



Comfort Care Makes a Difference: A Guide for Hospice Services

“It’s only when we truly know and understand that we have a limited time on earth — and that we have no way of knowing when our time is up, we will then begin to live each day to the fullest, as if it was the only one we had.”

- Dr. Elisabeth Kubler-Ross

Compliments of Continuum Care Hospice

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Considering Hospice

Even with the continual advances in medical technology, the fact remains that our bodies do not live forever. In everyone's life there comes a time when our body begins to slow or even fail. Sometimes it is the natural age progression or a chronic illness. At other times, it begins at a too-young age when a disease does not respond to even the best medical treatment.

If you or a family member is reading this, it is probably because you and your family are faced with making a decision about healthcare. You may be making decisions for yourself or on behalf of a loved one.

This pamphlet will help explain one option for medical treatment – comfort care. Comfort care is given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of comfort care is to prevent or treat as early as possible symptoms of a disease, side effects caused by treatment of a disease, and the psychosocial, emotional, and spiritual problems related to a disease or its treatment. Comfort care is also called palliative care, supportive care, and symptom management. It is usually given with the help of a hospice team.

When comfort care and hospice are introduced to a person and/or their family, it often brings up difficult questions and feelings. Most of us experience mixed feelings and reactions at the realization that we or someone we love may be in the final phases of life. We know and are very aware when things begin to change with our or the person's health. Feelings of disbelief, denial, anger, or overwhelming sadness are natural. If a new diagnosis has been sudden, there is also deep shock and grief.

To acknowledge the failing health of someone you love can feel like betraying them. To realize the curative treatments aren't working as everyone hoped, feels devastating. We want to "keep

fighting” and “have hope” for a cure even if a disease becomes “end-stage” or “terminal.”

There are times when that fighting spirit is helpful. But if the body is beginning to fail despite all medical treatment, then time may be shorter than we think. Refusing to acknowledge the situation won’t change it.

If we know that a person has a limited time to live, then spending time on medical treatments that are not helping may not be what you want to do with this precious time.

If medical treatment cannot bring a cure, then comfort and quality of life become priorities. Personal wishes become more important than waiting rooms, tests, or spending time at the hospital. This is where Hospice begins.

What Comfort Care is NOT

Comfort care is NOT:

- Giving up
- Losing hope
- Stopping everything
- Quitting
- Losing the battle
- Just letting someone die
- Doing nothing

It is important to remember that comfort care is not about giving up. No one would stop treatments that are working and restoring health. Curative treatment makes sense if it is likely to bring a cure, but may not be so helpful in the final phases of life.

Comfort care is about getting help, relief, medical care, and emotional support that the patient and family need to live as fully and comfortably as possible.

What is Comfort Care?

Comfort care is one path of medical treatment and family support for the last months of life. Comfort care is putting our energy, hopes, and actions toward quality of life. Quality of life is living comfortably in a manner we choose. Comfort care is striving for freedom from pain and distress for whatever time remains – be it months, weeks, or days.

Comfort care is for the whole person and family, helping with the physical, emotional, psychosocial, and spiritual issues. It is having a team of hospice professionals providing support, medical treatments, and guidance at a time when all are needed. Comfort care is relieving pain and other symptoms so that a person can do the things they want in the time remaining. It is about living.

Comfort care is letting go of treatments that are not working or cause distress but have no lasting benefit. The focus becomes comfort rather than cure. It is having the hospice team available who understand the unique needs of a patient and family in the patient's final phases of life.

Comfort care neither hastens nor postpones the natural dying process. The goal of comfort care is compassionate care to enhance the quality of life in the time remaining – not just more tests, more appointments, and more hospital stays.

Comfort care is different than standard medical care. In comfort care, the questions that guide decisions are: Will this contribute to comfort? Will it lead to feeling more at ease, more pain-free, and more peaceful with reconciliation and closure? The patient and family make autonomous decisions about what is or is not wanted. Care is personalized during these final phases of the life cycle.

