



*Putting heart  
and soul into care*

# Heart & Soul

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## Pardon me Doctor, but...

Pardon me, Doctor, but may I die?  
I know your oath requires you to try to keep me alive  
So long as my body is warm and there is a breath of life  
But listen, Doc, I've buried my wife  
My children are grown and on their own  
My friends are gone, and I want to go too.

No mortal man should keep me here  
When the call from Him is unmistakably clear  
I deserve the right to slip quietly away  
My work is done and I am tired.

Your motives are noble, but now I pray  
You can read in my eyes what my lips can't say  
Listen to my heart and you'll hear it cry  
Pardon me Doc, but may I die?

*Author unknown*

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Women who  
have inspired  
our vision:



Dame Cicley  
Saunders  
was a beacon for  
those who look  
deeply at life

‘We have to concern  
ourselves with the  
quality of life as well  
as its length.’

This was the message given to the medical world by Dame Cicley Saunders who was founded the modern hospice movement. She lived from 1918 to 2005 and like Florence Nightingale came from a wealthy family and aspired to serve God through her life’s work. Her home with tennis courts and vast gardens was not a happy one and her parents divorced. She was educated against her will at Roedean, an independent girls’ school in the North of England. Her time at school left her with compassion for those who were struggling in some way. This sensitivity was to influence her career.

Dame Cicley Saunders initially trained as a nurse. As a nurse she became aware that giving compassionate care to the dying also required the skills of a social worker. So she became a social worker. A surgeon friend advised her to train as a doctor if she wanted to influence pain management and care of the terminally ill. She earned her medical degree in 1957 and won an international reputation. As a doctor she was able to be an effective advocate for patients dying from cancer.



This training formed the basis of her holistic approach to care and she is known for establishing new methods of pain control. Her understanding was that pain had physical, spiritual, psychological and social aspects to manage. She coined the phrase ‘total pain’ and set about to reshape end-of-life care by insuring comfort in all the areas of a person’s life. This better overall care included space to be oneself and to have the opportunity to say ‘thank you’ and ‘sorry’ to family and friends.

Dame Cicley Saunders said that she prayed to know how best to serve God and found direction in 1948 when she met a young Polish Jew who had an inoperable cancer. At that time she was a social worker and appreciated the loneliness, loss and grief this man who had escaped from a Warsaw ghetto was suffering. His name was Tasma and she visited him frequently. He was to leave her 500 pounds to be a window in her hospice.

It was while volunteering at St Joseph’s Hospice in London that Dame Cicley Saunders learned to administer morphine before pain appeared—getting ahead of pain rather than responding to it. She discovered that if patients were given regular and adequate pain control the whole situation changed for them. At St Joseph’s she met another Pole who was to play a part in her life. 60 year-old Antoni inspired her to name her own hospice for people in the final stage of life’s journey after the patron saint of travelers, St Christopher.

St Christopher’s Hospice was opened in London in 1967. This event sparked the modern hospice movement. Tasma’s ‘window’ is remembered with a plain sheet of glass in the entrance. St Christopher’s is a haven for people of all faiths and cultures. Dame Cicley believed that to face death is to face life and to come to terms with one is to learn about the other. Her gifts included; planning, medical administration, clinical practice, fundraising, teaching and research. St Christopher’s Hospice became a Mecca for students of palliative care.

Unlike Florence Nightingale, Dame Cicley Saunders married at the age of 61. She fell in love with another Pole who was 79 at the time of their marriage. Her husband was an artist and she covered the walls of St Christopher’s with his pictures. They both died at St Christopher’s Hospice.

In 1980, the year of her marriage she was made a Dame. In 1989 she was awarded an honorary doctorate of medicine from the Archbishop of Canterbury, and in 1989 joined a handful of women to be awarded the Order of Merit. In 2001 she was awarded the largest humanitarian award—the Conrad N Hilton Humanitarian Prize for her life’s work caring for the dying.

‘You matter because you are you, and you matter to the last moment of your life.’

#### References

*BBC News, UK, Obituary: Dame Cicley Saunders*

*World Wide Web*

*Saunders, C. (2003) Watch with Me, Mortal Press, UK*

# Women who have inspired our vision: Naomi Feil

*The following is taken from Book 5 in our series of A Passion for Caring*

Naomi Feil is the creator of validation therapy which is a different way of caring for patients with Alzheimers Disease. It is practiced world-wide and responds to the feelings the person with Alzheimers expresses, rather than focusing on their cognitive function.

