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## **LOST IN TRANSLATION: COMMUNICATION WITH THE DYING**

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# Lost In Translation: Communication With the Dying

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Most people are quite unaccustomed to discussing death. People try to protect themselves from the pain of loss, often by avoiding and shunning those who are dying. The best time to begin conversations about death is before a loved one becomes ill with a life threatening condition. However, this is generally not what occurs. Discussions of end of life are usually triggered by the diagnosis or life threatening prognosis given starkly by a medical professional.

When a life limiting message jolts conversations to a halt, loved ones find themselves at a loss. What can be said? The dying and their loved ones weigh each word, fearing that something said, their tone, or an inflection might, without their expressed permission, reveal the fear and uncertainty within them. Visits become fewer and briefer. Interactions are littered with discomfort and cliché.

When death forces its way into language by nature of a poor prognosis, suddenly, all manner of communication becomes more important. Their tone, facial expression, body language, hand squeezes, quiet moments, and voice inflections are given stronger meaning than before. We guide them to listen to the leadings of their hearts and trust God to guide their words and actions as they take the journey toward end of life.

Many people put up barriers to the intimacy of dying, robbing themselves of the primal need to express themselves and share. They don't know how to say goodbye, but they NEED to. Our role is to help them break through those barriers of fear and avoidance and have the courage to express their thoughts and emotions. By doing so, we help them take the relationship to new levels. Grieving together draws them to the heights of intimacy and love.

Family and friends tend to talk about everything except dying and what is happening with their loved one. They may miss precious opportunities if they refuse to listen to what they are afraid of or do not think they are ready to hear. In some families, talking about dying is "taboo". ("We don't talk about such things") Many loved ones around the dying person fear talking will make "IT" happen sooner. It is at these times that bringing in a hospice or other objective professional can be most useful. The professional can often gently provoke the conversations to give opportunity for those necessary words to be spoken. The family can be reassured that just as talking about dying will not make it happen sooner, nor will not talking about it keep it at bay. Expressing feelings at the time of dying can be some of the purest communication there is.

As social workers, we must encourage the dying and their loved ones to make their wishes known to those around them. Resuscitate or allow natural death? Cremation or burial? Aggressive medical intervention or comfort care? Making certain their wishes are known far before necessary is the only way to insure that

their choices will truly come to fruition. Speaking about such things, putting them in writing, and appointing their decisions makers in advance are essential.

I encourage you to provoke these end of life conversations even before the dire prognosis is spoken. Use natural triggers; for example, a loved one's funeral, news reports of a celebrity death, the death of a pet, or word that a friend is terminally ill, to prompt open and courageous conversations about end of life.

But how do we help them even begin to speak about death and dying?

- With honesty. ("I don't know what to say except that I feel...(afraid, angry, frustrated...)
- Find out how much the dying person knows and how much he/she wants to know.
- Be curious to know what he/she thinks will happen next.
- Reassure him/her that he/she has your support.
- Listen with openness and avoid preconceived notions.
- Realize that in speaking about death, hope is not lost, however hope may be altered (to hoping for comfort in dying).
- Consider creating a wish list of things he/she wants to do before he/she dies.
- Find out how he/she has coped with stressful life events in the past.
- Balance realistic expectations with hope.

The road to hell, they say, is paved with good intentions. Often, we leave an assortment of things that have been left unsaid. It is imperative that we help family members and friends make the most of what may be their last chances to interact with their loved ones. We must be determined to help them create opportunities for good memories.

It is important to help the dying and their loved ones set goals to say those things that need to be said:

- I love you
- I am sorry for...
- Forgive me for...
- I forgive you for...
- I want you to know that...

We guide them to understand what is most important about communicating at end of life:

- Conveying love. I love you can never be said too often.
- Expressing appreciation and gratitude.
- Reminiscing about good times.

- Letting him/her know he/she will be missed.
- Emphasizing how his/her life has made a difference.
- Communicate statements that give tribute to his/her life.

We do not know which encounter will be their last, so we must help them walk in *completeness* of the relationship as much as possible. It does not matter how many times they say goodbye, even if they end up having the opportunity to say hello again.

Some refuse to say goodbye at end of life feeling it is evidence of hopelessness. Without the final completing words of the relationship, the dying loved one can be reluctant to let go. They may *will* themselves to stay alive long after what may seem physically possible. The most unselfish gift loved ones can give is to love them enough to let go. When the words just won't come, a letter or poem is sometimes helpful and fulfilling.

Sometimes, saying goodbye may be in the form of an action or project. The social worker may guide a project such as:

- Creating a legacy book
- diary
- Voice recording
- DVD
- Photo album

At the end of life, as in all times, God calls for decency and order in each aspect. This helps the person who is dying feel more relaxed, focused, and less likely to endure distress. Encourage loved ones to:

- Keep the living area in order
- Keep conversations in order
- Keep chaos at bay, there may be need for mediation away from the bedside.

In still moments spent with a dying loved one, family members frequently become distressed by the silences; not knowing what to say or how to act when their loved one is not able to verbally respond can lead to high levels of distress. We can guide loved ones through this by helping them to understand that their dying family member or friend is laboring towards death just as a woman labors during the birthing process. They are reviewing their life and seeking peace. In hospice, this is referred to as "transitioning". Just as there are changes in the physical aspects, the dying seem to be venturing emotionally, spiritually, psychologically, and relationally.

