with it its own risks, side effects, and tolerability. You should ask yourself if the treatment being recommended aligns with your personal goals and values. Additionally, Hildreth mentions, "If you are keen on an alternative therapy, mention it to the doctor. If others have convinced you that all cancer treatments produce horrific side effects, confess your fears." At the very least, this should open a discussion on the potential harms and benefits of each treatment that you are considering. Keeping an open mind and considering all of the information presented to you (as well as the source it comes from) will help you be ready to make an informed decision about your disease management that you feel comfortable with.



This is a lot of information to consider when thinking about how to best practice effective communication between you and your doctor. You may find it helpful to fill-out and bring the list we created for you on pages 22 and 23 to your next appointment to make sure you and your doctor are addressing everything that is important to you. You may fill out as much or as little as you are comfortable with, and in doing so we feel it's a good tool to start with.

In addition, we realize that sometimes it can be difficult to even know what questions to ask. It can be helpful to listen closely to your oncologist as doing so may answer some of your concerns or cause you to think of something new. Regardless, we have provided a list of some basic questions to start with. Your questions may become more detailed and personal as you move forward.

My appointment with Dr. \_\_\_\_\_ is scheduled for \_\_\_\_ / \_\_\_\_ / \_\_\_\_ at \_\_\_\_ : \_\_\_\_ am/pm.

The three most important things I want to discuss at this appointment are:

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_

The following things are new or have changed since my last appointment:

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_

The three most important things I want to continue doing in my life that bring me joy are:

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_

The one thing I am most worried about at this time is:

- 1) \_\_\_\_\_

The thing I am hoping for right now is:

- 1) \_\_\_\_\_

I also have the following questions that I would like to get answered at this appointment:

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_

It is important for you to discuss with your doctor what your current knowledge is about your cancer. That may sound strange but there are situations in which a patient may have misinformation about the type of cancer it is, its stage, how treatable it is, as well as some myths about treatment options. So talk with your doctor about what you believe you currently know about your cancer. Also tell the doctor how much you want to know about your cancer. There are some patients who only want information related to their current condition and don't want to talk much about what lies ahead. Most patients however are wanting to know everything they can, whether good or bad, so they can be better prepared for the future.

The following is a broad list of key clinical questions that may be a good place to start when you don't know what it is you want to ask about treatment choices. (Napolitano, 2015) Some, but not all of these questions apply to you.

- What is my diagnosis and how soon do I need to start therapy?
- What are my treatment options, what's involved, and how long will each treatment take?
- What are the benefits of the recommended treatment?
- What are its potential risks and side effects?
- Should I consider participating in a clinical trial?
- How will treatment affect my daily routine? Can I continue to work through treatment?
- What should I do if I develop new symptoms after I begin treatment?
- What support resources are available to help me cope with my diagnosis?
- Whom should I call if I have additional questions after I leave your office?

## COMMUNICATION WITH YOUR FAMILY MEMBERS

Your family is no doubt worried about you. Men are known for wanting to “fix” things and this is something that they, personally, cannot fix on your behalf, especially if that man is your husband. Adult children want to do a role reversal and take over the role of being your parent with you being their child. It is instinctive for them to try to do this. You however need to remind everyone that you are the patient and the patient must be the person in charge.

If you have a large family, it usually is best to communicate to everyone via email so that you do not spend extra time on the phone repeating yourself, especially if you have just come home from a doctor’s visit. This way everyone gets the same information at the same time and in the same way. (This avoids family members wondering if you “told them everything” or possibly “told someone else more or less information.” Yes, this happens.)

You need to determine who you want to have be the primary family member who will be accompanying you to doctor’s visits as well as taking care or helping to take care of you when you are recovering from various treatments at home. Sometimes it is obvious who this will be but sometimes it requires making choices. It will be important for close family members to understand how this selection was done so no sibling rivalry ensues. It may be a daughter who isn’t currently working and can more easily help you than a daughter who is working full time. It also might be based on geographic location—your adult children who live near you versus an adult child who lives out of state or travels for work a lot.

Your family will need to understand the type of cancer you have and that it is in an advanced state, meaning it is not curable. There will be some family members who feel compelled to search the internet for cures for you. There are websites that prey on vulnerable people, including yourself, who state they have the cure when they don’t. If there were a cure your oncology team would be offering it to you or directing you to a comprehensive cancer center where it can be given to you.

You will need to make your family members aware of what your wishes are and request that they respect them. Later in this guide you will find information about Advance Directives that outlines in detail how to also document your wishes to help ensure they are followed in the event you are not able to speak for yourself.

Always be honest with your family about your test results and the status of your cancer and its stability or that it is continuing to grow. Your family must trust that you are keeping them accurately informed. Don’t try to protect them from the facts and the truth. That can do more harm than good.

When you become sicker and it becomes more clear, especially to you and your oncology team, that you are approaching end of life in the coming weeks or few months, there is a tendency for family members to become more desperate in their need to extend your life, no matter what your physical condition is. They are not doing it to be mean. They simply want you here on this earth, no matter what. Sometimes family members will even go behind their loved one's back and talk to the doctor telling him that they will convince you to do another treatment even though you are very weak and have made a decision to stop treatment and preserve your quality of life which is far more important than quantity of life now. Be proactive and tell your family upfront and early on that you do not want this to happen and that you will decide when treatments continue or stop.

It may seem strange but as long as the patient is still breathing, even if on life support, family members will cling to the idea that their loved one might even get well again. This isn't fair to you however. You must make decisions about your care and not have someone else make decisions that are not in keeping with your wishes. Hopefully by being aware of these tendencies that family members have demonstrated for decades will arm you with the information you need to prevent such behaviors among your family members that would not be in your best interest.

Your family loves you. During frantic moments that can behave in ways that are not helpful however. It is because they are trying to control something that cannot be controlled by them, no matter how hard they may try.

The primary family member who will be serving as your family caregiver will be the person most stressed. This is because they will be worried about you, helping to take care of you, while still trying to likely work, take care of their immediate family's needs that will continue to need to be met, and will be taking on other additional responsibilities to help you. There is a known problem that this family caregiver abandons their own healthcare needs while serving as a caregiver to a loved one with a serious illness. Make sure this family member is still seeing their doctor for their annual physical, is getting the appropriate cancer screenings they need annually, is eating a healthy diet, exercising, and getting enough sleep. In a future chapter there is information about how family caregivers can get time off from work for care giving too, while still protecting their employment

## CHAPTER 4

### INFORMATION FOR FAMILY CAREGIVERS

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I thank you for your part in my Journey

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There is nothing harder than witnessing a loved one dealing with advanced cancer and not knowing how to help them. Your loved one may have been diagnosed some time ago with an earlier stage of this cancer or they may have been diagnosed from the start with advanced disease. Whatever the situation, you are reading this guide because they now have an incurable type of cancer that they are dealing with. That is a hard reality to have to accept.

Everyone who loves them is impacted by their diagnosis and its treatment, which of course includes you. You are likely reading this because you are going to be or already are serving as the family caregiver to your loved one, whether that be your spouse/partner, sister, brother, or even a best friend.

The most important thing for you to always remember is that the patient must be the person in charge of their care. Even after they are no longer able to speak for themselves, their wishes are to be carried out on their behalf. It is unfair for a loved one to try to interject their opinions and feelings and try to alter the decisions that the patient has made, unless their choices are very unusual (such as going off to Mexico with \$50,000 cash because they think a cure for cancer is down there.) The doctor can validate if the patient is thinking unreasonably. Even then, you need to exercise restraint in trying to take over and apply your decisions that you think are better than the ones your loved one has chosen with their oncology team.

Someone should be the point person to accompany your loved one to their doctor's visits. This person should also plan to take notes during the visit, and help make sure all of their loved ones questions are addressed by a member of their oncology team. In other chapters of this guide we have provided your loved one, the patient, with key questions to ask, questions also to answer for themselves that will help them in their decision making about treatment and next steps, and guide them through each phase of their care that lies ahead.

Sometimes when treatments begin to no longer work, there is a tendency for someone like yourself to want to try to take control then and transport your loved one to multiple other cancer centers in the hope that a different treatment will make a difference. More than likely however the oncology team knows what other treatments, if any, are available, and where, and whether they may be of help at this pivotal point in time. The fact is that at some point, treatments stop

working and each new treatment that is tried will likely have worse side effects along with a lower probability of actually helping him/her. Treatment for treatment sake is bad care.

Doctors, though they work in the oncology field, sometimes are not comfortable talking about discontinuing treatment and transitioning the patient into hospice care. After all they have been taught to treat the disease. Your loved one dealing with advanced cancer however is far more than just their cancer and deserve the opportunity to have their quality of life preserved and to die on their terms in and the environment of their own choosing which when asked the majority of the time will be at home with hospice care. The home environment may be their home or your home.

Hopefully early on in the treatment process, a member of the palliative care team will be introduced to your loved one, and to you. Palliative care gets a bad rap. It is assumed that it means hospice care when palliative care is intended to be provided way before hospice is ever discussed and planned for. Palliative care is symptom management. There are treatment side effects as well as symptoms that are caused by the cancer itself, especially as the cancer continues to grow and spread. No one should suffer when they don't have to. A palliative care specialist is expert in ways to diminish or even rid the patient of these types of problems that are directly disrupting their quality of life. So when you hear the term "palliative care" think of it as "quality of life preservation" or "quality of life restoration. Because that is actually what it is. Your loved one needs to be honest with you and their oncology team members about what aches and pains they are experiencing as well as other side effects and symptoms so that they can be appropriately managed. Sometimes patients hide these symptoms because they are worried the doctor will stop their treatments. If the side effects and symptoms can be effectively managed then treatment of course can continue. If you are aware of a symptom your loved one is suffering with that is being withheld from their doctors, bring it up during the doctor's visit so it can be openly discussed and hopefully palliative care specialists can assist with resolving or control it better. Palliative care doesn't mean giving more narcotics either. Palliative specialists actually avoid the use of sedating drugs because they want the patient to be enjoying their time, which means not sleeping the rest of their life away. Ask about palliative care.

In Chapter 8, there is information that is of value for you to read. Though written with the intent that it is read by your loved one who has advanced cancer, you will be able to gain great insights into what to expect as your loved one becomes more ill. Dealing with uncertainty is scary and exhausting. We hope this information will provide you what to expect to happen and when so that you can be prepared for these symptom changes.



## CHAPTER 5

### LEGAL & FINANCIAL AFFAIRS

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“A clear vision, backed by definite plans, gives you a tremendous feeling of confidence and personal power.” – Brian Tracy, *The Gift of Self-Confidence*

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The goal of treating metastatic cancer is to sustain life while preserving the quality of life. One of the ways in which we can increase quality of life is by alleviating the common anxiety and uncertainty of what will happen when we can no longer make our own decisions, or what will happen when we are gone. There are certain legal documents, such as an advance directive or healthcare proxy designation, that all adults should have – regardless of age or medical condition. As a patient with advanced cancer, you will likely find it helpful to have these documents completed, as well as other legal and financial documents, so that you may relieve yourself of this worry and concentrate on enjoying life. Ensuring that legal documents exist will help you maintain a sense of control and provide peace of mind for you as well as your family. In this chapter, we highlight the definition and reasoning behind such documents and explain how they can be of service to you and your family. We also outline important information on how and when to obtain legal services, in addition to advice on complex situations ranging from the protection of your estate, financial management of treatment, and, for those whose circumstance applies, the legal guardianship your children. Some patients believe that having such documents in place is a sign of giving up. It is not. If you weren't even diagnosed with cancer right now, we would still be encouraging you, and anyone else, to have these types of documents in order. If you have ever lost a loved one suddenly due to an auto accident or a debilitating stroke and were involved with having to then settle their estate or serve as a decision making about their care, and no documents were in place, then you would have already experienced the pitfalls of not having wishes known and legal and financial decisions in place.

#### LAWYERS

While, for some, the thought of consulting a lawyer for your needs may sound intimidating, there are some situations when the services of a lawyer are both needed and beneficial. However, there are other situations where the need to engage a lawyer's help may not be as clear. In either case,

a discussion with a legal professional can be useful in clarifying whether or not you will need their services or advice. An initial consultation may even be free. If the cost of hiring a lawyer is not realistic for your budget, we later explain how you may be able to receive free or low cost legal aid.

When determining the kind of lawyer you may need, it is important to know that – like doctors - many lawyers specialize in different types of law. For those dealing with advanced cancer, it is likely you will be looking for a lawyer who has expertise in Wills, Guardianships, Advance Directives, and Trusts. When looking for legal advice, it may be helpful to be aware of the following types of lawyers and what they are most suited to manage.

- **Testamentary lawyer:** A lawyer who drafts Wills, Guardianships, Trusts, and similar types of documents.
- **Insurance lawyer:** A lawyer who has had experience battling insurance companies on behalf of patients who have been wronged by the actions of an insurance company. Insurance lawyers generally have trial experience.
- **Medical malpractice lawyer:** A lawyer who can assist you if you have been harmed through negligent or wrong medical care.

Once you have established what types of legal professionals are relevant to your needs, there are many easy ways to go about finding a lawyer who is willing to help you. For some, the referral to a legal service may come from someone already on your healthcare or support team. For example, your social worker may be able to connect you with a lawyer that can help you with your specific needs. A referral could also come from your navigator, counselor, therapist, or someone at a support group meeting.

If, however, the name and contact information of an appropriate lawyer does not come so easily, you may consider trying the following resources:

- **Martindale-Hubbell Legal Directory**
  - Martindale-Hubbell is a free service that lists lawyers, their specialties and contact information. Search results are sortable by geographic location.  
See: [www.martindale.com](http://www.martindale.com)
- **Yellow Pages and other telephone directories**
  - Many directories separate the lists of lawyers by field of law. Unfortunately, any lawyer can be listed under any topic provided he or she pays the fee. There is no way to measure quality or experience.

- LegalZoom.com
  - This easy-to-use website provides a vast array of legal services, and can connect you with attorneys specializing in your case. Many documents can be drafted and reviewed by an attorney online, while also offering the opportunity to speak with the attorney over the phone. Prices for each specific service vary, and are listed on their site.

Additionally your nurse navigator or social worker will likely have access to pro bono lawyers that can assist you too. If she is a member of the navigators' professional organization known as AONN, then she has access to resources online through this organization that can help locate a pro bono lawyer in your community who can provide legal services for free due to the seriousness of your medical condition at this time.

Once a lawyer is found, the ability to afford their services can be a cause for concern for many people. However, you may find it possible to receive a discount, negotiate for a lower price, or even get a lawyer's services for free. Free legal services may be available in your local area. Most lawyers do at least some work for free. This is known as working "pro bono". There may also be free legal clinics as a service of your local law school. The National Cancer Legal Services Network (NCLSN) promotes increased availability of free legal services programs so that people affected by cancer may focus on medical care and their quality of life.<sup>xi</sup> This network of education and resources can be found online at: <http://www.nclsn.org>

### Advance Directives

It might not be enough to just tell your family about your medical care wishes. You can choose the kind of treatment you get and refuse any treatment that you don't want, but only if you plan ahead. If you haven't already made a decision about your care at the end of your life, now is the time to do it. An advance directive puts your decisions about your future health care in writing. Advance directives are legal documents.

All individuals who are adults should have an advance directive, whether ill or not. An Advance Directive is a type of legal document that explains to your doctor, and other medical providers taking care of you, what your wishes are regarding your health care. This is particularly important for individuals who are seriously ill and may not want all forms of treatment given to them, for example, in the event that they become too ill to communicate these wishes with the medical team themselves. At some point, this may be your situation too. Here is some general information about different Advance Health Care Directives, like health care power of attorney, living wills, do-not-resuscitate, and other agreements like these.

You have a right to be informed about treatment options as well as other medical care services and decide for yourself what you do and don't want done for you. And you have the right to change your mind over time, whenever your situation changes or you choose to make different choices. So do not worry that once you create an Advance Directive it cannot be altered by you. Adults have the right to control their medical treatment as long as they are mentally able to do so. You can choose which course of treatment you would like from those the doctor offers. You can choose the kind of treatment (aggressive, comfort care, or even none). This right is called *informed consent* and every state recognizes it. Whenever you have had an invasive procedure done, or received chemotherapy, had an operation, or received radiation treatments, you would have signed in advance an informed consent document.

*Informed consent* means that the doctor or nurse explains the purpose, benefits, risks, and alternatives of the treatment before you decide whether you want to get it or not. In most cases, treatment can be given only if you agree to it. Still, this right is not absolute. For example, if you need immediate or emergency care, the doctor may go ahead with treatment even if you can't take in information and agree (consent) to be treated.

It's also generally accepted that a competent (mentally able) adult may refuse medical testing or treatment if they understand the likely outcomes of refusing to receive it. This is sometimes called *informed refusal*. A competent adult patient may also ask that such treatment be stopped, even if it means they will die. For example, you might choose to not be given CPR if your heart were to stop beating on its own; this is referred to as a Do Not Resuscitate Order or DNR order.

Advance directives (also called advance health care directives) are a way for you to give consent for certain situations where you might want or not want treatment. They can also be used to appoint someone to make decisions for you if you can't do so yourself. An advance directive gives you a better chance of having your wishes carried out, even if you can't talk to the doctors about what you want.

Feel assured too that an advance directive will not affect the type or quality of your care while you can voice your own decisions. It only comes into play when you can't speak for yourself. Sometimes, family members make medical decisions for their spouses, parents, or adult children who can't speak for themselves. Whether this type of informal arrangement will be accepted most often depends on the doctor and which state you live in. Many US states have passed laws that say which family members (in a listed order of priority) may act on behalf of a person who can't speak for her- or himself. However, if there is disagreement between family members it can complicate and delay decision-making which is not in your best interest. So it is important to have clear documentation on special (Advance Directive) forms (which are available to you at all hospitals and also online) so there is a clear understanding who you have appointed to speak on your behalf if you are faced with a situation that you cannot speak personally on your own.

