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Bring Your Love: Therapeutic and Effective End-of-Life Discussions

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This article is to assist healthcare providers promote unconditional love, with the intention of the highest good and peace in the dying patient and their loved ones. It is intended to help them personally become more comfortable and knowledgeable with issues of life support, dying, critical care, and paperwork that communicates their patient's desires effectively. By gaining these skills and comfort, healthcare providers will be enabled to empower patients and families to make healthcare decisions they can live with. This in turn will also nurture and enrich the individual healthcare provider's own personal growth. This article provides examples and case studies, as well as visualization exercises to assist the health care provider in gaining self awareness and increasing their effectiveness in delivering end of life care.

ACHIEVING SELF- AWARENESS

Are you comfortable talking to someone about dying? Are you knowledgeable about issues of life support, comfort care, creating an **effective** Advanced Directive and Durable Power of Attorney for Healthcare (DPA)? Do you have an approach for creating therapeutic end of life discussions? Do your patients and their loved ones feel good after talking with you? These are questions health care providers need to ask themselves in order to reach a greater personal level of comfort and effectiveness.

People don't usually like to talk about dying. Everyone has their own beliefs and range of emotions regarding death. What the healthcare provider feels and believes shapes their approach and communications with patients. These are conveyed through words, body language and presence—one's energy. When approaching patients one consciously or unconsciously feels the patient's emotions—their energy. Ask yourself, do you act or react? Do you lose your self awareness and start to feel the way the patient/family feels? Do you have an agenda and think that you have to change the patient so that they match your agenda and your feelings?

As healthcare professionals, we know that a therapeutic conversation is not about oneself and what one believes—it is about the patient; what the patient believes and wants. If healthcare providers have not processed their own beliefs and feelings about dying, they will tend to react. This can limit their ability to provide help not only to one's self, but to others as well. When this happens, the loss of self awareness

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and the ability to clearly perceive a situation can hinder the healthcare provider's ability to flow with the situation and focus on assisting the patient and loved ones as they come to resolution, to peace, to love. In order to create a healing environment around them, one needs to have a healing environment inside of them. The best way to help someone is to bring them unconditional love. This can be conveyed in the voice, in touch and in one's very presence. It is important to be in the moment, in the "NOW", with senses open to inner awareness allowing the heart to lead the way, letting you know when it is the right time to listen, when it is the right time to speak, and what to say. Healthcare providers arrive at a readiness for self awareness at different times and on different levels. The more they are able to process through their own beliefs and feelings the more they are able to allow the flow of unconditional love guide them to assist the patient and the patient's loved ones. When asked, "Is this what you would like to do?" most health care providers would respond in the affirmative. With that in mind, take time to examine personal beliefs and feelings regarding death, dying, suffering, quality of life, comfort care, and euthanasia, relative to self and to loved ones. It is essential to take time to pay attention to your thoughts and emotions. Sometimes one finds that they are continuing to hold onto thoughts and beliefs they were taught, or, that they created in rebellion to what was taught or experienced. It is important that the individual determine the relevance of these feelings and beliefs in relationship to who they are NOW. Then the individual can choose to continue with these beliefs and emotions or choose to be open to the possibility that perhaps there is a better way to perceive, to believe and to feel. The individual can then choose to have the "better way". Sometimes when one tries to find and pursue the "better way" it seems elusive. By simply making the choice and allowing it to be, it is more likely that the better way will surface, perhaps in a thought, a feeling, a person, a book, a song, a movie. In whatever way one can best receive it, it will come. When the healthcare provider is in the energy of love and peace with dying, they will be able to help bring patients and their families to love and peace too. They will also learn to trust in the power of unconditional love and the intention of the highest good so that even if things do not appear to be progressing the way they thought it would, they will know it is progressing in exactly whatever way is best.

Creating the Energy

Even if one has not yet processed their emotions and beliefs or is not quite "in the mood", the healthcare provider can still get into that energy of love when needed. Physics teaches that everything is made up of energy. Depending upon its vibratory rate, it will manifest as gas, liquid, or solid. Recognizing thoughts and emotions as energy at another vibration rate, one is able to utilize this knowledge to choose the energy level on which to communicate or transmit. When visiting with the patient try to **think** and **feel** love inside, as this can help to **step up** personal energy vibrations that can then be transmitted to the patient. Just the presence of an aware healthcare provider can have a powerful effect on the energy and vibrations in the room.

Visualization Exercise

Visualization exercises are a good preparation for interactions with patients. Try this exercise between visits. Sit comfortably in your parked car with your eyes closed. Take some deep breathes to become calm and focused. Use your imagination and pretend to see unconditional love as a little ball of light. Then, eyes still closed, imagine looking for this ball of light inside of your body. You may see it or you may feel it. If this is hard to do, it might help to imagine you are watching yourself on a movie screen in your mind and see where that ball of light is located in your body. Another way is to imagine a blackboard where you draw figure of yourself and, using colored chalk, place a dot of light within the figure, and then imagine feeling that dot of light in your actual body. There is ALWAYS light present, sometimes it just takes looking through and beyond the darkness until it is seen, like a candle flame in the night. Pretend, make it up. When the light is seen or felt, you might feel a release of some emotional tension.

