

A Publication of Transitions LifeCare

# Touching Lives™

*Holding Hands. Holding Hearts.*

## Biggest Lies We Tell Ourselves

A Beautiful  
Way to Be

Record Your  
Life Story

3 Questions to  
Ask Yourself

Doing Life  
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**It takes a community to provide a full circle of care.**

# Welcome to *Touching Lives*



Dear Friend,

Each year when we begin the process of curating content for this magazine, we think about you, our reader. Who are you? Are you a caregiver, a griever, someone who's experienced a tough diagnosis? What do you need? Perhaps you're on the outside looking in at someone who is struggling with their own tough decisions, and you're seeking resources or even comfort. Perhaps you're a healthcare worker with a unique outlook on the heart, heads, and hands of today's ever-changing environment.

In this issue, our writers provide perspective on receiving a serious diagnosis, hospice experiences, and the biggest lies we tell ourselves (spoiler alert: not talking about death does not make it go away). We're especially honored to share words from our Transitions LifeCare colleagues on living and loving through a cancer diagnosis, the power of coming to terms with dying, and the concept of cultural humility.

This past year, we've sought to balance uncertainty with joy. After all, that's what life is, a series of challenges that hopefully move us to deeper understanding and equip us to face tough times, a series of joys that help balance out the struggles, and, yes, even sorrow that knocks us off our feet.

Our hope is you will find something or learn something in this issue that will help you add to your own life's series. It's your life. Your care. We're here for you at every point of your journey, and we're just a call or click away at 919.828.0890 or [transitionslifecare.org](http://transitionslifecare.org).

Warm regards,

*John Thoma*

John Thoma  
CEO, *Transitions LifeCare*

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*While the articles in this magazine represent the opinions of the authors, we hope you will find the content meaningful and helpful.*

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# Helping Children and Teens Adjust to a Loved One's Terminal Illness:

## Communication Tips

**C**hildren, grandchildren, and siblings are an important part of families, and they are aware of, and affected by a family member's illness in many ways. Including them in discussions about changes taking place prepares them for your or your loved one's death and will help build trust and encourage communication between them and the adults in their lives. These discussions can be emotional and challenging but listening and communication help make this transition easier for your family members.

Give prompt and concrete information about the illness and describe what is happening in clear, concise ways using simple language. It's important to name the disease (e.g., cancer, diabetes), rather than using an all-encompassing term such as "sick." Name and point out the affected body part(s).

Tell children and teens about the family member's illness early in the process, not waiting until your loved one is actively dying. This gives them the opportunity to adjust to changes and to plan together time. Use the word "die," not euphemisms such as "passing away," "be with God," or "expiring."

Teach what "hospice" means. Clarify that even though the family member will receive care from hospice doctors and nurses, the ill person will not get better and eventually will die. Often there is an instinct to "protect" children and teens from conversations about sorrow, illness, and death; however, this is a misguided kind of protection, as they benefit more from understanding what is happening, coping with the changes around them, and having the opportunity to communicate their feelings.

Communicate changes that are happening in the home, family routines, and in the appearance of the ill family member. For example, tell them the ill person may sleep more, may not eat as much, and may have mood swings. "Dad hasn't been walking very well, so we moved his bed downstairs now. He can sleep down here and won't fall going up the stairs."

Show you understand their feelings, fears, frustrations, and behaviors. Help them know this is a difficult time for everyone and that it's common to experience a range of feelings, such as sadness, confusion, anger, frustration, anxiety, and even joy. It's also common for children to want to be "normal" kids sometimes, too. Find ways to express feelings together in healthy ways (e.g., playing sports, crying, hugging, taking a break).