Even though others may be able to make health care decisions for you without an advance directive, such a document can give you more control over those decisions and who makes them. Some types of advance directives contain written directions or guidance about future medical care. Another type of directive lets you choose a proxy (a substitute person, also called an agent or surrogate) to make decisions for you when you can't make them for yourself.

Talk to your family about your wishes so they know what you want. Be sure your closest family members can quickly and easily find a copy of your advance directive. An important note: If someone calls 911 or Emergency Medical Services (EMS), even after an expected death, the law often requires that EMS try to revive the patient or take them to a hospital. Be sure that your family and friends are ready and know exactly what you want, so that they don't dial 911 in confusion or panic.

If you are over 50 and an AARP member, you can access Advance Directives Forms at this website:

<https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

Contained also on this website are the state by state specific forms so you can look up the state you live in and download the legal forms that are applicable for you and where you live.

If not a member of AARP, nor have a family member who is, you can also go to this website and download the various forms you need:

<https://www.everplans.com/articles/state-by-state-advance-directive-forms>

General information about different advance directives, like health care power of attorney, living wills, do-not-resuscitate orders, and other agreements can be located at these websites. *These documents apply only to your health care decisions and do not affect financial or money matters.* Because the laws on these documents vary by state, you'll need to find out what your state allows and requires. Your social worker or nurse navigator can help you with accessing this information that is specific for your state. Commonly oncologists' offices as well as all cancer centers have these documents readily available for patients to take home and complete and if needing help in completing them, can assist you while you are physically there for one of your oncology appointments.

Healthcare Power of Attorney -- Through the documentation that you will do on this type of form, you are empowering another person you trust with decisions regarding your healthcare and medical treatment in the event that you cannot speak on your own behalf. Healthcare [power of attorney](#) becomes active when a person is unable to make decisions or consciously communicate intentions regarding treatments.

Read more: [Healthcare Power Of Attorney \(HCPA\)](#)

<https://www.investopedia.com/terms/h/hcpa.asp#ixzz5LGrtRDTz>

Living Will-- Living wills serve as legal and medical guidance documents: they outline specific conditions under which people may or may not choose to remain alive, including the type and extent of medical treatments individuals desire for life-threatening situations. Living wills are also called advanced directives. People may complete these wills at any age; older adults frequently complete living wills, but younger adults benefit from completing them, too, as unforeseen medical situations may arise at any time. So you may hear the term “living will” or “advance directive” being used to describe the same type of information.

<https://www.doyourownwill.com/living-will/states.html>

Do Not Resuscitate (DNR) Orders – When someone is very ill, it can actually be detrimental to perform CPR on them because by the nature of their illness it may do more harm than good. For example, if you have metastatic cancer that has spread to your rib bones, doing CPR on you would likely cause the ribs to easily break which could puncture your lung or even your heart. And the purpose of CPR is to sustain life. When someone is approaching end of life usually they are asked if they want heroics done or not in the event they stop breathing or their heart stops beating. A DNR is usually written after the patient as requested that no heroics of this type be done. It is important to make your family also aware of this decision.

<https://www.everplans.com/articles/how-to-create-a-do-not-resuscitate-order-dnr>

### Letter of Instructions

Although this is not a legal document, it can be very helpful. This letter can be a guide for your family to help them make decisions at the end of your life and after you are gone.

In the instructions, you can name who you want to look after or take in your children or pets. This is useful if the guardian you’ve named in your will lives out of state. You may also list names and phone numbers of those who should be contacted right after your death. This could include relatives, your lawyer, your financial adviser, the human resources manager at your former job, your insurance agent, or whomever else might need or want to be involved at this time. You should list the location of important papers and bank and investment accounts. Note also the person who should contact these organizations. You may also want to leave instructions about the kind of funeral or memorial service you would like. Copies of instructions should be given to the executor of your will, trusted family members, and/or other loved ones. Be sure to talk with the people who will need to carry out these instructions. Be sure they’re willing to follow your requests and see if they have any questions about your wishes.

Keep all of these documents in a safe place in your home. You can put them in a safe deposit box if you want, but give copies to close family members, members of your health care team, and your lawyer. It’s important to make sure more than one person knows where these documents are and can get to them quickly. It’s also important to tell your health care team what the documents say when and if the need arises. If your wishes have changed since you last set up such a document, be sure that old copies are destroyed and that your loved ones know where your new documents are.



Last Will & Testament— Commonly referred to as a “Will”, is a document created by an individual, also known as the “Grantor” which in this case is you, which is used to lay out how a person’s real and personal property shall be distributed after their death. After the form is created, signed and notarized, the Will should be distributed to all the Beneficiaries (individuals who are receiving something upon the individual’s death) stated in the Will and to your Attorney. No State requires the document to be registered but it may be filed with certain County Clerks, Probate Courts, and applicable Secretary of State offices.

You might be thinking that you don’t own any property or have anything of value that you would be leaving. Think again. You do. You likely have a car, a savings account, a checking account, jewelry, maybe a great set of golf clubs and other items. You should decide who becomes the recipient for these things that are yours. Remember that any outstanding bills need to be paid before distribution can be done after you are gone. You also can make a list of who you want to have receive what, and use this list, if relatively short and doesn’t involve property or large sums of money, and distribute some or most of these items before your death. There can be great joy in doing this while you are still able and discussing with the recipient why you chose for them to receive something from you that you cherish.

#### Understanding and Managing the Financial Expenses of Your Cancer Treatment

Cancer is usually very expensive. It can take a toll on your health, your emotions, your time, your relationships – and your wallet. There will be unexpected charges, and even the best health insurance won’t cover all your costs. Here are some tips on what costs you can expect and some ideas on how to plan for, ask about, and discuss treatment costs with your cancer care team. Don’t wait until you have financial problems to discuss cancer costs with your health care team.

#### Health insurance coverage

Usually, doctors’ offices and clinics have someone who handles health insurance concerns and problems. Ask your doctor if that person can help you with claims and codes on the bills that are sent to the insurance company. Financial counselors should always be available too to assist you with these types of issues.

Out-of-pocket costs are costs you have to pay because your health insurance doesn’t. They can add up quickly and may make it hard for you to pay for other things you need.

You’ll want to be sure that your health insurance company pays or reimburses the bulk of your medical expenses. This means you’ll need to

Know the terms of your policy which a person at the insurance company in their Benefits Office can explain to you.

Be aware of preferred or network doctors, hospitals, or clinics.

You can find out more about health insurance and other costs at:

<https://www.healthcare.gov/blog/understanding-health-care-costs/> (you can find it too by typing in Understanding Health Insurance and Decision Making.)

### Planning for your treatment over time

It's a good idea to learn as much as you can about your cancer and your cancer treatment before it starts. This will help you know what to expect. It can also help you plan for and deal with the costs. Your nurse navigator, financial counselor, or social worker can help you to determine what expenses you will personally need to pay versus your insurance covering. Nurse navigators also know of local, regional and national resources that may be available to help you with your out of pocket expenses if you are going to experience difficulties paying these types of bills. Many people with cancer have medical expenses for things like:

- Provider visits which will include doctors, nurse practitioners, physician assistants, and possibly other medical providers
- Lab tests (blood tests, urine tests, and more, which are usually billed separately)
- Clinic visits for treatments which can include biopsies, radiation, chemotherapy, and other treatments
- Special genetic tests
- Special genomic tests to study the biology of the tumor cells that helps determine treatments that may work best for your situation.
- Procedures (for diagnosis or treatment, which can include room charges, equipment, medicines used during the procedure or treatments, different doctors, and more)
- Imaging tests (like x-rays, CT scans, PET scans and MRIs, which may mean separate bills for radiologist fees, equipment, and any medicines used for the test)
- Radiation treatments (radiation seed implants, external radiation, or both)
- Drug costs (inpatient, outpatient, prescription, non-prescription, and procedure-related)
- Inpatient hospital stays (which can include many types of costs such as drugs, tests, and procedures as well as nursing care, doctor visits, room charges and consults with specialists)
- Surgery (surgeon, anesthesiologist, pathologist, operating room fees, equipment, medicines, preoperative care, recovery room care and more)
- Home care (can include equipment, drugs, visits from specially trained nurses, and more)
- Palliative care for symptom management and preservation of quality of life
- Hospice care for end of life—in a hospice facility or in your or a loved one's home

Your health insurance company will also need to pre-approve or pre-certify any part of the treatment before your treatments get underway, including surgery, chemotherapy, radiation and other types of cancer treatments. Even tests such as MRIs and other imaging studies commonly cannot be done until your insurance company okays it. Even if your chemotherapy, for example,

is given in pill form, it still will require pre-approval because these drugs, though more convenient for you to take yourself at home, will still be very expensive. Some drugs are thousands of dollars a month. Treatment in pill form, known as oral chemotherapy, works just as well as drugs given by IV too, so don't assume that you are getting lesser treatment if given in pill form. Most health insurance plans don't pay for the oral drugs the same way they pay for the IV drugs (those put into a vein in the hospital, clinic, or office).

Oral chemo drugs are often treated like regular prescription drugs. You have to pay for them and, even if your insurance covers them, you might have a very high co-pay. For example, some insurance companies require a co-pay of 25% of the drug cost. This can still be thousands of dollars of expense for you to have to pay yourself. And this isn't a bill that you can pay later – you have to pay when you pick up the drug at the pharmacy. Most pharmaceutical companies who manufacture these drugs offer discount drug assistance programs for cancer patients. Your nurse navigator, or social worker, or someone else who works directly with your oncologist in clinic will be able to access these financial resources on your behalf. Just ask about them. Many patients, by the way, need financial support to afford these treatments today.

#### Other prescription drugs used with cancer treatment

Many kinds of drugs are used during your cancer treatment. These may be drugs to prevent nausea, treat pain, help with anxiety, or control diarrhea. Drug prices vary a lot. You (or a family member) may want to call different pharmacies to get information of where you can get the best price in your community. Comparisons are also commonly available online. Ask your nurse navigator or social worker about this as well.

#### Hospital, surgery, and clinic treatments

If you must have surgery, chemo, radiation, or will be in the hospital for part of your treatment, here are some questions you might want to ask:

Do we need to get my insurance company's approval (sometimes called pre-certification) before the test, surgery, treatment, home care, etc.?

Is there a co-pay for each treatment? (The co-pay is the cost you will be charged each time you get outpatient treatments in an office or clinic. Your health insurance company sets the co-pay amount.)

If I must go into the hospital, how much will it cost? How much will my insurance cover?

Is there a way to know beforehand if the doctors who will see me in the hospital are in my health plan network?

Counting all the charges (hospital, anesthesia, surgeon, pathologist, and more), how much will this surgery cost me? How much will my insurance cover?

Should I plan to be receiving home care and if so how often and for what purposes?

Keep detailed records of your treatments and your bills that are paid, unpaid, and have balances that you are to pay.

Consider assigning a reliable family member or close friend to help you with this so you can concentrate on getting well again and not having to worry about keeping track of all of your bills, payments, and other expenses.

If any of your treatments might be done by out-of-network doctors or providers, find out about those costs, too. Even when you know the terms of your policy, getting payments can mean re-submitting claims, appealing denials, and much more.

There are also financial specialists available for free through the American Cancer Society by calling 1-800-227-2345.

#### Making Treatment Choices that Consider Risk, Benefits and Cost

No patient wants to leave financial debt for their family to have to pay associated with the cancer treatment/care they received. So give thought to the choices you want to make as the next treatment option is presented to you by your doctors. You will be learning about the risks and benefits of each option and should factor into it as well the cost of the treatment too.

## **Work Issues for You and for Your Family Caregiver**

Family and Medical Leave Act (FMLA) (Information obtained from Legal Services as well as from the American Cancer Society's website)

#### What is the FMLA?

The Family and Medical Leave Act (FMLA) of 1993 was designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons. The FMLA gives certain employees the right to take up to 12 weeks of unpaid, job-protected leave per year. It also requires that the employee's group health benefits be maintained during the leave.

#### To whom does the FMLA apply?

FMLA applies to all public and private employers with 50 or more employees. These employers must provide an eligible employee with up to 12 weeks of unpaid leave each year for any of the following reasons:

For the birth and care of the newborn child of an employee

For placement with the employee of a child for adoption or foster care

To care for an immediate family member (spouse, child, or parent, but not a parent-in-law) with a serious health condition - so this means a family member serving as your caregiver can apply

When the employee is unable to work because of a serious health condition- this means you can apply once you have been diagnosed with your cancer, even before you are not able to work anymore.

### Special FMLA rules for Military families----

In 2008, the FMLA was expanded to include “military family leave entitlements.” FMLA can be used by military families for these purposes:

The spouse, son, daughter, parent, or next of kin of a member of the Armed Forces can take up to 26 work weeks of leave to care for the service member with a serious injury or illness.

Spouses that work for the same employer are limited to a combined total of 26 work weeks in a single 12-month period if the leave is to care for a covered service member. There are other differences and limitations in FMLA for military families. You can get more details from the Department of Labor (see “To learn more”) or read their fact sheet online at:

[www.dol.gov/whd/regs/compliance/whdfs28.p](http://www.dol.gov/whd/regs/compliance/whdfs28.p)

### Who can take FMLA leave?

Employees are eligible for FMLA leave if all of the following apply:

They’ve worked for their employer at least 12 months

They’ve worked at least 1,250 hours over the past 12 months, or about 25 hours per week

They work at a location where the company employs 50 or more employees within 75 miles

Military reservists returning from active duty are entitled to the rights and benefits they would have had if they had been continuously employed.

What counts toward the 1,250 hours that I or my family caregiver needs to qualify for FMLA?

First, the 12 months of service do not have to be continuous or consecutive; all of the time you’ve worked for the employer is counted. You can leave and then return, but you still must have worked 1,250 hours in the past 12 months to qualify (unless you are a military reservist returning from active duty). The 1,250 hours include only those hours actually worked for the employer or spent in active military duty. Paid leave time, previous FMLA leave, and other absences from work don’t count toward the 1,250 hours.

Your individual record of hours worked is used to decide whether 1,250 hours had been worked in the 12 months before you start FMLA leave. The following may help you figure out whether the 1,250-hour requirement has been met:

Roughly 25 hours worked in each of the 52 weeks of the past year, or

More than 104 hours worked in each of the 12 months of the past year, or

About 40 hours worked per week for more than 31 weeks (over 7 months) of the past year.

### How far ahead of time must I request FMLA leave?

If possible, an employee must give an employer at least 30 days’ notice before FMLA leave is to start. This only applies to planned medical treatments and elective surgery. Knowing that far ahead is rarely possible when you have cancer or when you are taking care of a loved one with cancer. In the case of unexpected need due to serious illness, you must let your employer know as soon as possible, at least within 1 to 2 business days of when you first learn you’ll need leave.

May I or my family member taking care of me use FMLA to take off several short periods?

FMLA leave can be taken all at once or it can be taken in shorter blocks of time, such as 2 days a week, or 1 week a month, as long as it's taken for a single reason. FMLA can also be used to reduce the amount of time you work each day, for instance, so that you work a part-time schedule for a while. You'll need a doctor's note to verify that the medical condition is serious and you are unable to work for these times, or that your family member's serious illness requires you to take this time for his or her care. See the section "What is medical certification and must I give my employer my medical records?"

Does time I took off for illness or pregnancy count against my FMLA time if I need to take off again for a new illness in the same 12 months?

Time taken off work because of any illness, pregnancy, or complications of pregnancy can be counted against the 12 weeks of family and medical leave in a 12-month period. The employer must let the employee know that the pregnancy leave was counted as FMLA.

Who defines the 12-month period during which I can take off up to 12 weeks under the FMLA?

In selecting your 12-month period, the employer may choose to use:

The calendar year, January through December

Any fixed 12-month "leave year" such as their fiscal year, or a year required by state law

A year that starts on the your anniversary date (counted from the date you were hired)

The 12-month period counted forward from the date your first FMLA leave begins

A "rolling" 12-month period measured backward from the date you last used FMLA leave

Can I use my sick or vacation time for FMLA so that I can be paid?

The FMLA only applies to unpaid leave. But it lets an employee choose to use accrued paid leave, such as vacation or sick leave, for some or all of the FMLA leave period. The law also lets the employer require the employee use paid leave for FMLA. The employer must decide if an employee's use of paid leave counts as FMLA leave, based on information from the employee. When paid leave is used instead of unpaid FMLA leave, it may be counted against the 12 weeks of FMLA leave if the employee is notified that this is the case when the leave begins.

Who counts as immediate family?

For FMLA purposes, an employee's spouse, son or daughter under the age of 18, and parents are immediate family members. The term "parent" does not include a parent in-law. The terms "son" or "daughter" do not include those age 18 or over unless they are unable to take care of themselves because of mental or physical disability that limits one or more of the major life activities as those terms are defined in regulations issued by the Equal Employment Opportunity Commission (EEOC) under the Americans With Disabilities Act (ADA). The term "parent" may include people who are acting as parents to the child, even though their legal relationship may not be formalized. For military families in certain situations, the son, daughter, parent, or next of

kin of an adult armed forces member can take FMLA to provide care for up to 26 work weeks. See the section called “Special rules for military families” under “What is the FMLA?”

If your family member is taking FMLA leave to take care of someone else, their employer may require that they prove their relationship with you. Sometimes it is also required to prove that you, as the patient, has a serious illness.

What is medical certification, and must I give my employer my medical records?

No, you do not have to provide medical records to use FMLA. But for any leave taken due to a serious health condition, the employer can request that you provide medical certification, which confirms that a serious health condition exists. This is usually a note or form signed and dated by a doctor that states all of the following:

That you (or your family member) have a serious illness

When the illness started

Whether absences are expected to be continuous or in short blocks of time

When you or your family caregiver may be expected to return to work – this one is tricky because it may be totally unknown when FMLA is initially requested and implemented.