After you see or feel the ball of light focus on it; let it become the only thing you see or feel. The light may fill your head and body. Once filled with the light, keep your body FULL, like a fountain that overflows and shares its runoff with others. This light has no limit, there is plenty. As healthcare providers it is important to remember to keep "self" filled up first and to share the rest. A beacon has to stay bright or its light cannot be communicated. By maintaining awareness of energy and love inside, one's vibrations are stepped up. This might be compared to playing a low C on the piano then playing it an octave higher, the vibration is higher, and just like tuning one instrument to another, if one can maintain the tone of the higher vibration, those around will tune in to the mood and vibration set, thus achieving a higher energy, sense of love and well being.

In the Patient Care Setting

As the healthcare provider enters the patient's home/room, it is important to be aware of how the patient's energy and the surrounding energy affects the way one's body feels and how it might feel differently from the way love feels. By maintaining focus on love, the healthcare provider can consciously communicate love and caring through their emotions, thoughts, voice, and touch. The purpose of this is to intend, in unconditional love, the highest good for the patient.

An Attitude

One of the most difficult dilemmas for a critical care nurse is taking care of the unsuspecting patient or family who arrives in the Critical Care Unit totally unprepared to make the major health care decisions that will be forced upon them. It is important that healthcare providers be able to inform and empower patients and their loved ones to make decisions based upon Love not Fear.

It is always more difficult to make good decisions in a time of crisis and can be even worse when there has been neither previous thoughts nor discussions. How can a person possibly make decisions for someone they love if they have never even talked about it? These situations should bring families together in love and support but, too often instead, there is indecision, arguments and guilt because there is no one in the family who knows what their loved one would **really** want done. In that case, the family and loved ones find it easy to feel out of control and victimized. But the decision making process does not have to be this way.

Knowledge is power and there are some simple fundamental things the healthcare provider needs to know to empower patients and to assist them to understand what they are choosing to experience. By understanding critical care issues, fear can be decreased and life put into a new perspective, which in turn can promote peace of mind. As a healthcare provider, it is important to remember to act before the crisis and to understand that knowing how to cope can help the patient survive critical care. Understanding critical care issues can help the patient and loved ones choose between life support and a peaceful death.

Generally people think this is going to be a scary, unpleasant conversation. In actual experience the conversation is about love, healing and life. Dying is a part of living and, if prepared, one can plan for a "good death" the way one might plan for a "good birth" or a "good wedding." While no one knows for certain when or how they are going to die, everyone knows that they will in fact die. And by changing one's attitude toward death we can choose not to be a victim. This author believes that when one faces dying they learn what's really important to them and this often leads to a change in priorities.

If an individual knew there was only one hour left to live, what would be their regrets? For things not done? For words not said? It is important to stop and reflect upon this at the present time. If someone was moving to another country and would not be seeing their family or friends again, would they put off to the last minute those things they wanted to say and do; or, would they take the time to see, do and say what was truly important to them?

Life is all about choosing. When one chooses between two things they desire, picking the thing that is most important to them will diminish regrets. In the end, whether or not they have been able to do everything they thought they wanted to do, they will still have done that which is most important to them. It is a win/win situation. Younger folks dealing with the illness of their parents or grandparents are often able to understand that this life experience will end sometime. When they do, this author has seen their perspective of life change; observed them begin to identify what it is they value the most and to start living it now rather than waiting until later. These young people appear to take more time to live love.

When the healthcare provider is able to bring unconditional love and the intention for the highest good into the environment, there is a sense of healing whether the focus is on trying to cure, provide palliative care, or, to promote a peaceful death. Anyone who has worked with dying patients knows that death can be a healing experience for the person dying as well as those around him. It is what this author calls the miracle of death and dying.

Planning For a "Good Death"

Healthcare workers can help create and promote the energy of a "good death" even in acute care within the Intensive Care Unit (ICU). Asking the patient (or family if patient is incapacitated) what he might want if he was planning his own death can be very self revealing and empowering. Questions such as:

- What would he want: a sacred ceremony or a party, if a party, then what kind of a party?
- Would the patient prefer to be alone at death or with certain people?
- Would he want silence, his favorite music, or the sound of his loved ones reminiscing and laughing?
- Does he have a favorite hat, blanket, or boots that he wants to wear?

By including these questions, the family and/or the individual will have the opportunity to plan a "good" death. For example, one unconscious lady, in her 80's, had still been playing in a five piece women's jug band prior to her illness. Originally, the family had planned a sacred Christian service for their Mother. The more they talked about what she was like in her life and what she might want in her death the more they realized that a sacred service is not what she would want. Instead, they planned huge birthday party for "mom" to celebrate her "first year in heaven." They had a cake with the number "1" on it, lots of food and people and, yes, the jug band played.

Why Talk

So "Why bother" having this talk? Because it is a gift of love from the patient to himself to remember to make choices in life that he will still love in the end. It is a gift of love from the patient to his loved ones, telling them what he wants and taking the decisions out of their hands. It is a gift of love from the loved ones to the patient to honor his wishes. Honoring the wishes of a loved one can really help with the process of grieving. Of course, an individual's desires change as they age and live their lives so these conversations should be ongoing and fluid.

Defining Questions

In the past, the medical system could only do so much to save lives. There was not as much to think about and consider because there were fewer choices. This meant that public education was not as necessary as it is today. Today, with transplants, better technology, and better drugs, health care can do a whole lot more and when one considers cloning and stem cell research; there are many avenues of decisions that can result. Patients have more options, but there are still many limitations.

In the 'old days' when a person went on life support it was perceived as the end of the line. Today patients face the questions of "what **kind** of life support do I need?" and "**for how long**?" In the past healthcare and patients thought only in terms of life and death, but now they must ask,

- "What will the quality of life be?
- Will this treatment bring me back to the way I was, and if not, will it be a kind of life I would want?
- Am I looking at the end of my life in the near future, if so, how and where do I want to experience it?

