



*The Foundation
for new nursing*

Heart & Soul

**The NurseLink
Foundation Newsletter**

Issue No. 10
Autumn 2009



Sharing the darkness

'We are all frail and wounded; it is just that some of us are more clever at concealing it than others. The great joke is that it is ok to be frail and wounded.... The world is not divided into the strong who care and the weak who are cared for. We must each in turn care and be cared for, not just because it is good for us, but because that is the way things are.'

The hardest thing for those of us who are professional carers is to admit that we are in need, peel off our sweaty socks and let someone else wash our dirty blistered feet.'

Sheila Cassidy—Sharing the Darkness

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Caring for the terminally ill: patient and family

Adapted from a talk by Dr Carol Douglas to Hospice workers in Kota Kinabalu, East Malaysia

We as carers meet our patients in the context of their illness. So as to fully minister to their needs we must try to understand the dying or aging patient in the context of his/her world. As carers we need to consider all the needs of the patient and family. The degree of distress experienced by the patient and family depends on many factors and its relief relies on the communication skills and personalities of the carers.

The patient's loved ones share in the three dominant emotions experienced by the sick person—fear, loss and anger. In addition to this, they are likely to experience the additional emotions of revulsion, weariness in well-doing, guilt and exhaustion. Some of the issues requiring consideration:

Fear

Close relatives share the patient's fear of death, of pain and of dying badly. They too have bad memories of cancer deaths, their misconceptions and their ignorance. They may fear that they will not be able to cope. As carers it is necessary to elicit the fears of the family and provide them with the reassurance and supports they are lacking.

Loss

Relatives inevitably bear the double burden of the fading before their eyes of their loved one and the increasing demands of the sick person. They may feel unable to cope with the added emotional and physical burden. This is especially hard when a partner who has been both dominant and supportive becomes ill manifesting in a role reversal. Eg, the parent becomes the child.

Anger

The anger expressed against God, the medical profession and their fate may be greatest in the relatives. Much can be done by listening patiently and when the anger has abated try to give an honest explanation and acknowledge the feelings of the person. It is important for carers to be able to absorb the anger of distraught people and realise that while it may be directed at them, it is the person's own frustration and feelings.

Guilt

Loved ones may not be able to express guilt related to believing that they could have sought other medical advice, or earlier advice. They may be suffering guilt related to a poor relationship with the dying person, especially if it has been an unhappy marriage. They may feel guilty that their life is spared. They may feel guilty that they in some way contributed to the disease. Eg, encouraging the person to keep working, cooking unhealthy food and adding to stress.

Revulsion

Gross disfigurement, uninhibited or inappropriate behaviour by people suffering with dementia, vomiting, incontinence and the like may make people feel revolted. This sense of revulsion can make family and loved ones feel very guilty. It needs to be explained that it is quite natural to feel this way and ways can be found to help them cope with improved nursing techniques and medical advice.

Weariness in well-doing leading to exhaustion

There is always a limit to a person's endurance, and a point is reached where the strain increases out of proportion to the actual demands because the carers run out of steam. It is important that carers recognise this so that respite options can be arranged. There may be tremendous guilt when the carer feels the need for time out and needs to pursue a pleasurable pastime.

Pre-existing difficulties with the family

Difficulties, disagreements and quarrels with families are frequent and often long-standing.

Family problems can become a major factor in a patient's emotional response when facing a terminal illness. Where feelings of guilt are involved, these may be serious enough to preclude a peaceful death. Even when relationships have appeared satisfactory on the surface, the stress of terminal illness may bring out pre-existing problems that have been contained while there was equilibrium. Deeply hidden emotional problems are often complex and difficult to resolve.

Communication difficulties within the family

The family is as much the patient as the dying person. Carers can facilitate the open discussion of matters, so that they may be able to draw together and face their impending and mutual loss. It is important to listen to what is not being said and to build a trusting relationship so that questions can be asked. Sometimes the carer needs to listen to the feelings of the patient on the one hand and the family on the other hand for it is often difficult and painful for direct conversations. Confidentiality is important in this area.

