

FINAL GIFTS

An interview with
Maggie Callanan
on
Nearing-Death Awareness
by
Gilles Bédard
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What is your professional background?

I am a registered nurse. I have been a nurse for 33 years. I first worked in high technology, emergency room, and intensive care, that sort of things; then I found hospice. So, in the first half of my career, I was snatching people back from the brink of death and on the second half, I am encouraging them to go forward.

How did come the idea of writing Final Gifts?

It was an accident, really. We didn't intent to do it, it just happened. Patricia Kelly, a co-worker, and I realized that our patients who were confused were having similar comments. We started to explore that direction, talked to other nurses and found that they were seeing the same things. We collected the stories and saw specific patterns. We then figured out that patients were trying to give us important messages.

You created the term "Nearing-Death Awareness"?

We named it "nearing-death awareness" (NDA) because the experiences that our patients were telling us about had a distinct parallel in the near-death experience (NDE). Yet it was very different. These experiences seem to occur as people dying slowly of illness get nearer or as they are approaching death. It is not so much an experience that is limited to a beginning and an end, as with NDE. It is a broadened awareness of things that we can't see! Of course, the profound difference is that our patients are not clinically dead, as most people who have a NDE - not all but most; they are able to speak while it's happening. You know, we've missed it because we did not understand what they were saying. It sounded confused. You know, it is a symbolic language. Why dying people talk symbolically, to this day, I don't know yet. that our patients are not clinically dead, as most people who have a NDE - not all but most; they are able to speak while it's happening. You know, we've missed it because we did not understand what they were saying. It sounded confused. You know, it is a symbolic language. Why dying people talk symbolically, to this day, I don't know yet.

And you related NDA with NDE?

We sensed that there was a parallel. The more we explored it, the more we could see that indeed our patients were talking about very similar experiences. They weren't exactly alike but were very similar. We wanted the name to be similar but different.

Did you know then about the works of Elizabeth Kübler-Ross, Moody, Ring et al.? Oh yes. We were familiar with their work. Very much so.

Did you know about the works of William Barrett and Osis & Haraldsson when you started writing your book?

We didn't know about the book of Karlis Osis and Erlendur Haraldsson, *At the Hour of Death*. I'm glad we didn't read them before, because they would have said, "That's what we wrote". We were not influenced, but, I think, would have been, having we read them before. We were very nervous when we wrote our book. We thought that we would get a lot of criticisms from other doctors and nurses. We were very concerned because they are scientifically trained and this is not "scientific" science. We were afraid to be discredited or considered weird or strange. Actually, the first thing we published was an article in the largest American nursing journal called *The Nursing Series*. We submitted very nervously an article to them and they accepted it. It was the cover story. We received many, many letters from nurses saying "Oh, we've seen the same things, we did the same things, we just didn't know what to call it," etc.. We found that nurses were not talking about this because it seemed strange and they were afraid that people would think they are strange. It's a very controversial subject and where you're having difficulty getting palliative care established, you don't want to start out with something controversial. Otherwise, you'll be considered as somebody who's cuckoo!

Somehow, it is what happened to Elizabeth Kübler-Ross when she began to chart unknown territories in death and dying.

It was very sad because a lot of very good works was discredited. They threw the baby out with the bathwater, so to speak. She did some very important works but when she started to explore these kinds of questionable areas, people discounted everything she did. I think people are still somewhat uncomfortable but they can't overlook the fact that so many hospice nurses had these experiences. They are not talking about it because they don't know how to categorize them.

Basically, the hospice people don't have to worry about choosing to go into it, because the patients will take them into it. You just need to learn how to listen and they will provide it to you. As long as you understand that not everything a patient says immediately makes sense to us. We have to listen with a different set of ears because there are hidden messages.

In your book, you identified six categories of NDA. Can you briefly describe them?