In the old days, doctors made these decisions and perhaps in the future they will do so again, as the concept of "futile care" grabs hold of ethics. At the present time, it is up to the patient and the family to decide and for this they need a guide. There are some defining questions which can be helpful in promoting revealing discussion:

- Where do you draw the line? Do you know what kind of a disability – what basic level of functioning – you are willing to live with? What is your bottom line?
- How much are you willing to go through and for how long to reach your bottom line? How long on life support? How much rehabilitation? A week, a month, a year, more?
- Are you the kind of person who wants to go down kicking and scratching or do you want a peaceful death?
- Do your advanced directives accurately reflect your wishes?

If the patient wants to have everything done then the healthcare providers are there for him, but it is important that the patient truly understand what that means. The patient needs to understand his options and what his choices mean and then, with this information, he can make the best/most informed decisions. So, where does the healthcare provider begin?

Function Is the Guide

First, let's talk about what the individual wants to achieve. Ask the patient what kind of disability he is willing to live with? This is this individual's **bottom line**. Here are some examples of actual individual's "bottom lines":

- One patient with cancer said that he wanted to keep going unless he was brain dead. When asked if that meant it was okay with him to live in a coma for the rest of his life, his response was "Yes." He was 35, had young children and was willing to live in a coma hoping that a cure could eventually be found, and then maybe he'd wake up and could be with his family.

- Another patient said that she would need to be able to talk, to share her ideas, and give advice to help other people. It would be okay if she were paralyzed as long as she could talk. What she really wants is not to just talk; she wants to be able to think, to understand what someone is saying to her, and to be able to speak well enough that others would not consider it too great a task to listen to her.
- Another patient said that if she could not be independent and go the bathroom by herself she wouldn't want to live. That allows for a lot of different disabilities including stroke, paraplegia, amputations, some brain damage, etc. Lots of people with disabilities live independent lives.
- Another said she would not want to live with any disability; she wants to function as fully as she does now.
- One man said he had to be able to eat food. It was his main pleasure in life.

It is important that the healthcare provider understand that everyone's bottom line will be different and that it will change as they age. So it is important to know what the individual believes to be his bottom line now and to re-evaluate as the individual's life progresses. For example does he/she need:

- his mind to work or to just be able to recognize those he loves?
- to be able to communicate in some form?
- to be able to use his body . . . to what extent?
- to be able to actually eat food?

Finding this out is important and can be very illuminating to the patient and his loved ones. It is amazing how often we do not know our selves nor our loved ones as well as we thought we did. One couple thought they knew exactly what the other would want—each thought the other would want exactly what they wanted for themselves. But, in actuality, the husband was willing to be a quadriplegic as long as he could think and communicate in some way, while the wife wanted no disability at all. When the patient knows what he is willing to live with it, this becomes the guiding light for making health care decisions, including what kind of life support is desired and for how long.

When helping a patient make these decisions, it is important that the healthcare provider be aware and sensitive to what the patient is choosing; take time to evaluate **why** he is making this choice. If he chooses to not have life support for any reason ask "why?" If he is choosing this because life seems hopeless or because he feels like a burden to his family, or, if the patient feels the family is pressuring him into making this decision, the healthcare provider needs to explore this further with the patient. This might be accomplished by holding a family conference and calling upon the resources of a social worker or chaplain. End of life decisions are best when made in an attitude of love.

No Code Case Study

For example, one woman who had taken care of her own mother for years before the mom died did not want to burden her daughter the same way. She had made herself a No Code. However, when speaking with the daughter privately and asking how she felt about the possibility of taking care of her mom, this daughter stated that she loved the idea; she wanted to take care of her mom. In an open discussion with the Mother and daughter together an agreement was reached, in that as long as the daughter loved caring for her Mother, she would do so, but should the time arrive when it was becoming too hard or she stopped enjoying it, another approach to caring for the mother would be found. This agreement was something they both could support and resulted in a change in the mother's desired code status.

Full Code Case Study

On the other hand, if the patient or family wants full life support for as long as possible, to "go down kicking and scratching", it is also important to take time to gently explore the reasons. What does the patient or family believe? How sick does the mind or body have to be before this individual is okay with letting go? How will they recognize the right time? It is helpful for people to have a guiding mark that they themselves have established. One older woman who had cancer had become very sick, but she still desired to stay alive and was willing to be on life support. She wasn't afraid of dying and she did believe in an afterlife, but she just was not ready nor did she want to go. In this case there was not an opportunity for the healthcare provider to explore this decision with the patient. However, both her son and daughter knew her strong feelings and will to live and when their mom became unconscious and all the caregivers were advising to let go, they did not. In this case, the mother recovered and they had one more great year together until once again she became very ill. And once again, the children insisted upon treatment knowing this is what their mother would have wanted. The healthcare staff kept going as long as possible and when death finally did occur, these children had no doubt they had done everything that could be done and that they had followed her wishes. In honoring her wishes, they were able to live with the decisions they had made.