Check in regularly with children and teens. Invite them to ask questions; give honest answers in return. Ask about fears or concerns or things they may be confused about. Talking to them about their thoughts and feelings validates them as an important part of the family and increases trust between you. ❧

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*With great thanks to many who have shared versions of this content over the years. Adapted from content shared in Transitions GriefCare's packet for kids who are adjusting to terminal illness.*



# 3 Questions to Ask Yourself

By Steven Pantilat, MD



**Imagine you are on a plane cruising at 36,000 feet, sitting back and relaxing when suddenly the plane drops 10,000 feet. Your drink goes flying into the air and flames leap from the engine. In sheer panic, you think “I’m going to die.”**

That is what it’s like when receiving a serious diagnosis. While it feels in that moment like you are going to die, it turns out there is a lot you can do. No matter how difficult the news, or how bumpy the ride, there is hope that you will feel in control again even in the midst of chaos.

In caring for thousands of people who have received bad news about their health, I have learned that we can live well with serious illnesses like kidney disease, chronic lung disease, or heart failure if we ask just three simple questions.

## **“Doctor, what is going to happen?”**

When dealing with a serious illness, understanding your prognosis is essential because it allows you to plan your life and make better decisions. Of course, it can be frightening to talk about your prognosis and what to expect. The tendency—for people with serious illness, their loved ones and even doctors and nurses—is to turn away from what is

really going on because it’s just too sad and difficult to face. We don’t want to make the person we care about sad or take away hope.

The truth is that even doctors don’t like to discuss prognosis. Your doctor may deflect by saying, “I don’t have a crystal ball.” While that statement is true, it’s also a cop out. Press your doctor for the information you want. Doctors typically know more than they share. Tell your doctor that the information doesn’t have to be precise to be helpful since a general overview helps plan for the future.

## **“When you look to the future, what do you hope for?”**

It’s one of the simplest and most important questions any of us can ask ourselves. A few years ago, I cared for Betty who, at age 72, had advanced Parkinson’s disease. During

our first visit, I asked Betty the question I ask every patient, “When you look to the future, what do you hope for?”

Betty thought for a moment. “I hope to see my daughter get married.”

I said, “Tell me more about that.”

Betty’s eyes lit up. “It’s in 10 months in the Napa Valley.”

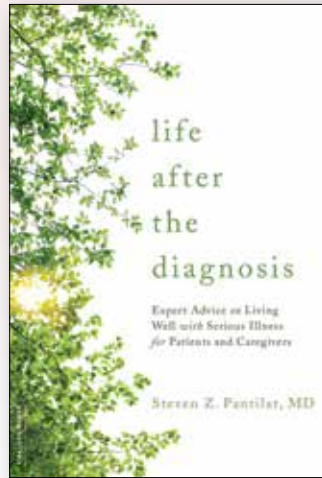
I was worried that Betty wouldn’t live that long and that even if she did, she would be too ill to attend. We talked about it honestly. The next week Betty called to say her daughter was getting married in a month. Betty died four months later.

Betty got to achieve the thing she most hoped for because she considered and answered this important question.

*What do you hope for?*

### **“Tell me, what is it you plan to do with your one wild and precious life?”**

This question comprises the last two lines of the poem “A Summer’s Day” by Mary Oliver, one of my favorite poets. She beautifully captures the essential question that each of us must answer and the one that serious illness makes urgent.



Think about how you want to *live* with serious illness. What is most important in your life? What do you want to accomplish? What is left undone? Life after the diagnosis is hardest time of life and also offers opportunities for connection and meaning. Focus on what is most important. Get help, have hope, live and love fully. Make the most of each day.

After a life well lived with serious illness, when the time does come, we can hope to land the plane gently. Too often we ignore the fact that all planes must land, that all lives must end. We think we can just fly the plane around and ignore the fact that the fuel is running low. One engine goes out and we just keep flying around until finally we run out of fuel and the plane crashes and burns to the ground.

The final question is how do we savor the flight and, as the fuel runs low, land the plane gently. The answer—ask for palliative care. When faced with serious illness, palliative care provides answers to these three questions on living well. ✨

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Steven Pantilat, MD, is Professor of Medicine, Chief, Division of Palliative Medicine and Kates-Burnard and Hellman Distinguished Professor in Palliative Care at University of California, San Francisco.