The messages fall in two main categories: the first one, the patient is telling us what the experience of dying is like. I'm not talking about the physical journey. In the second categories, the patient is making request of things that he need, so he can get on to a peaceful death.

- *1- <u>Preparing for travel or change:</u>* That belongs up really with "describing a place".
- 2- <u>Describing a place</u>: When patients describe a place that we can't see, they typically do so with a great sense of awe and wonder. Apparently, it's quite a beautiful place. It is interesting to note that this experience have a distinct parallel with the person's life; for example, an environmental engineer talks about a beautiful scene, an outdoor scene; a painter talks about a city of light across the

river; a golfer talks about a fantastic tournament, a beautiful golf course. Sometimes, they'll talk about wonderful music or beautiful colors. Typically, the descriptions are brief, with few details.

- 3- <u>Talking to or being in the presence of someone who is deceased</u>: That is typically a relative who has predeceased or a spiritual being. For example, the story that opens the book: Laura, a woman who's dying, tells me that it's the time to get in line. Her daughter, Susan who had died the year before of breast cancer is in the line. She was very joyful at this reunion but conflicted about leaving her husband who counted on her. That was very important for us to have the information that she was at peace and longing to go into death but needed to know that her husband would be OK. That was also very important, very comforting for her husband to know that she was with her daughter, that she wasn't alone and frightened. The language of patients being in the presence of spiritual beings that are loving and caring depends on their religious orientation. being. The terms and the language that they use have a parallel to their religious experience. In other words, Christian persons may talk about Jesus or Christ and use Christian terms, and so on. The story is the same; it's just the terminology that changes. This even happens to atheists who also have the same experience.
- 4- <u>Knowledge of when death will occur:</u> As an example, a nurse may say to the patient "I'm going on vacation, I'll be back in two weeks", and the patient will say "I won't be here". Many dying people seems to know when their death is going to happen even if they haven't been told. They often know better than the doctors and nurses.

Some years ago, it was common not to tell a patient that he was going to die...

This is still very true in Japan and in foreign countries where it is included in their beliefs. By telling a person they're dying, they fear it will rob their spirit, which they need to strength to deal with the illness. They often lie to dying persons telling them they are getting better. So, knowing that patients do know when death will occur, it's important for us to listen. Another example in the book: a patient said "Tell my wife to get the cake with the sparklers on it now". I asked the wife what that meant and she started to cry. Their wedding anniversary was on the fourth of July and this gentlemen always had sparklers instead of candles on his anniversary cake. This was in April or something like that. He was buried on the fourth of July. He knew far ahead that they needed to celebrate their anniversary early. The intriguing thing is that there's not any fear. It's not hysteria - "Oh my God, I'm not gonna be there"; it's more just a statement of fact, maybe even a sense of curiosity or puzzlement, but the patients are not frightened.

5- Choosing the time of death: This is another part of the ability of dying people. We know that many people can chose the actual moment of their death. Everybody can talk about a grandmother who waited for a grandson to come, or a grandparent who waited for their grandchild to be born. Dying people are very focused on particular dates, they may choose to avoid Christmas or wait for a wedding anniversary, that sort of things. Dying people can also speed up their dying and die sooner than we thought because the time is right for their family. It's often done out of a sense of concern for them. For example, we have the situation where the family gets exhausted; they just can't take care of dad anymore. So they arrange to put him in a nursing home, and as the ambulance gets in the driveway to take him, he dies. He just simply didn't want to go to the nursing home. That is no coincidence, it has happened many, many times.

6- Needing reconciliation: We found in dealing with dying people that there is often a desire to bring closure to their life as if there are unfinished business in their way holding them back . . . There is the personal reconciliation either with a relationship, perhaps a fight with a brother, or a problem with a relative or a friend. Dying people often need to fix these relationships before they die. Then, there is the spiritual reconciliation; often times, as we live, we drift away from the religious beliefs we had when we were growing up. People need suddenly to return back to those rituals. This is not everybody but this is common. For example, a catholic who left the church may want to see a priest again. And there is the moral reconciliation: for example, a couple living together without being married may suddenly find important to get married. Patients talk to us in language and also by making request of things that are important to them.