If your employer asks you for an update on your medical certification or for a second opinion, you might need to provide it to keep your FMLA rights (see below).

Can my employer or my family care giver’s employer ask questions about my leave or my caregiver’s leave while out on FMLA?

Yes, your employer can ask questions about your leave while you are out, but they can only ask you. Your employer may ask you questions to be sure the leave you are taking qualifies for FMLA. The employer may also make you give them reports on your status and ask whether you intend to return to work after leave. Whenever possible it is important to provide honest information so that your place of business isn’t left in the dark about your inability to return to work. And as it relates to your family caregiver taking FMLA, that person too needs to be honest and accurate to the best of their ability about the time they need off to take care of you. It is complicated when a loved one is approaching end of life how long a family caregiver may be needed. Your doctor however can provide some estimation for you both about what type of timeframe likely lies ahead of you both. Not an exact science but based on experience having taken care of thousands of prior patients with the same advanced cancer.

Will my family caregiver risk losing their job if I take FMLA leave?

Most of the time, employees will not lose their jobs if they use FMLA leave. When your family caregiver returns to work, employers must give them the same job or an equivalent one.

Employers are not allowed to interfere with, restrain, or deny any right provided under this law.

Employers cannot use taking FMLA leave as a negative factor in employment decisions, such as

hiring, promotions, or disciplinary actions. Also, FMLA leave cannot be counted under “no fault” attendance policies. (A “no-fault” policy might have a fixed maximum number of allowed absences and automatically discipline or fire a person who reaches that number, regardless of the reason for the absences.)

The employer doesn’t have to allow certain highly paid, salaried (“key”) employees to return to the same job after FMLA leave. But the employer still must allow the FMLA leave and maintain the employee’s benefits. The key employee can ask to be restored to his or her former job after the leave is over. It’s important to know that the employer may refuse to let the employee go back to his or her previous job if doing so causes “substantial and grievous” financial injury to the company.

Employers are also not required to continue FMLA benefits or give jobs back to employees who would have been laid off or otherwise would have lost their jobs if they had continued to work during the FMLA leave period as, for example, due to a general layoff.

#### Can an employer refuse to grant FMLA leave?

An eligible employee who has met FMLA’s notice and certification requirements (written information from your doctor), and has not already used up their FMLA leave for the 12-month period, may not be denied FMLA leave. But any employee who lies or uses fraud to get FMLA leave from an employer loses his or her FMLA rights to get back their job or keep their health benefits.

#### What happens regarding health insurance that is covered through the employer for someone who is on FMLA leave?

The employer is required to keep their group health insurance coverage while on FMLA leave if health insurance was provided before the leave was taken. It must be kept on the same terms as if the employee had continued to work. If the employee paid all or part of the health care premiums, arrangements will need to be made for the employee to continue to pay their share while on leave. The employer is not required to continue other benefits during FMLA.

#### Are federal government employees covered by the FMLA?

Most employees of the United States government are covered by the FMLA or similar rules. Federal employee leave policies are administered by the US Office of Personnel Management (OPM). You might need to contact your agency’s personnel or human resources office to find out exactly what applies to you.

#### Where can I find out more about the FMLA?

To learn more about FMLA provisions and rules, read the FMLA Fact Sheet posted on the US Department of Labor website at [www.dol.gov/whd/regs/compliance/whdfs28.pdf](http://www.dol.gov/whd/regs/compliance/whdfs28.pdf) or call the



Wage and Hour Division's referral and information line at the Department of Labor at 1-866-4-USWAGE (1-866-487-9243). They can give you other helpful information and tell you how to reach the Department of Labor division office nearest you.

You can also google and go to this website: Americans With Disabilities Act: Information for People Facing Cancer

#### What is the Americans with Disabilities Act?

The Americans with Disabilities Act of 1990 (ADA) is a law that helps protect the civil rights of people with disabilities. It can help people with disabilities have equal opportunities in:

Employment

Public accommodations (places that are generally open to and used by the public)

Transportation

State and local government services

Telecommunications

#### How can the ADA help me regarding my diagnosis of advanced cancer?

People with cancer can have long-term disabilities that make it hard to work or get around. The ADA is intended to make it possible for people who can do the essential parts of their job to go back to work or keep working during and after cancer treatment. Even when a person with cancer doesn't have a disability, they may be thought of as being disabled. This alone can set the stage for discrimination at work, and the ADA addresses this as well.

The ADA can help people who might have trouble getting into buildings and using public accommodations (such as commercial and other buildings, stores, libraries, offices, transportation etc., that are intended to be used by the public) due to a disability. The ADA can also help people with hearing and speech problems use phone and electronic communications.

#### What is a disability under ADA?

In most cases, a diagnosis of cancer falls under the ADA, even for those with cancer who have early stage disease and will become long term survivors. Given you have advanced cancer now, you should definitely be covered under ADA. You may already be experiencing some of the major life activities that are included as a disability that qualifies under ADA.

Some of the "major life activities" covered by ADA include but are not limited to:

Caring for yourself, doing manual tasks, seeing, hearing, eating,, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, working.

On January 1, 2009, the ADA Amendments Act of 2008 went into effect. It changed the way the definition of disability had been interpreted under the ADA. The Amendments Act covers disabilities in the body and mind, like the functions of the immune system, cell growth, digestive, bowel, bladder, brain and nervous system, respiratory, circulatory, endocrine, and

reproductive systems. These changes can help many people with cancer to clearly meet the definition of disability.

An employer cannot take action against you because you ask for your rights under the ADA. The Act also protects you if you are discriminated against because of your family, business, social, or other type of relationship or association with a person who has a disability. For instance, this means an employer cannot discriminate against you because your spouse or child has cancer. Still, the ADA does not completely protect your job just because you have a disability and are qualified for the job. The employer can still fire or lay off (terminate) an employee with a disability for legitimate business reasons. For instance, a disabled worker would not be protected during downsizing.

#### What does the ADA consider essential job functions?

If you have a disability, you must be qualified to perform the essential functions of a job in order to be protected from job discrimination by the ADA. Essential functions are the fundamental duties required by the job itself. An employer cannot refuse to hire you because your disability prevents you from performing duties that are not essential to the job.

But you must satisfy the employer's job requirements such as education, employment experience, skills, or licenses. Employers are not required to lower their job standards to accommodate someone with a disability. Nor do they have to provide personal-use items such as glasses or hearing aids. You also must be able to perform the essential functions of the job either on your own or with reasonable accommodation (see definition of accommodation in the next section).

#### What does the ADA consider reasonable accommodation?

Reasonable accommodation is how an employer makes adjustments to a job that allows an employee with a disability to perform the essential functions of that job. But reasonable accommodation can start even before hiring. For example, it may be a change in procedure that allows a qualified disabled person to apply for a job.

For those already working, reasonable accommodation can be a change that allows disabled people to have the same benefits and privileges of employment as employees without disabilities. Examples of reasonable accommodations may include:

Providing equipment or devices, or adapting them so the person with a disability can use them

Restructuring a job

Changing work schedules

Reassigning the employee to a vacant position

Adjusting or modifying tests, training materials, or policies

Providing electronic readers and/or interpreters

Making the workplace easy to get into and use by people with disabilities

An employer must accommodate a qualified applicant or employee with a disability unless the employer can show that making the accommodation would not be reasonable. That means that the accommodation would be very difficult or expensive (an “undue hardship”). These factors include the type and cost of the accommodation in relation to the size, resources, nature, and structure of the employer’s operation. In general, a larger employer would be expected to make accommodations requiring greater effort or expense than would be required of a smaller employer.

The facts of your case will help determine whether an accommodation will make it possible for you to do the job and, if so, what kind of accommodation is needed. Employers do not have to know about every kind of disability to know whether or how to make a reasonable accommodation. They are required to accommodate only those disabilities they know about and that do not cause too much hardship for the employer. The requirement is usually triggered by a request from a person with a disability, who often can suggest a workable accommodation. Accommodations must be made on a case-by-case basis because the type and extent of a disability and the requirements of the job will vary in each case. If you don’t ask for an accommodation, the employer is not required to provide one. If you ask for an accommodation, but cannot suggest one that will work for you, you and the employer should work together to identify one. There are also many public and private resources that can provide help without cost. See the “To learn more” section for some places to start.

#### Do I have to pay for it if I need reasonable accommodation under ADA?

Generally, no. The ADA requires the employer to provide the accommodation unless doing so would cause an undue hardship on the employer’s business. If the cost of providing the needed accommodation would be too much, you must be given the choice of:

Providing the accommodation yourself, or

Paying for the portion of the accommodation that causes the undue hardship

An employer cannot make up the cost of providing a reasonable accommodation by lowering your salary or paying you less than other employees in similar jobs. Typically, employers don’t pay a lot to accommodate employees with disabilities. When asked, employers noted that most accommodations cost nothing; the rest typically cost only about \$500.

#### As my cancer progresses I will likely not be able to work as much or be as productive. What happens then regarding my request for reasonable accommodations?

You need to look as objectively as you can, as well as talk with your doctor, about whether it is reasonable or not to continue to be working as your cancer progresses. Your employer needs to be able to rely on someone to get the work done. You need to re-evaluate how you want to be spending your time, which likely has a limit on how long that time will be. So retiring from your job, if you have enough years in and are of an age that it is possible, or resigning from your position may be the right thing to do. As someone who meets the criteria for being disabled, you

should qualify for Medicare benefits, if the driving reason why you are still trying to work is for the purpose of maintaining your health insurance coverage.

To assist your family in the future, it is important to review the list of documents outlined below so that they know where they are, when bills are due, and have other needed information from you that likely only you know. It can be incredibly complicated and confusing if after your death they don't know that some of these items even exist. Review the list below and also discuss it with your family caregiver.

### List of Key Documents You Should Have and Have Readily Available as You are Approaching End of Life

It is not something anyone wants to think about much less do, but many people with advanced cancer do not take the time to have their legal and financial affairs in order. When someone dies without having fulfilled this process, family members are not only grief stricken over losing their family member to cancer; they are also faced with a list of problems that could have been avoided had the patient done the right thing before passing away. Having these documents all in order, accessible by a key family member, documented as being such, who is serving as your point person as you are nearing death as well as after you are gone will prevent many problems later. For example, let's say you have a life insurance premium due in 2 weeks. No one knows about it other than you and you are too ill to deal with any paperwork or even the ability to explain to someone what might be coming due for payments, and that bill doesn't get paid, you may be automatically cancelling your life insurance policy without even realizing it. You die 4 weeks later, and your family later discovers that due to no premium being paid last month, your life insurance you planned to leave for your wife and children doesn't exist anymore. So do the right thing for yourself and your family and have these documents in order. They should be in a safe place too.

#### Insurance Policies

- Life Insurance
- Health Insurance
- Car Insurance
- Home Insurance
- Other Insurance policies (theft, fire, earthquake, etc.)

## Bank Accounts

- Checking accounts
- Savings accounts
- Money market accounts
- Certificates of deposit (CDs)
- Debit cards

## Credit Cards

- Card number
- Expiration date
- Recent account statements
- Login and password information for online account management

## Mortgages or Loans

- Company through which mortgage or loan was given
- A copy of the mortgage or loan agreement

## Tax Returns

- Most recent W-2 forms or federal self-employment tax return
- Income tax returns for the current and previous year, including 1040 variations and 1099s, if applicable
- Gift tax returns

## Pension Plans and Retirement Benefit Information

- 401(k) or 403(b) plans
- IRAs
- Roth IRAs
- Simplified Employee Pension (SEP) plan

- Salary Reduction Simplified Employee Pension (SARSEP) plan

#### Titles or Deeds to Any Property

- Real estate
- Motor vehicles
- Boats

#### Investment Portfolios

- Stocks
- Bonds
- Mutual funds

#### Will

- Copy of the Will
- Copies of previous versions of the Will
- Name of attorney or law firm that helped create the Will, if applicable

#### Trusts

- Declarations of trust or Trust agreements
- Name of attorney or law firm that helped create the Trust, if applicable
- Bank accounts associated with the Trust

#### Power Of Attorney

- Name of the person appointed to Power Of Attorney
- Power Of Attorney documentation
- Name of attorney or law firm that helped create the POA, if applicable

#### Safe Deposit Box

- Location of safe deposit box

- Safe deposit box keys or location of safe deposit box keys

#### Any Professionals Who Have Helped

- Lawyer
- Accountant
- Insurance agent

#### Advance Directive

- Living Will
- Health Care Proxy
- Do Not Resuscitate (DNR)

#### Proof of Identity and Relationships

- Social Security card
- Armed Forces discharge papers
- Birth certificate
- Death certificate
- Marriage certificates
- Divorce certificates
- Prenuptial agreements
- Divorce settlements

#### Household Utilities

- Electricity
- Gas
- Water
- Phone

- Cable
- Internet

#### Automatically Renewing Medications

- Names of medications
- Name of pharmacy where medications are renewed
- Name of doctor who prescribed medication

#### Email

- Gmail
- Hotmail
- Yahoo! Mail
- AOL
- Other email accounts associated with phone/internet services

#### Online Businesses

- Amazon
- PayPal
- EBay

#### Social Media

- Facebook
- Twitter
- LinkedIn



## CHAPTER 6

### PALLIATIVE CARE

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“We cannot change the wind, but we can adjust the sails.” - Anonymous

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Before beginning this chapter, it is important for you to know that receiving palliative care is not the same as entering hospice. Also, receiving palliative care does not mean you are nearing the end of life. In fact, we usually encourage oncologists to offer palliative care services at the time of diagnosis. A palliative care doctor should be part of your multidisciplinary care team. An effective treatment plan for advanced cancer can, and usually does, involve receiving the benefits of palliative care to manage symptoms caused by the cancer itself or side effects caused by treatment you are receiving.

Put simply, palliative care is an area of medicine that focuses on providing relief from symptoms, pain, and stress—no matter the diagnosis or stage of illness. It is specialized medical care that carries a specific goal of improving or maintaining your quality of life. It is often provided by a team of doctors, nurses, and other specialists who work with your existing care team to provide you an extra layer of support. Patients receiving palliative care can expect relief from symptoms and side effects that are disrupting your ability to enjoy your life, spending your time as you desire.. Providers that specialize in palliative care are experts in alleviating symptoms such as fatigue, pain, difficulty sleeping, anxiety, depression, nausea, shortness of breath, constipation, diarrhea, loss of appetite, and more. This kind of relief can help you carry on with your life and focus on other things that are important to you. It can also help you improve your physical and mental ability to continue receiving cancer treatments. Palliative care teams are also experts at utilizing effective communication, offering more time to discuss how best to align your treatment options with your unique and personal values. Furthermore, the palliative care team will help ensure that your emotional and spiritual needs are met throughout the time you and your family are dealing with this disease. All of this can be accomplished at a location that best suits your needs, including the hospital, outpatient clinic, or your home. (Johns Hopkins Medicine, 2018) (Center to Advance Palliative Care, 2018)

#### **A PATIENT STORY – QUALITY OF LIFE COACH**

A great example of how palliative care can improve the lives of patients is found in a story shared by Lillie in her book, *Fulfilling Hope- Supporting the Needs of Patients with Advanced*

*Cancers*. . She explains how her own father experienced these benefits in innovative ways during his journey with metastatic prostate cancer. She says:

*“When my dad was in terrible pain from a T-5 vertebral fracture, I arranged for him to have a consultation with the director of palliative care here at Hopkins. I personally feared that if Dad heard the term “palliative care” he would get upset and assume what I was trying to say death was impending. So I contacted the palliative care physician, told him my concerns, and told him I was going to introduce him as the “Hopkins quality of life coach.”*

*The doctor even removed his ID badge as to have nothing labeling him with palliative care. The consultation was just the right medicine he needed, beginning with a discussion about what were the things that gave my father the most joy.*

*The treatment was focused on those joys – restoring them to him so he could enjoy his life once again. The doctor took him off the narcotics he has been placed on. Nerve blocks enabled him to get back on his John Deere tractor. Other symptom management was achieved without having him sleepy from drugs. He was able to resume his chemotherapy at a later time, knocking the disease down, taking drug holidays when he wanted to be actively farming (planting and harvest seasons), and again resuming chemotherapy when his obligations to be out in the cornfields were less demanding (summer and winter). Symptom management provided him quality of life. Dad told the doctor, ‘Thanks for giving me my life back. Life is good again. ’” (Shockney L. , 2014)*

### **A PATIENT STORY – FRANK, THE ADVENTURER**

Dr. BJ Miller is a palliative care physician practicing out of San Francisco, California. He thinks deeply about how to create a dignified, graceful life for his patients. In his 2015 Ted Talk, which has been viewed over 6.5 million times, he shares a story that highlights how palliative care physicians act as reflective advocates for their patients, just as much as they are prescribing physicians:

“Now, let me introduce you to Frank. I've been seeing Frank now for years. He's living with advancing prostate cancer on top of long-standing HIV. We work on his bone pain and his fatigue, but most of the time we spend thinking out loud together about his life - - really, about our lives. In this way, Frank grieves. In this way, he keeps up with his losses as they roll in, so that he's ready to take in the next moment. Loss is one thing, but regret, quite another. Frank has always been an adventurer -- he looks like something out of a Norman Rockwell painting -- and no fan of regret. So it wasn't surprising when he came into clinic one day, saying he wanted to raft down the Colorado River. Was this a good idea? With all the risks to his safety and his health, some would say no. Many did, but he went for it, while he still could. It was a glorious, marvelous trip: freezing water, blistering dry heat, scorpions, snakes, wildlife howling off the flaming walls of the Grand

Canyon -- all the glorious side of the world beyond our control. Frank's decision, while maybe dramatic, is exactly the kind so many of us would make, if we only had the support to figure out what is best for ourselves over time.” (Miller, 2015)

An important component of palliative care lies in aspects that are not typically considered “medical”, but rather in the realm of psychological and spiritual support. As an outstanding palliative care physician, Dr. Miller had taken the time to really know Frank, and was able to provide him the type of support needed for Frank to realize his own values and how these values would fit alongside his treatment plan; ultimately enabling Frank to regain a sense of independence, control, and have a strong quality of life in the face of his illness.