Is Comfort Care Enough?

For some, tending to comfort doesn't seem like doing enough. Often it feels easier to "do something" medical instead, whether it is really helping or not. We may seek out new doctors and yet another new treatment. The feelings of powerlessness can be overwhelming. Choosing comfort care is a very loving decision, but can be a very difficult decision to make.

Yet, this phase can be a special time in a family's life. It is time to say the warm and loving things that need to be said and do the things we may have delayed. It is a chance to listen to family stories and a time of reconciliation.

The risk in denying that our loved one has entered this phase of life is that we may be so busy seeking medical treatments and "doing something" that we run out of time for doing and saying the things that we'll want to remember. When we cannot face things honestly, we remain unable to give or receive the reassurance and support that is so needed for closure.

This time is precious; to honor it requires courage. Having a hospice team to support you can really help.

How Hospice can Help

Many patients and/or families choose to get help from hospice when comfort care is needed. The hospice team is designed to support the patient and the entire family as they go through the challenges of care giving and grieving. Hospice focuses on the patient and family as an integrated whole.

Most hospice patients stay in their own homes or in their family's home. Some live at nursing or assisted living facilities. The hospice team works with your own physician in addition to the hospice medical director.

Hospice services are covered by Medicare, Medicaid, and private insurance. If the patient has no insurance, hospice support is still available. A hospice social worker can answer your questions about payment.

In addition to routine home visits, hospice will be available for consultation, emotional support, and visits for emergencies around the clock.

Hospice is much more than pain control – it is a way of life. It is also about helping patients and families cope with the special challenges of the final phases of life, as well as supporting families after their loss.

Some people think hospice is only for patients with cancer. Hospice cares for persons with any terminal illness such as lung, liver, or heart disease, Alzheimer's, and more.

Can you stop Hospice Services?

If you or your loved one's health improves, hospice may not be needed any longer – Wonderful! You can discontinue hospice at any time. The service will still be available later when it is needed. In the meantime, you can have a team of caring professionals to help you and your loved one. Many times the support of a Volunteer is continued when no longer on hospice services.

When is it Time for Comfort Care?

When to begin comfort care is a very personal decision. For some, the time becomes clear when the burden of medical treatment outweighs the benefit.

When hospitalizations, tests, blood draws, IVs, and treatment side effects bring distress but no progress, it may be time to choose comfort care. When you hear things like "I just want to go home," "This isn't doing any good," or "I'm so tired of these

hospitals,” or “I can’t take it anymore”, it may be time to talk about comfort care.

Some persons and their families realize the time to think about comfort care has arrived when the person’s physician mentions hospice. At other times, a person and/or family may hear words like “end-stage” or “terminal” when discussing the person’s care with medical personnel.

The Medicare Hospice Benefit covers comfort care in the last six months of life, sometimes longer when the illness runs its normal course on the health continuum. When physicians believe a person is entering the last six months of life – based on Medicare guidelines – that person is eligible for the Hospice Benefit.

Many times, the person and/or their family must first mention comfort care to their doctors. Once the person and/or family ask about comfort care, most physicians often find it easier to discuss.

But sometimes it is very difficult for a physician to acknowledge that treatment isn’t working or that the treatment is causing more distress than benefit. They too, want to inspire hope and help the person keep fighting.

When a person and/or family asks about hospice, a common response from some physicians is that it is “not time yet.” Try asking your physician if some persons and/or family choose hospice at this time. If your doctor says yes, then you know that you are at the point of making this decision.

Hospice specializes in caring for those in the last six months of life. If you wait to get hospice until the last few days or weeks of your loved one’s life, you will not get the full benefit of having a team to help you through the process.

Hospice works best when there are months rather than days to establish relationships and provide support. If you choose hospice now, you can change your mind at any time to stop hospice services.