# A Beautiful Way to Be

By Beth Carlton

**Today I knew I had to be still, without distractions, without having to put forth effort to talk about how I feel or to try to comfort someone who is worried about me.**

Today I felt peace knowing that the numbness that I feel is the mind's way of putting on the brakes until I am ready to move ahead. It is the brilliant design that allows us to not feel the need to be strong or be weak but just 'be' without explanation, apology or analysis.

It is the 'safe zone' that shields us and protects us during times of fear and uncertainty. It is the cast that blocks out intrusion and invaders, even loved ones who mean well.

When their words hit the cast of numbness, it deflects any of their anxiousness. The cast blocks the natural world from interfering with the brokenness while we are being spiritually healed in our soul.

"To be" means to be still, to rest, to avoid the temptation to distract, avoid, deny thoughts. "To be" means to not feel an obligation 'to be' anything other than what your spirit is telling you 'to be' ... it is your safe place of immunity ... it is allowing you to be healed by divine strength, not by human words, but by spiritual balm.

"Be still, and know that I am God." Psalms 46:10

I don't feel that God needs anything from me in this moment of being. I know that God understands that

I can give nothing, not a prayer or a request or even a conversation with him right now. As sad as I am with my numbness that feels like a barrier to him, I also feel that he is telling me that 'it's ok, let me be your strength.'

It reminds me of the poem with the image of the footprints in the sand .... he is carrying me and all I need to do is 'to be' ... to rest, to be numb until it's safe to feel again, knowing that I when I do feel, it will be different, it will be better, it will be wiser, it will be from my spiritual soul rather than my human self. *Thank you, God.* ❄

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Beth A. Carlton is a freelance writer who is living with a serious illness and hopes to inspire others to 'simply be' rather than become overwhelmed with fear and uncertainty.

# Doing Life *Together*

**Three ways hospice helps not only patients, but their loved ones, too.**

*By Paula Spencer*

**M**yths about hospice care abound: That it's just for the last days of life. (People with a prognosis of six months or more are eligible, and many even outlive this form of comfort-care support.) Or that it's expensive. (Hospice care has been shown to cost less more than conventional medical care, on average, at the end of life.) Or that signing up means "giving up." (It doesn't!)

Here's one more misconception that you may be surprised to learn is untrue: That hospice is just for the dying person. In fact, **hospice care is designed to support the entire family at the end of life.**

Hospice is a special concept of care designed to provide comfort and support to patients *and their families* when a

life-limiting illness no longer responds to cure-oriented treatments, according to the Hospice Foundation of America. "And their families" is no casual choice of words.

Here are three ways hospice supports loved ones, too:

## **Hospice helps relieve overall stress.**

Most Americans have limited experience with terminal illness. Coping with difficult medical decisions, fear and worry, and great sadness—usually while trying to continue some semblance of everyday life—can tax anyone.

A hospice team tackles the situation with diverse resources, both on site and a phone call away. Net result: Sadness obviously remains, but the shared burden means stress levels plummet.

Studies link hospice care to better quality of life not only for the terminally ill, but for their families as well.

A study of more than 700 cancer patients, for example, found that whose loved ones died in intensive care units suffered more physical and emotional distress than those whose kin died with home hospice services.

When Jennifer Wall Alamdari was 16, her 56-year-old mother was dying of cancer at home in Crutchfield, Kentucky. "My father and I were completely unequipped to take care of her," she remembers. "It was







such a relief to know that someone skilled was coming to take the weight off of us and that mom was being properly cared for.” Because her dad had another adult to talk to and consult with, Jennifer felt she gained some space “to be a kid again.”

She also learned ways to cope with impending loss. “Our hospice nurse showed me ways to be close to my mom and give her comfort: massaging her hands and feet with lotion, reading to her, buying her a new nightgown, making food that was easy for her to swallow (her throat was raw from the radiation),” she says. “Hospice helped us find ways to be there for her and ourselves.”

### Hospice helps with hands-on guidance.

When Alicia Garate-Golembiewski’s mother was dying at her San Francisco home of mesothelioma, a rare form of cancer caused by asbestos exposure, she liked her hospice caregivers so well she called them her “angels.” For Alicia, these angels were teachers as well.