### TRUTHS AND MYTHS ABOUT PALLIATIVE CARE

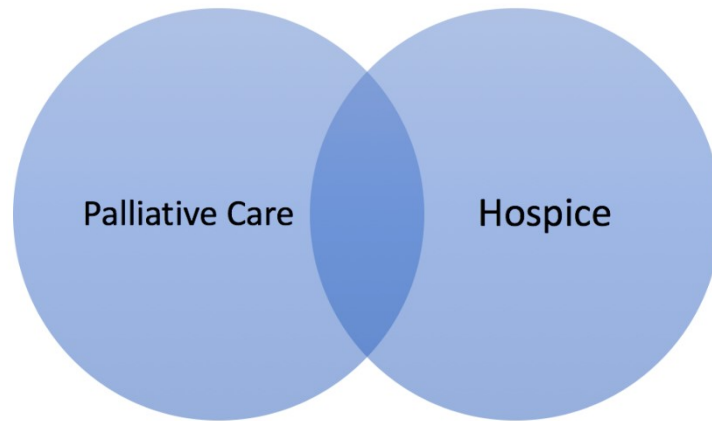
There are many misconceptions about palliative care; many of which will delay patients from receiving an improved quality of life. The following information from the National Institutes of Health (NIH) Clinical Center seeks to provide patients with increased knowledge about palliative care and to clarify the numerous misconceptions that surround it. (National Institutes of Health, 2017)

1) **Myth:** Palliative Care is only for people who are at the end of their lives.

**Truth:** Palliative care should be integrated early in disease process while disease modifying treatments are being offered to maximize quality of life and combat symptoms and suffering.

2) **Myth:** Palliative Care and Hospice are the same type of care.

**Truth:** Although both types of care focus on improving quality of life for the patient and their family through expert symptom and supportive care, palliative care is offered to all individuals at any stage of disease at the same time disease modifying or curative treatments are being offered. Hospice care is usually offered when treatments are no longer effective or no longer felt to be beneficial.



3) **Myth:** Palliative care is only used to treat pain and they will just give me morphine.

**Truth:** Pain is a common reason for a palliative care referral and sometimes opioids (pain medications) are prescribed for pain control. However, these medications are not the only option. Palliative care also utilizes non-medication therapy to treat pain such as nerve blocks or complementary therapies (massage, acupuncture, Reiki, pet therapy, etc.) that help with pain control.

There are many other symptoms an individual could be experiencing that would qualify them for a palliative care consult: nausea, vomiting, diarrhea, constipation, loss of appetite, trouble sleeping, anxiety, depression, itching, and restlessness, just to name a few. Referrals are also made to help with non-physical types of suffering such as anxiety, depression, spiritual distress, and other concerns that may impact quality of life of patient and family.

4) **Myth:** When I work with palliative care, I will no longer see my other physicians

**Truth:** Palliative care providers are specialty trained consultants that work with your other providers to assist in the management of your symptoms and quality of life. They do not replace your other providers. The palliative care consult team will work with your primary team to come up with a treatment plan.

5) **Myth:** Palliative care sounds like it would be expensive for me.

**Truth:** Palliative care is often handled much like a referral to a cardiologist, neurologist or other specialist. Most insurance plans, including Medicare and Medicaid, readily cover palliative care. The provider or organization offering the services will bill your insurance

accordingly; just be sure to understand what co-pays or fees – if any – you will be asked to pay. It is usually helpful to ask about your responsibility for fees and request a fee schedule from your insurance company before agreeing to receive services. (Start the Conversation, 2018)

The inclusion of this chapter was prompted after hearing stories from patients who did not know the benefits of palliative care or that it even existed for them. Some were sadly never offered it during their journey. We hope that this information has been helpful and enlightening. As we mentioned before, we usually advocate for oncologists to offer palliative care services at the time of diagnosis of metastatic or advanced cancer. If, however, you have not been offered palliative care, do not be afraid to ask. Simply let your doctors and nurses know that you would like to see how you can benefit from the palliative care team. An excellent, trusted resource created specifically for patients who are interested in learning more about palliative care is provided by the organization, “Get Palliative Care”. They offer an educational website designed to define and promote palliative care, and provide a nationwide directory of palliative care physicians and programs. The organization also regularly updates their website with articles, stories, videos, podcasts, webinars, and news. All of which can be found at: [www.getpalliativecare.org](http://www.getpalliativecare.org)

## CHAPTER 7

### HOSPICE CARE

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*“We used to think that hospice meant death, but as we watched you all take care of her, we realized it meant celebrating life.” – Mike M.*

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The term “hospice” comes from the word “hospitality”. It once referred to a place of shelter and rest for weary or ill travelers on a long journey. Today, hospice is a Medicare benefit that you are entitled to when you are nearing the last six-months of your life. It is a philosophy of care focused on comfort and quality of life, intended to give seriously ill patients and their loved ones meaningful time together when the focus is on the people, not the disease. (VITAS Healthcare, 2018) It involves a team-oriented approach to expert medical care, pain management, and spiritual support – all tailored to your individual needs. (National Hospice and Palliative Care Organization, 2017)

We hope that after reading this chapter you will realize why both patients and providers are beginning to see the gift that hospice truly is. Choosing to receive hospice care is an important decision that can greatly improve your quality of life in addition to providing support to your family. It does not mean you or anyone on your health care team is giving up, nor does it mean you will stop receiving medical care. In fact, there are some cases when it might make sense to continue with certain chemotherapy agents or radiation treatments if it will offer relief of certain symptoms. Choosing to receive hospice care simply shifts the focus of your health care team to providing you with the best possible quality of life, instead of trying to extend it. Learning more about hospice may help give you a clearer picture of what it includes. In addition, we hope this chapter is able to dispel some common myths many people believe when it comes to receiving hospice care.

Hospice can be very beneficial to patients and their families, especially when they begin receiving this care early – therefore if your oncologist does not bring it up, we suggest that you specifically ask to have a conversation about it. Having discussions about hospice care with your doctor and loved ones, well before you begin approaching the end of life, can greatly reduce the stress associated with making these decisions and prevent you or your family from being forced into uncomfortable conversations and situations that suddenly become time-sensitive.

Patients with advanced cancers should expect their oncologist to suggest enrolling in hospice once the doctor believes you have a reasonable prognosis of six-months or less to live. It is

important to note that patients can outlive this prognosis, and reassessment of your condition will be done at regular intervals. There is no limit on the amount of time a patient can spend under hospice care. In addition, if there is a change in your prognosis or you decide you want to return to attempting treatment again, you may elect to remove yourself from hospice at any time. Hospice is not a binding commitment to the end-of-life. Instead, it is a philosophy of treatment that aims to help you get the most out of life during a time when the end-of-life seems reasonably near.

When you and your doctor have decided it is best to begin shifting your goals of care to quality of life over quantity of life, your doctor will write a referral for you to receive hospice services. Usually within two days, a hospice program representative will be able to meet with you and your family to discuss your goals and desires. You can expect a team of many different experts to join your circle. The other members of your health care team remain the same, and will continue to be involved in your care as you need them. Enrolling in hospice will add the expertise of a specially trained hospice physician, as well as specially trained home health aides, social workers, counselors, or chaplains as needed.

Hospice care can be received almost anywhere. While some people prefer to receive this care in their home, others may have increasing care needs that require them to live somewhere else. Hospice care can be received regardless of your setting, whether you are or living at home, a nursing home, or residential facility. Care can also be received at a hospice inpatient facility or an acute care hospital. The location of care may change depending on the nature of your disease progression, your medical needs, as well as the plan of care established between you and the hospice. But no matter where you are, a team of experts will come to you in order to deliver specialized care and support for you and your family.

You may be wondering what, specifically, hospice care entails. Using the expertise of many team members, hospice utilizes a variety of means to alleviate physical and emotional pain and increase wellness to help you and your family cope with the change from fighting cancer to living life as fully as possible. The National Hospice and Palliative Care Organization provides a list of the many services that may be provided:

(National Hospice and Palliative Care Organization, 2017)

### **The Multi-Disciplinary Hospice Team:**

- Manages the patient's pain and other symptoms
- Assists the patient and family members with the emotional, psychosocial, and spiritual aspects of dying
- Provides medications and medical equipment

- Instructs the family on how to care for the patient
- Provides grief support and counseling
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Delivers special services like speech and physical therapy when needed
- Provides grief support and counseling to surviving family and friends

More specifically, services covered under the Medicare Hospice Benefit include: (American Society of Clinical Oncology, 2015)

- Care from a doctor
- Visits or care from a nurse, including 24-hour on-call services
- Supplies for your illness – For example, a brace, walker, or hospital bed.
- Medicines for pain and other symptoms – You might need to pay a small amount. But Medicare usually pays for the rest.
- Short-term care for your symptoms – If you go to a place Medicare approves, such as a Medicare-approved hospital.
- Short-term care in a care center so your main caregiver can rest. The medical term for this is “respite care.” You might need to pay a small amount.
- Services from a home health aide or housekeeper
- Counseling and spiritual support, including help with grief for you and your family
- Nutrition counseling

In regard to hospice, Medicare does **not** cover:

- Treatments for the cancer or other diseases that are causing your illness, except treatment to help symptoms.
- Care that is not from the Medicare-approved hospice program.

If you are not a Medicare recipient, your health insurance should cover the majority of these services.



Each individual will have unique conditions and preferences that may play a role in what treatments and services they would like to receive; as well as where they would like to receive them. It is important to express these preferences to your doctor, as well as your loved ones, as early as possible. In Lillie's book, *Fulfilling Hope: Supporting the Needs of Patients with Advanced Cancers*, she describes the story of when her father – after being diagnosed with metastatic prostate cancer – started conversations about what would happen when it was time for him to begin hospice. She writes, *“Included in this discussion was what setting he would want to receive hospice care. I knew that my mom would likely want him at home. I did as well. He surprised us and said that he wanted to be in the hospital at the cancer center. When I asked why, he said, “Because the people know me there. My doctors I trust and need are there.” This launched us, as a family, into a discussion about what the care would consist of and who would be providing it. Other factors were discussed like the ease of mom being able to spend more with him if he were to stay home, as well as dad's preference for control over his environment and the people in it. Thankfully, there was time before he would begin hospice care which enabled us to discuss this more. It was important that he not feel abandoned by his medical oncologist and palliative care doctor. Dad had brought up the time he experienced frustration a few months back when he was very sick with an infection and unable to bathe himself or even manage the toilet alone. The source of his frustration was that it caused him to lose his dignity having family members do this. This provided an important moment for me to explain to him that one of the benefits of hospice care will be the opportunity for nonfamily members to assist him with these types of activities of daily living - regardless of where he was living. He liked that concept, and soon thought it would be best to have hospice care at home. It was a way for him to maintain his dignity and spend more time with family, while still remaining in control of his environment – all of which aligned with his personal values.”* (Shockney L. , 2014)

This story highlights the importance of having conversations about your wishes surrounding hospice and end-of-life care as early as possible. In addition, it shows how it can be helpful for everyone involved when you communicate the reasons behind your desires. There are many ways to approach and receive hospice care, and how you do so will depend on your own values. Like all things when it comes to advanced cancer care, we find that early, open, and honest conversations will often lead to the best results for everyone involved.

## TRUTHS AND MYTHS ABOUT HOSPICE

There are many misconceptions when it comes to hospice care. Often, people do not like to ask questions or seek clarification of these misconceptions, as this may start what they feel is an uncomfortable discussion. However The Hospice Foundation of America has compiled a list of myths about hospice, while providing important information that dispels these common misconceptions (Hospice Foundation of America, 2014):

**Myth:** Hospice is giving up

**Truth:** Hospice is medical care toward the goal of comfort and dignity for someone whose life is drawing to a close. It is, in fact, the "something more" for someone who has been told nothing more can be done for them.

**Myth:** Hospice means I'm going to die soon

**Truth:** Hospice care neither hastens death nor prolongs life, although studies show patients with certain illnesses actually live somewhat longer with hospice care than those with the same illness who don't choose hospice care. And regardless of the illness, patient/family satisfaction with services received are consistently higher when hospice is involved.

**Myth:** You can't keep your own doctor if you enter a hospice program

**Truth:** Your family doctor or specialist is encouraged to remain engaged in your care. The Hospice Physician works closely with your doctor - who knows you better (medically) than anyone else - to determine the specific medical needs that will be addressed in your individual plan of care.

**Myth:** It is the doctor's responsibility to bring up hospice

**Truth:** While it is the physician's responsibility to determine whether a patient meets the medical eligibility criteria to receive hospice services, it is appropriate for the patient (or caregiver) to initiate the discussion if they choose. Since hospices consistently hear from their patients/families that they wish they had gotten hospice care sooner, it is a good idea to let the physician know AT THE TIME OF DIAGNOSIS that you are open to discussing hospice care at the appropriate time.

**Myth:** Once you choose hospice care there is no turning back

**Truth:** You are free to leave a hospice program at any time for any reason without penalty. You can re-enroll in a hospice program any time that you meet the medical eligibility criteria.

**Myth:** If you choose hospice care you won't get other medical care

**Truth:** While the hospice team will provide all aspects of care for the illness that qualifies you for hospice services, you are still free to seek treatment for unrelated illnesses or conditions. For example, if you are receiving hospice care for heart disease, you can still get treatment for a broken bone.

**Myth:** All hospices are the same

**Truth:** There are thousands of hospices in the United States. If they participate with Medicare, as most do, they are required to provide certain services to the patient and documentation to the government. In that respect, they are the same. However, hospices may be nonprofit or for-profit;

they may be community-based or serve many communities, cities or states from a central location; they may be independent or part of another organization such as a hospital, health system or private company. The point is that all hospices (that participate with Medicare) meet the same basic requirements although there likely are differences from one provider to the next.

The Hospice Compare site allows patients, family members, caregivers, and healthcare providers to compare hospice providers based on such important quality metrics as the percentage of patients that were screened for pain or difficult breathing. Currently, the data on Hospice Compare is based on information submitted by about 3,876 hospices:

<https://www.medicare.gov/hospicecompare/>

The National Hospice Organization and the Hospice Action Network has a great source of information on Hospice Care and the associated Medicare Hospice Benefit. This file provides written information as well as infographics to help you further understand the details of hospice.

[https://www.nhpco.org/sites/default/files/public/communications/Outreach/The\\_Medicare\\_Hospice\\_Benefit.pdf](https://www.nhpco.org/sites/default/files/public/communications/Outreach/The_Medicare_Hospice_Benefit.pdf)

The Hospice Foundation of America provides a free and confidential “Ask an Expert” form on their website. This offers personalized, confidential guidance to patients, families and other interested parties who have questions regarding hospice and care at the end of life.

<https://hospicefoundation.org/Ask-HFA>

## CHAPTER 8

### ORCHESTRATING AND PLANNING AHEAD TO EXPERIENCE A PEACEFUL DEATH

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#### MAY YOUR CHOICES REFLECT YOUR HOPES AND NOT YOUR FEARS- A QUOTE FROM NELSON MANDELA

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Your oncology team wants to help ensure that you receive the best care possible, delivered in the appropriate setting, in keeping with evidence based high quality standards of care, and is specific to the needs and desires of you, their patient. This could be summed up by calling it high quality patient centered care. There are times however that physicians and other oncology specialists don't know how or when to embark on a serious discussion with you about what your goals are, especially if you have found yourself going through different drug therapies and each time the treatments working less effectively than before. That's when it is time to speak up so that your voice is heard because treatment for treatment's sake is frankly bad care. You need to express your wishes, your goals, and make sure that what is being done now, today, is what YOU want. If you are getting sicker, and new lines of therapy are not working, and your time is spent getting treatments instead of spending it as you would prefer, then it's time to discuss taking a different path. A path that is more quality of life focused, to preserve your quality of life and steer away from less toxic drugs that are not helping anymore.

This chapter will focus on how to orchestrate such care, which in many incidences does not mean actively treating your disease but instead focuses on preserving quality of life as the priority. No one wants to see you suffering and in pain. We also don't want to see their family members looking devastated as they hold vigil at the your bedside hoping for a miracle, or hoping that some good will happen... anything at all good to happen. Unfortunately, family members can be content as long as you are still alive and breathing. Their anxiety about dealing with loss causes their brain to not be thinking about your well fair, but instead about theirs. This chapter will also define the components of a good death experience, as referenced in the title. By defining it, we are assisting the efforts needed to improve end of life care by learning from the breadth of preferences of dying patients and their family members who have come before you. Think of it as their legacy they are leaving for you. A wealth of wisdom and strategies that will enable you to reach a true sense of peace and have improved quality of life, free of toxic treatments. These elements become our framework for creating over time a good death [Steinhauser, Clipp, McNeilly, et al 2000].

Physicians find that providing quality end of life care can be hard but incredibly fulfilling for them and most importantly for you and your loved ones. Just as an orchestra is cued up by the conductor with all of the musicians playing from the same sheet music the same song, in the right key, that is specific to their contribution by playing their specific instrument, so will your

oncologist and the rest of the oncology multidisciplinary team taking care of you to orchestrate a good end of life final song. You however are the conductor. Remember the patient must remain in charge.

All clinicians take an oath---- “to do no harm.” Yet, somehow oncologists seem to lose sight of that when they are confronted with patients and their family members turning to them in the hope for a miracle cure or an extended time on this earth even if that extended time is riddled with so many side effects from treatment that it can hardly be thought of as really living. That’s why you need to take a pause and do some personal reflection. What do you want to do now that you know treatments are not working anymore? How do you define quality of life for yourself? Are you existing or still living and finding joy in each day?

