Living with a Life-Threatening Illness

How much do you want to know?

There was a time in the not-too-distant past when the diagnosis of a serious, life-threatening illness was often not shared with the person affected most—the patient. The thought was that knowledge of the diagnosis would rob the patient of the hope to survive and death would come sooner because of this. In our increasingly legalistic world, the patient's right to know has become increasingly respected. Now the patient is typically informed of the diagnosis for otherwise the patient would not be able to give "informed" consent for treatment. In pediatrics, however, where legally a patient may not have to give informed consent, there exists more persistent ambivalence about how much and how to tell a child about his or her diagnosis.

While improvement has been made in informing patients and families about the diagnosis—the name of illness or condition—there continues to be struggles in telling patients and families about what is known about prognosis—the educated estimate of the future with the illness. In some ways we now tell people what they have but we too often avoid telling them what this means for their lives in terms of both quality and quantity.

For anyone who has been on the giving side of bad news, there can be some real empathy on the part of healthcare professionals. It is not easy to tell someone bad news—to feel as an accomplice to someone's trauma and psychic pain. We like to give good news—the scan is clear, the tumor benign, it's not as bad as we feared, we can cure this, we fully expect you to survive this. It's so much harder to give bad news—the scan is worse, the tumor malignant, it's worse than we thought, it is incurable, this illness will eventually cause you to die. Again, if this kind of communication is hard with adults, most find it even more daunting when a child is the patient.

When pressed, most adults in my experience say that they want clear and frank medical information. "Give it to me straight, doc" would be the theme. In reality, we on the patient side are often ambivalent, too. We want the truth, but we can get cold feet and pass up opportunities to ask questions, seek clarification and ask for reassessments of the "big picture." In this way, we can be accomplices with our healthcare providers of a "don't ask, don't tell" policy and a paternal/maternal/parental "need to know"-only policy. And when the patient is a child, both these policies can be especially present and complicating.

What's the problem with blissful ignorance? It's a matter of context and choices. Context makes big differences for choices. What are the expected risks and benefits? Will this treatment extend life, and if so, by what amount and at what cost? What is the life expectancy of the various options? Without context we don't understand well what we are choosing.

Life expectancy makes a significant difference in terms of context for the choices we face. We make different decisions—what must be done and left undone—on Monday mornings than we do on Friday afternoons. Context matters and we need to know what day it is in order to make a good decision. Understanding diagnosis and prognosis helps us know what day it is and thus can help us get the most out of our week (and life). We can "get it" that life expectancy often is a best guess. We also acknowledge that much of life is a "best guess" and that a "best guess" is may be preferable to no guess at all.

These are heavy things and they are no lighter and no simpler when a child is the patient in the middle of such things. How much do you want to know? How much does your child want and need to know? We healthcare providers need to continue becoming better and more forthcoming communicators, and we patients and families need to decide how much we want and need to know and then not settle for less.

Styles of coping

Some people cope with a life-threatening illness in themselves or their family by focusing on hope. These people want to focus on the positive and not worry about what might happen. For them, they'll "cross that bridge if we come to it." No talk of failure or fears. Some would say it's a positive attitude or a perspective of hope or adaptive denial. Whatever one calls it, it is an approach that works for many people. The risk of this style is coming to the bridge and not acknowledging it and dealing with what it means to be at that place.

Other people could not cope like the first group if their lives depended on it. For this group, they need to "what if" and imagine what they would do and how they would respond if things go wrong. It is a wrestling with the angel and the dark night of the soul that can't be truly avoided but must be engaged. This kind of imagining is helpful as these people can feel less anxiety once they have problem-solved some contingency plans. The risk for this style is getting lost in the "what ifs" and not being able to focus on and value the present.

Because no two people cope exactly the same, coping together as family can be a challenge. A "focus on hope" family member can look at a "what if" family member and say, "Why are you even thinking like that? We don't even need to go there! We need to be positive and you're giving into pessimism." The "what if" family member, on the other hand, might say to the "focus on hope" family member, "Don't you hear what they're telling us? (and maybe what they're not telling us?) We've got to be prepared for whatever could happen and you're not dealing with reality."

The message that many families hear is that they should pull together, get closer and cope with the life-threatening illness together. This can certainly happen, but it can also be that the coping style of one family member is a challenge rather than a comfort to another family member. In these situations, space needs to be given for different ways of coping, and often an outside person—friend, counselor, pastor—can be a real help as a supporter able to hear both stubborn hope and concerns about what if the worst happens.