We named our book *Final Gifts* because we realized that dying is really a time of exchanging gifts back and forth. The patients are giving us the gift of this very comforting, peaceful information, asking us to help them finish their unfinished business, so that they can get on. We are given them the gift of assisting them in the things that need to be done. Families are very moved by these very powerful experiences.

Is there a common pattern, so to speak, in those visions?

In fact, children talk more freely about it; they are less concerned about people thinking they are crazy. The elderly are also much less bothered by what people think. It's those of us in the middle who are socialized to be worried about those things that tend to be a little closed. It spans all ages, all religious orientation, all diseases. It has nothing to do with the drugs; if a patient is too sedated, he can't tell you. We have patients that are on nothing stronger than Tylenol who have the same kind of experiences as patients on morphine. So, it's not the drug. But there again, there are people who are very open and share their life. They are the one that tend to tell us these things. If somebody is very closed and very introspective, he may not share his experience with you, but that doesn't mean he is not having them.

In At The Hour of Death, Osis and Haraldsson talk about the difference between deathbed visions and hallucinations. What is your opinion?

I'm not here to say that everything a confused patient says has great significance. It's often very hard, even paying close attention, to find exactly what the person is saying. Seventy percent of people dying of illness, at some point, have some confusion; that's a lot of confusion. However, our point is to always listen specifically to the words. I'm not saying don't use medication or don't do other intervention to help with the confusion but never ever stop listening to the actual words of the patient. Often times, something becomes clear after the person has died. It's not as easy as I make it sound. I missed it with my own father, but that was for a different reason; I mean, that was emotional, really. It doesn't matter; it's still a gift.

How do families react when they see a patient talking about their visions and being very peaceful about their dying?

For most families, it's easier to call somebody confused and stop listening to what they say than to deal with what they are saying. Often times, the patient is far more realistic and far less denial than the family is. Families are very quick to blame the medicine. Families can handle the physical changes much better than what they perceive to be a change in the patient's mind. If someone's loosing his mind, he becomes a stranger to you. So families get very, very upset when people start talking about things they don't understand. They are very quick to call it confusion or say it's the medicine rather than listening to what the person is saying. They react to the situation rather than to what the person is saying.

How the knowledge of NDA can help us to prepare for death?

I think it is very comforting. It can help one look at death as more than a physical journey. Our patients tell us they have a sense of control, a sense that they don't die alone. They have the companionship of dead relatives or spiritual beings. They know that they are dying. They prepare for this journey; they see where they are going as a place of great beauty. They die peacefully instead of frightened. These are the lessons that we can learn from to prepare for the anxiety of dealing with our own dying. When you've seen as many deaths as I have, so peaceful and comfortable, it certainly changes the way you view dying. Our patients are teachers. You need to be close to them and pay attention, learn what you can from them. The most important message is that there is more to dying than the physical journey. We have been so focused on this that we are overlooking more powerful aspects of dying that are more important to the person who's dying. I think people who are dying are prophets or guides. We can learn from them because we will have to do it in the future ourselves.

What is of crucial importance to know when we are accompanying a dying person?

First of all, most dying people are not asking us to fix it. Secondly, we are really there to be a witness to the process rather than to stop it. I'm not here to say that we shouldn't do cardiopulmonary resuscitation or have emergency room. Slowly dying of an illness is a natural process. Patients are not asking us to stop that process; they are asking us to share the journey. It means listen, watch and learn rather than do. Medical people or caregivers need to look at themselves as students, realize that there are still so much to learn. We sometimes have to unlearn what we already know because it's in our way of learning new things. We must read, study and listen to what people tell us.

From your experience, what are the impacts of NDA - be it personal, professional, psychological and spiritual - on caregivers, nurses and doctors?