Life Support and Code Status

When the patient knows where he wants to draw the line he needs to know what he may be willing to go through. In this author's perspective it is very important to help patients understand what life support is and what they may be choosing to **experience**. There are a lot of end of life choices made based upon misperceptions of life support. In your healthcare position, you may never have taken care of people on life support. "When your patient knows where he wants to draw the line he needs to know what he may be willing to go through. You need to explain what life support is" (Ingalls, 2003). It may be helpful for you and your patients to read more in depth about this experience in the book, *Where Do You Draw The Line? An Insider's Guide to Effective Living Wills, Healing, Critical Care*. (Ingalls, 2003)

Life support can be classified as Emergency, Critical, and Long Term. There are some distinct differences and a lot of overlap. This can be confusing to the patient or family trying to decide whether to start or stop life support. The bottom line, from a functional perspective, is that if you can't live without it, its life support.

Emergency Life Support

Emergency life support includes Basic i.e. cardiopulmonary resuscitation (CPR) and Advanced i.e. defibrillation, pacemaking, cardioversion, intubation and emergency drugs. This is a CODE situation.

Critical Care Life Support

In critical care, some life supports include intubation and ventilation with a ventilator, drugs, tube feeding, pacemaking, balloon pump, ventricular assist devices and dialysis. Some "long-term" life support drugs or devices that the patient has been using in his routine daily life could become "critical care" life support and be the one thing that is keeping him alive. This could be an important consideration for the patient or family trying to decide whether to continue life or to plan a peaceful death. Life support can be thought of as "therapy". It is "therapy" until it crosses the line—the patient's bottom line.

Long Term Life Support

Long term life support may be continued as ventilatory support via a tracheostomy, internal pacemakers/defibrillators, ventricular assist devices, dialysis, frequent blood transfusions, drugs, tube feeding, etc. As a healthcare provider you know there are many drugs and technologies which patient's take for granted as normal and routine that are actually life supports. When a patient's quality of life falls below his bottom line, he can choose to stop using his life support. One person put it: "I know that even when it is time for me to go, my pacemaker/defibrillator will keep my heart going. I have told everyone to just turn the thing off and let me have a peaceful death." It is very empowering to a patient to know they can still be in charge. Even if he is no longer conscious or mentally competent, if he has taken steps to understand and communicate his wishes effectively he can still have things his way.

Code Status

When the patient has an idea of his bottom line and what he is willing to go through, he can decide what upon his CODE STATUS. Code Status describes how much or how little life support a person wants. **Everyone has a code status**. By law everyone in the United States is a FULL Code unless a person has written otherwise. The code status is actually fluid and can be changed by the patient or his surrogate healthcare decision makers if he is not competent. This will be addressed in more detail later in this article.

A patient who is a Full Code receives all the available life supports. A patient can be a Full Code his entire life, or, start as a Full Code then if it seems that the patient will not recover to his bottom line, he or the surrogate decision maker can choose to change the patient to a Limited or No Code [if that is what the patient wanted].

The patient can start out as a Limited or No Code and change it to Full Code. In a Limited Code the patient specifies which life supports he wants used. For example, CPR might be acceptable but not defibrillation or intubation. Or in some cases, the patient has indicated that only defibrillation is acceptable. A Limited Code is often a customized mix and match code status.

The patient can refuse all of the supports. This is a No Code. No Code refers to **not** being resuscitated via basic and advanced life supports. It means allowing a natural death. The patient can further decide to not have antibiotics, blood transfusions, nor tube feeding. It is important for healthcare providers to make certain their patients understand that being No Code does not stop usual healthcare or palliative care. A patient could decide to be No Code at age 18 and still receive all usual healthcare, except resuscitation, for his entire-life. Even a No Code hospice patient receives palliative care.

Reassure the patient that being a No Code does not mean having to suffer at the end of life. The patient and family should know that Comfort Care will be provided and can be requested. This is an opportunity for the healthcare person to be a strong patient advocate by ensuring that a customized amount of pain and tranquilizing medicines is given to help keep the patient comfortable and allow a peaceful natural death.

The Healthcare provider who has taken the time to increase self awareness can take the next step in being more effective with patients by taking time to decide their own code status and helping their own loved ones decide about their code status. Remember, everybody has a Code Status. In an emergency situation, if there is no written documentation, the law obliges one to be Full Code.

Communication

After the Healthcare worker has helped the patient decide his bottom line/ basic level of functioning and know his desired Code status, the next step is to help him communicate his wishes effectively. It is important to encourage the patient to tell his spouse, significant other, kids, parents, doctor, and anyone else who might be involved in making major health care decisions for him. Even if his family lives in other parts of the country, it is wise to let them know the individual's wishes. It is surprising how a serious illness can bring people "out of the woodwork'', to the bedside. This can either make healing easier or more difficult.

If a family member asks the healthcare provider how to promote this discussion with the patient, the following suggestion helpful. They can say, "Hey mom, I've been thinking about what I would want done if I should ever become really sick or injured. I realized that if I became unconscious my family should know what I would want done so they could follow through with my desires and decisions. Then it occurred to me you might have thought about this for yourself. If you have, what would you like to have done?'' One young woman tried to talk with her father about his wishes, but he would never answer her. So she said to him, "Dad, you won't answer me, so I am going to tell you what I will do if I ever have to make health care decisions for you. If you don't like what I say, you better speak up and tell me about it.'' In the end, she did exactly what she had said she would do.

Sometimes it may be very hard for the patient to express his wishes. His loved ones or even his doctor might not agree with his decisions. The patient may even need to assign someone **outside** of his family to be his surrogate decision maker. The healthcare provider can be a good sounding board for the patient and can remind the patient that his family and doctors are people with their own beliefs and desires and need to be treated with love and respect, while he [the patient] gets his own needs met. It's important that the patient **knows** what he wants. If he is unsure or vacillating the family or doctor will believe that he really doesn't know what he wants, and then, if and when the time comes to make decisions, the family and doctor will not know what to do. If the doctor doesn't agree with him, he may need to find another doctor or utilize the services of an Ethics Committee.