There are another two kinds of people in the world—those who can hear and accept your coping style and those who insist that you cope as they imagine they would cope. More of the former would be appreciated.

Expanding hope

No matter what we are told of or believe about the future, it is hard to imagine living without hope. Whatever the trial, people search for and cling to hope. The search itself is a thing of hope—hope that there exists something to hold onto, some place to stand. Several generations ago the thought of living without hope motivated healthcare professionals and family members to keep the diagnosis and prognosis of a life-threatening condition a supposed secret from the person bearing the diagnosis. The worry was that if the person were informed, hope would be lost and not found. Too often today a patient will be told the truth of the diagnosis but not the whole truth of what the diagnosis likely means for both quality and quantity of life.

Part of the problem is that hope has been too frequently treated as a small, fragile thing—perhaps like Emily Dickinson's description of hope as "a thing with feathers." We have thought of hope as a narrow thing as if the only hope worth having and holding onto was the hope for the rescue of a cure—If hope for a cure cannot be supported medically, then the situation is without hope or hope-less. Hope need not accept such a narrow definition.

In the setting of a life-threatening illness, hope can be for many things: for cure, for pain-free or pain-less living, for extended life, for good life no matter the length, for a peaceful and dignified death, for meaningful life until life's end, for a miracle which takes away the threat of death. These hopes need not be mutually exclusive. Some may experience the need to let go of one kind of hope—such as the hope for cure—in order to focus on another kind of hope such as finding a new quality of living for the life that is left. Others do not accept the need to give up any hopes but expand their original hope for cure to include other simultaneously existing hopes. These families hope for a miracle while hoping for more good days, less pain, meaningful interactions and, if it comes, a death with no suffering. Hope is remarkably elastic like that—it can expand, stretch and continually change its shape.

A person's need for hope deserves understanding and respect. Hope also deserves understanding and respect for the resilient and expansive thing that it is and can be.

Why questions

When someone gets a diagnosis of a life-threatening illness, two kinds of "why questions" generally rise to the surface—the "medical why" and the "spiritual why." The "medical why" wants to know where this illness comes from, how did it start, is it contagious, is it from something we ate, is it from a problem in pregnancy, is it genetic? Increasingly through medical research there are good answers for these questions. Our knowledge remains very limited, nevertheless, compared to the complexities of our bodies, so there are still many "we just don't know" answers to these very good and natural questions. For the person with the life-threatening illness and the person's family, it is important to be offered as much information as is available and will be helpful to address the "medical why" questions they have.

A very different but very common companion "why question" is the "spiritual why question." "Why me? Why not somebody else? Why anybody?"—if we're the patient; "Why my child? Why not some other child? Why any child?"—if we're the parent; or some variation—"Why him? Why my sister? Why my friend?"--depending on our relationship. These are "why questions" that defy an answer which have any consensus—medical, spiritual or otherwise—and for many, this is the more important "why question" because it touches deeply on the meaning of a person's life and perhaps even the meaning of life itself.

Wrestling with the "spiritual why question," many respond to say, "Everything happens for a reason" or "There's a reason for everything" but "I don't know the reason for this—it's a mystery." Those of us with this response may say, "God didn't cause this, but there's reason..."

Some of us would respond to the "why question" with an experience of insight—we know the reason or at least part of the reason. Here we could hear statements such as "Look at how our family has been drawn closer together" or "We have grown in our faith and have had our priorities straightened" or "See how many lives have been touched through this experience." In this place, we may not see all the reasons, but we have a glimpse of what some of them are.

Others of us would reject any reason given in response to the "spiritual why question" and would not accept that there is a reason to be found. For those of us in this place, we don't "know the reason" because there is "no reason." Here we would say, "There is no divine hand manipulating genes or cell division so that illness is caused. We will find no reason for this, things just happen. What reason and purpose we find will be ahead of us—how are we to live now and in the days ahead."

Some mysterious reason, know the reason or no reason responses to the "spiritual why question" can be found in the same family, in the same Sunday School class or religious group, and in the same circle of friends. Change the situation and we may change how we respond to the "spiritual why question" or we may find ourselves dancing back and forth among the responses for the same situation. "Spiritual why questions" can also defy internal consensus.