Children

Children of a young dying patient have special problems which need careful attention. They frequently have difficulty in understanding or talking about what they see and hear. Adolescents who assume adult roles are easily overburdened with responsibilities for their age and need extra support. Children may have guilt and feel responsible in some way—magical thinking. For example they may have expressed an angry wish that the parent was dead and may feel that this expressed resentment is the reason for the illness.

Family coping

As with the individual person, families exhibit a range of coping mechanisms. These can compound suffering rather than lessen it. The management of poor or maladaptive family coping includes family meetings with counselling to highlight problems so that a common purpose may be found. Normal family rituals or routines if continued may provide a sense of stability, particularly for children. Issues of loss and grief are individual and will be different in every situation.

Financial and legal needs

If the patient is the breadwinner of the family, the illness may have devastating consequences for the family and require the assistance of a social worker. Problems related to legal and business affairs need to be addressed. This may include writing a will, appointing an Enduring Power of Attorney and a Medical Agent and making Advance Medical Directives if they apply. Disorderly worldly affairs may be a source of stress to the patient and the family and the carers need to encourage action with this regard.

Depression

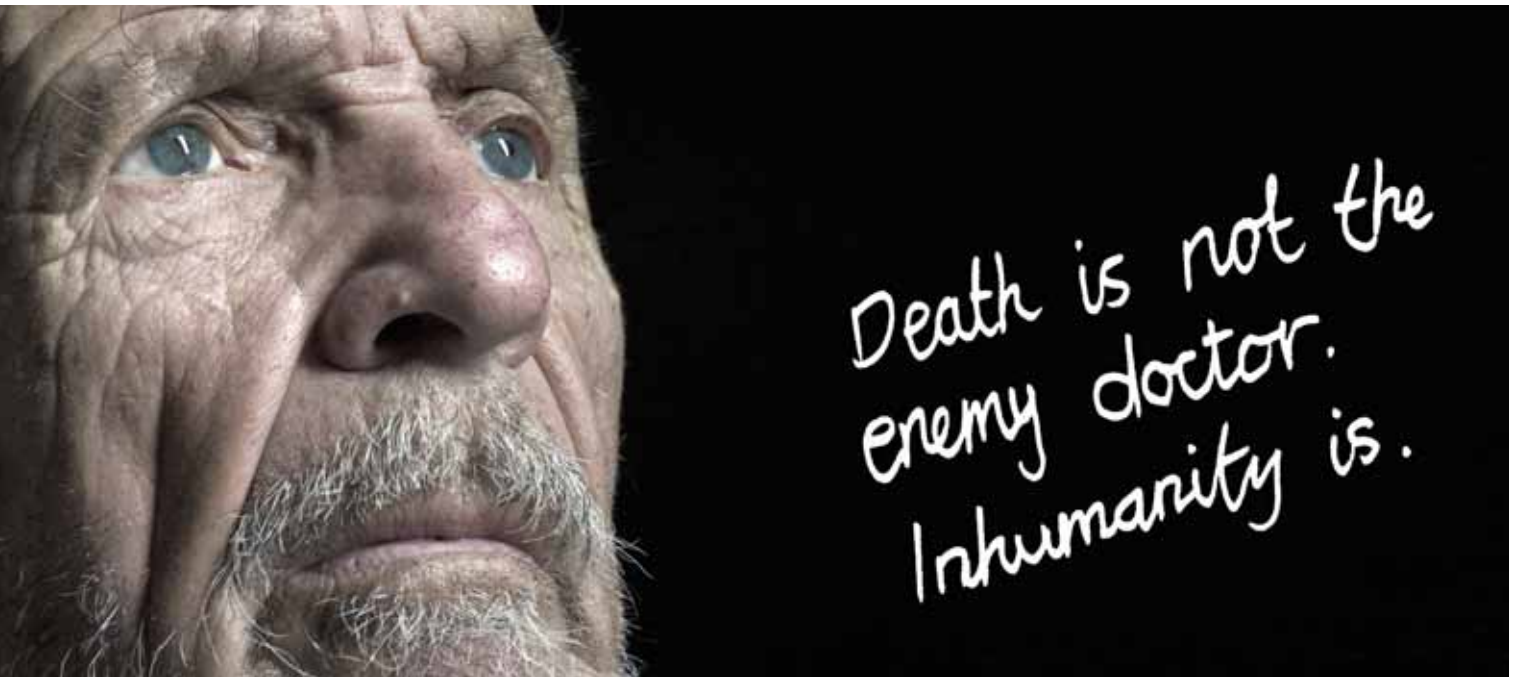
Sadness at failing strength and impending separation from loved ones is inevitable in an incurable illness. The carer needs to provide a sensitive combination of listening, encouragement and comforting. However, altered sleep rhythms, persistent low mood, guilt and low self-esteem may indicate the presence of a clinical depression. It is important, however, to differentiate between sadness and depression as medication may be helpful.