That’s because in addition to providing hands-on care like bathing, changing sheets, and medication dispensing, hospice workers also show curious families how to manage common situations when they can’t be present.

“When I would try to lift my mom to take a shower, she’d cringe,” Alicia says. “The nurse would show us how: ‘Put your arm like this, let her move with you, move the sheets this way.’ I loved that they took the time to show us all those little things. And I could call any time with questions—they truly were angels.”

### Hospice helps with grief support, both now and later.

Grieving doesn’t begin at a loved one’s death. “Grief started the day Steve was diagnosed,” says Tyra Damm of Frisco, Texas. Her 39-year-old husband of 15 years eventually died of a brain tumor they soon referred to as the “Damm spot.”

The emotional pain of losing a loved one, felt before death, is called anticipatory grief. A 2001 study in *The Gerontologist* called anticipatory grief equivalent in intensity and breadth to the response to death. It’s real grief—and not surprisingly, it’s very common among those who care for the terminally ill.

Beginning while Steve was in hospice care and for 11 months after he died, hospice grief counselors met with Tyra and her two children, Cooper, then 8, and Katie, 4. The children’s therapy included music and artwork—“things they could control, when they couldn’t control everything else going on,” Tyra says. “They helped me work through things like Steve’s first birthday without him and what was normal for grieving kids when I wondered about how to discipline,” she says.

“I was surprised to get grief help for both me and the kids even before Steve died,” Tyra adds. “We all needed it.” ❧

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Paula Spencer is a writer based in San Francisco, CA. When each of her parents used hospice services, she gratefully experienced the hospice care described in this article.





# Biggest Lies We Tell Ourselves

*Some of the biggest lies we tell ourselves center around death. We may avoid thinking about mortality by refusing to write a will. We may have no idea what end of life options our parents or loved ones want when confronted with death because no party involved wants to talk about it. And most of us think that being diagnosed with a terminal illness is simply something that “couldn’t happen to me.”*

*The truth is that all of us will die. Everyone we love will die. And a large number of us will be diagnosed with a terminal illness before our ultimate demise.*

*My mother, Dr. Karen J. Warren, describes the questions she had to answer for herself after being diagnosed with a terminal illness. Through the process of self-honesty and evaluation, she hopes that these questions can serve as a practical example of how to use death as a platform to understand yourself and embrace the time that you have left.*

—Dr. Courtney S. Warren, PhD, ABPP

I am dying. Unless I get hit by a truck, I know how I will probably die. And it won’t be pretty.

I was diagnosed with a terminal illness called Multiple Systems Atrophy (MSA). It is a fatal, progressive brain disorder that affects the neurological body functions such as swallowing, digestion, and blood pressure.

Learning I had MSA was a blow. I was scared. Angry. Sad. I thought,

“Okay, I have this disease. Now what do I do? What do people do when they learn they have a terminal illness? How do I proceed with my life?”

Looking back, I see that my process for dealing with my MSA diagnosis involved answering seven questions. These questions may be helpful to anyone diagnosed with a terminal illness and their loved ones as they move forward from the diagnosis.

## 1. Whom should I tell about my illness?

When I was first diagnosed, I had to figure out who to tell—and how.

I began by telling those I am emotionally close to—my daughter, my siblings, and my dearest friends. Then, I told people who needed to know because I would need their assistance to “put my affairs in order”—my lawyer, financial advisor, accountant,

and various healthcare providers.

When you tell people, they will want more information. Like me, they had never heard of MSA. And like me, they were full of questions that I could not answer. There may be conflicting emotions. It's important to remember that you don't owe anyone information. Tell who you want or need to tell, and don't feel pressured to tell anyone else.

## 2. What do I need to prepare for life moving forward?

Once I told a few people of my health news, I felt totally overwhelmed. I am a single mother who has lived alone for almost 25 years. I was comfortable with that—until I was diagnosed with MSA. Now, the reality of living alone was terrifying because I now knew I would need help beyond what is provided by physicians and health care practitioners.

