



Caregiver Support Line Telephone Education Group

Series: Care for the Caregiver

Topic: Palliative Care: Improving the Quality of Life for Caregivers and Veterans with Chronic Illness

Many of our Veteran caregivers are providing support and care to Veterans with chronic illnesses. Suffering from chronic illnesses such as heart or lung disease, cancer, kidney failure or other serious and debilitating illnesses present a multitude of daily challenges. It is difficult for anyone who is not faced with such challenges to appreciate the many ways in which one's life may be impacted by such illness or how illness impacts those that love and care for them. Veterans not only cope with the pain and physically disabling aspects of the illness. Veterans also deal with the life limiting, energy draining, emotional aspects, that these illnesses deliver. They are not alone in their suffering. Their caregivers and loved ones are right beside them bearing witness and attempting to support and live with the fallout that these illnesses bring.

Our Veteran caregivers know too well the burden that these illnesses bring to bear on their lives as well as the pain and suffering that you see your loved one endure. You know too well the worried, sleepless nights of caregiving. You have been there as a source of comfort when they were fearful, angry, hopeless, or helpless. You know all too well how illness may have contributed to you both feeling isolated, alone, or misunderstood. You have experienced together the frustration with the health care system that can contribute to feeling confused and uninformed. You have witnessed the toll that illness has taken on one's time, energy, strength, social life, interests, and abilities, for everyone concerned.

Despite the significant difficulties, caregivers also say there are rewards that come in providing care. Yes, there are the difficulties, and uncountable losses when chronic illness strikes, but you may also find there are gifts as well. You alone know how these shared struggles may have deepened the sacred bond you share, as you and your loved one meet life's challenges together. This may be one of the rewards you recognize that has come from your caregiving.

Recognizing the positive is not to deny or diminish that chronic illness. It has the capacity in so many ways to wear at the threads that hold a quality life together, for both the Veteran and caregiver. This is one of the primary guiding principles of Palliative care, enhancing the quality of life for those that suffer from chronic illness and supporting and engaging the family and caregivers that care for them.



What is Palliative care and when should one consider talking to a Palliative care team? How can connecting with Palliative Care Providers help to improve the quality of life for Veterans with chronic illness and their caregivers? What are some of the important considerations you will want to be aware of? What critical conversations can you engage in now, no matter what your current health status, to empower you to take charge of your healthcare decisions. What do you need to know and how do you talk with loved ones about making informed healthcare decisions? What interventions and life sustaining treatments do you want to make that align with our own personal values and desires? These are some of the questions we hope to explore in this presentation.

Let's begin by defining Palliative care, which remains one of the most misunderstood and underutilized medical services available to those with chronic illness. Palliative care is specialized medical care for those suffering from chronic, serious, or life limiting illness, at any age, or stage of illness. Palliative care may be considered when you have been diagnosed with a serious or chronic illness for example cancer, heart and lung disease, dementia, or kidney failure, and is best started early to enhance quality of life throughout the illness.

Palliative care is provided by a team of specialists, which can include, among others a doctor, nurse, social worker, chaplain, and other medical professionals who provide consultation or work in conjunction with your current medical providers. The goal of palliative care is to help patients find relief; from pain, debilitating symptoms, and the emotional distress caused by serious illness and its treatment. The Palliative Care Team is focused on improving the quality of life for the patient while also recognizing the significant role of the patient's family and caregivers. The goal of this team is to support the family and the patient's wellbeing throughout their illness.

Some people confuse Palliative care with Hospice care. Palliative care and hospice care share many common goals such as: supporting the patient with a serious or terminal illness and their family, the management of pain and symptoms to relieve unnecessary suffering, and supporting the independence and functioning of the patient. Both will address the array of issues or concerns of patients and family who are facing chronic or terminal illness.