Very profound. You can talk to anybody working with dying people and they will tell you that this is not a job; this is a spiritual path that they are on. I don't necessarily mean religious, I'm talking about the spiritual. You can't help but being move by this work. It's an honor and a blessing in our life. Our reward is the privilege to witness such an important event in someone's life. You know, those of us working in hospice see many parallels between birthing and dying. I often tell to people asking me what I do that I'm a birthing coach at the other end of life: I help people do the transition from this life into whatever happens next, just as a new baby is coming from the womb into this world.

Do medical teachings include talking about NDE and NDA?

Unfortunately not. It's beginning to be included but not nearly as quickly as it needs to be. That's part of what the International Association of Near-Death Studies (IANDS) is trying to do. We have a professional advisory committee of doctors, nurses, social workers, psychologists and psychiatrics to make ourselves available to go and talk to medical schools, nursing schools, colleges, because this is crucial information. It's important for doctors to hear other doctors talk about it, nurses hear other nurses talk about it, because, very often, professional people scientifically trained don't believe experiencers. But you know, there are doctors, nurses, social workers and even a cardiologist who have had NDE! We've got very accomplished people who have had these experiences or witnessed them at first hand. One of IANDS' goals is not only to provide support for near death experiencers but also to share this research and information. Every single school should have at least a guest speaker on it. It should be include into the curriculum. We want to be very aggressive at marketing this. We have all the material for any program that wants it. But it's difficult. We are not looking for the shock value or to sensationalize this. We simply want to get this information to other professionals. For example, every ambulance crew should know about NDE. The vast majority of them happen on the scene of the accident or while

the person is in the ambulance trying to get to the hospital. So, it's important for emergency personnel to have this information. We're trying very hard, but we're not nearly making the progress that we would like to make.

Nowadays, the whole term "near-death experience" is becoming better known. You even have it on soap opera and movies. People are more familiar with the subject. The last Gallup pool indicated that, in USA, 13 millions people have had a NDE; that's a lot of people. It's critical for nurses and doctors to know about it because they are frequently the one at the bedside when the person comes back from the NDE. How they validate that experience determine in large part how that person will integrate it into his own life. They then can get on having a healthy life rather than thinking they are crazy because some doctors and nurses told them that it was the drugs.

When you started as a nurse, what was your perception of death?

When I started hospice work, my perception of death was that it was lonely, powerless, and frightening. Of course, that is not my perception now.

How did it changed?

Just by watching patients and listening to the things they are telling us. You know, patients don't die alone. They talk about people being with them, they name them, they have conversation with them. It's usually somebody who they know that has already die, or sometime, a spiritual being. They are very comforted, almost curious by this, but not upset. So, as we listened and learned about this language, we came to realize that death was not what we thought it was. And there again, many parallels fit the NDE when you're talking about being in the presence of other beings and that sort of things.

Do you foresee a time when we may know more about death?

I think so. It's my life's work to understand more about it. I know I will completely understand it when I'll be dying myself. I hope then that the conclusions I have made beforehand were right.

From your experience, would you consider NDA as proof of an after-life?

I don't want to get into that. I've made very important conclusions for myself, but they are personal. I don't share personal conclusions because my job is not to tell people what this means but to make them see that this is happening. They can make their own decisions about what it means.

It is said: "We die accordingly to how we lived".

This is very true. It's really more in behavior. We find that busy organised people often get busier and more organised when they approached dying; happy people seems to be happier; mean people get meaner; angry people get angrier; and so on. The way we react to life is unique for each one of us. Those mechanisms protected us in life. They will intensify as we deal with this ultimate life crisis, which is dying. I say to families: "Suppose your father is dying. How does he normally deal with crises? Does he get very quiet; does he get very busy, irritable? As he's dealing with his dying, you will see his normal behavior intensified by ten." This is very helpful for them to understand that. Sometimes, families expect people to suddenly change, that a very mean, very selfish, or self-centered person suddenly become very loving and open, and discuss all these issues. If they weren't that way in their living, they probably won't be in their dying.