This chapter will also hopefully demystify opinions and myths associated with the purpose and role palliative care plays in the care, so that when a doctor explains it to a you and your loved ones you and they will embrace it rather than see it as being forced to give up on them. This chapter also will provide information about hospice services and their tremendous value in supporting patients like yourself and your loved ones’ needs.

At the heart of this chapter is the importance of communication. Communication not just once when a doctor initiates a discussion with you about what treatments are available to try to get your cancer into control but the imperative need to keeping these communications going throughout the trajectory of this your care so that the oncology team is always focusing on what your needs and desires are. Your medical oncologist is standing alongside of you at the helm of your ship. Doctors cannot change the direction of the wind but they can by adjusting the sails. They need to know the direction you want to take in order to get you to the safe harbor you are seeking. Most patients trust their oncology team to be providing them the right care. Trust has been considered a primary factor in relationship building—building the relationship between the oncologist and the patient. Without trust, a cancer patient cannot experience a good death.

## INTRODUCTION

Terminally ill cancer patients are very concerned about experiencing pain and suffering that is not appropriately relieved, have fears regarding their future, feel frustrated with uncertainty, depressed about their loss of independence, worried about their family, and fear they are being a burden on their loved ones. These are universal concerns for such patients like yourself. Their personal experiences of these feelings are new and feel unique to them but in fact we hear and witness it every day. Since we have this knowledge and upon completion of this chapter hopefully even more knowledge about these concerns, then your oncology team needs to be held accountable to see it as their responsibility to address them. Some can be addressed as they occur; others can perhaps be addressed in a more proactive way through thoughtful and candid

discussions doctors have with their patients as they reach certain milestones with their care and approach end of life.

The oncology team has the ability, tools and resources to have their patients, including you, get to experience what would be referred to as a “good death.” And when your oncology providers reflect back on the care and treatment they provided to you, rather than having bad memories of the dying experience they can personally reflect on happy memories knowing they created a good experience for you and your family. (Remember we cannot change the direction of the wind but we have the power to still adjust the sails.) When we know within our hearts what the final outcome is going to be, we should prepare well in advance for it so it is done right. This is the most important medical care you will ever receive.

### **DEFINING WHAT IS MEANT BY THE PHRASE “A GOOD DEATH”**

What do we mean by a good death? Research has been conducted to provide a means of understanding from patients what constitutes a good death. A research study by Steinhauser et al provides insight into the major components of a good death. They are: management of pain and suffering; clear decision making; preparation for death; completion; contribution to others; and affirmation of the whole person [Steinhauser, Clipp, McNeilly, et al 2000]. Oncology specialists need to discuss each of these attributes of a good death with their patients and their loved ones so as to provide them the information they need at specific points in time. No one should die in pain. No one should feel confused or untrusting of how decisions are going to be made with them and potentially for them acknowledging and honoring their final wishes. Patients usually want to know what they might expect during the course of their illness and want to plan for these phases that would eventually lead to their death. Family members also need to learn from us what to expect with a special focus on the physical and psychosocial changes that would occur as their loved one approaches end of life and dies. Patients need to feel a connection spiritually and from that confirm a deep importance in the meaningfulness of their life at end of life; this needs to include resolutions of conflicts, spending time with family and friends, and even saying good bye. Contributing to others may seem odd but it is also very important. Giving to others doesn’t mean money, though for some it may. It could be a gift of time or gift of information that provides new knowledge. Most will say before their passing that they have learned that family and relationships are important above all else including money and careers. The patient also wants to be acknowledged as a whole person and not defined by their cancer. This too is very important for families to witness [Steinhauser, Clipp, McNeilly, et al 2000]. This too is important for you to experience.

### **LET’S BEGIN WITH SPIRITUALITY**

Spirituality is a prevalent experience that is inside of all of us unrelated to our religion or affiliation. When approaching end of life, even if a patient says they are not spiritual, they will

turn to a higher power of some kind usually for spiritual comfort. During times of uncertainty, human beings are known to feel a stronger sense of spirituality within themselves. It is a natural process associated with uncertainty at the end of life [Stephenson, Berry 2014].

Spirituality is a broad term and does not necessarily mean the patient or family have now acquired religious feelings or connections. It is considered part of everyday life and appeared in both religious and non-religious forms including a spiritual meaning of family relationships recognized as the chain of life, and seeking meaning and purpose and transcendence in life [Asgeursdottir, Sigurbjornsson, Traustadottis, et al 2013].

#### A Patient Story--- I bought a bible

*A patient with metastatic ovarian cancer was continuing to lose weight and feel weak. She asked her sister to buy her a bible from the bookstore as she did not previously own one. On a day I was visiting her she told me that she was reading the bible, a few pages each day, and was struggling to interpret the wording and in turn its meaning. She was very worried about this and stated so. When I asked her why she was worried she told me that she has not been a religious person in the traditional sense. She didn't go to church and had not read the bible before. She was worried that there would be a bible test in heaven that she would be required to take before allowed to enter heaven. At present she was confident that she would fail such a test. I told her that I doubted there would be an exam to pass and that perhaps it is better to focus on spirituality than religion. We sat and talked about that for a while. The hospice nurse arrived and I told her what the patient was fretting about. She arranged for the hospice chaplain to come to the patient's home. A few days later when I visited her again, she looked so much more peaceful. Her disease was of course progressing but her anxiety was low. I asked her what had happened to help her feel less worried. She told me that the chaplain had told her that reading the bible isn't necessary and that the patient in his opinion was a spiritual person and that one of the ways she was most connected to a high power was when she was out riding her horse. Connecting to nature and connecting to her horse the chaplain reassured her meant that she was spiritual person. The look of relief on this patient's face was palpable. A dear friend of hers, recognizing the importance this horse had in her life, tracked down where the horse was at that time. The patient had not seen this favorite four legged friend for 15 years. This friend arranged for the horse to be transported more than a thousand miles to her own horse farm and also arranged for the patient to stay there for several weeks so that she could enjoy seeing this animal and talking with him in the pasture. And when this patient died several weeks later her ashes were sprinkled in that field where the horse was. A year later when the horse died the cremated remains were also sprinkled there to blend the two forever together.*

## Patient Story- I don't like middle men

*I recall when the director of palliative care asked my father if he was a spiritual man and he confirmed he was. He went onto say however that he didn't trust priests or ministers per se. He didn't "need a middle man to talk to God." Hearing this provided more information about who my father was, which meant that the doctor could incorporate this spiritual knowledge into his treatment planning processes going forward.*

When one thinks about it, this all makes sense. We all need to feel we have had purpose in our lives and were valued for that purpose and understand it at a spiritual level. We also want to feel at peace with ourselves, our family, and feel a relationship with a higher power. We want to be thought of fondly after we are gone. We want to leave some kind of legacy (which doesn't necessarily mean money). When dealing with uncertainty, any concrete information about what lies ahead of them is valued. Being heard is important. Being treated with dignity and respect is key. The patient must know they can confidently trust us. We are responsible for preparing the patient and their loved ones for the patient's death.

## A Patient Story---- Experiencing and witnessing pain and suffering

*At each of our metastatic breast cancer retreats I ask the patients in one room and the spouses in another what their greatest fears are regarding what lies ahead. Along with worry about raising young children alone, no matter what the age of the patient, the person who is terminally ill will say, "The fear of pain and suffering and having my family witness it happening, leaving them with that image of me as I die." In the other room where the husbands are privately talking with a facilitator, their concerns focus on "being forced to witness their wives' experiencing pain and suffering and not being able to do anything about it." This tells me that there needs to be discussions about this concern early on. Rather than patients and their loved ones worrying about this, we need to explain that we know this is a common concern for patients and spouses and provide insight into how pain management will be effectively managed whenever it is needed. It is the perfect time to describe the role of palliative care. Palliative care is really quality of life preservation or quality of life restoration. All too often it is only discussed when a doctor initiates a conversation about hospice care. Palliative care can and should stand on its own and be introduced very early on, even before a patient actually needs this service.*

## A Patient - Analogy of a ship sailing out into the ocean

*At the metastatic breast cancer couples retreats I rely on an analogy to describe the process of death taking place. It is a verse about a ship authored by Henry VanDyke and is commonly found in hospice literature. When I describe it for the couples however I choose to paraphrase it for them. The paraphrased version goes like this--- It describes a family standing on a dock*



*watching as a huge magnificent looking white ship as it gets its cargo loaded on. Once that is completed the sails go up and the wind snaps the sails totally open and the ship begins to slowly leave the harbor sailing out into the ocean. Once it has gotten some distance from the shore the family admires the ship even more, looking at her powerfulness, her size as well as her grace. The ship gets smaller and smaller on the horizon line until then someone in the family says, “Oh no! She is gone!” But gone where? She is only gone from our sight. She is just as large in mast and hull as she was when she was at our side and just as able to carry her great freight to her new and final destination. Her size is just diminished in us but not in her. And as we stand here as family and friends and say “There she is gone” there are others on the other shore sending up the glad shout, “Look! Here she comes!” This is an extraordinary way to look at death in a peaceful way. It provides perspective that may not have been there before. The husbands who attend these retreats with their ill wives talk to me one by one and I explain what they will see in physical and psychological changes as their wives approach end of life. We discuss things like loss of appetite, weight loss, jaundice, urine darker and less output, wanting to just focus on simple things and feeling joy in simplicity, sleeping more, obtunded state, breathing changes..... However when the husband calls me following a doctor’s visit or hospice nurse assessment they don’t use these clinical terms. Instead they will say, “I think her sails are up this week.” or “she has definitely left the dock and is about half way out to the horizon line.” Then they will call me again to tell me when she “landed on the opposite shore” and who he believes was waiting there for her.” Husbands have candidly shared with me that by using this analogy they were able to talk to family and friends without breaking down emotionally. And that it is a peaceful way to picture their soul mate reaching a wonderful shore on the other side of life.*

Before reading more information, take a moment to watch this short animated video which is part 2 of the video series created specifically for you and your family:

<https://youtu.be/daYihwstRpM> part 2

## ELEMENTS THAT DEFINE QUALITY END OF LIFE CARE

Another study that truly taps into understanding the patients’ perspective regarding the hope of experiencing a good death was published by Singer et al. This study resulted in the following domains of quality end of life care being understood as important; they are: receiving adequate pain and symptoms management, avoiding inappropriate prolongation of dying, achieving a sense of control and relieving burden and strengthening relationships with loved ones [Singer, Martin, Kelner 1999].

Receiving adequate pain control and symptom management, a primary goal of palliative care, has been discussed in some degree here as well as a prior chapter. Avoiding inappropriate prolongation of dying however has not been and deserves to be further understood. Having a DNR (do not resuscitate) order can only happen with the patient if such a discussion takes place

between the doctor and the patient. There can be hesitancy to do so however. There are also family conflicts that can occur from the patient being too ill to speak on their own behalf leaving it to a family member to make decisions. The family member may want their loved one here “no matter what it takes” forgetting that the patient may be even suffering to stay alive. Again the oncology specialists must go back to what they all agreed to when becoming oncology clinicians—to do no harm. So discussions about life support, ICU admissions, invasive tests and procedures as well as treatments should be candidly discussed with you having the family present so that there is a clear understanding about what you want and why.

Patients also want a sense of control. Remember you are the one in charge. This means even when you reach a point in which you are not able to make decisions for yourselves. Your proxy is to ensure that your wishes will be carried out and not altered in anyway. This is after all your life and no one else’s.

Patient Story ---I am going to have it done my way

*My dad is big on control. When he was diagnosed with metastatic cancer he realized that his ability to predict the future was suddenly very limited. He doesn’t like uncertainty in any situation. So he turned to things that he first wanted to control, a primary one being that he wanted to make sure someone would be responsible for ensuring he was pain free as he died, that he was at home, and that he would die peacefully in his sleep. This of course required trusting others to carry these needs out on his behalf.*

*Next he decided to make all of his own funeral arrangements, from selection of the coffin, that he wanted to be buried wearing his shoes, that he didn’t want a viewing or formal funeral service, and who he would “allow” at his gravesite burial which was to be short and to the point. No fanfare. No one talking about him other than the minister saying a few brief words and even those words would be bible scriptures. He even wrote his own obituary which was incredibly brief and also to the point. He wanted a grave side service. Brief. Immediate family only. These were all things within his control and it gave him peace of mind I believe.*

There is a large price tag associated with the cost of hope. It is important to understand that you, the patient, doesn’t want to be a burden on your loved ones. This means physical burden, financial burden, and emotional burden. In the research study by Singer et al, patients specifically commented on these three burdens: provision of physical care, witnessing their death, and substituting decision making for life sustaining treatment [Singer, Martin, Kelner 1999].

Integral to their dying experience is the desire to have family members involved in communication about their upcoming death; this included discussing matters that may feel uncomfortable but in your eyes are very important [Singer, Martin, Kelner 1999]. Oncology providers need to help facilitate these discussions by discouraging the temptation to allow buffering to happen, thus avoiding a discussion about what the issues of importance are for you.

Relieving burden and strengthening relationships of loved ones are interconnected too. You may want their family involved in decisions about end of life treatments in some cases but commonly the patient wants to call the shots. This promotes comfort for the patient and a feeling of not being so isolated and alone. Treatment decisions in such cases become a group decision that may provide added comfort to the patient [Singer, Martin, Kelner 1999].

This particular study included information that compared various studies and organizations that have conducted research work associated with this important topic. Though overall they shared the same domains, there were some idiosyncrasies that made each organization or study results slightly different. We hope by having you read the types of dialogue and use of supportive questions your doctor may engage with you that you are better prepared for this type of candid and thought provoking discussion. There are situations too where the doctor fails to engage in this type of conversation. If that happens, you take charge and bring these issues up. You are not there to sooth the doctor's feels and enable his use of avoidance as his way to deal with this emotionally charged discussion. Simply take these statements and turn them around so that they are coming from YOU. We are letting you in on an inside track to learn how communication training is done so that you can optimize your discussions with your oncologist. This information is found in Figure II (164):

Figure II Practices: End-of-Life Communication Strategies by Oncologists

Theme	Supporting Questions
Communicating because of physician responsibly	Communicating about the end of life] is difficult in the sense that it is emotionally trying, but in terms of having the discussion . . . that has to be done at the time, and I see it helping to prepare and making sure that down the road that they know what to do. It's an educational piece of what we do.
Open and honest communication	Just by being open . . . trying not to hide things. I do not give timelines to people unless they ask me specifically. I think in terms of dealing with a palliative situation, I try to let them know this is not a curative situation, they will pass away from their cancer. I think throughout it all, it's just being open and honest.
Ongoing, early conversations	I'm pretty honest about expectations and things from the beginning, so it's not like something new . . . it's not like a bombshell or anything. It's pretty much from the first time you know that something is not curable; I think I'm very honest about telling the patients that.

Communicating about treatment goals	<p>I say, “we’re in a situation now where we’re going to be able to control your symptoms, hopefully you can have an appetite, not having pain . . . but this is not something that we can expect to cure and will likely cause your death.”</p> <p>They say, “What’s the success rate?” and I say to them, “Well what do you mean by success? We have very many measures of success. That doesn’t mean we can’t treat it, and we have to really talk realistically about our goals for treatment.” I mean these are words that I use every day of my life for my new patients.</p>
Balancing hope and reality	<p>I try let them know this is not a curative situation . . . on the other side of that, you don’t want to take away all hope as well too, until the point where there really isn’t much. So . . . you want them to be realistic but also not completely devastated.</p> <p>I think you do have to have good communication skills and you have to have a lot of true empathy and be able to express that well and be supportive. To be able to walk that very fine line of being optimistic and being hopeful, whereas not give people false hope or unrealistic expectations. That’s a challenging thing but I think it’s important. Some of my patients used to call me Dr. Death because they thought I was perhaps too negative sometimes, and I think that’s probably something I’ve developed. I don’t think you do people a favor by letting them think they’re going to live forever or so I think I’ve probably become better in terms of balancing hope and optimism with the difficult reality sometimes.</p>
Taking cues from patients	<p>There’s not a specific plan for discussions about death and dying. I will talk about whatever you want to talk about, and again, for things you don’t want to talk about, that’s okay.</p>

	If they tell you that they're not comfortable with the fact that they're dying, then I guess they already know, and I don't think that it's really up to me to give them information that they don't necessarily want to hear
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Communicating about the end of life with patients has been reported as one of the most difficult and stressful parts of an oncologist's job. There is little training however provided how to do this well or how to gain confidence so that doing it becomes less difficult. We know however that communicating well is very important to our patients and that the ability to communicate well results in good patient care and better patient satisfaction [Granek, Kryzanowska, Tozer, et al 2013], [Covinsky, Fuller, Yaffe, et al 2000].

Without effective communication that occurs each time you are with the doctor and also with your loved ones, your oncologist will not be successful in supporting your needs in the manner in which deserve and deserve. Your doctors and other support staff should be working to help you to live in harmony with your cancer until the time comes to receive end of life care which at its core is palliative care and hospice services. This is what fosters a good death experience. Even the Institute of Medicine National Cancer Advisory Board determined that most cancer patients experience suboptimal outcomes and that it is because of lack of communication primarily being the barrier [Smith 2000].

## **DISCUSSIONS WHEN CHEMOTHERAPY MAY BE FUTILE**

There is a point when what your doctors need to do is to help you reach the conclusion that more treatment is not wise and instead hospice support and the continuation of palliative care is the path to now take. This discussion should cover what is important to you. Here are several discussion points that should be covered:

Curing you of this disease is not possible. Knowing that, what are your goals and hopes for the future? Your future? Your family's future?

Take some time to talk about options to help ensure that you are comfortable and enjoy the highest quality of life possible in the time that remains of your life.