Despite these similarities between palliative and hospice care there are some differences that define each of these levels of care and it's important to understand how they may differ. One significant difference between Palliative care and Hospice care is that patients receiving palliative care are still actively receiving treatment meant to cure the illness. Hospice level of care is when there has been a determination of 6 months



or less to live. There are no more treatment options to cure the illness, and the focus is solely on providing comfort and quality of life care. So again, with Palliative care you may still be actively treating illness toward hope of a cure and with hospice it has been determined that there are no more treatment options to pursue, and the focus is solely comfort care.

The VA has recognized the critical value and need for Palliative care services, and as a result has put in place Palliative care teams at 100% of VA medical centers. VA is deeply committed to providing these critical patient-centered services to reach as many Veterans as early in their illness as possible. Research has shown the many benefits of providing these Palliative care supports as early in the diagnosis of chronic illness as possible.

Why is Palliative and Hospice care so underutilized when research has shown that people with chronic and terminal illness often actually live longer when these services and supports are put in place early? Why would a patient put off having these specialist supports in place for both them and their loved ones? It has been recognized that people aren't seeking this support as soon as possible when research is confirming the benefits of Palliative care for those with chronic or terminal illness. What are the barriers that interfere with connecting those that have chronic or terminal illness with Palliative care? What keeps those in need of this specialist care from benefiting from its expertise?

One barrier that certainly contributes is a lack of awareness, knowledge, or understanding of the benefits of Palliative Care. There are a number of myths and misunderstandings that people hold about this care. Many misunderstand that accepting Palliative Care means you are giving up or walking away from treatment or a cure. This just isn't the case, rather it is a decision to actively choose how to manage your chronic illness and how to pursue and support your quality of life. Those with chronic illness continue to receive curative care when receiving Palliative Care. Often people attribute Palliative or Hospice care to giving up on life and accelerate death when in actuality, as mentioned earlier, it could lengthen life and substantially improve its quality. Often people assume they are giving up control to enter into a Palliative or Hospice Care when this care actually supports your control, your decisions, and your unique individual goals. It provides each patient with the knowledge needed for you to make informed choices in your care and treatment.

How active of a role do you take in your own healthcare and the decisions about treatment? Do you rely on your healthcare provider to make all the decisions? Does a



lack of knowledge and understanding of your medical condition, potential options for treatment, or understanding of what the potential side effects of these treatments keep you from being an active participant in your own medical care? The illnesses, potential treatments and the healthcare system as a whole can be so complicated. It is easy to feel overwhelmed and uncertain, and as a result, hand over the reins to the doctors involved who may have little understanding of what matters to you.

Modern medicine has at its fingertip's complex technology, mechanical devices, and treatment interventions, aimed at staving off death. However, modern medicine is far less comprehensive or capable of assisting the individual in fully understanding treatment options and making informed decisions about what treatment fits with your values, beliefs and goals. Interventions such as another trial of chemotherapy, ventilators for breathing, permanent feeding tubes, CPR, and dialysis, are among some of the interventions that have potentially both positive and negative outcomes for the patient. Even another return visit to the emergency room or ICU has inherent risks. Both doctors and patients at times will engage in all kinds of desperate attempts to fend off death, when at times this can result in patients who suffer needlessly both in the quantity and in the quality of their life.

Often the decision for these heroic interventions are made by doctors, patients or families driven by hope for a cure. At times this could be without recognition of the realities or facts of the positive or negative outcomes that can be expected with this treatment. Any medical decision, whether it is to take a medication, receive diagnostic tests, a medical or surgical treatment or intervention, all have inherent benefits and risks. Does the information about the benefit receive the greatest share of your attention? How often are you fully informed about the potential risks and how often are you clear about the actual rates that this intervention will provide a successful outcome? Could this intervention contribute to potentially shortening your life or significantly damaging your quality of life?

Let's just look at one potential intervention called CPR. We may all be familiar with this intervention used when someone's heart has stopped from watching any typical medical emergency show on TV. The reality of this procedure is not the picture of success painted on TV. In studies that have explored people's misconceptions about the success of CPR, respondents believed the success rate of this intervention is at 70%.

