



*Supporting life
to the end*

Heart & Soul



Two wolves

One evening an old Cherokee told his grandson about a battle that goes on inside people. He said, 'my son, the battle is between two wolves inside us all.

'One is Evil—It is anger, envy, jealousy, sorrow, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority, and ego.

'The other is Good—It is joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, truth, compassion and faith.'

The grandson thought about it for a minute and then asked his grandfather: 'Which wolf wins?'

The old Cherokee simply replied, 'The one you feed.'

A Philosophy on life from the world wide web

The NurseLink
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Looking at how different cultures support their elderly

Within the Chinese culture there is tremendous diversity and it is important to realize that cultural differences in Asia are similar to those of Europe where Germans, French and Swiss are all European but differ vastly in ethnicity. Spoken language is one example of this diversity as are the wisdom, philosophical and religious traditions. The major philosophical and religious perspectives that have guided Chinese culture are Confucianism, Taoism, and Buddhism. These influence end of life care and highlight the need for an individual approach that avoids general assumptions.

Guidance can be sought from common threads that distinguish Chinese culture. For example, a common thread emphasizes loyalty to family and devotion to tradition. Individual feelings may be hidden for the good of the whole. This is in contrast to a Western approach which tends to praise self-reliance and personal freedom. A Chinese family is supportive of family members and in return for security and meeting needs expects loyalty and subordination to one's elders and superiors. Values include filial piety, avoidance of emotional expression, maintaining harmony, face-saving or keeping the family name honourable. The family is an entity that continues to exist after death. This belief forms the basis for life sustaining rituals and ceremonies.

Misfortune as well as achievement is felt by the individual and the family as a whole. This includes sickness and an illness common to old age such as dementia may be hidden behind closed doors. Maybe this attitude contributes to the belief that Asians do not have problems associated with ageing as they care for their own. The care of a person with a terminal illness is a family responsibility and duty. Part of this caring is seen with the request to spare the ill person the nature and prognosis of the illness. This is contrary to Western beliefs which encourage the person suffering from an illness to make their own informed decisions regarding their health care. The benefits of openness in one culture may be seen as burdens in another culture. Freedom and independence come at a large price and at the end of the day may be seen as a poor substitute for the warmth of a caring family.

Holistic care is well accepted by the Chinese as their traditional medicine has been developed over 3000 years and poor functioning in one area of the body may affect the performance of others. The body is seen as a set of dynamic processes where energy needs to be balanced for health, and social harmony. Imbalance of yin and yang results in illness or disease. Yang represents physical strength and masculinity while yin represents emotional force and femininity.

Psychological well-being for men and women is a balance of these forces. In Chinese medicine, the human spirit is an integral composition of body, mind, and spirit. They cannot be separated as they tend to be in Western culture. Chinese medicine emphasizes that healthy Qi, or vital energy, flow corresponds to the natural order and rhythm of the universe. Western medicine is primarily a physical and technological medicine.

Achieving a balance and respect for both can surely be of benefit to all. The aim of NurseLink's model of holistic care is to express in simple practical ways how great philosophies can be directed to basic nursing care.



NurseLink's Diagram of Holistic Care

Spiritual

Searching:

- for meaning in life/self
- for personal values/beliefs
- for trusting relationships

Practising:

- meditation/contemplation/prayer
- living in present moment with love
- listening to/trusting intuition
- appreciation of nature/natural order

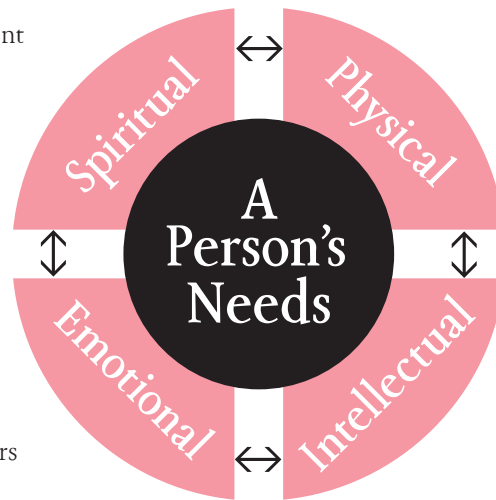
Emotional

Experiencing:

- unconditional love
- forgiveness of self/others
- choice

Feeling:

- a sense of freedom/control
- the comfort of belonging
- a sense of usefulness / satisfaction / role
- the essence of realistic hope



Physical

Obtaining:

- relief from troublesome symptoms
- appropriate nutrition
- bowel / bladder care

Experiencing:

- comfort/safety
- therapeutic touch/massage
- frequent hygiene
- periods of rest / activity

Intellectual

Obtaining:

- health information
- involvement in decision making
- effective communication

Understanding:

- benefits of positive approaches
- changes need not promote stress
- legal aspects of living
- funeral planning

“The little child whispered,
“God, speak to me.”
And a meadowlark sang.
But the child did not hear.

So the child yelled,
“God, speak to me!”
And the thunder rolled
across the sky.

But the child did not listen.

The child looked around and said,
“God let me see you.”
And a star shone brightly.

But the child did not notice.

And the child shouted,
“God show me a miracle!”
And a life was born.

But the child did not know.

So the child cried out in despair,
“Touch me God, and let me know
you are here!”

Whereupon God reached down
and touched the child.

But the child brushed the
butterfly away and walked
away unknowingly.

Take time to listen.

Often times, the things we seek
are right underneath our noses.
Don't miss out on your blessing
because it isn't packaged
the way that you expect.”

— Anonymous

Children and Grief

by Joy Nugent

(An extract from Book3 A Passion for Caring Series)

Do children grieve?

Children grieve differently from adults. How they grieve depends on their age, but we can't protect them from the reality of death or from their feelings. By facing up to death and by being honest, we can help children to learn about death, to learn to recognise and express their feelings, and how to resolve their grief. Giving time, talk and permitting tears is a grief strategy for children and adults.

Protecting children

Protecting children in the event of death and keeping them away from death as much as possible, does not stop them from suffering. Parents who try to protect their children from the experience of loss, from the expression of grief, and from a participation in mourning deny their children the opportunity to ask questions and to express their feelings. It is better for children to express their feelings and release them, than to bottle them up inside. Children who see their parents cry and grieve will know that it is OK for them to also feel sad about the loss. Children have vivid imaginations and keeping them away from a death bed may mean that what is imagined is more traumatic than the reality.

Education about death

It is difficult to pinpoint a child's concept of death because younger children are often unable to verbally describe their knowledge and feelings. We know that the majority of children are aware of death through stories, television, video games and movies. However, many adults assume that children have no curiosity about death and that they remain idyllically ignorant of the process of death and dying. Despite valiant efforts to spare children from the grim aspects of life, children learn more about death, and at an earlier age, than one might realise.

Many adults speak and act as though children are oblivious to death. Adults often prefer to ignore the fact that children think about death and dying. The view that young children do not, or should not, think about death remains prevalent today, possibly because it protects adults from having to deal with the realities and responsibilities of children and death.

A reluctance to discuss death with children may be due to many reasons, from philosophical to religious. This may also be because some adults find it difficult to acknowledge the finality of death themselves. Consequently they avoid talking to children about death, in a misguided effort to shelter children from the harsh reality.

A child's concept of death and dying tends to reflect the concepts of the society in which they are reared. Children learn much more than they are intentionally taught. The way a child views death also depends upon their age and maturity level as well as what they are taught and learn from first hand experience.

I remember being in awe of the wisdom of one father who encouraged his two pre-school children to climb up on the bed after their mother had died. He showed the children that their mother wasn't breathing any more because she had died. He then helped them to remove the rings from her finger so that they could keep a small part of her as a remembrance. It seemed at the time to be the most natural and loving experience to give the children in a time of great loss.

From my experience as a palliative care nurse I have learnt that children view death differently from adults. One mother died on her youngest son's eighth birthday. All three children had participated in the pre and post death nursing care. The eight year old said that he wanted to put cream on his mother's lips because she didn't like to have dry lips. It didn't matter that she was cold and lifeless.



He still wanted to care for her. While the adults who were involved with the death expressed horror that the anniversary would somehow dampen future birthday celebrations, the son seemed to be proud that his mother had chosen his birthday to die.