I (Lillie Shockney) have personally had the privilege of being in the consult room with Dr. Thomas Smith, the director of our palliative care program at Johns Hopkins. He recommends asking these questions of the patient:

1. What are you hoping for?
2. What is important to you?
3. What are you most worried about?
4. What brings you joy?

These questions are actually carried on the lanyards of each oncology clinician at Johns Hopkins as a friendly reminder to glance at them before going in the room with a patient who has advanced cancer. These questions are not only poignant but also provide great insight into where a patient is across the various transitions of hope. Dr. Smith, who personally took care of my own father, specifically asks these questions when engaging in a dialogue with him about his current information needs as well as his understanding of his current health situation. We begin in this manner:

- We ask the patient---
  - How much do you want to know about your cancer?
  - Tell me what you currently know about your cancer?
  - Who do you want to include in discussions about your cancer and its treatment options?
  - Do you want to have information written down by me regarding your cancer
  - Tell me what is important to you?
  - Tell me what you are hoping for?
  - Now tell me your understanding of your clinical situation....

By applying these questions in the right environment, spoken in a soft tone, with good eye contact and pauses between the questions to allow for adequate thought and response, your doctors are able to more effectively address your emotional needs as well as their practical, functional and spiritual needs while simultaneously reducing or at least minimizing your distress. It can be hard for you to accept their diagnosis and its prognosis. Some patients want to sustain life at any cost. We hope that you are able to take a step back and reassess what will be the best thing for you, and for your family when you eventually reach this juncture. [Weissman 2004].

If you are not being asked such questions, consider taking the questions with you and YOU using them as talking points with your oncologist. Take these questions every time you go for your appointments. Provide the information in statements such as “What I am hoping for now is the ability to leave my family without any financial debt caused by my cancer treatment. They keep

telling me that money doesn't matter and they want me to continue to fight and get treatment but I am a realist and can see that I am getting sicker and treatments are not working."

#### Patient Story—Quality of Life Coach

*When my dad was in terrible pain from a T-5 vertebral fracture, I arranged for him to have a consultation with the director of palliative care here at Hopkins. I personally feared that if dad heard the term "palliative care" he would get upset and assume what I have just described has happened with other cancer patients—that death is impending. So I contacted the oncologist, told him my concerns, and told him I was going to introduce him as the "Hopkins quality of life coach." The doctor even removed his ID badge as to have nothing labeling him with palliative care. The consultation was just the right medicine he needed, beginning with a discussion about what are three things that give my father joy. The treatment was focused on those joys—restoring them to him so he could enjoy them once again. Nerve blocks and other symptom management was achieved without having him sleepy from narcotics. He was able to resume his chemotherapy at a later time, knocking the disease down, taking drug holidays, then when it resumed a certain growth level the chemo was administered again to knock it down. Symptom management provided him quality of life.*

### CHOOSING THE SETTING OF CARE FOR END OF LIFE

Though most patients prefer to receive end of life hospice care at home, unless there is a discussion about this important issue, patients can end up hospitalized in a cancer center without hospice being initiated, or at a Hospice facility, when they wanted to be home with hospice care. Lack of understanding what types of hospice care can take place in the home setting or if goals are not understood, can result in patients ending up dying where they least prefer. There can also be disagreement among the family members where they want their loved one to be. It is important that the patient be the one making the decision and that the rationale for their decision is understood by everyone. Without effective communication, patients may make a decision that is not in their best interest. Without family members knowing how a patient made their decision regarding the setting for end of life, some family members may get frustrated and want the setting changed once established. Below are two patient stories that echo these issues. So you need to give thought to this regarding what you want. Remember, the patient is to remain in charge.

#### Patient Story—You didn't ask me

*A young woman who was originally diagnosed with stage IIb breast cancer had reached her 6 year anniversary post treatment and was given the "go ahead" by her oncologist that it was*

*okay to proceed in trying to have a baby. While literally trying to conceive, she experienced a grand mal seizure and was rushed to the cancer center by ambulance. The outcome sadly was the discovery of brain metastasis. After extensive treatment, decisions were made with her and her husband to stop active treatment and begin hospice care. The patient, age 36, decided she preferred to be at a Hospice facility than to receive hospice at home. The husband respected her wishes and a few days later she was admitted to a hospice facility. This facility was 45 minutes from their home. Her husband visited daily after work and grew more and more frustrated with the amount of time he was spending in travel time that he felt was “lost time” for them to be together. She only smiled when he verbalized his frustration about this. As weeks progressed and she grew weaker and more obtunded, her husband was advised to stay with her. The day before she died I had the good fortune to visit her. Her husband was very worried and frustrated that day as he could see his wife slipping away from him. He blurted out that he wished he knew why she chose to be “in this place instead of in our home.” He was happy with her care but wanted more time with her and felt that had been forfeited allowing her to be admitted to this hospice facility. The patient opened her eyes and said, “You never asked me why I wanted to be here instead dying at home.” He just stared at her. I then asked, “Tell me why you wanted to be here instead of home.” The patient told me that as I knew they were trying to conceive a baby when she had a seizure and the rest of her story was well known to me. She wanted her husband to remarry and become a daddy and she knew he would be a great dad. She worried that he wouldn’t feel comfortable conceiving a baby in their home if she died in their house, especially if she died in their bedroom. (Wow. This was a gift to him that nearly was lost due to a failure to inquire of the patient her rationale for wanting to die outside of her home.)*

#### **Patient Story—I want to be cared for by people who know me**

*My dad reached a point of needing to make shared decisions regarding continuing treatment versus stopping treatment. Included in this discussion was what setting he would want to receive hospice care. I knew that my mom would likely want him at home. I did as well. He surprised us and said that he wanted to be “in the hospital at the Hopkins cancer center.” When I asked “why” he said, “Because the people know me there. My doctors I trust and need are there.” This launched us as a family into a discussion about what the care would consist of, who would be providing it, the ease of mom being able to spend more time with him if he was home with her, and that he likes control over his environment and the people within it. There was time before he would begin hospice care which enabled us to discuss this more. It was important that he not feel abandoned by his medical oncologist and palliative care doctor. During this time he mentioned to me his frustration a few months back when he was very sick with an infection and unable to bathe himself or even manage the toilet alone and that it caused him to lose his dignity having family members do this. I mentioned to him that one of the benefits of hospice care will be the opportunity for nonfamily members to assist him with these types of activities of daily living. He liked that concept. He agreed to have hospice home care.*



## TALKING THE SAME LANGUAGE

There is a tendency for oncologists to use terminology that can cause confusion or misinterpretation. Below are common medical language you will likely be hearing and what its intended meanings are:

Figure VIII Medical Language versus Common Language (572)

Medical Language	Common Language
Cure	The cancer is gone and won't come back
Control	Slow or stop growth for a time
Complete response; remission	There is no evidence of cancer, but it could come back
Partial response	The cancer is still there, but smaller
Stable disease	The cancer is still the same
Progressive disease	The cancer is worse

Patient Story—I trust you...

*Last year I received a phone call from one of our medical oncologists. A patient who had completed her treatment for stage Ia breast cancer had developed symptoms that appeared to potentially be related to metastatic recurrence. Prior to seeing the medical oncologist for the first time a series of scans were performed for staging work up purposes. The oncologist then called her and told her that he needed to see her, recommended that she bring a family member with her, and told her that he had concerning news to give her. Her response was not what he anticipated. She told him, "If I am going to get bad news I want to get it from someone I trust. I don't know you yet. I want the news, whatever it is, to come from Lillie Shockney. I trust her." The oncologist in turn contacted me and relayed the information to me and her request. This patient was someone I knew well. She was also an employee at Hopkins. I called her and asked her to come over to see me when she was free. We spent more than an hour together. We discussed the goals of treatment—control of the disease and not cure of the disease. We talked about what likely would be the treatment that begins first, such as hormonal therapy rather than chemotherapy and why. We discussed her son who was a teenager. No husband and no other children. I told her that the mission now was to get the disease to shrink down, hopefully relieving some of her pain symptoms, and that we hoped she would live in harmony with the disease for several years. We discussed how to communicate this information with her son, and with her boss. She wanted to work for as long as possible. When she left me she said, "Thanks for being candid and honest with me. I trusted you from the start when I was diagnosed 4 years ago. I knew I could trust you to tell me the truth so I know how to plan for what lies ahead."*

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## MAINTAINING HOPE THROUGH SETTING GOALS

If your oncology team uses the right language when communicating to you and your family about the goals of treatment and what to anticipate next and encourage you to ask questions then you are well underway in getting the support you deserve. Your doctor should want to perform decision making in such a way as to still promote hope while avoiding the pitfalls of unrealistic hope. This is accomplished by setting goals. When you first met your oncologist there are several possible goals that you were hoping for—a cure, a prolonged life, an understanding of what to expect will be happening to them, to feel comfortable free and from anxiety, to not feel frightened, or to improve or maintain their quality of life [Von Roenn, von Gunten 2003]. Having a thoughtful conversation with you about which of these goals are hoped for, which ones are your doctors trying to accomplish, and which goals are the most important to you sets your team and you on a pathway with them that will foster understanding and maintain hope. Each time, starting with that first visit, your doctor will want to prepare you for goal oriented care discussions. Your doctor should discuss how information will be shared between you and him and the rest of the team. Request that your doctors and nurses are always be honest with you. It is important that you know how and when decisions regarding your care and treatment will be made. Your doctor should make you aware of the process that is planned to followed (such as scans or progression of symptoms) to know when a new decision point will next occur. You may be ready to discuss perceptions of your prognosis and goals of treatment the first time you meet with the doctor and other patients may not be as ready. It is critically important for this to be an ongoing conversation over time and not a one-time discussion. You are on a journey and your oncology team is accompanying you on this journey, leading you, guiding you, but always with your input so you stand with the doctors at the helm if you wish. And early access to palliative care is critically important. Remember it is quality of life preservation. Engaging in palliative care late really is an injustice to our patients and their families.

There are patients, and you may be one of them, who will want to try everything possible to attempt to overcome the disease. These people are fighters and they feel hope in demonstrating their ability to fight. Others may take a different tact and want to do things in a more methodical way, analyzing each clinical situation and making informed decisions about the risks and benefits of each option. Whose goal is it that the patient is trying to achieve is important information to factor in too [Bon Roenn, Perlin, Bylund, et al 2003]. Is the patient's decision to continue treatment to please their daughter? There will be a point in time however that the doctor needs to reorient you and your family to focus on end of life planning. The doctors need to provide factual information about the high risk and low benefit of treatment and reiterate the importance of preserving quality of life so their remaining time is spent comfortably with family and friends.

## A Patient Story—I think I will buy that jacket today

*A metastatic cancer patient was attending a cancer awareness function. Her treatments had ended and she was receiving hospice care at home. Girlfriends had gone to her home, swept her up, and took her to this luncheon for part of the afternoon. There was a room of vendor tables adjacent to the place where the luncheon was held. Part of the proceeds went to support patients diagnosed with cancer. She made her way around to several of the vendor tables and spotted a fall jacket she liked. This event was held in the spring. She decided to purchase the jacket. When she got back to her luncheon table and showed everyone what she had just bought they were quiet at first and then commented how beautiful it was. What people were worrying though was whether she would be here to be able to actually wear in the fall. Would she live to wear this jacket? Obviously that was her hope, and quickly the hope became a shared hope around that table.*

## A Patient Story--- You have a tough job

*My dad was here at Hopkins for the purpose of discussing what would be the next steps for him regarding his metastatic prostate cancer. He was in bed 20 out of 24 hours a day. He was only up for some meals, to watch a special TV show, or just watch the birds outside which became something he enjoyed. He was walking short distances with a walker but mostly was relying on his wheelchair. He had been on oral chemotherapy for a few months without it slowing down the cancer at all. Drugs he had been receiving were making him very very sick, stealing away his quality of life.*

*I had had conversations with both his medical oncologist and his palliative care oncologist 2 weeks prior to his appointments and again one week before hand to give them information about his performance status and gain a sense of what to expect would be happening at this consultative visit. The response I received from both was this--- hospice. This was hard for me to hear as a daughter but certainly the right thing to here as an oncology clinician. I visited my parents prior to this appointment to discuss with them how dad was doing and what was he “hoping” would be the outcome of this upcoming visit. He said that he was tired of being tired. He was frustrated with not being able to do things for himself. He felt that his cancer was likely growing despite taking the chemo pills. He was hoping that they would tell him that he doesn’t have to try to be up more and to try to be more active but instead to let him just be comfortable now. He even said that he was ready to die. My mom did not like hearing that however she was quiet. I told him that likely a discussion about hospice care may take place and what that means. He totally trusted these two physicians and would expect them to tell him the truth as he always knows they have and agreed to do from the first day he met them. He didn’t want to be in pain. He was worried at first of the concept of hospice at home but it was due to the fear that my mother would be upset about him dying in their bed. She assured him that this was not a problem*

*for her and that she too liked the idea of hospice at home if this was the point they were now reaching in his care.*

*These appointments took place on the same day. He saw the medical oncologist first at our satellite outpatient cancer center location. The doctor was thoughtful and pragmatic in explaining that his blood test done today showed his PSA to be in the thousands now whereas before it was 80. The cancer was definitely growing and spreading and the chemotherapy he was taking orally at home was not working. There was one other IV chemotherapy he was a candidate for but it was high risk for him to attempt to take likely causing him hospitalization and might even hasten his death and the benefit was marginal. He then said that he felt the time was right now for hospice. He talked about the types of care provided by hospice for him as well as for us, his family. He discussed the importance of taking time to get closure with his life, spend time with family, and gain a sense of spiritual peace. He said he was sorry that he “could not do more for him.” The doctor talked about what an amazing family he has with a loving wife and 2 children he is very proud of. He mentioned the long farming career he aspired to and served as a mentor for other young farmers in his region. Though I felt choked up hearing these words I felt the need to speak up and remind the oncologist and my dad that when dad began his treatment for metastatic disease the hope was that he would survive 2 years and that now he was at 5 years and still with us. This seemed to perk up both the doctor and my father, realizing that in a way dad had beaten the disease after all. When however the doctor left the room to get a prescription pad to give dad a medication needed to control mucositis, my father’s face looked like a deer caught in the headlights. He said, “Even though I thought I would be hearing today what I just heard, it still is a shock.” As we were leaving the oncologist’s office with just my mother and I remaining, the oncologist stopped us to give us both a hug and tell us what an amazing man my father is. He also told all of us that he was just a phone call away and would also remain in touch with the hospice team that would be taking care of him at home. (In other words, dad was not being abandoned; nor were we). My father ended our meeting with the doctor by saying to him, “You have a very tough job. I know today must have been hard for you, knowing you would be giving me this news. But it is okay and I thank you for all that you have done for me.” The doctor said privately to me before I that he knew this had to be hard for me, not just it being my father as the patient but also hard since I work in this field. He was right. We next traveled downtown to the cancer center building for dad to meet with the palliative care oncologist. He explained first that he and the medical oncologist had spoken on the phone so he was aware of what had transpired a few hours ago. He then talked with dad about how he was feeling physically and emotionally. He wanted to know his pain level, whether he was sleeping or not. Then he asked probably the most important question of all.—what was his understanding of how much time he had left to live? Dad said that he had had this discussion in the car after having left the oncologist’s office and now was downtown seeing him. My dad thought he had 2-4 weeks to live. We, his family (my mother, brother and I) told him we thought more like 4-6 months. The doctor responded by saying that his family was correct. There was a bit of a relief*

*on his face now. Was he hopeful? Yes he was. Then the doctor asked him more personal questions—how long had he and mom been married (67+ years), how long did they date prior to that (4 years). He talked to dad about leaving a legacy through his children and grandchildren and great-grandchildren. Dad said that he had had his affairs in order for quite some time because he is a planner. Always has been. Always plans for the worst too. My mother agreed. Dad reminisced for a few moments about their married life and farm life together. The doctor was quiet, listening to every word, never looking rushed, and always engaged. He reassured my dad as well as us that he would still be involved in his care and was just a phone call or email away whenever needed. (Again, providing that reassurance that no abandonment was going to be happening to dad or to us.) The doctor then told him that when he goes home today nothing is going to change except that now there would be additional resources to support him and his family. He also mentioned that hospice would remain in his family's life even after he was gone. Dad looked surprised but liked knowing that. The doctor asked him farming questions which immediately perked up my dad. The doctor also grew up on a farm. They shared a connection. They have had a long standing relationship of trust and respect throughout dad's care. So the focus now would be on palliative care and preservation of things that gave my dad joy. And he still had hope... and would until his last breath on this earth.*

*On Christmas Eve, which occurred ten days after dad's last appointments at Hopkins, I got my husband into a Santa suit and traveled the 2 hour distance to surprise my parents with a visit from Santa. Santa asked dad what he hoped for Christmas. Just in talking to him on the phone that day he sounded better than he did prior to last week's visits to his doctors. He knows where he stands. He knows that the goal of care is focused on doing what he needs and wants done for him. No more blood draws. No more Ivs. So what does he want for Christmas? A good death. (He died January 11<sup>th</sup>) (Shockney, 2014)*

## THE ELEMENTS THAT ARE NEEDED TO ENSURE YOU EXPERIENCE A GOOD DEATH

Everyone deserves to experience a good death, no matter what their cause of illness. For those of you dealing with advanced cancer, you have time to do this right, and do it the way you want to have it done. Below is a recap of the elements. Read each one and think about each one. Consider reviewing one a week or several if you can. Use them like a check list. You and your family will be glad you chose to take this approach to getting closure with your life, your loved ones, and doing things your way:

### First element: Know One's Purpose for Living

You need to know what your purpose for living has been and that it was valued by at least one other person. Everyone, including ourselves, needs to know why we are here—why are you here—what was the purpose of having been born and lived out your life however short or long it

was. For some patients this comes easily. A school teacher may reflect on all of the students she has taught over her 35 years being in the school system, and takes pride in knowing she provided perhaps the foundation of learning and created enthusiasm among her students to learn. She reflects on where some of these students are today, the career paths they chose, and the differences they are now making in the world. Ideally, your navigator could communicate with your family and ask that the school system help in reaching students from long ago to write this patient letters of about her importance in their lives to further reaffirm that she had a significant purpose in having lived.