In fact, we have to change our attitude towards dying?

Typically, we have looked at dying people as tragic victims. I prefer to look at them as enlightened teachers. They are living closer to the end of life and the beginning of whatever happens next than anybody else we will know. If we pay attention, listen and watch, we may learn things that will help us. My father said, "One out of one go; why don't we talk about it?

How can we learn about it?" There are two groups we can learn from: near-death experiencers and people who are dying slowly. They are the only one that get us close to death as they do.

Speaking of your father, could you tell us about his dying?

My father actually chose the moment of his dying. He was very concerned that my mother would be alone with him when he dies. He was very worried that she would have to deal with his dying all by herself. I went over to visit them on a weekend and felt very unsettled. I came all the way home to my family but wasn't at ease, something wasn't right. Even though I had small children at home, I went back. I was going to stay the night and go to work from their house the next morning. My parents were very surprised to see me back. When I went to see my father the second time, he said, "I'm so glad you're here, now I can lie down." You see, he has been unable to get out of bed for three weeks now; he'd been lying down. And I missed the message. You're not supposed to see the forest from the trees. He was really waiting for me to be there so my mother wouldn't be alone. He died that night, in 1981.

Were you aware of nearing-death awareness then?

I was busy writing the book at the time. Even though Pat and I were doing the research and writing. I missed the message because of my own emotional involvement; which is fine. It still worked out right; I was there.

Did you feel prepared for that?

I don't know if there is such a thing as being prepared to loose somebody that you really love. You can know it's happening, you can try to get ready but there is no ready. There are times you are more reconciled with it than others. No matter how much you know about dying, it doesn't stop your pain of loss or your grief.

What, in your opinion, keep people from talking about death?

Fear is at the basis and ignorance is the basis of fear that keeps us from confronting things. The only way to deal with fear is to deal with the ignorance, to learn as much as we can. The more we learn, the less the fear of death is.

People usually tend to ignore death unless they are confronted to it.

Well, it's too bad because we should prepare. It's the most important thing we do. If you look at it, from the instant we are born, our body starts to die. The only inevitable thing in our whole life is that we will die. And, it's the one thing that nobody ever prepared for.

Are you afraid of dying?

I'm not at all afraid of dying. When you work with dying people as I do, my whole concept of death has changed; I have no fear of dying. It would be very inconvenient in my life right now; I have things to do. But I anticipate it in a very positive way. I look forward to reuniting with the people that I loved that have already died. I've got so many friends on that side as you can imagine after 18 years of working with the dying.

What would you do if you'd got one month to live?

Well, I'd have to get busy because there's a lot in my life that is unfinished. There are many things I would need to do to get my life in order, my house in order, so to speak. I would make sure that that my legacy would be given to my children the way I wanted to be. They are grown now but are still children in my mind. I think the final chapter of your life can be your most creative. I would feel shocked, feel anger; I would feel what everybody else feels in a certain extent, but death is not a stranger to me.

Sort of a friend, would we say . . .?

I don't know if I would go as far as saying a friend (laughter). I would say that death is familiar; I'm familiar with death.

How would you prepare yourself to death?

It depends of what illness I would be dealing with. To me, it would be more important to be able to keep my faculties and interact with my family than to be aggressive in treatment. Sometimes, when you have limited time, when your life is going to be shorter than you thought, people continue to push for very aggressive treatments. Then, at the time of dying, they look back and realize that all they did was to focus on treatment for a hopeless situation rather than taking the illness gracefully and using their remaining time joyfully and creatively. I think I would instead take this time and really enjoy my family and loved one. To me, the quality of my life is more important than the quantity of my life. We get swept up in trying to stay alive one more day, when, in fact, what is the point if there is very poor quality of life. I guess, in that regard, I would want to stay in control rather than have the treatment control me. But it's hard to say, I have never been there.

