

Care of a Person at the Time of Death

Cultural and religious influences will play a major role in the rituals and spiritual support given to a person who is dying, and in caring for the body after death.

Looking back upon my experience as an independent nurse practitioner specialising in palliative care, there have been many opportunities to share unrestricted intimacy with a person who is dying, and to form a relationship with their family and friends. The aim of this chapter is to share experiences with you, and to reflect on the uniqueness of each person at the time of death. “Walking the journey” with a person who is dying requires comprehensive insight and assessment. While medications assist the patient’s mind to free itself from the discomforts the physical body may be experiencing, a comforting presence may go a long way in providing emotional support. Kind words may give reassurance and expressions of love will support the spirit.

The first death I would like to share with you is that of a person I will call Charles, who was in his eighties and dying of cancer. He was supported by a very caring wife and two children. He cheekily called his wife his “Brown Sugar” – sweet, but needing a little refining. He was a staunch churchgoer and felt secure in his Christian faith. As he entered the final stage of his illness, he received opioids for pain relief and a small dose of sedative. He was being nursed in his chosen room in his own home. This gave him a sense of security and protection.

One day I was giving him a massage, and in a calm voice, I was taking him through a visualisation, with images that incorporated the colours of the rainbow. I invited him to be a feather on the breath of God (his language and the words of Hildegard of Bingen). His wife was holding his hand. The whole atmosphere in the room was peaceful and calm. As the massage continued, his breathing became slower and slower. I tried to match it, while continuing with the imagery. I thought this was a wonderful way to die. Suddenly Charles opened his eyes and said, “I can’t do it – I’ll have a cup of tea!” I responded with a smile, “Would you like porridge too?” It was an incredible moment. Here was a man trying to die consciously. I felt like a midwife to the soul. One day I left him with Cheyne Stokes breathing, and carefully monitored my pager for a call, which did not come. When I returned, he was sitting up in bed with all his family around him. He had awoken and summoned them. He said that he had seen the glory of God and wanted to give them all a blessing. He did in fact die several days later, but only after sharing what he was “seeing”.

Often as the body gets weaker, the spirit becomes stronger, and I believe that life and death are continuous. Or, as Elisabeth Kubler-Ross (1969) says, that death is a transition when a state of all knowledge is experienced. Those near death have said that there is an awareness that their deteriorating bodies are not “them” – rather, they feel a “real self” or boundless understanding of their true nature - a spirit, a soul, energy or a force. Stephen Levine (1991 Pg 270 - 271) says that many find it useful to “practice” dying. He says that learning to die is learning to dissolve past the holdings of this moment, opening fresh to the next, without clinging anywhere. He likens the process of dying to a sense of expanding beyond oneself, of dissolving out of form, of melting into the undifferentiated...Imagine trying to hold on to that which is melting away. Perhaps this is what some call purgatory. The hellish holding back from the next unfolding, resistance to what is?

It has been said that the wisest people in the world are the people who are dying and who know it. Rather than fearing and hiding from death, new insights can be gained by those who sit at the bedside of a dying person. This reminds me of an elderly woman who was dying from cancer. She said that her family was upset with the diagnosis but she wasn’t. She was pleased to be in her own bed at home and was content to look back on her life and her many achievements. I had

spent several nights with her, and on this particular night, I informed her that I wasn't able to be with her any more, as I was going away. Her response stays with me: "That's all right Joy – we have met many times before and we will meet again." I told her that Elisabeth Kubler-Ross says that people who are dying are the wisest people on earth. To this she replied, "I think you may be right."

Working with the breath, as in midwifery, is helpful for many patients who are entering the dying process. I have been inspired by the Tibetan Buddhist tradition. At a workshop for Phowa practice (transference of consciousness) I learned about a technique that can be used by people of all faiths and religions. The patient is encouraged to imagine a narrow hollow tube connecting the region of the heart and the top of the head. Inside the tube is a pearl, which represents the patient's essence or soul. With every breath, this pearl rises and falls. While this is happening, the tube ending at the crown is opening. The person invites their God (from whichever spiritual practice), when it is time, to harvest their pearl through this opening. Rinpoche (1997 pg 215) describes other practices. Comforting words in the Christian tradition are those Jesus said on the cross; "Not my will, but Thine, be done." Longaker (1997, Pg 117) gives examples of helpful prayers and verses from other traditions.

Physical comfort can be giving by moistening the mouth and creaming the lips. Jumbo swabs or foam swabs are useful. Water with a soluble gel is all that is needed. I recommend a Lanolin product for the lips. I usually have the patient nursed on an air filled alternating pressure mattress and medical woollen 'drawsheet' so that there is no need to disturb the person who is preparing for death. I encourage those at the bedside to massage the patient gently with a lavender cream and to hold a hand. Face washers soaked in water to which an essence such as eucalyptus has been added, can be rolled and stored in the refrigerator, and later used to wipe hot and sweaty skin. I usually sprinkle lavender essence on the pillows. There may be a smell of impending death, and it is important to use aromatherapy to override this.