#### Second element— Leave a Legacy

You need to know what legacy you are leaving on this earth after you are gone. Such a legacy does not mean you need to leave a boatload of money for something, like an endowment in your name. It can be a philosophy of how you approached your cancer journey.

We all need to have a legacy. A patient of mine with stage 4 breast cancer left a mantra that I carry for her now. Her mantra was--- “Those of us with advanced cancer have the ability to choose whether we know it or not. We can choose to live each day with our cancer or die each day with our cancer. I chose to live each day. I hope you do too. “I tell this constantly to patients. My own father heard my patient say these words at an event she wanted to hold that was on her bucket list. This event gathered together families of multiple generations for which one of these family members had metastatic disease. My dad had metastatic cancer and upon learning that verdict sold his farms. He loved being a farmer and now was a depressed couch potato. He attended this event. Four generations of my family were present. The following day he called me at work and said, “Guess what I did this morning? I bought back one of my farms. I listened to that lady yesterday. She said that I could choose to live or die with my cancer. I had chosen the wrong way so now I will continue to be a farmer because farming is my greatest joy.” So you can see how such a philosophy became that patient’s legacy. I told her I would always carry that mantra with me. I also reminded her of the huge impact her words had on one family that was there—my family—and that no doubt other families had similar inspirational experiences happen too.

#### Third element– Leaving no financial debt for family to pay associated with your cancer treatments.

Today, with health care costs more out of control than ever, patients are destined to be in debt when their treatments are finished. For those with metastatic disease, that debt snowballs during the last month of their lives usually. Drug costs are staggering and insurance no longer is paying 100%. Between deductibles and co-payments, it is easy to leave debt of hundreds of thousands of dollars to be paid by family members left behind. Patients do not want to leave any financial debt to be assumed by their loved ones due to cancer treatments that failed or even those that worked, for a while. This means you and your doctors need to have thoughtful candid discussions

together about what YOUR goals of care are. What your financial situation is like. A navigator may be able to get discounted drugs for you but that is likely not adequate in covering the real healthcare expenses you are and have already dealt with. Your navigator's mission on your behalf needs to be avoid financial toxicity. Treatment for treatment sake is bad car. Your navigator needs to advocate for you. If you want to stop treatment because you are looking at risks, benefits and cost, that is your right. Let your navigator or other member of your oncology team to be your voice to ensure this happens as you wish for it to.

#### Fourth element—forgiveness: giving and receiving it

Giving forgiveness and receiving forgiveness doesn't happen in an afternoon or even overnight. This requires thoughtful reflection, planning and decision making. There can be family feuds that have existed for decades. There can be grudges still being held by both sides. And you by no means are required to forgive or ask for forgiveness. You do need to think about these people however and these situations and make conscious decisions if you want to leave this world as things are—broken—or consider mending some fences. Some fences are only mended on one side too. It is wrong to ask you to “forgive and forget” – forget? That's really impossible. It's an unrealistic expectation so discuss this because the person you are considering forgiving may actually request them to forgive and to forget.

Those in need of forgiveness may decline to come. Those who you want to forgive may not be ready for such a discussion either. This may therefore require you to write a letter, with help from others if you are too physically weak to manage it on your own. There is a sense of a freeing of the spirit when someone gives and receives forgiveness. This process takes time. Usually several weeks. It must begin sooner versus later.

#### Fifth element— being spoken of fondly after you are gone

To experience a good death you must feel confident you will be spoken of fondly after you are gone. Some patients actually decline to have a viewing and sometimes even decline a funeral because of concern they will not be spoken of fondly by those who attend either one. Reminds me of Charles Dickens' A Christmas Carol when Scrooge got to witness townsmen talking about him in a negative way just hours after he was found dead at home. Ask yourself how you believe you will be spoken of later on. Are you viewed from your perspective as a kind person? Loving father? Hard worker? Are there any negative images you have of yourself or you worry others may have of you? Talk about them with someone you trust.

#### Sixth element --- Being pain free

The greatest concern that patients have about approaching end of life is not dying but experiencing the dying process for which they fear will be riddled with pain and suffering. This is why palliative care is so important to engage early. Also let's undo the myths of what palliative care is. I personally don't refer to it as palliative care—it is quality of life preservation or quality of life restoration. Pain management is the number one concern and priority. You need

to meet with palliative care provider and form a relationship early on. There is comfort in knowing that they will be there for you when you need them. Learn how they go about deciding what are the best ways to manage your symptoms so that you can experience a peaceful closure with your life and passing. Narcotics are not the only way to manage pain either. It may be nerve blocks that solves the problem. Focused radiation on one spot where a nerve is pressing on a cancerous lesion. Oncologists more commonly use narcotics and keep increasing the dosage. Palliative care doctors look for ways the patient can remain awake and still interacting with their loved ones, so they are not merely just existing, sleeping away the remainder of their life.

#### Seventh element—dying with dignity and in the environment of your own choosing

Patients want to die with dignity and in the environment of the patient's choosing. If asked 91% will choose hospice at home. Only 24% get asked. Sadly 26% die in an ICU because there was no end of life discussion that ever took place. Awful. Again, this is a discussion that needs to happen sooner vs later. It needs to be tied to YOUR goals regarding WHY you are getting treatment. Is this how you want to live out the remainder of your life? Getting toxic treatments? Usually not, but you "don't want to your doctor's feelings or your children's feelings, or somebody else who expects you to keep on fighting. Doing toxic treatment to the end hastens death and robs you of any quality of life. That is just plain wrong. Remember, you need to call the shots how long you want to receive treatment, when you want to stop and where you want to die. Write down for yourself what criteria you are using to reach these significant and profound decisions.

#### Eighth element – Having all legal and financial affairs in order

Unfortunately it remains even today that an oncologist doesn't mention getting these affairs in order until he discusses hospice care and that means there isn't enough time to do this important element. The average number of days a patient receives hospice care in the US today is just 5 days when it is intended to be for 6 months. So frankly, every person on this earth who is an adult should have their affairs in order, long before these affairs need to be actually carried out. If this isn't done, family members can be left with a real legal mess on their hands, and during a time they are already grieving losing you. If you didn't even have cancer, you still should already have such documents in place. So do this one soon. Don't delay. Earlier in this book there was information provided about what is needed to fulfill this important element and pro bono lawyers are available to help you get this done for free.

#### Ninth element—spiritual connection

This was mentioned at the beginning of this chapter because it is commonly something patients worry about. Not all patients are religious. Actually some abandon God due to having become diagnosed and feeling cheated out of the remainder of their lives. Others are spiritual from the start, which can rub their family members the wrong way who are now the ones angry with God. Talking about hope, soul, spirit, and not necessarily religion per se is a good way to embark on a



discussion about this important subject. It is important for you to feel a connection to a higher power, even if that doesn't happen until the nth hour.

So now you know all of the elements that are needed to be in place to orchestrate a good death experience for yourself. It is absolutely one of the best things you can do for yourself and for your loved ones. The peace you will feel will be profound and long lasting. Now let's discuss information about what to expect as you are approaching end of life. Rarely is this discussed with patients or even their family members, unless brought up in broad terms by a hospice staff member. Removing some of the uncertainty will be helpful however. Keep in mind that what is written here doesn't apply to everyone; each has their own experience and their own closure. This section will provide you insight that removes some of the guessing about what certain symptoms mean, and how to help relieve them too.

## Nearing the End of Life

(Abstracted from the American Cancer Society's Website [www.cancer.org](http://www.cancer.org) )

This can be a time to focus on physical, spiritual, emotional, and family concerns. Patients and family members often have questions about what might happen during these last months of life. Understanding what to expect both physically and emotionally during these last few months might help you live fully and get the most out of this last phase of your life. This is written for you who has advanced cancer, but it can be helpful to the family caregivers who is taking care of you and love you, too. So consider encouraging them to read this section of the guide too.

### Emotions you may experience

Knowing that death is coming soon takes an emotional toll on you and your loved ones. This is an emotional time, and though it's hard to talk about them, these issues must be addressed. Knowing these feelings are normal and expected may help you cope with what's happening. Some of the emotions you can expect to have include:

### Fear

People are often afraid to die, but pinpointing what part of death they're afraid of can be helpful. Are they afraid of dying alone? Are they afraid of suffering or pain? Are they afraid they'll die and there will be nothing beyond earthly life? Is there a fear that their lives had no purpose or meaning? These are some of the more common reasons that people fear death.

Trying to figure out what you fear can help you face it and manage it. It will also help others support and care for you better. For example, if you're afraid of being alone, share this with your family and loved ones so they can try to always have someone with you. Sharing with loved ones and your health care team gives them a chance to help you find ways to cope with and ease some of your fears. It gives them a chance to correct any wrong ideas you may have, too. It can also give you a chance to look at and deal with some of your fears in new ways.

A common fear is the fear of dying in a state of pain and suffering. This is why palliative care as well as hospice care is so important and should not be saved for the finale. You deserve being pain free, dying with dignity, and with as much quality of life preserved as possible for you.

### Anger

Anger is sometimes hard to identify. Very few people actually feel ready to die. It's perfectly normal to feel angry about your life ending – maybe earlier than you expected. It's unfair and you have a right to be mad! Unfortunately, anger often gets directed at those closest to us, the ones we love the most. We feel safest with these people and know they'll probably accept our anger and forgive us for it. But it might help to try to direct your anger at the disease and not your loved ones. Also, you can try to channel your anger as a source of energy to help you take action where it's needed. You can use it as fuel to solve problems, to become assertive, or to get your needs met. Try to re-channel your anger to do meaningful, positive things.

### Guilt and regret

In the last few months of life, a person might regret or feel guilty about many things. We feel regret when we think that we should have done something differently. Or maybe there's something we wish we had not done at all. We may feel guilty when we don't meet our own or think we don't meet someone else's expectations. But how does it help anyone if you hold onto guilt or regret? Worrying endlessly about these things won't make you feel better about them. It won't improve your relationships with family members. It won't ease the burden they're carrying. It won't make you feel better. It won't make you live longer. It will only make you feel bad.

Sometimes the best thing to do is to decide to “let yourself off the hook” and spend your last days and months not feeling guilty about things that are out of your control. Simply let it go. You can't change the past, but there are things you might be able to do today. Apologize for the things you regret and ask for forgiveness. Be willing to forgive others and yourself. Fix what can be fixed and try to let go of the things that can't be changed.

This is a good time to talk with your children about the important things you want them to know. It's also good to talk to them about how to handle their feelings and the loss they will soon go through. You may want to write letters to the people you love, record messages for them, or make videos they can watch – give them things they can keep to remember their time with you. Tell your kids who they can talk with when you're gone and encourage them to be open when they're hurting. Spend your time focusing on your children's future, not feeling guilty about the past. Strengthen your relationships with loved ones. Live the best life you can, and use your time for what's most important to you.

## Grief

It's natural to feel intense grief during the last months of your life. You're grieving the loss of the life you planned and expected. You can no longer look ahead to a seemingly "endless" future. And you may have lost many things already, such as the strength to walk or get around like you used to, or the interest in eating the things you enjoy, or maybe the ability to get together with friends. You may feel distanced from friends who cannot handle the fact you are going to die soon. This is another loss that can cause sadness and grief. Many physical and emotional losses come before the loss of life itself.

The people you love are grieving too. They know they're about to lose you. How can you and those who love you find meaning in what's happening? Try to talk to your loved ones about the grief and loss of dreams you're all going through. Being able to rise above the grief and connect spiritually to something greater than one's self might help your loved ones heal after you are gone.

Talking with someone about these feelings – a partner, a dear friend, a spiritual advisor, someone you trust – can help you process these feelings so that they no longer weigh you down. It may take many tries, but once you've done this you'll feel a burden has been lifted and you can move on to the other physical and emotional tasks that are part of the end of life. There are many important tasks at the end of life, but coming to terms with the losses is one of the most painful.

## Anxiety and depression

What does anxiety feel like? Anxiety has been described as having a nervous stomach, a shaky feeling all over, being short-tempered, a sense of dread or worry, or a fear of the unknown. It can be quite unpleasant.

Some anxiety is expected, but if it's severe it may need to be treated through counseling or with medicine. The goal is to make you more comfortable and help you better cope with the changes that are taking place. Anti-anxiety medicines or even anti-depressants can help. Counseling can be especially helpful in changing how you think about things so that you can focus on the present and not worry about tomorrow. Breaking problems into smaller, easier-to-manage pieces can be a good way to handle some kinds of anxiety.

Depression is more than just feeling sad. Depression includes feeling hopeless or helpless, feeling useless, feeling sad for weeks at a time, and having no joy in any activity. These feelings are not normal, not even when life is ending. Depression can sometimes be helped with anti-depressants, counseling, or a combination of both. Managing anxiety and depression well can make a big difference in how much joy or pleasure you can find in your last few months of life.

### Feeling alone

When someone knows for sure they're facing their last months of life, there can be a loneliness that's different from any other. It's a loneliness of the heart, even when you have people around you. Frankly, there may be very few people who can really talk with you in a way that helps you feel less lonely. Some of them may be experts who are comfortable talking with people at the end of life, such as hospice social workers, nurses, or other end-of-life caregivers. They may have that special gift for silence or listening when you need it. Finding a few people that you can truly connect with is critical to ease this sense of intense loneliness. Your health care team may end up being one of your greatest resources in this area.

### Seeking meaning

Almost everyone wants to feel their life had purpose – that there was some reason for their being on earth. Some people find meaning in their work. Others find that raising a family has brought them the greatest sense of joy and accomplishment. It's helpful to go through a process of reviewing your life and figuring out for yourself what your purpose in life has been. What was your special contribution to the world? What have you done to make the world a better place? How would you like the world or your children, family, and friends to remember you? What were the things that you thought were really important and want your children to know about for their future? It doesn't have to be something huge or earth-shaking – look for those things that have been important to you and those around you. The end of life experience is full of meaning that can be uncovered using personal reflection. Sharing your thoughts, experiences, and wisdom is a gift that your friends and family can cherish for years to come.

## **Physical Symptoms in the Last 2 to 3 Months of Life**

This is written for the person with cancer, but it can be helpful to the people who care for, love, and support someone with advanced cancer, too. This information may help you find answers to your questions and concerns during this very sensitive and difficult time.

This is a list of some of the things a person goes through as death gets closer. We also try to give some tips on what can be done to help manage these symptoms. Be sure to tell your health care team how you are doing. Don't assume it's normal to feel bad. There are often things that can be done to help you feel better.

### Fatigue

Fatigue is the feeling of being tired physically, mentally, and emotionally. Cancer-related fatigue is often defined as an unusual and ongoing sense of extreme tiredness that doesn't get better with rest. Almost everyone with advanced cancer has this symptom.

What can you do about fatigue?

To manage fatigue, first, control the symptoms that make it worse, like pain or constipation. Then you can help prevent more fatigue by carefully balancing rest and activity. Your health care team and your caregivers can help you find ways to manage the things that can make you feel more fatigued. Tell them how you feel, and try different things to see if they help you feel less tired.

Some medicines can make you feel tired, too. You may need to talk with your team about switching to new ones or taking them at different times. You might even be able to stop taking drugs that aren't helping or aren't needed any more.

Keep safe when you're active. If you're unsteady on your feet, make sure you have help when walking. You may feel safer if you have a walker or wheelchair. Your doctor or hospice team can help you get the equipment you need to be comfortable and safe. Plan activities around the times you feel the best and have the most energy. Sit outside, listen to music, go for a ride in the car, spend time watching a meal being prepared – distractions and stimulation of your senses may help ease fatigue.

Some people find a bedside commode or toilet chair helps – they don't waste energy traveling to and from the bathroom. Plan rest stops when you are out of bed so that you can sit to regain energy. Take short rests during activity – keep chairs close by.

Some people may find that they're afraid to go to sleep because they're afraid they won't wake up again. Again, this is a natural and very real fear. Needing more sleep is normal in the last few months of life. Withdrawing from people, turning inward, focusing on yourself, and talking less are also common at this time. Although some people want to surround themselves with friends and family, others want a quiet, peaceful environment. Listen to your body, tell people what you need, and save your energy for the things or people that are most important to you. Focusing on getting the most from each waking moment is a good way to redirect your worries and fears.

### Pain

People with cancer often fear pain more than anything else. Pain can make you feel irritable, sleep poorly, decrease your appetite, and decrease your concentration, among many other things. But pain can be controlled and managed in expert hands. It's important to know that pain does not have to be a part of dying. If you have pain, it's very important to talk to your health care team about it. They should understand that your pain is whatever you say it is. You should expect that your pain can and will be controlled. You and your team must work together to reduce suffering, relieve pain, and enhance your quality of life.

Your health care team should check in with you often to find out how much pain you're having. It's important to keep them up to date on all changes in your pain and other symptoms. They'll

need you to tell them how well each pain control plan work is working. Don't be discouraged if your medicines must be tweaked a few times to get the best pain control with the fewest side effects. You may want to ask your team to refer you to a pain specialist if your pain isn't being controlled.

Describe your pain in as much detail as you can, including:

- Where it is
- What it feels like
- How long it lasts
- When it started
- What makes it better
- What makes it worse.

Keeping a pain record of all of this may help. Often your health care team will ask you to describe your pain using a number from 0 to 10, with 10 being the worst pain you can imagine and 0 being no pain at all. Using this pain scale is also a helpful way to describe your response to pain relief measures. You can find a Daily Pain Diary and a lot more information on pain control online or call us for free copies.

#### Types of pain medicines

The nurse or doctor will assess your pain and figure out the average level or degree of pain you have. There are a lot of different pain medicines available ranging from acetaminophen (Tylenol®) to opioids (morphine-like drugs).