Overwhelmed by this question, I

turned to my primary care physician for help. I asked her, "Who will take care of me? What do I need to ensure that I am cared for?" Her answer: "You need a case manager."

My first phone conversation with my case manager was just what I needed. She encouraged me to make choices about what I want to do with the rest of my life and to figure out how to give life meaning as a dying person.

That stumped me. As a retired philosophy professor, surely I was capable of knowing what gives my life meaning. But, in fact, I didn't really know. So I began by asking myself what I really cared about and wanted to do.

## 3. What do I want?

For most of my life, I have done what I needed to do or what I should do. Now the question was about what I wanted to do.

Listening to others who were dying from a terminal illness, I realized that

often what many of us want is just to do ordinary things—wash the dishes, clean the house, go for walks, work in the gardens, go for a swim, or use an exercise machine. Most importantly, we want to be with the people we love.

For me, this meant spending time with loved ones doing what they loved doing. During this past year, I have gone to an opera, The Ryder Cup golf tournament, Vikings football games, a glorious day at a spa, Hawaii, and Florence, Italy—all with my treasured family members.

## 4. What really matters?

After several months of living with my illness, I knew that what gives my life meaning, what really matters to me, are relationships—relationships with myself, with other people, with animals, and with the natural world. Creating and nurturing these relationships is what I value most.

How does this translate into how I live my life going forward? It comes down to this: When I am no longer able to communicate or have interactive relationships with others, my life will have lost all meaning to me. When I am nearing the end of life, I want to be permitted to die. I have an Advanced Care Directive that specifically states which medical treatments I do—and do not—want when I get close to dying. Ultimately and unequivocally, I want end-of-life options that permit me to have medical aid-in-dying.

## 5. Do I have time for this?

The precious time I have left matters! I found myself asking, "Will doing this or

saying that make a positive difference to my health or enhance my well-being?” For example, does it make a difference to me whether I participate in a research program, take an X-ray, or have a mammogram? My guiding principle has been this: “If doing something makes a positive difference in my life or enhances my well-being, then do it; If it doesn’t, then don’t do it.”

## 6. Will this action enhance my quality of life?

Medical professionals (and others) often suggest to people with a terminal illness that we can and should do things that enhance our quality of life. But what does that mean? I don’t know, exactly. But there are many practical things I can do that enhance my day- to-day living. For example:

- Save the cards, letters, emails, and text messages people send you. They are living eulogies—eulogies before you die—that you can read and enjoy now.
- Post updates about your health and experiences on a website designed expressly for interaction between you and those who care about you (such as Caring Bridge).
- Find a support group—for you and your caregiver(s). There really is no substitute for being with others with the same challenges. Invariably, they’ll provide helpful information of the “this is something I do” nature.
- Write letters to your family and friends that they will have after you

die. I am writing “electronic love letters” to my two grandchildren. Every few months I make a video recording for each one.

- Plan to do something fun or pleasing each day.
- Do something new, especially if it nudges you to overcome the “What will people say?” question.
- Schedule activities to look forward to. It really makes a difference to one’s mood and quality of life.

## 7. What can I do to help others in my position?

Being diagnosed with a terminal illness is tough. In the midst of the emotional process of dealing with the illness, there are a number of legal issues we all encounter as we die—including, most importantly, medical aid-in-dying options. For me, this came in the form of supporting legislation to legalize end-of-life options for the terminally ill. For others, it may be another type of engagement. Staying connected to a social group or cause is helpful on many levels.

## Conclusion

Although there are challenges with having a terminal illness, there are also great gifts.

I have time to prepare for dying—for example, by giving away things I don’t need, doing things I love but may have neglected, renewing relationships with old friends, healing unresolved conflicts, and ensuring that I am comfortable with my relationships before I die.

Additionally, I now understand that I am dying and I am living. Dying is a part of living and living is a part of dying. Every day, I remind myself that knowing I am dying offers me the opportunity to be my best self and to spend the time I have left living fully in the present.