This is a time when all involved need unconditional love to allow the patient to have the life experience he wants. Because the family loves this person, often they want to keep the patient with them for as long as possible, in almost any condition. They are probably willing to do whatever it takes to take care of him. It can be very hard to remember it isn't what **they** want that counts, it's what the patient wants. It is a greater love to allow the patient's wishes to be met. Healthcare providers must be sensitive to cultural and spiritual expectations that may be different from their own.

In this author's experience, it is important to inform and support patient and families while they process in order to reach the desired decision. The decision may not be what the healthcare provider thinks is best, but initially, it must be all about the patient. First and foremost respect what the patient wants. If the patient is unconscious and the **informed** family is not making what appears to be the best decision as surrogate decision-makers, then healthcare providers might have to expand their perspective. They will need to realize they are now working with a "unit'' of which the patient is a part and they must then begin to be more sensitive to what may be best for the whole unit. The healthcare provider may even need to expand their perspective further and be aware that the patient may be part of a broader community and now must be sensitive to what is best for the whole community. When the healthcare provider has done their best by informing and supporting in unconditional love and with the intention of the highest good, they must then learn to trust that whatever is best **is** exactly what is happening and let it go. Any judgment about the situation will, in fact, only be hurting the one judging and can lead to a feeling of helplessness, anger and burn out. These situations can be an opportunity of self evolution for the healthcare provider. One can choose to examine what feelings and thoughts are being stimulated—what "button'' is being pushed within themselves that is making them feel the way they feel. They can then choose to honestly explore the beliefs that created that "button'' and, if desired, choose a new perspective—a better way.

The Forms

Forms are fairly generic throughout the United States. It is most helpful to the patient if the healthcare provider knows and understands the forms and any variation within the particular state. When the healthcare provider has taken time to achieve a degree of self awareness, the next good step to take is to complete the details of filling out these forms for themselves and then assisting their own loved ones to do the same. A lawyer is not needed to fill out these forms for healthcare. The forms are available in many styles and vary in length from one page to several pages. Forms are available from many places: business supply stores, doctors, hospitals etc or they can be downloaded from the Internet. State specific forms can also be downloaded.

It is recommended that the individual fill out a Living Will, or an Advanced Directive (AD) (these two forms are essentially the same thing) **and** a Durable Power of Attorney for Health Care (DPA). This is not the same as a Power of Attorney for a person's estate, which deals with money, property and assets. If your state has Physicians Orders for Life Sustaining Treatment (POLST), it is also recommended that his doctor fill out this form if it is appropriate for his situation.

In some cases the Courts are asked to appoint a guardian or conservator for a patient. Legally, this court appointed Guardian ad Litem has more power than anyone else in making surrogate healthcare decisions for the patient. This person may be a professional guardian, a friend, or someone in the family who meets the qualifications of guardianship. For example, one woman went to court to get guardianship of her grandfather who was incapacitated from Alzheimer's. She did this because her mother, the patient's daughter, was not taking good care of him. The court acting in the patient's best interest granted the granddaughter guardianship.

Durable Power Of Attorney for Healthcare (DPA)

In the Durable Power of Attorney for Health Care (DPA) the individual assigns someone to be his surrogate healthcare decision maker in case he is incapacitated and unable to make his own healthcare decisions. It is best if the individual informs this person of his choice and confirms that this person wants the job and is **agreeable** to making decisions that follow the individuals stated wishes. Recently, a patient had filled out her DPA and assigned her primary and secondary choices but had not informed either of the individuals. When it came time that someone was needed to make the decisions, neither of these people wanted anything to do with it and they both refused to make decisions. Making these decisions for someone you love is hard. It is important to choose someone who is comfortable and capable of handling this responsibility. Too many DPA's are unable to stand up to the pressure placed on them by other family members, doctors or nurses. The patient needs someone to be their champion! The patient can help their DPA by not keeping it a secret. It is also suggested that the individual tell the other concerned folks what his wishes are and who he has been designated as his DPA. Also, it is important to know that once the patient has been pronounced dead, the DPA's authority over his body stops. The body is then part of the estate and decisions are made by the heirs, etc. So, if the patient wants something special done with his body, like cremation, organ donation, etc. he needs to write this down. In some cases the Advanced Directives forms have a space for this, if not, then it is recommended that the information be written in the margins.

Advanced Directive (Living Will)

To help the DPA make decisions, not only should the individual discuss his desires with his DPA, but he should also fill out a Living Will or Advanced Directive (AD). The best forms for this purpose are the forms that have a place where the patient can write down exactly what he wants, this is **his bottom line**! Most forms come only with generic statements that are intended to be checked off, such as something to the effect of: I direct my physician to withhold or withdraw life sustaining treatment and to let me die if . . . I have an incurable injury; disease or illness causing irreversible terminal condition that will cause death within a reasonable period of time and if the use of life sustaining treatment would serve only to artificially prolong the process of dying. The individual is to check the appropriate items.

Carefully read and consider these prepared statements and ask yourself, if they really say what the patient wants them to say? The above statement draws the line at an "irreversible terminal condition that will cause death within a reasonable period of time." Is that where your patient drew the line? Does this meet his bottom line— basic level of functioning? Does the prepared statement represent the patient's desires?