Because "spiritual why questions" and their responses are so individual and personal, the job for those of us in the support role is to offer respect, listening and support. How we make sense may be nonsense for another, and it is not our role to make meaning of another's life or experiences. Sometimes we supporters can help with getting good information so that good understanding can happen—no reason to blame genetics if this is not a genetic illness, for example. But mostly we supporters avoid explanations and justifications. "Spiritual why questions" may be (nearly) universal, but our answers to such why questions are not.

Different ways to fight for life

If one described an elementary, middle school or high school student as a "fighter," it would probably not be a positive thing. If someone is described as "itchin' for a fight", we would probably want to steer clear of such a person and warn our friends to do likewise. In many areas of our lives, fighting has a negative connotation, but when we talk about life-threatening illnesses and conditions, fighting takes on a whole different meaning.

When a diagnosis of a life-threatening illness or condition comes, it is the start of a battle for most of us. The illness is a threat to our lives and way of life and we fight to defend ourselves, our families and our living. We fight the illness, the side effects of the treatment, fears and worries, and sometimes other people and the healthcare system in order to get what we need to fight the illness. Life can feel like one struggle after the other and some of us are incredible, awe-inspiring fighters—the kind of people that we would want on "our side" if we were ever in a battle or conflict. This determined fighting has strength and an inspiring sense of determination. It says, "I will not be broken, I will not accept defeat, I will not take 'no' for an answer." Fighting of this kind can extend lives, beat the odds and fiercely protect one's quality of life. We have seen this kind of fighting in the face of death which promises that if I go down, I will go down swinging. It is this kind of fighting of which the poet, Dylan Thomas, references when he writes,

"Do not go gentle into that good night…Rage, rage against the dying of the light."

For many, this kind of fighting and approach to illness is not easy to let go and people live and die with dignity fighting all the way until they take their last breath. It may not easy for us to watch but we can respect and admire it as a way of living until life is no longer possible. Often we can support this fighting, too, if we can avoid supporting a kind of fighting which causes harm and offers little to no help.

There is another way to "be a fighter" which follows a different path. In the beginning, these two ways of fighting travel side by side looking very much the same. The difference comes in a crossroads of sorts. At this crossroad, the "going down swinging" fighter keeps up the struggle for cure despite terrible odds and whatever costs may be involved. The alternative path is also a fighting path but the fight is not a fight for cure but still very much a fight for life. This fight is for more good days, for making meaning and memories, for avoiding preventable suffering. This fighter conserves strength, avoids no-win situations and concentrates efforts on where differences can be made.

Whether or not one way of fighting is easier or more difficult is not always knowable or the same for different people. The important point is this—there is more than one way to "be a fighter" and not "give up." Fighting for life can take as many forms as there are people. There is more than one way to live with dignity and die with dignity.

Holding on and letting go

No one wants to "give up," but "letting go" can be a different matter.

When facing a life-threatening illness, even when there are no curative options available, no one wants to give up. Giving up has quite negative connotations in our culture. Those who give up are losers, not strong enough, lack faith, guts, devotion, commitment and dedication. Fair or not, giving up is not an acceptable option for most of us. One could consider what it means to "give up" exploring both what the "give" and the "up" could mean in the context of the end of a person's life, but that is another topic for another day.

Letting go is different than giving up. Letting go suggests that there are some things that can be controlled and for those things we hold on, but there are other things which are beyond our control and for our own sake we let go of those. Trying to hold on to that over which we have no control does us little good and takes away our energy for those things that we can influence and have some hope of control. In the midst of a life-threatening illness with limited energies and potentially limited time, it can be life-affirming to let go of that we takes away from our life—both quality and sometimes quantity—and focus our efforts elsewhere.

A woman with cancer wrote this about letting go:

We are not the ocean or the storm; neither patient nor physician can control the outcome…But I do not have to give up control, because I never had it. Control is an illusion that we preserve to manage the randomness and chaos of life and death. What we must let go of, then, simply is an illusion.

Martha Gaines

An Odyssey of Hope

A poet, not surprisingly, may say it even better:

We need, in love, to practice only this:

letting each other go. For holding on

comes easily; we do not need to learn it.