There are also many forms of pain medicine, such as long-acting, time-released forms of opioids that are around the clock. These long-acting drugs work by keeping your blood levels of the drug steady, which helps keep your pain under control for long periods of time. Fast-acting, rescue drugs can be used to quickly control pain.

Opioid pain medicines come in many forms that can be given in many different ways. Patches that stick to the skin, lozenges or "suckers" that don't have to be swallowed, drops that go under the tongue, and even rectal suppositories can be used when needed.

Sometimes, very severe pain may be better controlled with a pain medicine pump which gives the drugs either under the skin (subcutaneously) or into a vein (intravenously, IV). If you need this type of pain control, you can still get it at home.

It's very common for a person with cancer to take more than one drug to manage chronic and breakthrough pain. And some people need much higher doses of opioids than others. Don't be

concerned if you seem to be taking large amounts of drugs. It has nothing to do with being unable to withstand pain, nor does it mean that you are a complainer. Some people need less, and some need more to keep pain in check.

Over time you may also find that you need higher doses of pain medicines because they aren't working as well as they once did. This is because the body can become tolerant to a drug, so it has less effect. Needing to increase your pain medicine does not mean that you are going to die soon. In fact, evidence has shown that poor pain relief hastens death.

Sometimes other drugs may be used. For instance, certain anti-depressants or anti-convulsants (seizure control drugs) often work well to help with nerve pain. Steroids may be used to help with certain types of pain, such as that caused by swelling or inflammation. These medicines are often given along with the opioid drugs.

#### Signs that a person is in pain

If the patient is not able to talk about the pain they may be having, there are things caregivers can watch for that show pain or discomfort. Some signs of pain they may see include:

Noisy breathing – labored, harsh, or rapid breaths

Making pained sounds – including groaning, moaning, or expressing hurt

Facial expressions – looking sad, tense, or frightened; frowning or crying

Body language – tension, clenched fists, knees pulled up, inflexibility, restlessness, or looking like they're trying to get away from the hurt area

Body movement – changing positions to get comfortable but can't

Being able to identify these things and give pain medicine as needed helps the caregiver take good care of the patient and keep him or her as comfortable as possible.

#### Other ways to help cancer pain

With certain types of pain, doctors can do special procedures such as nerve blocks, targeted radiation treatments, or even surgical procedures to control pain. If your pain isn't well controlled, your doctor might also refer you to an expert in pain management. The pain specialist might have some different options to help you.

Medicines and medical procedures are not the only ways to help lessen your pain. There are other things you can do. Some people find distractions like music, movies, conversation, or games help. Using heat, cold, or massage on a painful area can help. Relaxation exercises and meditation can help lessen the pain and lower anxiety for some people. Keep in mind that for most people with cancer pain these measures alone are not enough to control pain. But, they may help improve comfort when used along with pain medicines.

### Appetite changes

As time goes on your body may seem to be slowing down. Maybe you're feeling more tired or maybe the pain is getting worse. You may become more withdrawn and find yourself eating less and losing weight. This is a normal part of the last months of life, but it may be the start of a battle between you and your loved ones.

You're moving less, have less energy, less appetite, and less desire to eat. Food no longer smells good or tastes good. You seem to become full more quickly and are interested in fewer foods. While this is going on, the cancer cells may compete with the normal cells in your body for the nutrients that you do manage to digest.

### Avoid family food arguments

It can be very upsetting to your family to see you eating less. For them, your interest in food may represent your interest in life. By refusing food, it may seem to your family that you're choosing to shorten your life. They may take this personally and think that you want to leave them or are trying to hasten your death – even unconsciously.

It's important that you and your loved ones talk about issues around eating. The last few months of your life should not be filled with arguments over food. Loss of appetite and being unable to eat happens to most cancer patients before death. It's normal in the last months of life for parts of your body to start slowing down and eventually shut down. When you feel like eating less, it's not a sign that you want to leave life or your family. It's just a normal part of the dying process. Explain to your loved ones that you deeply appreciate all their efforts to feed you and that you understand their attempts are acts of love. You're not rejecting their love, but your body is limiting what it needs at this time.

Your body is going through changes that have a direct effect on your appetite. Changes in taste and smell, dry mouth, stomach and bowel changes, shortness of breath, nausea, vomiting, diarrhea, constipation – these are just a few of the things that make it harder to eat. Drug side effects, stress, and spiritual distress are also possible causes of poor appetite. As you near end of life, your brain sends messages telling your body that it no longer needs nourishment because it cannot any longer really be sustained. This too is confusing to family members. If you are receiving hospice care, and hopefully you are at this point, the hospice professionals will also discourage your family from trying to force feed you. At later stages, these efforts can even make the person feel worse.

Some causes can be managed with medical treatment. For example, nutritional support can be given in the form of tips on how to get the most out of each bite you take or through supplemental drinks or shakes. There are also medicines that can stimulate your appetite, decrease nausea, and help food move through your stomach more quickly. You might be surprised to find that you're able to eat more when others are at the table. You may be able to



take small frequent meals or snacks during the day instead of trying to eat full meals 3 times a day. These measures may work for some, but they won't help most people who are very close to the end of life. It's important to recognize changes in appetite so that you can get help when it's needed. Talk to your medical team about how much you've been eating and whether you need to do something about it.

### Problems breathing

Even thinking about breathing problems can be scary. Trouble breathing and/or shortness of breath is very common in people with advanced cancer, but it can be managed at the end of life. You may feel short of breath or like you need to breathe faster and harder than normal. You might feel like you have liquid in your lungs and it makes you want to cough. Often these symptoms come and go. Tell your health care team if you're having any problems breathing so you can get help with them.

A number of things can be done to make it easier for you to breathe:

Sitting up

Propping yourself up on pillows

Leaning over a table

Sometimes oxygen coming through a small tube you wear under your nose will relieve most of your symptoms

Opioid pain medicines can work well to decrease shortness of breath and relax your breathing.

If there's fluid in your lungs, medicines can be given to slow the fluid build-up.

Sometimes opening a window, a cooler room temperature, or having a fan blowing on your face will help you feel less hungry for air.

You can be taught breathing and relaxation techniques to use when breathing is hard.

Medicines to reduce anxiety may help you worry less about shortness of breath.

Many people with cancer fear that this problem will get worse as the disease progresses. There are steps to manage each change in your condition and treat each problem. Just like pain, your health care team should be able to help with your breathing problems

## **The Importance of Communication When the End is Near**

This is written for the person with cancer, but it also can be helpful to the people who care for, love, and support someone with advanced cancer. Use this information to get answers to your questions and concerns about this very sensitive and difficult time.

## Who do you need to talk to?

### Your health care team

Once the health care team says, “There are no more treatments that might cure your cancer,” the patient often thinks, “The ball is back in my court.” This is a healthy approach. Rather than being a passive recipient of care, you may now want to start thinking about how to help others accept and enjoy the time you have left. To do this, you need complete and honest information. Telling your doctor exactly what you want to know and getting the information you need are empowering steps.

### Your partner

Focus on the good times and happy memories. Cancer takes up a great deal of time and energy. Cancer and end-of-life care puts a huge physical and emotional burden on those closest to you. Your partner may be either your greatest ally or a big disappointment as a source of support. There are obvious reasons for this. Your partner is probably dealing with his or her own emotions and yet feels a lot of pressure to come through for you and try to meet your every need. Some people just can’t handle that kind of pressure and might withdraw under these circumstances. They could pull away just when you feel you need them more than ever. This can be very painful.

On the other hand, your partner can be right there for you and that can be painful, too. It can be very troubling to know everything your partner is feeling and thinking and to see the pain they’re going through. Sometimes partners try to protect each other from the pain they’re both going through, but when this happens, honesty is sacrificed. Walls are built up, topics are avoided, and relationships can become strained and uncomfortable.

The death of a partner is one of the most stressful events a person can experience. Living with and anticipating this loss every day is even more stressful. If at all possible, try to talk with your partner about what each of you is feeling. You’ll probably find that you’re both going through the same kinds of emotions. Try to accept what each person says without judgment, argument, or defending yourself. Simply let each person say what they feel. Don’t try to fix the feelings. Be aware of them and express your love and care for each other. This is another chance to try to make any past wrongs right and comfort each other. But having cancer doesn’t mean that you won’t get angry and frustrated with each other. Try to focus on the comfort you can give each other and let petty arguments go. Focus on the good times, happy memories, and the times you have been there for each other.

### Alone time

It’s also important to allow each other personal space and private time. Reassure each other that you still love each other, but it’s OK if you both need some time to be alone. This is a common

need as a person faces the end of life. No one can be with someone 24 hours a day. And you can't squeeze a lifetime into a few months. Make the most of each day, be grateful for it, and greet the next one as a new chance to enjoy each other.

### Sex and intimacy

At this stage of your illness it may be hard to be as sexually close as you have been in the past. You may be tired, in some pain, or simply not interested in sex. But you can still keep physical contact in your relationship and share intimacy. Talk with your partner about your needs. Tell him or her that you want to be close but that you don't feel you are able to have sex. Make sure your partner understands you want physical closeness and affection. At this time simply touching, hugging, and holding hands may feel more intimate than other forms of physical contact.

### Help take care of your partner

You may need to talk to your partner if you're worried about being a burden to them because they're taking care of you. Ask how he or she is managing it. Your partner may show signs of emotional and physical stress, such as depression, headaches, trouble sleeping, or weight loss or gain. Remind your partner to take care of him or herself. Ask a friend or another family member to help out if you think there's too much for one person to do. Be sure to tell your partner you're going to do that. In this way, you can help take care of your partner, too.

### Your family

Cancer is a family illness. Your loved ones are hurting too. Each member of your family is working through the idea of losing you. They need your love and understanding. Though it might seem unlikely, there are things you can do to help them manage better.

### Adults

You can help adult family members by being open about your disease process, the amount of time you've been told you have left, and any other needs you may have.

Explain to your family that you're open to discussion and that you're willing to talk about anything. Explore their thoughts and feelings with them.

Tell them there may be times you don't feel like talking and you'll let them know when that is.

Tell them that you'd rather not try to put on an act and have to pretend you're happy if you don't feel happy. Explain to them this doesn't mean you aren't OK. It might just mean you are feeling tired or a little down.

Tell your family that you'll be as honest with them as you can be and would like the same from them in return.

Tell them what you expect to happen in the future so they'll be prepared. It also helps to share with them the expected signs of the dying process, and how to manage them should they occur.

Tell them about plans you've made or need to make and get their input.

Adult children may be juggling their own children, jobs, and caring for you. It's a stressful time. Sometimes they might not be able to meet your expectations. Open, honest communication will help you support each other through this time.

### Children and teens

It's natural to want to protect children from the harsh reality that you won't be there in a few months. But professionals who work with families would strongly encourage you not to try that. Even the youngest need some type of preparation for the future. Honesty is important. Children can usually sense changes or stress in the household and know when something is wrong. Many times what they imagine is far worse than anything you tell them.

For more on talking with children and teens, see *Helping Children When a Family Member Has Cancer: Dealing with a Parent's Terminal Illness*. [www.cancer.org](http://www.cancer.org)

### Your friends

Some friends respond as you would expect them to – they're warm, supportive, and available. Other friends may seem to be more awkward around you. They may act as if they don't know what to say or do and seem to have a hard time being "normal." Sometimes you can talk to your friends about their discomfort. Explain that you're the same person and you'd like to spend some of your remaining time with them, if they're willing to do that. Try to understand that what you're going through may cause your loved ones to think about the fact that they, too, will die. Because this is not a pleasant thing to think about, some people may avoid spending time with you.

### Religious or spiritual counselor

Religion can be a source of strength for many people. Some find new faith during a cancer experience. Others find cancer strengthens their existing faith or their faith provides newfound strength. On the other hand, those who have never had strong religious beliefs may not feel an urge to turn to religion.

Spiritual questions are common as a person tries to make sense of both the illness and his or her life. This may be true not only for the person with cancer, but for loved ones, too.

Here are some suggestions for people who may find comfort in spiritual support:

A spiritual counselor can often help you find comforting answers to hard questions.

Religious practices, such as forgiveness or confession, may be reassuring and bring you a sense of peace.

A search for the meaning of suffering can lead to spiritual answers that can be comforting.

Strength through spiritual support and a community of people who are there to help can be priceless to the patient and family members.

For those who are interested, a minister, priest, rabbi, other clergy member, or a trained pastoral counselor can help you identify your spiritual needs and find spiritual support.

### What do you need to talk about?

#### Treatment decisions

You may find that some people aren't willing to accept your decision to stop getting cancer treatment. Even if they don't understand or agree, you still must follow your own sense of what's right for you. As long as you have fully explored all options, your friends and family will most likely support you.

Keep in mind that no decision is forever. You can change your mind about treatment at any time. Still, it's your choice and you have to be comfortable with your decisions. You may want to share the reasons for your decision so they can better understand. Making your medical team and your loved ones part of the decision-making process will help things go more smoothly.

At this time, you may prefer to focus on the quality of your life. You may want to feel as well as you can without any more cancer treatments and side effects. Know that any symptoms you have can always be treated. Treatment of symptoms, like discomfort and pain, is called palliative or supportive care, and it's different from treatment aimed at the cancer itself.

It's usually not the act of dying, but the quality of dying that's the biggest concern at the end of life. Most people who come to accept dying as a natural and normal part of life do not want to prolong the process when it won't really change the outcome. But thinking about a good death is not something most people do. Some people want to stay at home and have hospice care there. Others choose to go to an assisted living center, a nursing home, or an inpatient hospice program. Some are in the hospital and want any treatment available to keep them alive as long as possible, no matter what their condition might be. Again, you should make the choices that you feel are best for you, your family, and your situation.

The goal of any cancer care is to give you the best possible quality of life. This is a very personal issue. There are ways you can be sure that your family and your health care team know what's important to you and what you want to be able to continue to do.

At this point it's important to think not only about how you're going to live the next few months, but also try to think about and prepare for how you're going to die.

### Choosing hospice care

Hospice care puts you and your loved ones in the care of experts on the end of life concerns.

Hospice care focuses on quality of life rather than length of life. The hospice philosophy accepts death as the final stage of life: it affirms life and neither hastens nor postpones death.

Hospice care is used when your disease can't be cured, and you are expected to live about 6 months or less if the illness runs its usual course. It gives you supportive or palliative care, which is treatment to help ease symptoms, but not cure the disease. Its main purpose is to improve your quality of life so that you can be as alert and pain-free as possible. You, your family, and your doctor decide when hospice care should begin.

The last two senses you will experience up to the moment of death is acute hearing and sensation. So your family can talk to you to the very end, if you wish them to. They can hold your hand and you will know they are there.

In closing know that you are an extraordinary person who has been placed on this earth for a purpose. You will be missed and never forgotten. On the following page is a verse called Gone from Our Sight that we use as an analogy to death when talking with patients and their loved ones who attend our metastatic breast cancer couples retreats. It is a verse that brings peace to those who choose to embrace it. The title of this guide, The Guiding Light between Shores, was chosen with this verse in mind. We hope it provides you and your family peace too.

## Gone from My Sight

I stand at the shore— a ship spread her white sails to the morning breeze and starts for the blue ocean.

She is an object of beauty and strength as I watch her like a speck of white cloud just where the sea and sky come down to mingle with each other.

Then someone at my side says, “There, she is gone!”  
Gone? Gone where? Gone from my sight, that is all. She is just as large in mast and hull and spar as she was when she left my side... and just as able to bear her load of living freight to the place of her destination.

Her diminished size is in me, not in her; and just at the moment that someone at my side says,

“There, she is gone”, there are other eyes watching and other voices ready to take up the glad shout, “Here she comes!”

Henry Van Dyke

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Lillie Dierker Shockney, RN, BS, MAS

Professor Shockney is the Administrative Director of the Johns Hopkins Breast Cancer and Director of Johns Hopkins Cancer Survivorship Programs. She is nationally renowned for her work in the fields of breast cancer, cancer survivorship, and patient advocacy with a special focus on metastatic cancer patients. She has received 56 awards, 50 national and 6 state awards in recognition of her contributions to developing and teaching innovative quality cancer care. These awards include being inducted into the Maryland Women Hall of Fame as well as being chosen by Johnson & Johnson as the Most Amazing Nurse in America. She is a registered nurse, with a BS in Healthcare Administration and a Masters in Administrative Science from Johns Hopkins University. She became the only nurse to hold a distinguished service faculty

designation in the JHU School of Medicine. Known as a national and international public speaker, she has also authored 15 books and more than 250 articles on cancer care. She co-founded the Academy of Oncology Nurse and Patient Navigators in 2009 and serves as its program director. She is also a breast cancer survivor, originally diagnosed in 1992

Lillie met Tyler Trahan several years ago and learned of his passion for wanting to understand how to deliver patient focused care. He was a medical student at the time at the Central Michigan University College of Medicine. Tyler has attended several of the metastatic breast cancer retreats with Lillie to get a firsthand experience with what the issues are that patients with advanced cancers are struggling to deal with, including challenges in understanding how to communicate effectively with their oncology specialists. Stage 4 breast cancer patients who have met Tyler at these retreats see him as the hopeful future of cancer care and take pride in realizing part of their own legacy is educating him so that he becomes an outstanding doctor, truly focused on the whole patient and not just the disease.



Tyler J. Trahan, MD, MSc

Dr. Trahan is a resident physician of Internal Medicine at Beth Israel Deaconess Medical Center and Harvard Medical School. As an alumnus of the C.U.P.I.D. Translational Oncology Program at the Johns Hopkins School of Medicine, Dr. Trahan has been involved in many facets of cancer research, building community-based programs and having since been published in *The Oncologist*. While earning his medical degree from the Central Michigan University College of Medicine he continued to receive mentorship from Lillie Shockney, and has been a regular attendee of her metastatic breast cancer 3-day retreats. His focus continues to be on addressing the unique social and psychological aspects of metastatic cancer care, helping patients fulfill their hopes and enhance their quality of life.