The healthcare worker should encourage the patient to customize these prepared statements so that they represent what is wanted. The patient can add to them or to cross them out and make his own statement. For example, in the case of one woman's wishes, on both her DPA and AD one woman had crossed out the prepared statements and had written down in the margins, "Don't give me life support for any reason. Don't give me CPR . . . no defibrillation, no intubation, no life sustaining drugs, no food or fluid, only give me the comfort care of pain medicine and tranquilizing medicine, and let me have a peaceful natural death." This lady knew what she wanted and she communicated it. She didn't believe death was the end of life; rather, she called it, "My Life . . . Part Two: The Adventure Continues."

These documents can provide important guidelines to emergency and critical care healthcare providers **if** the patient has expressed and written down his desires. They will also be written support for the surrogate decision maker. Too often a very ill or injured person comes to the critical care unit only to have family and friends disagreeing, even arguing, about what the person **really** wants. Even worse, everyone is focused on their grief, the potential loss and what they want for themselves rather than what the patient would want. If there is disagreement among the significant others, even if the patient's desires are written down, the medical staff may not follow them. Not only are they trying to avoid causing more trauma to the family, they don't want the legal problems. Multidisciplinary healthcare providers try to help the family and friends by educating them about the patient's situation; by helping them work through their emotions so that all of them can come to agreement and, hopefully, peace about the decisions being made. The aware nurse can make a huge impact.

If it comes down to legalities, the actual order of who has the legal power to make surrogate healthcare decisions varies slightly from state to state. (The guardian and DPA are always the top two.) The American Bar Association website offers a good comparison of what different states do. The following is the most commonly found order:

1. The appointed guardian/conservator of the patient, if any.
2. The assigned durable power of attorney for healthcare (DPA)
3. Spouse. (some states, the Domestic Partner)
4. Adult children (all of them have to **agree**, or, in a few states, "majority rules"
5. Parents of the patient. (have to **agree**)
6. Adult siblings (all of them have to **agree**, or, in a few states, "majority rules") (ABA, 2004)

The person who is highest on the list makes the decisions whether or not those lower on the list agree. If there is a **group** of people on the same "level" then everyone within that specific "level" has to agree and give a unanimous decision, **or** , a few states go by "the majority rules" for the group in that level. The people making the decisions need to resolve their differences and come to an agreement. This is a great opportunity for the healthcare provider to promote healing in the patient's family and friends. The important thing is to focus on what their loved one would want to experience. This may be their final gift of love.

On a precautionary note, if the patient knows there will be someone who will go against his wishes, suggest he make a note on his AD or DPA that says something like, "Don't listen to Aunt Mary; she doesn't have my best interests at heart."

Another issue is that elderly seniors seem to have the perspective that no one would bother to put them on life support at their age. This author has personally taken care of people in their late 90's and early 100 's who were on life support and the family wanted it that way; maybe the patient did too, maybe not. It doesn't matter how old the patient is, it is important for healthcare providers to encourage patients and families to think about these things, decide, and communicate.

Emergency Medical Service [EMS] – No Cardiopulmonary Resuscitation (EMS-NO CPR)

In Washington State, as in some other states, when a person definitely did not want resuscitation, they can their doctor to fill out a form called an EMS – NO CPR form.

This form tells the emergency medical services (EMS) to not resuscitate the patient if he has **no** pulse and is **not** breathing. Patients are supposed to wear an EMS – NO CPR bracelet to identify them to first responders. This was a good initial attempt to meet people's wishes. But the problem was that often when people had this form done they didn't understand that, in order for the EMS to follow it, the person had to have stopped breathing or to have no pulse. It did not prevent life support therapy if they were having only difficulty. It did **not** mean patients received comfort care and were allowed to die a peaceful natural death. There have been a number of times when elderly or terminal folks thought that when the time came they would die peacefully, but, actually ended up in critical care on a ventilator still wearing their EMS – NO CPR bracelets. Fortunately, in Washington and Oregon a new form called Physician Orders for Life Sustaining Treatment [POLST] can be used more effectively. If your patient has an EMS – NO CPR form, it will still be honored but remember its drawbacks. POLST is a more viable option.

Physician Orders For Life Sustaining Treatment (POLST)

The Physician Orders for Life Sustaining Treatment (POLST) is appropriate for any person but especially for anyone who wants to be a NO CODE, LIMITED CODE, or wants limited medical treatment. The POLST was created in Oregon where it has been widely used and it is now also being used in Washington State.

The POLST does not replace the Advanced Directives or DPA. The patient still needs to know what he wants, talk to his family, and fill out the forms. The POLST is the **doctor's orders** that reflect the patient's wishes. The POLST is better than the EMS – NO CPR form because it **is** an actual Doctor's Order that spells out code status, comfort care, antibiotics and artificial feeding. It can be followed by first responders. Healthcare providers can be an important advocate for spreading the use of this kind of a form. To do this effectively, they need to become familiar with how it is used and updated as a patient's level of care changes. The patient always keeps the current, updated **original** and it goes wherever he goes. Everyone else, including the hospital, gets copies. Hopefully the POLST or something like it is available in your state.

When the patient has filled out his paperwork (AD, DPA, POLST) suggest that copies be given to his loved ones and doctor; that they always are on hand to bring to the hospital with each admission, as copies in the Medical Records department might not be readily available. In particular it is important to bring the current, updated, original POLST form because, remember, these are actual doctor's orders; which can and should be followed by the EMS and Emergency Department [ED] staff.