Finally, the most significant gift was totally unexpected: Sometimes, I am happier than I have ever been, perhaps because I have let go of the past and the past has let go of me. It simply isn’t relevant anymore. I live more centered in the present moment than I ever have, and I am just plain happy to be here—right now.

—Dr. Karen J. Warren, PhD.  
1947–2020. ❧

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Dr. Courtney S. Warren, PhD, ABPP, is the daughter of Karen Warren. She is a board-certified clinical psychologist and Adjunct Clinical Professor of Psychiatry at the University of Nevada School of Medicine. For more information visit [ChooseHonesty.com](http://ChooseHonesty.com)

# Caregiver *Stress Relief*

Caring for a loved one strains even the most resilient people. If you're a caregiver, take steps to preserve your health and well-being.

*By Mayo Clinic Staff*

**A**s the population ages, more caregiving is being provided by people who aren't health care professionals. About 1 in 3 adults in the United States provides care to other adults as informal caregivers.

A caregiver is anyone who provides care to someone in need although often family members who are actively caring for an older adult often don't self-identify as a "caregiver." Recognizing this role can help caregivers receive the support they need.

For most caregivers, being there when a loved one needs you is gratifying yet it's important to recognize caregiver stress and risk factors which include social isolation, financial difficulties, difficulty solving problems, poor eating habits and lack of sleep.

## Strategies for dealing with caregiver stress

- **Accept help.** Be prepared with a list of ways others can help. Maybe ask a friend to take the person you care for on a walk a couple of times a week, run an errand, pick up your groceries or cook for you.
- **Focus on what you are able to provide.**

It's normal to feel guilty sometimes, but understand that no one is a "perfect" caregiver. Believe that you are doing the best you can and making the best decisions you can at any given time.

- **Set realistic goals.** Break large tasks into smaller steps that you can do one at a time. Prioritize, make lists and establish a daily routine. Begin to say no to requests that are draining, such as hosting holiday meals.
- **Get connected.** Find out about caregiving resources in your community. Many communities have classes specifically about the disease your loved one is facing. Caregiving services such as transportation, meal delivery or housekeeping may be available.
- **Join a support group.** A support group can provide validation and encouragement, as well as problem-solving strategies for difficult situations. People in support groups understand what you may be going through. A support group can also be a good place to create meaningful friendships.
- **Seek social support.** Make an effort to stay well-connected with family and friends who can offer nonjudgmental emotional support. Set aside time each week for connecting, even if it's just a walk with a friend.

- **Set personal health goals.**

For example, set goals to establish a good sleep routine, find time to be physically active on most days of the week, eat a healthy diet and drink plenty of water. If you have trouble getting a good night's sleep, talk to your doctor.

## Respite care

It may be hard to imagine leaving your loved one in someone else's care, but taking a break can be one of the best things you do for yourself—as well as the person you're caring for.

Most communities have some type of respite care available, such as:

- **In-home respite.** Health care aides come to your home to provide companionship, nursing services or both.
- **Adult care centers and programs.** Some centers provide care for both older adults and young children, and the two groups may spend time together.
- **Short-term nursing homes.** Some assisted living homes, memory care homes and nursing

homes accept people needing care for short stays while caregivers are away.

## The caregiver who works outside the home

Nearly 60 percent of caregivers work outside of the home. If you work outside the home and you're a caregiver, you may begin to feel overwhelmed. If you do, think about taking leave from your job for a period of time.

Employees covered under the federal Family and Medical Leave Act may be able to take up to 12 weeks of unpaid leave a year to care for relatives. Ask your human resources office about options for unpaid leave.

## You aren't alone

If you're like many caregivers, you have a hard time asking for help. Unfortunately, this attitude can lead to feeling isolated, frustrated and even depressed.