Most people are relieved to know that you can go ahead and get the support of hospice, but that you also have the choice to discontinue hospice at any time.

Who makes the Decision?

It may be even more difficult if you are making this decision on behalf of someone else who cannot speak for themselves. At best, they left instructions, such as a living will and/or a durable power of attorney for health care. If not, sometimes we must put aside our own feelings and ask “What would his or her decision be?”

It is stressful to make decisions on behalf of someone who did not leave instructions. It may be helpful to consider:

- Would my loved one want aggressive curative treatment with little hope of success?
- Are current treatments helping the person get better or prolonging the dying process?
- Would comfort and quality of life be his or her priority?

There are no easy answers. Sometimes the pain of seeing a loved one ill is so great we allow or request medical treatments that have little long term benefit. For most of us, it would be easier to experience distress ourselves than to watch a loved one go through difficulty.

One of the greatest challenges is to distinguish our pain from theirs and separate our fears from their fears.

Sometimes we have known someone long enough that if we imagine asking what they would want, we know what he or she

would probably say. It is as if we can hear them speaking. Having the courage to honor their wishes is what will ease our hearts most.

Sometimes family members disagree on what is the best course. This situation, while common, is especially difficult for the person who has been legally designated to make the decision. There may be some comfort in remembering the proxy was chosen by the patient as the person most able to follow the patient's wishes, even if other family members disagree.

If you are making this decision for yourself, you may know what you would do, but think your family may want something different. You may feel it is your obligation to keep fighting on their behalf.

Yet behind any family's personal feelings is a longing for honesty. If you haven't talked with your family about what your wishes are, it is time to do so.

It is very important to get the support you need to tell your loved ones what you really want to do.

Consider asking a trusted friend, pastor, nurse, or social worker to help you with the conversation.

It is no easy task, but one that must be faced if you are to go through this process truly together.

Is there still Hope?

Sometimes in the long battle with an illness, we begin to place all our hope in the next medical treatment. All our hope depends on finding a cure. When a cure does not appear, we "lose hope."

Yet hope is much bigger than a medical treatment. Hope is much deeper than a medical cure. Hope is the feeling and belief that everything will turn out for the best.

Nearly every individual, and every spiritual tradition, seeks deeper answers when our initial hope for a cure goes unanswered.

Many persons and families have said that when a cure didn't happen, they felt helpless and abandoned. Hope seemed lost. Then they describe finding a different hope: hope for time remaining, hope for comfort and freedom from pain, hope for family resolution, and hope for good memories from this life passage.

Hope is learning there is an option for care that focuses on you and your needs. For some, there is hope in knowing they are still fighting – for quality of life and dignity. Others don't want to fight anymore, and turn instead to acceptance and faith.

There is hope for the final months of our lives to be at home, comfortable, and surrounded by love. Sometimes hope can simply be a good day telling stories and sharing memories.

It is one of the most difficult journeys we will make in our lives – gradually letting go of what we wished would happen, and turning to what is happening with a new sense of hope.

Does Comfort Care mean Less Time?

You may hear people compare comfort care to “going for a cure” by saying it is “quality versus quantity.”

However new research has found that patients live longer under hospice care.

The study showed that patients in the last months of life who chose hospice averaged longer life expectancies than those who pursued the routine (curative) treatment course.

Why is it that hospice patients live longer? Could it be when our bodies begin their natural dying process – a process that usually occurs over months rather than days – we are less able to handle the intensive treatments of the curative course? Or is it the support and care given to the patient and family by their hospice team? Only more research will answer these questions.

Physicians work tirelessly on behalf of their patients. Yet as healthcare consumers, it is important for us to know all the facts. Medicare supports using hospice services for the last six months of life, but most patients only receive these benefits for a few weeks.

Some physicians wait too late to refer their patients to hospice. Other times the person and/or the family chooses to “go for a cure” even when hospice is recommended. Sometimes the comfort care option is just never mentioned.