Despite what people think or may see in the TV version of providing CPR, research statistics paint a very different picture of the success and the negative



outcomes of this intervention. The reality is that studies of those patients living in the community that received out of hospital CPR for presumed cardiac arrest, the success rate was only 10% for someone 40-59 years old and the rates of it being successful went down two or more percentage points for every decade older the patient is. For those who were already nursing home patients, there is only a 0-4% chance they will leave an acute hospital after cardiac arrest. CPR is a very stressful experience, which can result in broken ribs, lung collapsing, and or hemorrhaging. CPR often results in admission to an ICU, which as stated earlier also brings about its own risks. Furthermore, many of those that do survive this experience will have increased physical and mental impairments resulting in greater dependence. So, are there situations in which you wouldn't want this procedure done?

These decisions are often colored by powerful emotions not only on the part of the patient and family but also on the part of the physician as well. What is needed is to be informed with the facts. This requires that you are not a passive participant in your care but that you are thinking, planning ahead, and asking detailed questions of your healthcare providers. It would be helpful to have a plan in place ahead of time with your values, preferences, and goals in mind.

You may want every possible intervention provided to you, however little the possibility of its success, or however detrimental it may be to the quality of life. You may say you want to be kept alive at all costs, no matter what the sacrifices may be. What is important is that you have thought about these things, communicated with those that you love, informed your doctors, and completed the necessary paperwork so that your decisions are respected

These decisions are highly personal and unique to each individual. Exploring these decisions prior to having to make them or having someone make them for you will provide you the security of knowing that your wishes are followed. It would be a relief knowing that your loved ones will not be burdened or conflicted about following your wishes should you be unable to make them yourself.

Knowing the potential risk benefit ratios of any medical intervention is critical in proactively taking charge of your own medical care and making informed decisions about the risks, benefits, potential side effects, or impacts on your quality of life. These are discussions that you can had before you ever become ill or at any stage of your illness. These are questions that every adult should reflect on and put a plan in place to provide directions that reflect what you want. Only one third of adults have an advance



directive. Why don't the vast majority of adults actually put these critical wishes for their care in place?

One of the most profound barriers in seeking Palliative care or defining our wishes in an advanced directive is our innate resistance to facing the diagnosis of chronic illness or talking about the certainty of death. Through the ages, it has remained a fearful taboo topic that is avoided. Unlike olden times however, the experience of the dying process has changed dramatically. In earlier times, death often came swiftly as a result of a violent cause, serious illness, or infection, which took a life quickly. Now the process of dying can become a prolonged medical struggle against incurable conditions.

The vast majority of deaths now are the result of prolonged illnesses that have a fairly predictable course. 70% of illnesses such as heart failure, COPD, dementia, and Parkinson's disease, among others, account for a slow or steady decline, in which there is an opportunity to plan for your healthcare decisions.

We are living in a time where medical advances have prolonged life and have also prolonged the process of dying. Has this struggle to fend off the inevitable actually resulted in destroying not only the quantity but the quality of life as well? Palliative Care Specialists help you understand the choices that you have before you, help you clarify your goals for treatment, and support you in having the best quality of life possible given the limitations of your illness.

Again, every adult over the age of 18 should have taken some time to consider the difficult questions and planning that occurs in an Advanced Directive but especially critical to your wellbeing if you have been diagnosed with a chronic disease. If you or your loved one has been diagnosed with a chronic disease, Palliative Care can help you to make informed decisions about the risks and benefits of treatments available, and develop a plan in keeping with your preferences and values. They are also there with a unique expertise in managing the pain and discomfort of your symptoms, therefore diminishing the burden of your illness so that you are free to live your life more fully. They are an expert in understanding chronic illness, the symptoms, the typical path or trajectory, and the treatments and interventions available. Palliative Care specialists are there to help you understand what you may expect and are there to help you make decisions and plan for your future based on what you want and what your goals are.