Personality traits

Disability and weakness result in the progressive loss of control over one's life resulting in patients having to give up one by one those activities which have characterised them in a particular role. Those who have been most independent are particularly affected and see their loss of control as a personal failure. Rigid, domineering, controlling people may be overwhelmed when faced with helplessness. They find it difficult to accept help. 'People die in character' (Elisabeth Kubler-Ross). How a person has coped previously with life's trials is a good guide for assessing coping skills.

Unfinished business

For many people the resolution of unfinished business is important in achieving a sense of completeness that promotes tranquillity. The unfinished business may be related to work or to self-esteem or may be of an economic, interpersonal (needing forgiveness of self and others) or spiritual nature (returning to a previously held belief). By unveiling and assisting unfinished business the dying person is more likely to have a peaceful death. What surrounds the time of death tends to affect the bereavement period for those left behind.



Do doctors know the real enemy?

By Nancy L Caroline

His name was Eli Kahn. He was 78 years old. He was admitted to the hospital because of abdominal pain and vomiting. X-rays taken on admission suggested a small bowel obstruction. Having reviewed his films, I walked over to the division to 'work' Kahn up.

He was a thin frail old man with a weathered face and marvellously bright eyes. When I entered the room, his attention was fixed on Kovanich in the next bed, an old man recently operated on for colonic cancer. Kovanich had not done well, and now he lay entwined in a tangle of drains and tubes, breathing laboriously.

I introduced myself. Kahn wrenched his gaze from his neighbour and looked up at me. 'I'm dying', he said.

'Don't be silly.'

'What's silly about dying?'

'Nothing. But it's not allowed. You are in hospital, a university hospital, equipped with all the latest technology. Here you must get well.'

'My time has come.'

'Time is measured differently here.'

'What do you understand about time? Wait until you have lived 78 years. Wait until you are 78 years old and tired and alone and have a pain in your belly.'

There was no arguing with him. Physical examination revealed an erratic heart beat, a few crackles in the lungs, a tender, distended abdomen, an enlarged prostate, and arthritic changes in the joints.

'You see,' said Khan, 'the engine is broken down; it is time for the engineer to abandon it.'

We discussed the case with our ‘attending’ and elected to decompress the bowel for a few days before attempting surgery. When I went into Kahn’s room to pass a Miller-Abbott tube, I found him again staring at the patient in the next bed. Kovanich was comatose.

‘We have to pass a tube down into your stomach, Mr Kahn.’

‘Like that?’ He gestured towards the tube protruding from Kovanich’s nose.

‘Something like that.’

‘Listen, doctor. I don’t want to die with tubes sticking out all over me. I don’t want that my children should remember their father that way. All my life I tried to be a mensch, you understand. All my life I tried to live so I could hold my head up. Rich I wasn’t, but I managed. I put my sons through college. I wanted to be able to hold my head up, to have dignity even though I didn’t have much money and didn’t speak good English.’