Many patients and their families have expressed fears of there being a mistake when death has been pronounced. Once death has occurred, I find that it is helpful to involve a family member or other person who was close to the deceased, in the preparation of the person's body. This not only brings a sense of reality, but it is also a vital step in the grieving process.

Emotions are not necessarily rational, and even health professionals are often in need of support and explanation when confronted with strong feelings. An example of this occurred with the death of a patient, whose wife was a nurse. The man had just died from cancer at a rather young age, and his wife had a fear of a deep coma state being mistaken for death. By inviting her to help in the washing of her husband's body, she was able see the pooling of the blood in his back when he was turned over. She could see with her own eyes that the heart was no longer circulating his blood. Together we washed and dressed her husband in clean pyjamas and tidied the room, ready for the children to spend some time with their father. Acknowledging that death had occurred and a life change had begun were the first steps in her grieving process.

The moment of death is very special, and relatives will often want to be present. How can a nurse recognise the signs of approaching death? Doyle (1983 Pg 89) says: "All colour drains from the lips, the eyes immediately lose their lustre and moisture, breathing stops, the pulse in the neck is no longer seen and a deep peace descends – a peace which, for all that it is real, is difficult to describe." The pulse is certainly a significant sign that death is imminent. Contrary to what many lay people think, rather than slowing, the pulse becomes rapid and shallow near the time of death. When death is expected, the person's breathing becomes very shallow and irregular and those present may wonder if each breath is to be the last. The breathing may also be noisy, as secretions collect at the back of the throat - this is normal and may respond to medication being given subcutaneously. Suction is not advised, as this tends to cause distress. The patient's eyes may roll back as they do in deep meditation. Those at the bedside appreciate an explanation of what is happening and what is normal.

When those waiting for the moment of death are not able to be present, it may be a comfort for them to think that the person has some control over the time of death. I will say that sometimes the patient's spirit or energy is held by the energy of those around them, and for the spirit to leave, this energy needs to be absent. In the Buddhist tradition, we are told that the subtle mind, - the essence of the person - expands, and there seems to be an ability to connect telepathically. Rinpoche (1997 Pg 303) says that the clairvoyant consciousness of the dead person in the bardo of becoming is seven times clearer than in life. This can bring them *either great suffering or great benefit*. I reassure those who were not able to be present that if they were thinking about the dying person, they were indeed connected. For those who sit in the vigil, there is often a desire to help the person to make the transition. Sometimes the patient actually needs permission and encouragement. Thoughts at this time may include "let go", "focus on feelings of love", "feel good about yourself", "let the balloon go", "go to the light". I tell the patient to think of a situation when they felt love – be that the moment of a birth, or a wondrous sight in nature, or feelings for a spouse. If it seems appropriate, I say that God is love, and that by holding love in the heart, God is also there.

The process of grieving begins long before death and I find that by being present at the time of death to share that special moment, a trusting bond has already been formed. In hospice services where palliative care nursing and bereavement support are separated, it takes a longer time to build up the therapeutic relationship necessary for grief work.

On the practical side: Note the time when breathing ceased. A doctor will be needed to certify death. In the community setting, I establish if the regular doctor wishes to be notified should death occur at night, or if he/she would rather be notified in the early part of the morning. Sometimes the family doctor advises that a locum doctor is to be called. It is wise to be supported and have regular visits from the family doctor for legal as well as health reasons.

When there is an established relationship between the doctor and nurse, I begin preparing the body for family viewing and the important vigil period. Preparations include straightening the body, replacing any full or partial dentures (sometimes these are ill-fitting, but by closing the mouth, the facial form is restored), and closing the eyes (this sometimes requires a moist film of cotton wool or tissue to be placed under the eyelid). Urinary drainage catheters and subcutaneous lines or cannulae, are removed if present. Medical equipment such as oxygen masks, mouth care trays and air mattresses need to be removed. Broken skin is sealed with an occlusive dressing. An all in one incontinence pad is positioned to secure any leakage from the bowel or bladder. A man may need to be shaved. Hair may need to be shampooed and dried and finger nails manicured.

