

How Social Workers and Counselors



Hope

Can Help Those Facing Serious Illness

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How Social Workers and Counselors Can Help Those Facing Serious Illness

Seven Suggestions for Palliative Care Social Workers and Counselors

Helpful Tips on What to Say and How to Say it When Facing Difficult Conversations

Anne Front, MA, LMFT, shares just a few of the resources from the CSU Shiley Institute for Palliative Care that are applicable to all social workers and counselors caring for seriously ill individuals and their family caregivers.

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Hope in the Face of Illness

To a large degree, our culture denies mortality. We pride ourselves in having invincibility and longevity. “I’m a fighter, I can get through this,” and “I can beat the odds.” We are a culture of mind-over-matter. We don’t talk about death in relationship to ourselves. Studies show that 75% of us don’t have plans for our death. So when one feels something in their bodies that isn’t quite right, and goes to a physician, it can be an abrupt entry into realizing that health is often outside of our control. When we feel out of control, it is easy to lose hope.

We are hard-wired to survive, and part of our survival is in setting goals to live and prosper. Research demonstrates associations between hopelessness and death.

When we give up on our goals, our hopes and dreams, we become hopeless. Patients with hopelessness are noted to have poorer quality of life, lower self esteem, and ultimately, higher mortality rates that those with demonstrations of ongoing hope in their lives.

Jerome Groopman, in his book “The Anatomy of Hope” writes, “Fear is often the most significant hurdle - fear of pointless pain and suffering. For my patients, as for me, it was hope that inspired the courage to overcome fear and solidified resilience during an arduous treatment.”



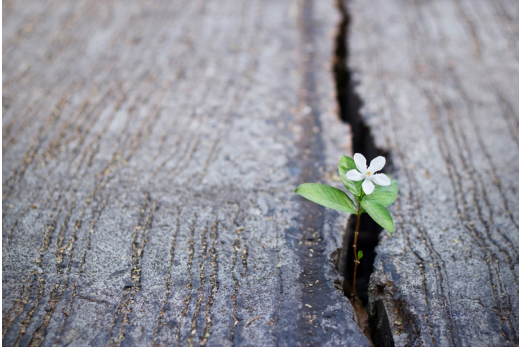
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Hope is an important part of coping with illness. Studies show a correlation between hope and a sense of control. People rely on hope to get through hard things. According to Oxford Press, the definition of hope is “a feeling of expectation and desire for a certain thing to happen, a feeling of trust, wanting something to be the case.” In order to go through treatments that sometimes have severely uncomfortable side effects, one has to believe that there is a purpose, a reason.

People with illness and hope tend to examine the priorities and what is important in their lives. Cheryl Nekolaichuk describes hope as the “thread...woven into the fabric of each person’s illness experience. For some, the threads are tightly woven, while for others they are raveling strands.” Often, people will confront issues related to uncertainty, spirituality and existential beliefs. For those going through serious or life-limiting illness, uncertainty and lack of hope can come from not knowing the full information related to their diagnosis, prognosis and treatment. Hope helps us by being aware of the future but also focused on living in the present.



Regardless of the nature or stage of illness, people have the right to maintain hope, and should have that right. They have the right to know information about their illness, or to not know, or control how much they want to know. As health care providers, the idea of hope can be a scary thing. We want our patients to maintain hope when there is a chance of recovery. We want to instill hope in someone who is “fighting the fight,” even in the face of pain and suffering. But what happens when a cure is no longer possible? If we impart hope, isn’t this giving the person a false sense of recovery? If we don’t want to give false hope, what other kind of hope is there?

A few of the most isolating words are “There is nothing more we can do.” For a person who has been doing whatever possible to achieve either a cure or (at least a prolongation of life,) a statement that “treatment” is no longer an option can be devastating. When faith is put in medical professionals to help and then learning that those professionals have nothing more to offer is cause for losing hope. As health care professionals, there is a moral obligation to be mindful of the words that we use. If there is truly “nothing more we can do,” is this not an admission that we are abandoning the person in their care?

“Rather than abandoning a person, we have the opportunity to be with them as they shift the focus of care from curative to comfort and symptom-management.”

Rather than abandoning a person, we have the opportunity to be with them as they shift the focus of care from curative to comfort and symptom-management. We can provide the person the knowledge that they are not alone, that they have a support team and that new goals can be created for optimal quality of life as they walk a new path in their journey. We can support a person in being realistic about his or her condition, and also that individual’s choice to believe that things will get better, whatever that means for that person and situation.



Dr. Wendy Schlessel Harpham writes about healthy hope – a combination of reality and faith. She writes, “When illness strikes, hope takes on a new meaning. Healthy hope is the belief that you can help improve your situation and feel happier. You can cultivate a genuine hope even when you are acutely aware that things are not going well and the likelihood of a good outcome is small. Hope is an ongoing choice.”