You may die of a heart attack...

I'd be very angry if I do! I think I deserve an illness where I would have warnings and the opportunity to realize that it's time to shift gear and start to get my house in order. I would like my grand finale (laughter). If I drop over dead of a heart attack, I won't have that. I would like to have a very rich final chapter, and falling over with a heart attack won't give me that. But seriously, it tells you how important it is to live your life as tough it is your last breath. You don't wait for the crises to tell people that you love them, that you value them, that you're proud of them. Be grateful now for what you have because nothing is given to you. We have no promises.

How do you see the change of view towards death and dying since you began to work in hospice care, twenty years ago?

I think we've just recently discovered death and dying. It's becoming very popular and some of that is good. Where do I see it is going? My hope, my prayer, my dream is that people get more comfortable with the concept. I would like to see people stop being victimized by death. That way, they can better prepare. Death can be as we choose it to be. We can have a sense that we are dealing with the last chapter of our life as creatively and as in control as possible. Because it is possible.

Preparing for death as we prepare for our vacation?

Of course. We prepare for our baby to be born, for their education, and so on. We prepare for everything except dying! And dying is the only given.

How do you see the growing interest on death with books like *The Tibetan Book of Living and Dying* by Sogyal Rinpoche or books by experiencers?

I've heard Rinpoche speak. He is incredible, wonderful; a true spiritual guide. He offers a gift to us. The wealth of books available are tools to help us control this process that is inevitable. As you know from your NDE, the reason we are on this earth is to learn. What is it that we're learning? We're here to learn how to die! By learning how to die, we learn how to live. Most of dying people will tell you that we may learn from them so much more about living than about dying. We stop bothering yourself with such stupid things that we worry ourselves with. I have never heard a dying person say "I wish I spent more time at the office" or "Wish I drove a Mercedes" or "Wish I'd belong to the right country club". When it comes to the final hours of life, this is not what matters.

When you deal with people who are dealing with the purity of life, it helps to keep you very rooted in what is important. My children know I love them, that I'm proud of them. I don't wait until I'm dying to tell them those things.

How do people with material and superficial concerns die?

Many die with regrets that they wasted their time on stupid things. I've heard people say "Why didn't I spent more time with my family? I was so busy working to make money, to buy things; right now those things mean nothing to me."

What did you learn, personally and professionally, from working with dying people?

Oh my! I'll tell you what I've learned personally and professionally: it's called *Final Gifts*. It took a whole book to tell about it! Unless you'd like to spend another six hours on the phone! (laughter) What I learned is... it's so much! I learned to care about each other; love each other. That's what is important. It's too bad that some people don't discover that until they are dying. I've learned that dying is nothing to fear; it's not a scary thing. Often times, dying is not the enemy, living is! There are worst things in this life than dying. There are just a few things that I have learned, but you have to read the book.

Before concluding, could you tell me about the *Shades of Rainbow* workshops you are giving with Diane Corcoran, president of IANDS.

I met Diane Corcoran at an IANDS conference. Diane is a retired US army colonel who actually forced the military to include NDE in their nursing curriculum. She was in charge of all the nurses in the "Desert Storm" mission in Iraq. In USA, she is the foremost-published nurse in the area of near-death experience and I happen to be the most published in nearing-death awareness. She writes on the experience of people who have a dying experience suddenly and I write on the experience of people dying slowly. We realized that the information we each had combine nicely to cover pretty much everything you want to know about death and dying, be it slow or be it fast. The title, "Shades of the Rainbow", refer to the fact that NDE is rapid and brilliant while NDA is slower and more gradual. Diane's patients are the brilliant colors of the rainbow while mine are the soft pastel shades. You see . . . it's one continuum.

Maggie Callanan, thank you very much for this interview.

You are welcome.

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Reference:

Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying, by Maggie Callanan & Patricia Kelly, Bantam Books, 1992