Rainer Maria Rilke

Requiem

Those who find a way to let go and hold on can do amazing things. They can hope for a miracle and make arrangements for a funeral. They can live in the in-between land of different kinds of futures. In his book, *The Anatomy of Hope*, Dr. Jerome

Groopman writes of a friend who pursued an incredibly aggressive chemotherapy regimen for a very high-risk cancer although his friend understood well the poor chances for a positive outcome. His friend eventually completed his treatment and survived, paying a high price in present and future quality of life. It wasn't until after his friend's treatment was complete that Dr. Groopman learned that his friend had planted flower bulbs that he expected would provide blooms for his likely funeral after the treatment failed. His friend found a way to fight for life but let go of the responsibility of the outcome. He found a way to both hold on and let go.

In a hospital a patient's family member will share with a hospital staff person something like this: "I was up most of last night. Spent a lot of time in the chapel until finally I turned it over and let it go. I don't know what will happen and I still want and pray for the miracle, but whatever happens, I know that ultimately it will be OK." Letting go.

Not everyone gets to a place of letting go and not everyone who visits there is able to stay. But for those who find their way to letting go of that which ultimately refuses to be held, they have something to teach the rest of us. Lessons which are worth holding on to.

A life-affirming conversation: Talking of dying with the dying

Lord Voldemort is the villain in the Harry Potter books who killed Harry's parents and continues trying to kill Harry and anyone else who gets in his way. The wizarding community in conversations and even in the daily newspaper, however, refuse to say his name and instead refer to him as "He Who Must Not Be Named" or "You Know Who." Now "Lord Voldemort" is not the villain's original name but one that he gave to himself in order to make himself appear more intimidating. Lord Voldemort's real name is Tom Riddle. Voldemort's nemesis on the side of the good is named Albus Dumbledore and he is among the few who will say the name "Voldemort." Harry is encouraged by Dumbledore to follow in his example and "always use the proper name for things" for "fear of a name increases fear of the thing itself." Dumbledore goes even farther when confronting Voldemort in person as he calls him just "Tom." Which sounds more frightening—"He Who Must Not Be Named" or "Tom"?

If we choose to talk to the person who may be dying about dying and death, the challenge is to eventually use the words—dying or die—themselves. The words can be uncomfortable but helpful as otherwise we make the situation even more intimidating and frightening than it has to be. The more we cannot say the words, the more difficult to truly face the reality of the situation.

In the counseling the mantra is to start where the person is and this is a helpful concept for beginning conversations. How is the person feeling, what has been said by the doctors or other healthcare professionals and what is understood about the present situation? These are good places to start and sometimes the person will express concerns about dying in the midst of this conversation. If not, more questions may be needed. What are the person's biggest concerns at this point and for the future, what does the person see for themselves in the future—six months from now, a year from now, what have they been told by the healthcare providers about their future and chances of survival? If the topic of the possibility of dying continues to be elusive, then more direct questions may be considered: What happens if the treatments don't work well enough or how worried are you about the possibility of dying?

If someone acknowledges being concerned or worried about dying, the nature of these concerns needs to be understood. People—children, too—worry about different things when considering their own deaths. Some are worried about the possibility of pain and some worry about a loss of control of their bodies. Some are concerned about how their family and friends will respond and cope. Others worry about spiritual matters related to an afterlife or the possibility of an afterlife. Sometimes there are tasks still left to do—unfinished business that needs tending. Still others wonder how and if they will be remembered. There is help and assistance with all these concerns but such help may not be offered if we caregivers don't understand the individual nature of the dying individual's concerns.

Throughout any and all conversations about dying, we need to be sensitive and respectful of those who would choose to not be a part of any such conversations. We offer these conversations with respect and gentleness acknowledging that the dying person may decline. Our hope and goal is that any such declining will be related to the person's true preference and not a felt need to protect us caregivers from our anxiety about the conversation. Some say that people will talk if they want and thus our job as caregivers is to respond but not to initiate or invite. There are those people confronting their own deaths, however, who need and desire to talk but will not start the conversation without an invitation.

Death has enough power and influence in our lives so that we need not give it more by refusing to speak its name and acknowledge its presence. Naming death and our concerns about dying can be a powerful affirmation of life. And that is a good thing—affirming life from beginning to end.

Risky business: Not talking of dying

It has been said that we are a death-denying culture, reluctant to have honest conversations about death. From another perspective, however, we talk about death all the time—who died, how many died in a particular disaster, how many homicides there have been this year, how many have died and may die in a war. Talking about death after the fact—after the death has occurred—does have its difficulties. For most of us, talking about death before the fact—talking about the possibility or probability of dying—is even more challenging, especially if the potential conversation is with the person who is at risk of dying. And if the at-risk person is a child, the challenge can feel greater still.