We may see them reach out for the unseen, speak to those long passed, and smile or laugh at words unheard. At times, this transitional time may be filled with distress and agitation. Some who are dying seem to be doing battle,

moving about restlessly, speaking words of distress and discontent. Those near the dying can best assist by validating their struggle and reassuring them. ("I can see your struggle and I want you to know I am here with you and praying that you will find peace.") Minimizing or trivializing can be very harmful, yet loved ones instinctually seek to calm these times immediately, often by adding medication or restraining the physical and emotional restlessness.

Research in this area shows that the dying often describe this point of the process as a journey. Those interviewed use words and phrases such as "traveling", "going on a trip", or "being on a journey". The dying speak of needing to prepare, pack, or get ready for the venture. They may speak of flying or driving long distances. Sometimes, they may describe crowded stations or rooms filled with people, some known, some unknown. For loved ones, this may be comforting or stress producing. However, for the dying, most often these shared utterances are expressed with delight and curiosity. The dying may share these things with a sense of urgency, not wanting to be left behind. Encouraging the dying to partake of the journey before them can be difficult, but validating their experience is an act of love. Some loved ones are quick to "yank" their loved one away from such experiences out of a fear of losing them too quickly. These moments deeply carve death into reality.

In those final moments, we can help loved ones to be in the present; we help them determine what is right for them. We encourage them to honor their own limitations. We guide them to approach gently, telling their dying loved one that they are with them. We teach through modeling to speak to him/her directly: "I see you are resting comfortably" not "he/she looks comfortable. We encourage them to:

- Speak soothing words, reassurances, and validation.
- Speak to their loved one in their first language.
- Include humor, smiles, even laughter.
- Sing or hum well known songs or songs of childhood.
- Give their loved one permission to go.
- Reassure their loved one that though you will miss him/her, you will be okay.

Each time loved ones leave the side of the dying, encourage them to leave in completeness. The more complete the relationship, the better the season of grieving, the fewer regrets. Assist them in not leaving things left unsaid. Help them to permit each loved one his/her own individual responses to the dying. Each relationship with that person is unique, so their grieving will be unique as well.

Some who are dying choose to do so alone. Often, this is a final act of caring for loved ones. (This is frequently seen with fathers/daughters, mothers/sons.) The dying person may wait until the very moment when loved ones step away to breathe that final breath. If, by chance, the loved one is not at the bedside when

he/she slips away into death, help them to understand that the last breath merely represents a brief moment in their relationship.

We help loved ones understand that their relationship with their dying family member or friend is multi-dimensional. Their walk during the end of life season is as well. Completing the relationship actually occurs in many stages:

- Caring for the dying family member.
- The actual death, in the funeral services, or memorializing.
- Living with the essence of their loved one in times to come.

When verbal communication is no longer possible, loved ones can still say what they need to say as hearing ability stays long after verbal ability is lost. Even if they cannot hear, I am convinced there is a communication of the heart. Much can be said with a simple smile, the squeeze of a hand, warm eye contact, and just being present. Sometimes, even the familiar scent of family members surrounding the bedside is comforting. Familiar music in the room as well as the laughter of family members reminiscing and sharing stories is also a comfort.

Silence is, at times, the most comforting to the dying. However, it is a form of communication that is often very uncomfortable for loved ones. They feel pressured to fill those silences with SOMETHING in order to ease their distress. This pressured communication is sensed by their dying loved one and can lead to restless responses. According to Plato: "Wise men speak because they have something to say; fools speak because they have to say something." Helping loved ones grow comfortable in the silences and understand that silence, in and of itself, is communication can comfort them.

As helpers who walk alongside the dying and their family members, we must understand that presence has healing power. Studies conducted clearly show this. Physician John Kendall, for example, studied the impact of presence on women in childbirth. In this study, his three groups included women giving birth with a doula and a non contact observer, women giving birth with just the non contact observer, and a control group with neither a doula or observer. The outcome profoundly indicated the women having a doula at their side significantly reduced cesarean sections, need for epidural, and need for forceps delivery. However, surprisingly, the non contact observer group also had a profound impact on the need for cesarean delivery, epidural pain relief, and the need for forceps delivery. The mere reality of a of an inconspicuous presence traveling with the woman in labor in the crowded and chaotic delivery room is significant.

Walking alongside the dying is and incredible honor and privilege for a professional. To be included in the intimacy of the dying process is a role to be walked in with deep humility. From our simple acts and words of empathy to our physical presence; each moment we traverse with the dying and their loved ones may seriously impact the journey. As a final guide, I have few simple tips:

- Never stand between a dying person and their loved ones. Move to the side or behind them. You are never the most important being in the room.
- Never allow your therapeutic touch to stop emotion. So often, when one is crying, we rush to embrace or touch. This may often stifle the true response. Allow the feelings to flow. This need to touch may be rooted in our own discomfort with the emotions shown.
- Reflect the emotion in the room, allowing feelings to be in the present. Sometimes in the effort to help, we may have an agenda that doesn't match what necessary grief work is happening right before us.
- Accept what is "true" for those in this process. Don't trivialize or try to circumvent the feelings shared. Walk beside them as they explore those feelings and come to new conclusions.
- Slow your pace. Professionals are notorious for giving the sense of rushing. End of life is not the time for this. For the dying and their loved ones, when end of life is nearing, what "more important" situation could we possibly be rushing to?

**Life is eternal, and love is immortal, and death is only a horizon, and a horizon is nothing save the limits of our own sight.** -Rossiter Worthington Raynard.

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