So that the hands can be held, they may lie on top of the bedclothes, either beside the person or across their body. A thin cake of soap inside the cardboard tube of a toilet roll, or a long lipstick case wrapped in a handkerchief or scarf, are often useful for propping the jaw in a closed position. There is no need to cover the face, and often, as the tension disappears, the person looks very peaceful and 'special'. Candle or dim lighting seems appropriate. Those present may wish to sit for a time beside the bed with their reflections and feelings. For some, grief may be too acute to appreciate staying by the bedside and this is acceptable too - they may prefer to go for a walk, or to take solace with another person, or visit a favourite place. Flowers can be arranged in the room or on the pillow. Music can be played if desired by the family. A favourite memento or verse may be placed with the person who has just died. Jewellery is usually removed, but some people express a wish to be buried or cremated with a sentimental item. Others will act as the father of two young children did, when he put his children on the bed to see that mummy wasn't breathing any more. He symbolically removed his wife's rings and said to the children: "We will keep these as a memory of her."

Choosing how to dress the person who has just died is important and again it is helpful to involve the family. For a patient who was a grandmother, I experienced a touching moment when her eight-year-old grandson asked if he could help after his grandmother had died. I asked him to choose a nightdress, which he gave to his mother to iron. As I prepared to wash his grandmother's body he asked me, "Why are you doing that?" A little taken aback, I replied, "Out of respect for the house she lived in." When she was lying peacefully in state in her own bedroom, with the bed covered by the bedspread that matched the curtains she had made, I asked the husband and daughter when they would like me to arrange the transfer to the funeral home. The husband, who initially wasn't keen to accept the responsibility of having his wife at home, changed his mind, and wanted to keep her for the night. The little boy put his teddy bear on the chair beside her – to keep her company! At the funeral he was there dressed in a bow tie, holding the attendance book for all to sign. He looked very proud and I'm sure will have a reassured approach to death in the future.

Asking the dying person about what clothes they would like to be dressed in is an opportunity to enforce the reality of death and to explore preferences and symbols. For example, one woman wanted to be clothed in the dress she had bought for her daughter's wedding. It was her celebration dress and she chose this symbol for her own important life event. Lamerton (1980, Pg 210) says that whatever one believes, all great teachers have accepted that the dying must prepare for another world. Never should this preparation be interfered with. It is helped by simple qualities such as goodness and beauty, with which we should surround the dying. Sometimes it is appropriate to say a prayer or to have a quiet moment around the bed - for example, reciting the Lord's Prayer or just saying something spontaneous like: "You died well", "There is a feeling of love and light" or "Thank you for being you". Reading a poem or inspiring verse, playing recorded music such as the music of Chants from Taize' (a spiritual centre in France run by Protestant monks) or just holding hands, can often express feelings when no words can be found. It is important to ask those at the bedside if anyone needs to be contacted and given the opportunity to say "goodbye." This may include a leader from a spiritual tradition or a person who supported the family by caring for the garden or house.

Depending on circumstances, it is often aids the grieving process if the body is not hurried away. Funeral people will come at any time, although there is usually an extra charge for "out of hours". The process of grieving, expressions of love, and goodbyes are helped by the vision of a body that is not suffering and is peaceful - a shell. Valuable time can be spent "viewing" or being with the body. I saw an example of this benefit when a husband, father and grandfather died in his home at the age of ninety. It was a timely death that occurred in the early hours of the morning. The wife who suffers from dementia was sleeping in a twin bed in the same room. The daughter, who had personality issues with her father, was present at the time of death and willingly helped me with washing and dressing her father's body. It was very much a healing time for the strained relationship. The man's wife watched the procedure from her bed and asked questions (often the same question) from time to time.

The family doctor advised that he would call in the morning to certify death. It was decided to ask the funeral people to come in the evening, as that would allow two daughters to travel to say their good-byes in the privacy of the home. Grandchildren (teenagers) came throughout the day and experienced their first view of death. They sat on their grandmother's bed and talked about their grandfather and what they would remember him about him. It was all very natural. Singh (1999, Pg 54) quotes Sigmund Freud as saying that he viewed the fear of death as a most prominent part of our psychological makeup and, in sublimated form, of civilization as we have always know it. I believe that the role of the nurse is to help dispel this anxiety surrounding death. In this case, the daughters arrived and all the family and the nurse shared a meal. Following the meal, which was really a celebration of family life, there were photographs taken of the family including the dead grandfather. For them this was a family event and they entered into the spirit of farewelling this man who had provided well for them. It seemed that the wife "forgot" about the death during the day, but when the funeral people came, she stepped forward

as head of family to take them into the room where her dead husband lay. She could touch him and feel that he was cold. This realisation helped her to accept that he had left her.

Some other personal experiences include a widow who kept her husband's body in the bed next to her all night, saying: "I knew he wasn't there but I just wanted him for one more night - I let him go in the morning." A fourteen-year-old girl tied her friendship bracelet around her father's wrist. Confessions, acknowledgments, tears and fears are expressed at this time. Those who die from a disease process are seen to be free from suffering and that helps the feelings of loss and love.