When someone is facing the possibility of dying, the last thing we want to do is make things worse or more difficult. We want the person to be happy rather than fearful, comfortable instead of anxious, hopeful rather than hopeless. Support is offered with distraction and encouragement and both these approaches are worthy and generally appreciated. We may know what we're facing but why talk about it and give it attention? Why stir up fears and worries if we don't have to? Let's not make matters even worse.

There are at least two significant problems with this "don't ask, don't tell" approach when someone is at risk of dying. The first is that it leaves the person at risk for dying to deal with this possibility alone. One of the most common questions when a person has a serious injury or illness is whether or not the person will be "OK." When we ask, "Are they going to be OK?" we first wonder if the person will survive and then if the person will be back to their baseline—able to live life as they did before. These are questions that confront the person at risk, too—"Am I going to be OK?" "Am I going to die?" "If I live, will I be back to normal?" These are common, understandable and important questions for adults and for many children. Some might say that we address these questions only if they are asked but this leaves the burden on the person facing death to risk further upsetting those around him or her who are already clearly upset. In our culture we value sacrifices offered for the peace and protection of the group, and too many times persons facing death sacrifice themselves by not disturbing the surface peace of those around them by not raising difficult issues of living and dying. Instead, they deal with these questions alone. Some may not want to talk about such things, but there are many who do and will if offered a supportive space for such a conversation. For these, it can be both comfort and help to have someone acknowledge the "elephant in the room" and be with them as they try to understand what is happening and what may happen. It is the message there this is nothing that we can't talk about and face together—you don't have to face this alone.

The other problem with avoiding the conversation about the possibility of dying is that of choice. When death is possible, probable or expected soon, realization of death's place in the picture affects the choices we make. How do I want to spend my time? Are there things that I want to do but need to know a best-guess of how much time is available in order to choose? How likely is it that this treatment will extend my life and what will my life be like with the treatment or without it? How can I make wise and informed choices about my life if I am not aware of the possibility of my death? We all know that prognostications about length of life and times of death are guesses and are often wrong—most of us have personal examples that go "the doctors told us…but…" Nevertheless, human estimates are have and can be helpful for the one who deserves to be in the center of the discussion about one's own life. Someone may choose to not talk about the possibility of dying but that choice cannot be made without information and the option to do otherwise.

What does it mean to be loving, faithful and merciful?

Being a decision-maker for someone who is too young or too sick to make decisions for themselves is an especially heavy burden with many questions to answer. What would the person choose if they were able? How much intervention? What about a ventilator? What about blood pressure medication? Antibiotics? Scans and tests? Resuscitation? CPR? Every time or just in certain conditions? Stay in the hospital or try to be home? Another round of treatment? Experimental treatment? Hospice? Can the person understand what is happening to them? If so, what do we say? If the person dies, what funeral home to use? Burial or cremation? When and where and who to be involved? So many questions all along the way.

Among all the particular and specific questions regarding treatments and interventions, there are some basic questions that do not change although the answers to these questions will change depending on the situation:

- What does it mean to love this person?
- What does it mean to be faithful?
- What does it mean to be merciful?

To love someone is to want and work for the best for that person, which, of course, begs the question of what is best. Parents and decision-makers are faced with the challenge of searching their hearts, minds and motivations to find where love for the person would take them. Other things can get in the way—fear of what could happen, insecurity and anxiety, need for the other person for companionship and purpose, fear of failure as a caregiver—of making a decision based primarily on love for the other. And loving decisions can take many forms—both holding on and letting go.

Being faithful involves living up to one's promises and commitments, spoken and unspoken, as parent, spouse, son or daughter, partner, brother or sister or friend. What does it mean to be true to the person, their best interests, values and how they have lived their lives? Being faithful can involve sacrificing for another and a high calling to provide what is best.

Mercy is not a word we use often in healthcare but it is fitting word in many situations. Mercy involves providing relief, forgiveness and grace. Being merciful can involve doing and not doing and mercy is generally something one gives or offers to another.

What is loving, faithful and merciful codependently overlap and interrelate and yet each question offers something different and important. Among all the detailed questions that come up in the course of a life-threatening illness or condition, these questions will remain as caregivers are challenged to acts of love, faithfulness and mercy.