Let's compare the stories of Matthew and Ted. Both men have a history of independence, family, work success and hopes for the future. Both of them have been diagnosed with cancer, and likely there are no curative options. In the face of this reality, the palliative care team sits and talks with both of them to find out what is important in their treatment. They are both asked what their hopes are.

Matthew, a 58 year-old divorced man recently retired from the Sheriff department. After seeing his doctor for severe abdominal pain and bloody stool, he was diagnosed with stage advanced colon cancer. His hopes are for:

- Extending his life as long as possible.
- Being able to maintain his independence.
- Researching his ancestry and traveling back to Ireland to find his "roots."
- Having his symptoms managed so he can "eat what I want and go where I want."

Matthew is given a prognosis that doesn't look good for the short term. However, it sounds like he has more time to do some things, and opts to do what he can within reason. He understands what is important to him in being able to maintain as much independence and dignity as possible. His desire for independence is an important factor that will be useful in setting long-term treatment goals. For instance, would he want feeding tubes, breathing machines, nursing homes if he eventually needed that level of care? Or would he want a more natural course of treatment that may include palliative care support for symptom management and quality of life goals.



Ted is a 75 year-old man who is in the final stages of liver cancer, metastatic to lungs and brain. He no longer has options for curative treatment and is moving towards comfort-focused care. His hopes are:

- To be home with his wife of 53 years.
- To look out the window and see his garden
- To have his son from New York come see him "one last time."
- To not suffer in his final hours.
- To make sure his wife knows everything she needs to so that she will be okay on her own.

Ted has some real limitations due to the stage of his illness. If he or his family were to hold on for a miracle, there could be many aggressive interventions that could be provided in a hospital setting – biopsies, MRIs, lab tests, infection management, invasive airway support – bi-pap and artificial ventilation. As his needs became more serious, the interventions would increase. In listening to Ted's wishes to be at home and put the final pieces of his life together before he dies, he is able to get home with a qualified hospice program. By allowing him to express his hopes and desires, he is able to control the quality of his end-of-life care.



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It is important to notice that both gentlemen chose to place hope in the areas that are most important to them. With cure not being an option, both tend to focus on what is in their control. This isn't to say that perhaps they have a faithful hope that there will be a miracle or some change of fate. Yet they aren't allowing themselves to wait around for that hope at the expense of missing what options are right in front of them.



Studies have demonstrated positive correlations between hope and coping skills. Hope is interpreted as a source of strength and resource. Hope aspects include: loving, being loved, setting short and long term goals, autonomy, involvement in one's care, humor, having potential, values and work. Hope can be a tangible strength from within, a healing force. Others attribute spiritual experiences with hope or connect hope with a higher calling, a plan in place that they may not necessarily know the outcome. Hope is something that is communal and becomes stronger as we share it with others. The converse is true as well.

When someone loses hope, it might take someone else to help find it.

Palliative care social workers and counselors are experts in communication. We are trained to meet people where they are at, and walk alongside them as they face challenges. Getting to know our patients helps us foster hope and nourishment. As advocates, we can ask the questions to learn how our patients can prepare for whatever is coming. We can support them in their care, encourage them to define what is important to them, prioritize and plan accordingly. We can help them regain a sense of choice and control in their care. With this, there is an opportunity to renew hope.

“In our work, we can impart and foster hope in whatever stage of illness and treatment patients are in.”

In our work, we can impart and foster hope in whatever stage of illness and treatment patients are in. Here are seven suggestions for palliative care social workers and counselors to consider in working with patients and families.

1. Symptom Management

Delivering quality care that addresses symptom management and comfort. Studies have demonstrated that unmanaged symptoms directly correlate with feelings of hopelessness. It makes sense that when you feel better, you can think more clearly. Palliative care social workers and counselors can be advocates for our patients in communicating with physicians and nurses regarding pain and symptom control needs. We can provide alternative therapies within our scope and training including stress management skills, creative therapies (art, music, expressive), cognitive therapy and more to help address the mental suffering that partners the physical distress.

2. Psychological Care

It has been said that pain is inevitable, but suffering is optional. While our patients may not be able to alter the discomfort they are in, the talk or “mind chatter” that goes along with pain and discomfort can be addressed. Ways to provide psychological care include being emotionally present with our patients and families, building trust so that they know they are not alone in their journey, therapeutic listening, clarifying needs, advocating and addressing inequalities in care needs, screening for more complex issues such as depression, anxiety, suicidal thinking and other mental health concerns, providing crisis counseling or ongoing counseling depending on care setting and resources (or referring to mental health provider when needed.)