‘Now, I’m dying. Okay. I’m not complaining. I’m old and tired and have seen enough of life, believe me. But still I want to be a man, not a vegetable that someone comes and waters every day—not like him.’ He looked over at Kovanich. ‘Not like him.’

‘The tube will only be down for a few days, Mr Kahn. Then we’ll take you to surgery and fix you up.’

‘What, are you going to make me 25 years old again with your surgery?’

‘No, we can’t accomplish that.’

‘We’re trying to make you feel well again.’

He seemed suddenly tired of the conversation. ‘You don’t understand,’ he said more to himself than to me. ‘You don’t understand.’

That evening, I stopped by to insert an IV.

‘Another tube?’ Kahn asked.

‘You’ve become dehydrated. We have to get some fluids into you.’

He nodded, but said nothing. He watched silently as I started the IV line and secured the line with tape. Every so often he glanced across at Kovanich. Still he said nothing.

Early the next morning, I heard the hospital page issuing the code for a cardiac arrest. I raced up to the division to find nurses dashing in and out of Kahn’s room. Inside, I saw Kovanich lying naked on his bed in a pool of excretions with the house officers labouring over him—pounding on his chest, squeezing air into his lungs, injecting one medication after another, trying to thread a pacemaker down his jugular vein. The whole thing lasted about an hour. Kovanich would not come back, and finally all labour ceased. The nurses began clearing the resuscitation equipment out of the room, while we filed out to begin the round of post-mortem debates.

‘Doctor, wait a minute.’ Kahn was signalling to me. I went over to his bed.

‘What is it, Mr Kahn?’

His eyes were frantic. ‘Don’t ever do that to me. I want you should promise you’ll never do that to me.’

‘Mr Kahn, I know this has been very upsetting...’

‘Promise!’ He was leaning forward in bed and his eyes were boring through me. There was an interminable silence.

‘All right, Mr Kahn, I promise.’

Satisfied, he leaned back against the pillow and closed his eyes. I was dismissed. I wandered out into the hall, where my colleagues were discussing Kovanich’s defection.

‘It looked like a pulmonary embolism. I knew we should have anticoagulated him.’

‘Did you get permission for an autopsy?’

‘Don’t lose his last ECG; we’ll need it for the conference.’ I walked away. I had other things to think about.

On the fourth hospital day, Kahn went into congestive heart failure. I found him cyanotic and wheezing on morning rounds. Swiftly the house staff swung into the practiced and coordinated action of acute care: morphine, oxygen, IPPB, tourniquets, digitalis, diuretics. But despite our skilled efforts, Kahn responded poorly. ‘He’s exhausting himself trying to breathe, and he’s still hypoxic,’ our ‘attending’ said. ‘I think he ought to be intubated; it will give him a rest and will help us oxygenate him and get at his secretions.’

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When the anaesthesiologist arrived to intubate him, Kahn was gasping. I explained to him about the endotracheal tube. His breathing became more laboured as he struggled for words. ‘You promised...’ was all he could say.

‘But this is different, Mr Khan. This tube is just for a short while—maybe just a day. It’s to help you breathe.’

He stared off in another direction. The anaesthesiologist intubated him without difficulty, and we hooked him up to the ventilator.

‘I think he ought to be monitored also,’ our attending said. So we brought in the cardiac monitor and pasted the leads onto Kahn’s chest while he looked on, not stirring, his face expressionless, his eyes dull. Kahn was asleep that night when I stopped in for an evening check. The room was still save for the beep-beep of the monitor, the rhythmic whoosh of the ventilator and hum of the nasogastric suction apparatus. And Khan looked suddenly so very old

and frail, lost among tubes and wires and enormous, imposing machines. I could not help thinking of the physiology laboratories in medical school where we used to put dogs to sleep and hook them up to all kinds of intricate recording devices. I checked the settings on the ventilator and slipped out of the room. There were a lot of other patients to see.