On Death

Death is feared to some extent by all of us. We seem to have a survival gene which is connected in some way to the sense of ego or what defines us as individuals. There is a desire to live and a desire to stay in control of present and future. Since death is generally unwanted, the topic is faced only when a death occurs or becomes inevitable.

Death-fear is only natural and the degree of fear among individuals appears to be related to a number of factors including age, sex, state of health, race, family support systems and religion. A manifestation of this death-fear is an inability to communicate appropriately with children about death. This is primarily because as adults we have difficulty in discussing both our own impending death and the death of loved ones. Euphemisms and subtle expressions, such as 'passed over', 'gone on', are based in a belief that life is a continuum. Scientific expression is more direct and speaks of 'death' or 'died'.

Another important factor is the protective mechanisms some parents use when communicating with children about death. For example, pets are 'put to sleep' rather than 'killed'. The natural tendency is not to be too direct, open or descriptive with children. The desire to protect is perhaps more common among parents with very young children. However, when their developmental age and psychological readiness are taken into account, young children can handle death as well as, or better, than adults can.

Helping children deal effectively with death and dying has been identified by many writers in this area as a major responsibility of parents. Just as with sex education and other controversial and sensitive issues, the subject should be confronted openly, honestly, naturally, and as the opportunity arises. Parents and teachers of young children need to work together to provide clear, non-confusing, and developmentally appropriate experiences in an effort to communicate about this sensitive subject of death with children.

The manner in which the grief of a child or an adolescent is acknowledged and honoured determines how they will cope with grief for the rest of their life. For many children their first feelings of separation and abandonment occur on the first day at kindergarten or school. For most it is the fear that their parents won't come back for them. Also, with the breakdown of traditional family structure through divorce and single and same sex parenting, even very young children are experiencing loss and grief.

Explaining death to children

Even at a very young age, children are confronted with death and the process of grief, when life no longer exists in a familiar form or way.

For example:

- A parent dies or goes away
- A pet is killed
- A family breaks up
- They experience a disability or some kind of child abuse
- A grandparent dies
- A leader is assassinated

The child encounters death in many forms. Silence only deprives him or her of the opportunity to share grief. But if parents and teachers are confused, and if adults are not open to explore the meaning of death, then how can they help the child? We have the inescapable responsibility to share, with the child, the fragments of our experience and knowledge. An example of this sharing is found in Danielle's story.

Danielle's Story

Danielle was sitting talking to her grandchildren when out of the blue her four-year-old grandchild said to her, 'Gran, what will you wear when you die?' Danielle told her that she did not know, but asked her grandchild if she thought they should talk about it now? 'Yes', was the reply. After much discussion Danielle shared what she wanted to wear and why she wanted these garments. Then the granddaughter said, 'And what about beads?' Danielle again asked if her granddaughter thought she should wear beads. There was agreement. Then the granddaughter said that she would like to choose them. So it was agreed that this should happen. And that was the end of their discussion.

By evading a child's questions the child is left in doubt about their capacity to deal with a particular situation. It encourages the child to develop the capacity to 'forget about things' and does not prepare them to deal with life's realities. A child's imagination, in fact, may paint a more horrific and distorted picture than reality.

Helping Children Grieve

How do we achieve this?

If a pet or bird dies, allow children to respond and be involved if they want to. A child may want to touch the dead animal, examine it for a while, ask questions, and then participate in burying it. They may feel sad. If so, adults can help them to talk about their feelings and to learn to recognise and express them in whatever way is appropriate.

If they were very attached to a pet, then they need time to grieve before the pet is replaced. Early replacement of a pet can sometimes encourage denial of the child's real feelings. Children can learn to live with death and not be crushed by it if they are given time to grieve.

How to tell children that someone they love has died

It is most important to be honest. Explanations should be truthful, clear and as simple as possible. It is important not to mix medical and religious explanations. For example, if a young child is told that God has taken his brother to Heaven because he was very good, then the child may assume that he is not good, because he wasn't taken - and he may not want to be good if it means he will die. Euphemisms should be avoided because children can misinterpret them. For example, if a pre-schooler is told that daddy has gone to sleep, when he has in fact died, then they may be too frightened to go to sleep.

Practical Considerations

How can we help children to grieve?