3. Education

There is a balance in health care between hope and denial. It is important to not provide patients and families false hope, but to encourage realistic hope, where they are given information that allows them to define their own hopes and wishes. As health care providers, we must ask the questions to learn how best to treat our patients. As palliative care social workers and counselors, we can help to make sure physicians are talking to our patients and educating them on care options, risks, benefits, long and short term outcomes. When patients and families have this information, they can make informed decisions about their health care choices.

4. Positive Thinking

Encouraging positive thinking is not about giving patients and families a false direction or hope, but allowing them to look at the advantages of a difficult situation and use those advantages to better their outcomes. As western medicine develops from segregated care with specialists for each organ and system, we are embracing more eastern medicine approaches and holistic care. The idea of a mind-body connection is now generally accepted. Along with this comes positive thinking and other cognitive strategies as way to cope with an illness. Maintaining a positive attitude can be an important part of the treatment process. But even when curative treatments are no longer available, hope is still necessary and an essential part of coping.



5. Cognitive Reframing

A useful intervention in helping patients and families find hope in difficult times is cognitive reframing. This intervention is a way to change the lens in which the situation is viewed. Watzlawick, Weakland and Fisch state “To reframe, then, means to change the conceptual and/or emotional setting or viewpoint in relation to which a situation is experienced and to place it in another frame which fits the ‘facts’ of the same concrete situation equally well or even better, and thereby changing its entire meaning.”

We frame ideas and situations with our unique perspective based on beliefs, values, culture, unspoken assumptions, etc. and create meaning based on that experience. Reframing is another way to say, “let’s look at this another way.” Examples of reframing might be “a problem as an opportunity,” “a weakness as a strength,” “unkindness as a lack of understanding.” For our patients with severe or life-limiting illness, reframing disappointments can be a way that instills hope, increases self-control, and provides concrete direction.

6. Goal Setting

Goal setting has been found to help in maintaining hope. As the disease progresses, bad news becomes more likely, and occurs more often. It is hard for patients and families to stay in the here and now. The stress accumulates. In these times, hopes and goals need to be renewed and nourished often. Research has pinpointed hope to be a strength that is part of healthy coping in the dying process. Hope helps people identify what is important to them and make decisions on how they want to live in the time that remains.

When people have hope, they are able to set realistic goals and channel their energy into achieving desired outcomes. For example, hoping to see a loved one who is coming home in two weeks might help a patient be motivated to do whatever is possible to be strong for that visit. This could mean

the person will try to get out of bed and exercise, maintain eating patterns, or even positive thinking. Researcher Gum writes, “Dying patients are likely to use such active coping, if they are hopeful that their strategies will be effective in researching their desired goals.” This again speaks to the balance of maintaining realistic and faithful hope in working towards understanding the worst, but always maintaining hope for the best possible outcome for the person’s situation.

7. Never giving up on a patient’s hope, faith and quality of life goals

It has been proven time and time again across health care professionals and needs that a central aspect of medical care lies in relationships. While the hope of cure may not be attainable for some of our palliative care patients, having an empathic, caring relationship is always an option.



With our therapeutic support, social workers and counselors can be coaches, cheerleaders, advocates, and shoulders to ease and share the burdens our patients and families are going through. Physician James Salwitz nicely states, “It seems to me that while we should never forget the possibility of the miraculous, and try always to avoid despair, that our patients are powerful beings and perhaps our true goal should be to move from the limits of hope, to the freedom and possibility of cope.”

Ready to learn and discuss more?

[Critical Palliative Care Skills for Social Workers and Counselors](#) is an 8-week online course that teaches the essential skills that every social worker and counselor needs to know. In an engaging, on-line classroom, you will have the opportunity to focus on different aspects of caring for patients and clients with serious and life-limiting illness. Through lessons and discussion forums, you will interact with participants from all over the world. If your career involves even occasional involvement with palliative care, then you’ll find this engaging and interactive course an ideal way to build your confidence and keep your knowledge and skills up to date.

About Anne Front, MA, LMFT

Anne Front is a licensed Marriage and Family Therapist in Studio City, CA. She is the Palliative Care Counselor at Henry Mayo Newhall Hospital in the critical care, oncology and medical units. She serves on the hospital’s Cancer Committee and Bio-Ethics Committee. She is a certified Grief Recovery Specialist and an Allied Health Professional. In her outpatient private practice, she sees a variety of clients and families dealing with relationships, depression, anxiety, grief and loss, chronic illness and addictions. She facilitates caregivers and cancer survivor support groups. Anne has completed, and is now an instructor for the CSU Shiley Institute for Palliative Care’s online courses, Critical Palliative Care Skills for Social Workers and Counselors and the Post-MSW Palliative Care Certificate.



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