Be sure to check with local emergency medical service about where to keep the forms, especially the POLST, to ensure that "first responders" will find them. Some EMS like them on the refrigerator doors, some in the freezer.

Hopefully, the forms will prevent resuscitation mistakes, but the reality is people often change their mind in an emergency. Or the individual might be in a shopping mall and stop breathing and a Good Samaritan resuscitates him. The bottom line is whether or not the patient wanted it; there is a big chance he will end up in critical care on life support. That's the bad news. The good news is that he can still be in control whether conscious or not. How? Because he has **thought** about what he wants, where he draws the line. He has **talked** this over with his loved ones and doctor, and he has **written** down guidelines. What has been started can be stopped. However, now that he is on life support, he might want to re-evaluate his Code Status. If the patient had wanted to be a No Code, maybe he'd be willing to try the life support if it could get him over a rough spot and return him to his usual level of functioning. Or, maybe he was a Full Code, but now that he and/or the family is experiencing the reality of life support he/they may decide that this is not what the patient really wanted. Now he/they needs information.

What's the Scoop?

The patient should frequently evaluate his progress. If he is unconscious, the DPA/family should be making this evaluation. In order to get a big picture; encourage them to ask questions of the doctors, nurses, respiratory therapists, physical therapists, social worker, etc. One suggested approach to asking questions regarding prognosis is to phrase questions this way: "**In your experience** how have you seen cases like this progress? **In your experience**, how often does someone in this kind of condition get off of life support?" Based on the level of functioning desired, ask specific questions such as, "**In your experience**, to what level of functioning have you seen people in this condition reach? Are people able to recognize their families, to talk, to eat, go to the bathroom by themselves, etc.?" "How long does it usually take to achieve this—a week, month, year?" By asking for the various caregiver's **experience,** the patient or family can get a clearer answer because the caregiver doesn't feel as if they are being put on the spot and having to predict what will happen specifically to this patient. They're just responding based upon what their experiences have been with similar cases. This provides a broader picture. If the patient is unconscious and did not previously express his desires, the DPA/family can take that broad picture, couple it with what they know about the patient's character and make more effective decisions. Patients and families can become very confused by the varying "opinions" of caregivers. It is helpful to remind them that doctors and nurses are just people and have their own beliefs and life experiences that will affect their perspectives. They will find caregivers who range the continuum from overly pessimistic to overly optimistic and everything in between. It is helpful for this "variety" of opinions to be perceived as a "big picture". Schedule family conferences with as many of their doctors as are available to give them a complete picture. If there are serious conflicts with doctors, inform them they have the right to change doctors and they can utilize the services of an Ethics Committee. When patients/families feel informed and empowered there is less fear and more opportunity for healing to occur.

Window of Opportunity

The patient or family must stay informed so they can track the progress and compare the answers with the patient's bottom line. In critical care there are continuous ups and downs. Advise them to watch for the trend: are the ups and downs trending upward or downward? Many times the patient will come to a fork in the road where he or his family/DPA will have a window of opportunity to choose continuing life support therapy or to stop it and create a peaceful natural death. The healthcare provider has a golden opportunity to support and guide families to make decisions based upon love, decisions they can live with.

Case Studies: Windows of Opportunity

1. One patient had a massive myocardial infarction and a long down time without CPR. He was resuscitated and then kept stable in the ICU. He wasn't brain dead, but his function was seriously impaired. The family was informed that although their loved one may be able to eventually come off of the ventilator and be able to breathe on his own, he had extensive brain damage. Right now he was in a coma, but would probably come out of it and could possibly recover to a point where he would be alive, but would need total physical care and likely not recognize his family. This was a window of opportunity. Stop life support now, and he would pass away peacefully. Continue and he would be facing extremely limited functioning. There was conflict in the family; the wife and one son did not believe the Dad would want to live this way. The other son wanted to give him a chance. In an atmosphere of unconditional love for the whole family **unit**, the nurse gently explored the family dynamics. It was revealed that this son and his father had not had a great relationship, and only recently had begun working things out. This son wasn't ready to let go. While supporting the son with his **personal** wishes the focus was kept upon what would his dad want? If dad had this chance, would he have the capability and more importantly, the **desire** to face this challenge? He finally decided that Dad would not want to do this. This family chose to stop life support and the dad had a peaceful death.

2. If the patient is conscious they can always change their mind and override their written desires. There was a woman with a progressive nerve disease who knew she would eventually need to live her life on a ventilator and this was okay with her. However, after being on the ventilator for awhile she knew this was NOT how she wanted to live. She was distressed because she felt stuck in the situation and was requiring a lot of tranquilizers to cope. She didn't know she had the right to change her mind and choose to come off of life support. In this case, the nurse was able to provide information and empowerment as well as guidance and support. When the patient learned she could change her mind and her situation she became calm and stopped the medication. She had her family come to the hospital and wrote them what she wanted to do and lovingly guided her children through their grief. One by one she nurtured them until they could accept her decision to die a natural death. Then she had to convince not one but two doctors and a psychiatrist that she was not depressed but had just come to grips with the fact it was time to let go. After this, she set a date and planned her "good death". She was moved to a larger room in critical care. Her family, friends, and minister came. She had requested to see a particular video of a benefit given to raise money for her. At one point during the benefit while the band played "Unchained Melody" people would drop money into a jar and then take a turn dancing with her. One by one her loved ones had taken her into their arms and slowly moved around the floor. Her face was radiant with the love she felt for each of her partners. That love filled the critical care room as all watched the video, and there was peace. When it was done, she communicated

her good-byes, and then indicated that she was ready to go. Comfort medicine was given and life support withdrawn. Within minutes, while holding her daughter's hands, she died. There was a smile on her face.