Some time late that night, Kahn woke up, reached over and switched off his ventilator. The nurses didn’t find him for several hours. They called me to

pronounce him dead. The room was silent when I entered. The ventilator issued no rush of air, the monitor tracked a straight line, the section machine was off. Kahn lay absolutely still. I mechanically reached for the pulseless wrist, then flashed my light into the widened,

unmoving pupils, and nodded to the nurses to begin their ritual over the body.

On the bedside table, I found a note, scrawled in Kahn’s uneven hand: ‘Death is not the enemy, doctor. Inhumanity is.’

Quality of life can only be measured by the patient’s perspective.

NurseLink palliative care course



Former Public Advocate, John Harley, sits among the 26 nurses at the NurseLink Foundation 5 day Palliative Care Course held at Eldercare Evanston Park in April. This popular course is made possible with a grant received from the Thyne Reid Foundation and from support given from the Northern Division of General Practice. John’s topic was the all important one of Legal Consideration and Advance Directives for end-of-life care. Joy Nugent is seen completing her session on the Myers-Briggs Typology for understanding how personality influences decision making and effective communication. Participants travelled from far and wide to attend the course.

We are what we think.
All that we are arises with our thoughts.
With our thoughts we make the world.
THE BUDDHA



Foundation news

Barbara Baldwin (Back row third from right) is seen here with her assistant Janet (Back row second left) with Joy and nurses from Nepal following an accent modification class for our wonderful nurses from Nepal. This is one of our charitable activities – supporting new nurses to our country.

Shangkri, our office manager who has been with us for a year is on annual leave. She is returning to her native country, Malaysia and also travelling to India. Morris, her assistant will take over many of her duties but office assistance would be appreciated for a mail out to Schools of Nursing and TAFE Colleges of Joy's book on New Nursing. Geri Marr Burdman, Ph.D. the founder of GeroWise International and author of 'The Search for Significance' says this about Joy's book:

Joy Nugent writes and works with integrity and purpose and great love for those she serves. As a nurse leader in innovative private nurse practice she is an inspiration to younger nurses and her respect for and understanding of Florence Nightingale is outstanding. May this new nursing model of care be taught and practiced globally to new generations of nurses. I am grateful to call Joy my friend and fellow nurse colleague.

This book is available from the office for \$20 plus postage.

Risk

- To laugh is to risk appearing a fool.
- To weep is to risk appearing sentimental.
- To reach out for another is to risk involvement.
- To expose feelings is to risk exposing your true self.
- To place your ideas, your dreams, before the crowd is to risk their loss.
- To love is to risk not being loved in return.
- To live is to risk dying.
- To hope is to risk despair.
- To try is to risk failure.

A vision without a task is but a dream.

A task without a vision is drudgery.

A vision and a task is the hope of the world.

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.

Charitable activities

The NurseLink Foundation newsletter **Heart&Soul** will be published four times a year. The next edition will be released in Winter 2009. If you would like to receive our newsletter, or have something you would like to contribute, send us your details:

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tel 8232 0211 or *fax* 8232 3923

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

This newsletter is printed on recycled paper.

The education for rural nurses made possible from the Thyne Reid Foundation continues with a course for nurses in Gawler during April and in Murray Bridge during May.

A successful application to the CMV Foundation is enabling NurseLink to assist the Northern Division of GPs with a palliative care update day in May in Gawler by providing a team of presenters headed by Emeritus Professor Ian Maddocks. We wish to thank CMV Foundation for helping us to further help the rural community.

Tessa Colliver from TNT Grant Writing Services has been most helpful in assisting NurseLink with grant applications. Thank you Tessa!

Fundraising activities



BIRD
in
HAND

We wish to thank all those who attended the James Morrison concert at the Bird in Hand Winery. Bird in Hand generously donated a percentage of the profits to NurseLink Foundation. This donation of \$2,000

is covering the cost of our project to assist the nurses from Nepal and India with speech and language. On April 7th we held our first session for them with speech therapist Barbara Baldwin from Leading English. As a voice coach she uses her expertise to identify limiting speaking habits and teaches a person to develop and enjoy the power of their voice.