Rather than struggling on your own, take advantage of local resources for caregivers. To get started, check out the Eldercare Locator or contact your local Area Agency on Aging (AAA) to learn about services in your community. ❖

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# Signs of Caregiver Stress

As a caregiver, you may be so focused on your loved one that you don't realize that your own health and well-being are suffering. Watch for these signs of caregiver stress:

- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications



# Record Your Life Story

By Kathy Boccella

As a defense lawyer, Alan Goldstein, 68, was used to being the one who asks all the questions. But when his wife, Cheryl, arrived at his hospice bed one afternoon accompanied by a volunteer ready to record a Q & A session with him, he was all too happy to talk about himself and his life story.

Cheryl could not believe how much Alan, who had lung cancer, opened up as they asked him questions for forty minutes and recorded his memories.

"It was a wonderful experience," she recalls. "The volunteer came in ready to film, I was the interviewer and Alan was the storyteller. We talked about his days in Brooklyn, being a little boy, what his life was about, going to law school, the children, and the hospice and his sickness."

Leaving a legacy, as Alan did, is a highly rewarding experience for hospice patients and their loved ones. Whether it's an audio or video recording, a scrapbook or written diary, or simply conversation with family members, sharing a lifetime of memories helps patients in hospice care find the meaning in their lives, recall the good times, come to term with regrets, and pass along lessons learned to the next generation.

Here are some ways to gain the most from a legacy project.

**Plan ahead.** Take time to think up great questions to ask. There may be something from the past that you've always wondered about. Rather than focusing on their own

issues, relatives should encourage the patient to guide the conversation. Be ready and willing to go with them wherever they lead you on their journey.

**Use prompts.** Bring in photographs, letters, cards, or other cues that will refresh old memories. One son used his father's past artwork. Or take a loved one on a trip to former homes with photos or other nearby places to invoke nostalgic stories.

**Tell the whole story.** Don't shy away from the hard times. Having someone listen to your story, even if it's sad, can help you realize what you've gone through and overcome, and that can be beneficial.

**Follow up.** After the interview, encourage family members and friends to continue asking questions. For example, come back with grandchildren, who will benefit enormously from those moments together. The experience of recording memories strengthens family bonds and creates a legacy that will live for generations to come. ✕

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Kathy Boccella is a journalist who specializes in writing about health care issues.



# Cultural Humility

*Meeting people where they are, even when we're not sure where that is*

By Betsy Barton

When we think about going to the doctor, we often think about it as a simple process: make an appointment, find out what the problem is, treat it, and then OK! we're good until the next bump in the road. But those of us who have dealt with, or are dealing with, a serious illness know that it's not nearly so simple. Going to the specialist for the first time after learning you have a serious illness, dealing with the death of a parent, or experiencing a sudden loss, or supporting a friend in one of those situations—none of these is simple. For the most part, we aren't taught how to navigate these waters. We have to figure it out ourselves.

Often, the bumps in the road we run across look different for each of us. Our journey is different because we bring our own unique life experiences to the examining room table. Even once we bridge this gap of "don't get it" to "get it," we still have a situation where we live in a society composed of people who live in a variety of different cultural contexts: different races, religions, skin colors, family traditions, sexual orientations.

So how do we provide the best care possible when we have such different perspectives? That is where the idea of cultural humility comes into play. Kimberly Curseen, MD says that "**Cultural humility is the ability to meet with**

**another person, and despite all the things you have heard, still be open to hearing their story.**"<sup>1</sup>

Sounds easy, right? Just listen!! Welllll... not so fast. Think about the last time you truly listened to someone—really listened. Without having an agenda. Without trying to offer a solution. Without judging. Without bringing in any assumptions or opinions based on your past experiences. Without trying to categorize, name, or label them. Hmm... might be a little harder than it sounds, yes?

If we as providers approach our clients with cultural humility, we are learners, too. We are on a journey alongside our patients, clients, and their families to support them to discover what they already know; to learn from them—who are, after all, the experts on themselves. This does

not mean we don't offer our expertise, but we do it within a partnership. ✕

Betsy Barton, MPH, CT, Hospice & Palliative Care Educator at Transitions LifeCare, has learned a lot from her experiences in advocating for family members and loved ones who faced serious illness. Educating clinicians about cultural humility is one of her strongest interests.