After the funeral people have transferred the body, strip the bed, leaving the room with an acknowledgment of change and "knowing". Medications prescribed for the person who has died need to be destroyed safely with the permission of those responsible for handling the deceased's affairs. The family may wish to be spared the transfer of the body to the funeral vehicle, so that their last memory is of their loved one looking at peace in the bed where the final goodbye was said.

Those present may appreciate help with telephoning the news to family and friends and making practical arrangements, such as notices for the newspaper, writing the obituary, and organising accommodation for travellers to the funeral. Those left behind may want solitude, or a walk on the beach, company to share a cup of tea, or to have a drink and reminisce. Some may just want to sleep - especially after a long vigil.

A continuum of palliative care nursing for nurses and carers is to attend the funeral if appropriate. I have found that it is common for family to be touched by this action, which in reality, is a way of debriefing and saying thank you for the opportunity to gain further insights into death and how best to offer comfort and empathy. The funeral service can be one way of celebrating the person's life, as well as a means of helping the bereaved. Remember that each person is an individual and that what is right for one person may not be right for another. For some it is useful to plan the funeral before it is needed. This involves a special honesty and acknowledgment, and is rewarded by knowing that the person's life was marked by an event that was personally meaningful. One example of this was at a home funeral - as the coffin was leaving the house a racing pigeon was released. It circled the house before returning to its home. (As well as being symbolic, racing pigeons had played a part in the man's life)

CONCLUSION

As a first step towards "walking the journey" with a person who is dying and the "unit of care" (patient, family and friends), health professionals need to address their own conscious and unconscious issues about death. An unconscious anxiety regarding death can so easily be projected onto another person.

"The unconscious needs to be explored for it is wiser than we are and is our interface with God" - M.Scott Peck USA religious psychiatrist and author

The unconscious communicates through symbolic language. It may be by a dream, or a feeling that is roused when we look at a cross, a country's flag, or a painting. It may be when we hear a particular sound, like the sea or a piece of music. It has been said that art and music are the language of the soul. Flames may be a symbol of purification, while the snake is the traditional symbol of healing. Fairy tales are full of symbolic language. Professor Ian Maddocks says that cancer itself is a symbol - a symbol of death and decay. Sports heroes and actors have become symbols. For many, Princess Diana was a symbol, representing the struggle of life, the disappointments, betrayal, hope, service to others, caring, motherhood, beauty and humanity.

We can never give away that which we ourselves do not have. If we are fearful and uncomfortable at the deathbed, those we are trying to assist will feel this. In the words of social worker and counsellor John Ashfield:

“Our capacity to genuinely help others is almost directly proportional to the extent to which we stand on ‘solid ground’ within ourselves - ie. the extent to which we accept and are comfortable with who we are”

Carl Rogers and Abraham Maslow, major spokesmen for humanistic psychology, suggest the following principles to bring about adjustment and change for patients:

- Give attention to love, creativity, joy, and “peak experiences” – aesthetic needs
- Focus on the person rather than the problem – “how can I become myself?”
- The therapists themselves must be genuine – not phoney professionals
- Establish a therapeutic relationship based on empathetic understanding
- Give unconditional positive regard, real caring and acceptance

Carl Rogers believed that if caring stems from the helper’s own need to be liked and appreciated, constructive change or knowledge of the self is inhibited. It is important for the helper to enter into, and identify with, the patients’s private world, without losing the separateness of their own identity.

We need to be familiar with grief and what is a normal grieving process. We need to appreciate what the Bible describes as “the seen and the unseen” in life. Many people who are dying have sense and sight of another reality. Patients have said things like: “Are you still on this side?” “There is a man here who knows about that.” (As I talked about going to a lecture on Neurolinguistic Programming to a visitor); “I can see my black dog”; “It is all an illusion.” To my mind it is indeed a privilege to be present at these times. Near death nursing care is much more than caring for the physical body.

REFERENCES

- Doyle, Derek. *Coping with a Dying Relative* MacDonald Publishers Edinburgh 1983
Kubler-Ross, Elisabeth. *On death and dying*. MacMillan Publishing Co. N.Y. 1969
Lamerton, Richard. *Care of the Dying*. Cox & Wyman Ltd. G.B.
Levine, Steven. *Who dies? Investigation of Conscious Living and Conscious Dying* Gateway Books G.B. 1991
Rinpoche, Sogyal. *The Tibetan Book of Living and Dying* Rider U.K. (1997)
Singh, Kathleen Dowling. *The Grace in Dying* Gill & Macmillan Ltd. Dublin 1999