- By grieving openly ourselves, and sharing our feelings with children. This gives children a model for grieving and provides an atmosphere where grief is permitted.
- Encourage participation at funerals. Children will need to be told what will happen beforehand and have a supportive adult close by at the funeral. The child needs to know that funerals are part of life and that they will be well looked after at the funeral. Encourage children to plant a tree or shrub in memory of the loved one who died.
- Help children to share and express their sorrow, for example, by placing a drawing or special object in the coffin, by talking, crying, or writing a letter to the dead person, by making a scrap book about the dead person or the family, or through painting, dancing, music, movement, or using their soft toys to tell a story. Read children books about death which have been written for children.
- If children have any feelings of guilt about their thoughts or actions toward the dead relative in the past, help them to see that this is normal and did not cause the person's death. Explain the cause of death in understandable language.



- Children may not only be experiencing the loss of a loved one, but also the loss of the family as it was. Their mother may not be functioning normally, may not be as attentive, or may not be keeping the routines that give security. It is good to discuss this with children, explain it, and reassure them that things will return to normal in the future.
- If you have a religious belief, share it with the children, as well as the medical facts.

Physical expressions of affection, and extra attention, will help overcome children's fears and insecurities. It appears that, until the age of 12, children can only focus on grief for short amounts of time. They find it necessary to distract themselves and to resort to various defences against grief. We need to understand this and not be critical if children sometimes seem callous. Without our help, children may not be able to identify their feelings. They may not know that they feel frustrated and angry because Grandma has died, but they may throw themselves down in a tantrum. We need to be accepting, and not punishing, while maintaining acceptable standards of behaviour.

Report on DVD 'Say it Forward— planning for end of life'

The DVD has been loaded onto the Foundation website and we have received orders from far and wide including Swinburne University Library in Victoria. It has been shown at 4 Rotary clubs as well as at the 'Confident Care in Palliative Care Forum' March 25th in the Barossa Valley. Thank you to all those who donated towards the cost of making it.

New membership application

A new membership application form is enclosed. Please give it to someone who may wish to join—someone who wishes to see nursing advance in the spirit of Florence Nightingale and to change the way we care for the frail and elderly.

Memberships are current to June 30 each year, after which a Tax Invoice will be issued for renewal. Members of the Foundation receive the **Heart&Soul** newsletter sent out in the mail on a quarterly basis.

Conference for volunteers

On Thursday 20 & Friday 21 May 2010 *Searching for Balance* palliative care volunteers conference 2010 will be held at the Stamford Plaza Adelaide, 150 North Terrace Adelaide. This conference is organised by the Palliative Care Council of South Australia and features plenary speakers such as:

Dr Nick Wickham on:

Why use chemo- and radio-therapy in palliative care?

Mr Tim White on:

Competing needs between lifestyle and continuity of life.

Ms Janine Haynes on: *It's my life—It's my death.*

Sister Angela Mahar on: *Self care, physical, psychological, spiritual.*

Full Registration for Volunteers for 2 days is \$150.00

Registration forms available from NurseLink Foundation office.

Board room news

A strategic planning session resulted in a new tag line *supporting life to the end* to more accurately capture our work. Please observe on the front of this Newsletter.

Thank you to Bird in Hand Winery for supporting the Foundation's raffle which was promoted at their Teddy Tahu Rhodes and David Hobson 2010 Concert Series and for donating the 3rd prize of Bird in Hand wine, olives and oil valued at \$500.



BIRD
in
HAND

We also thank Oliver Travel, 194 Hutt

St for donating the 2nd prize of a day trip for 2 people valued at \$600. For the 1st prize we are again indebted to Patron Maria Kenda for donating a magnificent pearl and gold drop pendant attached to a pearl necklace valued at \$2,500. The raffle was drawn on the night.

Christine Hammat is welcomed as our new Office Manager. Christine comes from many years of office experience as well as involvement in parish work.

The NurseLink Foundation newsletter **Heart&Soul** will be published four times a year. The next edition will be released in Winter 2010. If you would like to receive our newsletter, or have something you would like to contribute, send us your details:

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The publishing of newsletter contributions is subject to consideration by the NurseLink Foundation Board.

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