<sup>1</sup> Curseen: "Implicit Bias and Its Impact in Geriatrics, Hospice and Palliative Care," GeriPal October 27, 2017: <https://www.geripal.org/2017/10/implicit-bias-and-its-impact-in-geriatrics-palliative-care.html>

**At Transitions LifeCare, we not only provide care to people from an amazing and wonderful variety of cultures, but we also ARE those people – our staff members come from diverse backgrounds and life situations.**



# The Power of *Hope* Against All Odds

By Sara Sousa

June 21, 2012

I will never forget Greg's phone call from the emergency department in Alabama, the feelings are still visceral. There was a strange, crackly message on the answering machine. I caught that Greg was in the ED and they were running some tests. He left a phone number— either a co-worker's number or the number of a nurse in the ED. I went out to our back porch to call back, away from the children. I could tell that something was very wrong. He'd had a seizure and a CT revealed a brain lesion. At the time, I didn't even consider cancer. I decided that "lesion" was a generic term that could mean almost anything. In my imagination, I pictured a small wisp of something, perhaps a bit of scar tissue left from a childhood concussion. I got off the phone and called my  
parents, my body pulsing  
with anxiety and  
adrenaline. I was

overcome with sobbing as I explained Greg's call. Over the next few hours, we sorted out the details of my getting to Greg and of having [our children] cared for. I remember nothing else from this day.

*Over the course of the next four years, Sara Sousa recounted experiences, emotions, blessings, and grief as her husband Greg hoped through anaplastic oligodendroglioma, a rare, malignant brain tumor. Here is a blog post she wrote, entitled "BE STILL!"*

People connect with cancer in different ways. Some "fight" cancer, going bravely into battle, armed with chemo, radiation, and indomitable spirits. Others "beat" cancer, standing next to it at the start line and sprinting full force to the finish lines. Or, maybe they stand face to face with cancer in the boxing ring, punching hard until there's a knockout. I appreciate humor—I had to chuckle when I first saw a "Save the tatas," pink ribbon bumper sticker. A dear friend whose father recently died from cancer said that when she went bowling the other day, she bowled a strike when she imagined the pins as Greg's tumor—Ka-POW—Gottcha!!!!

Am I capable of loving cancer? Can I give it a big hug and whisper gently, "settle down little cells, don't be so rambunctious." What would those cells do if I could bathe them in a warm, loving light? Would they settle down? Would they quit being so angry and dividing into space where they don't belong? I'm too much of a pacifist to feel connected to "fighting" cancer. I'm not ready to start loving it either.





The image that clicks for me comes from Maurice Sendak's "Where the Wild Things Are" (Harper & Row, 1963). After arriving at the island where the wild things live and witnessing their rowdy and rambunctious behavior, Brave Max commands "BE STILL!" and tames the beasts. I see Greg as Max—mischievous, adventurous, loving, loved. The tumor surely is a wild thing—misbehaving and scary (and, yet, doing the only thing it knows how to do). With beautiful authority, Max commands the wild things to "BE STILL," and they dutifully obey. For now, on our cancer journey, this is the image I'm going with.

**"But the wild things cried, "Oh please don't go— we'll eat you up—we love you so!" and Max said, "No!""**

**July 22, 2016**

Since Greg died, I've realized that an aching, scary, angry hope is infinitely better than no hope at all, than the emptiness of being hopeless. With family, friends, and his medical team by his side until the very end, Greg was never hopeless. Social media is filled with beautiful and funny memories of Greg. A dear friend tagged some posts with, "livelikegreg." To live like Greg would be an accomplishment, an honor, even a victory. When swamped with the sadness and mystery of being human, I will think of Greg and the power of hope against all odds.



Sara Sousa, RN, BSN, MPH, CCM, is a mom and a nurse, as well as Transitions LifeCare's performance improvement coordinator. Since Greg's death in 2016, she and her children have laughed and learned to take a breath. Sara has also learned how to split firewood satisfactorily. She is the author of "The Woodstove Widow," a compilation of blog posts written throughout Greg's sickness.



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