There are many reasons we may put off thinking about these issues. Thinking about a diagnosis of chronic illness and the path that you may take towards death can be filled with fear and anxiety. We may avoid talking about it with an ill loved one,



attempting to not cause them distress. You may not want to lose hope or send that same message to your loved one. Oftentimes, family and even medical providers simply are stuck in the desire to continue to fight the illness so ferociously that the critical discussions never occur. Palliative Care can support those important discussions.

How might you have these discussions with a loved one? Maybe one place to start is to take the time to reflect on how you would want to be cared for if your time was short. Have you considered what interventions you would want if you were struck with a chronic illness or if you were diagnosed with an incurable illness? If you were in a coma and there was no chance of recovery or had severe dementia and unable to recognize yourself your family or friends, what interventions would you want to keep you alive in this state. Would you want to die at home or in an ICU? What would matter to you and what kinds of decisions would you make, or would you want your loved ones to make on your behalf if you were not able. There is a wonderful guide for these difficult conversations developed by The Institute of Healthcare Improvement in conjunction with what's called "The Conversation Project", which can be obtained online or via the link provided in the handout for this presentation.

When Dr. Susan Block of the Dana Farber Institute and a Palliative Care Physician was asked how she approaches these hard conversations, she identified four questions that help guide these discussions with her patients. She asks first if they know their prognosis. Does the person understand or are they clear what the diagnosis means and what is expected? Secondly, she asks what fears they may have about what is to come. Third, she explores what goals the person has, as their time gets short. What matters to you and how do you want to spend that time? Finally, the fourth question is what are you willing to sacrifice or how much suffering are you willing to go through for the sake of having more time?

In these four questions, some very significant and critical knowledge and personal values and decisions can be clarified. The first question actually starts by making sure the patient is empowered with an awareness of their illness and its path or course. This is a place where there can often be confusion, especially when multiple medical providers are involved. Many times, patients get either unclear or conflicting messages from providers, so this clarity is essential. How can you be in charge of your own care if you are not altogether clear about what is happening? If there is a lack of clarity, then Palliative care can assist in advocating and empowering you with the information you need.



The second question really explores the individual's fears about what is to come. Fears may be related to physical suffering. Many times, people have seen others suffer and are unsure how it will be for them. The providers provide information to help you understand what you might expect as the illness progresses and also the measures that can be taken to keep you from suffering needlessly. Providers will work to assist you in remaining comfortable and enjoying the best quality of life. The Palliative care team also has providers, such as psychologists and chaplains, which can assist the patient with the emotional or spiritual struggles that can come. Social Workers can assist the physician in preparing the Advance Directives and can work to support the caregivers and family members in managing care and supporting the patient's wishes.

The third question really explores what matters most to the individual, as time gets short. This question looks at what makes life meaningful to you. Where do you want to be, who do you want to spend your time with, and what activities matter most to you? Do you want to remain at home, or would you prefer to be cared for in another setting? Are there people or concerns that are important for you to connect with or problems that need to be reconciled? Are there spiritual practices that are important for you to maintain? Are there things that you want to do, see, or accomplish, as time gets short? These questions really explore you as a unique individual and recognizes your determination of how your unique wishes, needs, values and beliefs can be realized.

Finally, the fourth question speaks to the decisions and choices you can make with your Palliative Care or medical provider about the life sustaining treatments you want to occur. These are difficult determinations to make and are best made when you have a clear appreciation of what they entail, both the risks and benefits. So, for example, do you wish to have a feeding tube placed for hydration and nutrition if you no longer recognize yourself or others? If your values are that you want to fight to stay alive at all costs, you may decide to have the feeding tube placed. Another person may say if I cannot recognize my spouse or children, I don't want any life sustaining treatments. I want my family to let me go. The Palliative care provider can help you look at the potential risks and benefits of these life-sustaining interventions and see if they fit with your goals and values. These discussions then lead to developing an Advance Directive, which is the document that provides your medical team and your loved ones with instructions about your decisions for care.

The Advance Directive is such an important document but despite its importance, only about one third of adults have them. Without an Advance Directive or Health Care Proxy, you are leaving these significant decisions to medical providers that don't know



you or leaving the burden to family members to make decisions if you are not able to yourself.