Whatever the cause, it means the person and/or their family face months without the help they could have had. Many persons and/or their family are offered the comfort care option too late to get the help they needed.

What about Food & Fluids?

Many questions may arise about food and fluids at the end of life. Poor appetite is very common in the last months of life. This can be confusing to many families who blame the person’s decline on not eating enough.

Yet it is usually the underlying disease that is causing more weakness and less appetite. If this is the case, then eating more will not help – and could make some symptoms even worse.

Some people who experience a severe loss of appetite find that being endlessly encouraged or forced to eat is distressing. This is very difficult for families and caregivers since food has not been just a bodily necessity, but a universal symbol of love.

In comfort care, one important way of honoring a person's dignity is to let him or her decide when, what, and how much to eat and drink.

If your loved one is unable to tell you what they want, you may worry about 'hunger pains' or that he or she will 'starve to death' if not force fed. Some families wonder if they should have a feeding tube placed to administer artificial feedings. Others believe feeding tubes at the end of life extend the dying process without adding quality of life.

Some families wonder if IV fluids would help, yet there are significant risks to adding IV fluids when someone is in a fragile, end-of-life state. Medical treatments that may be helpful in other situations may not be so helpful in the natural dying process. Your hospice physician, nurses, and social worker will help you and your family work through these situations as they arise. They have been with many patients and their families as they deal with this part of the life cycle. Talk to them about the concerns you have.

Common Hospice Myths

Myth: Hospice is for the last days or weeks of life.

Research has shown that persons and their family members benefit more when they have more time with a hospice than just a few days or weeks. It takes time to build trust and relationships as well as provide support at such a challenging time of life.

Myth: I will have to change doctors.

In most cases, your physician becomes part of the hospice team. Your doctor consults with the hospice physician to give you the best care. Very few people change doctors.

Myth: A hospice is a place you go.

Some hospices have inpatient units or hospice homes. However, the large majority of hospice patients stay in their own home, the home of a family member, and the hospice care comes to them. Hospices also take care of patients in nursing homes, assisted living facilities, and many other settings.

Myth: Hospice care is only for patients with terminal cancer.

Hospice care is for patients with any health condition with a likely prognosis of six-months or less. This includes heart, lung, or liver disease, Alzheimer's and more. With each diagnosis, there are guidelines for when hospice care is provided.

Myth: Hospice is expensive.

Hospice care is covered by Medicare, Medicaid, and private insurance for those who meet eligibility guidelines. For those without insurance, support is still available.

Myth: If I am not in pain, I don't need Hospice or comfort care.

Comfort care is much more than just pain control. Hospice focuses on the whole person and the physical, psychosocial, emotional, and spiritual issues that can arise in the last months of life. Support is given to patients, caregivers, and family. Grief support is available to the family during care giving – as well as 13 months following the loss.

Myth: You can only have Hospice care for six months.

There is not a six-month cut off for hospice services. Patients are re-evaluated by their physicians on an ongoing basis and if the prognosis remains six months or less, hospice services may continue.

Myth: Hospice care is for people who are giving up the fight.

Hospice and Comfort care is for people seeking quality of life, comfort, and support. Remember, no one is giving up on you or your loved one. If his or her health improves so that hospice is no

longer needed – Wonderful! The service will still be available later when it is needed. In the meantime, you can have a team of caring professionals to help you and your loved one.

Myth: Once I choose hospice, I can't change my mind.

If you choose hospice now, you can change your mind at anytime in the future. Most people are relieved to know that you can go ahead and get the support of hospice, but that you can also discontinue hospice at any time.

Who to Call?

Your comfort or the comfort of your loved one and supporting you and/or your family during this journey of life are top priorities for the hospice team.

With hospice, the primary objective remains to provide quality comprehensive family-centered, coordinated, and compassionate care necessary for the peace and tranquility in the last phases of life.

If you and/or your loved one have questions or want more information on hospice and comfort care contact:

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