3. At the other end of the perspective, was a lady with extensive cancer who had never sought treatment because she was afraid of hospitals. Although she had neither an AD nor DPA, her family and friends knew she didn't want to go to the hospital, let alone have life support. But when she became very ill at home, having trouble breathing, her husband didn't know what to do, so he called 911. Of course the paramedics were obligated to intubate her. When she became conscious she was terrified to find herself exactly where she did not want to be. In this case, the nurse acknowledged her fear and her wishes and then taught her how to work with the ventilator and critical care therapies. The nurse informed the patient of her rights and her options. The patient found she could cope with the ventilator and that she was still in control of her life. She became very calm and decided to stay on life support while tests were done to verify whether or not her cancer was treatable at this stage. She knew she could stop at any time and she knew she had the support of her family, doctors and nurses. The tests came back showing her cancer was at a terminal stage and at that time she too elected a peaceful, natural death.

Challenge or not?

There are many stories of "heroes'' who have faced the challenge of a disabling injury or illness. Some are famous, like Christopher Reeves and Stephen Hawking, but most are the people next door. When life gave these people "poop'', they turned it into fertilizer, and grew. As a healthcare provider you may have even been instrumental in assisting patients to create new lives for themselves. You may personally or professionally know someone who became a happier person within himself and in his life because of the changes the disability made. These people personify the strength of the human spirit. The strength of a person's spirit and will to live can never be discounted. Every nurse has seen people recover despite the odds. These recoveries are called miracles because they don't happen everyday.

Yet, when making decisions for someone else, it's very important to remember that it's **that** person who will have to experience everything it takes to recover and live with the disability. Too often people are saved with life support and then are forced to face challenges they didn't want. Society has adopted the adage, "You don't know your own strength until you are tested'', thereby making it **right** to face every challenge that comes our way. This implies that a person is weak or cowardly if he elects to **not** accept the challenge. Is it not important to allow a patient the right to choose the life experience he/she wants? Would it not be beneficial to the patient and the healthcare system as a whole to have an idea of what a patient would want **before the crisis?** It's the individual's choice rather than society's. Just because we can keep someone alive, does that mean we should? Some answers this author has heard regarding Technology are:

- God gave us the gift of technology to help us live.
- God gave us technology so we can play at being God and learn wisdom.
- God gave us technology so that we could learn the difference between God's will and man's drive to live.
- God gave us technology so we could have a choice. Then when HE calls us home we can go joyfully, or we can whine and say "Aw, do I have to come now? Can't I stay out and play a little longer?''

It is the healthcare provider's job to help patients cope, adjust and adapt. This is done along the whole continuum of specialized care from emergent to critical to rehabilitation to skilled nursing to home health. It may be hard to set aside one's own feelings and make a decision based on what the patient or family would want, but it's even harder if the patient's desires are unknown. Whatever decision is made the healthcare provider, the patient and the family must live with it. You may always wonder if it was the right thing. However, if the patient has expressed his desires, then it is a matter of simply **honoring** the decision the patient made; following his wishes. This is a final gift of love. It is extremely helpful in the ER and ICU to have effective, **expressive** forms filled out, acting as guidelines helping to direct care. It is also helpful to have unified surrogates to help provide the care a person wants.

Withdrawing Life Support

There is a difference between withdrawing life support and assisted suicide. In one, the body that has been kept alive artificially is finally allowed to have a peaceful natural death. In the other, a body that is alive and suffering is helped to peacefully and comfortably die. Life is precious, yet death will happen. How much better it would be if we could have it be just the way we want.

In critical care when a person is taken off of life support they may die right away or it may take a few days even several weeks depending upon the cause of death. Generally, in this author's experience, if it is due to a ventilation or hypotensive issue they will not last very long, a minute to a day. On the other hand if life support is being stopped because the patient's injury or illness has disabled them beyond what they would want, such as following a stroke or other brain injury, it may take longer to die. Artificially provided food and fluids are stopped and only comfort care given. In this way, the body that cannot take care of itself anymore will naturally shut down and peacefully die. If it will be more than a day or so, the patient may be transferred out of critical care to a medical room in the hospital where family and friends have more freedom to stay. The patient might even be transferred to a Hospice inpatient center if the hospital is associated with one.

Spiritual Communication

The aware healthcare worker can utilize their knowledge of energy and their "imagination'' to mentally communicate with a patient and family spiritually. It helps you to get a greater sense of who he is, where he is at with dying, the family dynamics and how you may further help. Then go with the flow; listen to your heart and let it guide you to say and do things that help bring the family to a place of love and peace. It is a profound experience to assist people on this level (Ingalls, 2003).

Summary

It is an honor and a blessing to be with someone at the end of their life; to see and be part of the profound love, awareness, and healing that can happen. Working with patients and families in an aware, holistic manner—physically, emotionally, mentally and spiritually—can teach healthcare providers what they need to know about death and dying.

Approaching patients and families with a clear attitude of unconditional love and the intention for the highest good; providing information to empower them; being able to flow with them and guide them to decisions of love and peace will not only assist them to make decisions they can live with, it will also enrich and nurture the healthcare provider in their own evolution of being.

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