Oftentimes when these decisions are not clearly spelled out by you, there can be tremendous internal conflict for individuals making the decision wondering what you would want. There can also be tremendous conflict amongst family members about life sustaining treatments when family members differ about what should be done. Without spelling out your wishes in an Advance Directive it not only leaves you vulnerable to having care and interventions that you don't want; it also leaves a terrible and sometimes lasting burden of conflict for others. Family conflicts that result may be difficult to heal and individual turmoil may remain when one is wondering, "Did I do the right thing?"

Making sure that you have developed an Advance Directive and Health Care Proxy will provide you greater control and will reflect what life sustaining interventions you want. The Advance Directive defines the life sustaining treatments you want, and the Health Care Proxy identifies the individual that you trust to make decisions for you when you are not able.

It is especially important when you consider who you want to ask to be your health care proxy that the person knows not only what you would want but that they are also able to advocate for your wishes even if they don't agree with them. It is also important that the health care proxy be able to hold firm to your wishes if family or others are not in agreement. Some medical professionals have found that the Health Care Proxy was never told they were chosen and may not want to or may not be able to act on the patient's behalf. It is really important that you are sure the person you choose to be your proxy knows what their role is and that you are confident that they are able to act on your behalf and support your wishes.

These documents can be requested from your VA treatment team, or the Palliative Care providers can help with these documents. These documents may change overtime, and they can and should be reflected yearly to make sure they are up to date, still reflect your treatment wishes and include the current Health Care Proxy of your choice.

These can be difficult conversations to have but they can also provide you an opportunity to share what matters most to you with those you love and also provide those suffering from chronic illness the opportunity to take control and make their wishes and needs known. It can also be a tremendous relief and security in knowing



that you have prepared for the potential outcomes of your illness and defined what you want to have happen.

Facing a diagnosis of chronic illness and facing the inevitability of death is a powerful challenge. It is a complexity of fears, unknowns, suffering, and layers of loss. Facing this diagnosis may also be an opportunity to truly clarify who and what is deeply important to you. Whether you are the person struggling with the illness or the caregiver, walking with them in this journey, it can hold tremendous potential to deepen your connection to one another and what you value in life. Facing these most difficult challenges can help to crystalize your deeply held beliefs and values. What gives your life meaning? What do you cherish and what will you fight to hold onto? How can acceptance of the reality of your illness bring you closer to embracing and capturing the moments that give your life meaning despite the limitations of your illness? Strangely, when one is faced with loss it is often then, that the recognition of what matters truly emerges.

Palliative care is not giving up, rather, it is giving in to the reality of chronic illness. Palliative Care is opening a door to knowledge about your illness and potential treatment interventions. It is relief of suffering from your symptoms, it is greater control and direction of your healthcare, it is support for you and your family, it is help in developing a plan for your future, and potentially, as a result of this care, it may actually add quality and quantity to your future.

Whether you have been diagnosed with a chronic illness, caring for a loved one with a chronic illness or simply an adult who wishes to take charge of their healthcare future, this presentation hopefully encouraged you to take the necessary steps to assure that you are caring well for your health care decisions. Reflecting on the ideas presented today, proactively thinking, and making formal plans to complete your Advance Directives and Health Care Proxy, will assure that your wishes for care are known and that you are assured the Proxy you will choose is able to advocate for your wishes if you are not able. These documents can be secured for Veterans by requesting assistance from your health care team and for non-Veterans, the state specific Advance Directive forms can be found at www.caringinfo.org Talk to your doctor or healthcare providers to assist you in completing these forms.

If you or a loved one have been diagnosed with a chronic illness, we encourage you to tap into the unique skill and expertise that Palliative Care teams can provide. You needn't be alone in managing the complexity, uncertainty, and the physical and emotional challenges that can come with chronic illness. There is help available to you



in managing your symptoms and your pain, so you are better able to live your life to the fullest. There is help available to assist you in making decisions about your care. There is support for you and your loved ones so that you are not alone in your journey ahead.