Naomi was born in Munich, Germany in 1932. With her parents, she fled Nazi Germany in 1936. She grew up in Montefiore Home for the Aged in Cleveland where her father, a psychologist, was the administrator, and her mother the social worker. They pioneered rehabilitation for older people. As a child, she soaked in their humanistic philosophy. She learned to respect the wisdom of the older residents with whom she lived. Her father began the first occupational and physical therapy departments in nursing homes. In 1943, he established the first 'Special Service Department for Disoriented Aged' which we now call 'Alzheimer wings.' Naomi spent her summers working with these residents.

Naomi Feil graduated from Columbia University in New York with honours. Her undergraduate work was in behaviouristic psychology. She received her M.S.W. from Columbia University New York School of Social Work in 1954, specialising in Psychiatric Group Work with older people. In 1963, she did post-graduate studies at Case Western Reserve University School of Applied Social Sciences in Cleveland, where she became an adjunct instructor in Group Work.



From 1958 to 1963 Naomi studied theatre and film writing at the New School for Social Research and Herbert Berghof School of Theatre in New York. She directed Group Work services at William Hodson Community Centre, Bird S. Coler Rehabilitation Hospital, Springbrook Golden Age Centre, and the Summer Camp for Older Adults, from 1956 to 1963.

In 1963, Naomi returned to Cleveland to direct Group Work Services at Montefiore Home where she grew up. Working in the 'Special Service Department' for confused residents, Naomi developed The Validation Method from 1963 to 1980. She found that Reality Orientation, Behaviour Modification, and Freudian psychotherapeutic techniques did not help these disorientated residents. They became hostile or withdrew. With her graduate students, Naomi conducted research studies and found that listening to the residents and exploring their emotions helped. She worked with the families of confused residents, and found, in case after case, there was a reason behind their acting-out behaviours. In each case, the older person, now diagnosed with an Alzheimer's-type dementia, was resolving unfinished issues from the past. These old people had bottled up strong emotions. Now, in old age, when brain damage unleashed social controls, blocked emotions surfaced. Naomi's husband, a professional filmmaker, documented her work.



The Validation Theory and Method slowly emerged. With her husband, Naomi produced 9 award-winning films documenting Validation. These films have been translated into seven languages. She published the book, *Validation, The Feil Method*, in 1982, and numerous articles on aging. She wrote *The Validation Breakthrough* in 1993. Her books have been revised and are now translated into Dutch, German, French, Italian, Swedish, Danish, Finnish and Japanese.

Naomi began conducting workshops throughout the U.S., Europe, and Australia in 1972. She continues to teach Validation through role-play, films and demonstration. She received the Emmy Award for her Television film, *My First Hundred Years*, in 1983. There are now 14 Authorized Validation Centres teaching Validation, worldwide.

Naomi Feil is a Board Certified Diplomat in Clinical Social Work, and is listed in the 2001 International 'Who's Who of Professional and Business Women.'

Validation has three components:

It is a theory, a method, and an attitude. First, Validation is a theory for late life development. Changes in the brain are not the only reason behind the older person's behaviour. The very old struggle with social and psychological changes that also affect how they act. A 90-year-old diagnosed with a neurological disorder, such as Alzheimer's dementia, senile dementia, or multi-infarct dementia, expresses emotions that have been buried for a lifetime. For the first time, jealousy, passion, rage, guilt or fear erupt. For the first time, a 90 year old man spits out hate against a father who had dominated him. The old man had hidden his hate for 85 years.

Research shows that feelings that are suppressed can become toxic. Freud, Jung, and Erikson have documented that denied emotions grow, locked inside, and give physical pain. The old-old do not want to die in pain. They enter a final life struggle: Resolution. The Validating worker listens, respecting the old human being's need to heal. Emotions that are expressed to someone who hears with empathy are relieved. Socially, old people are tying up loose ends with parents, children, siblings and spouses. Physically, the old person can no longer control emotions. Psychologically, the old person wants to express emotions to relieve pain. This final Resolution struggle is age appropriate.

Here is an example: A 93 year old woman, smiling, her eyes filled with tears, strokes her forearm lovingly, crooning a lullaby. Physically, she cannot see her arm. Her damaged brain no longer informs her of her body's position. She has lost clock-time, logical thinking and cognition. Her feelings spill, but she can no longer name them. She has lost objectivity and self-awareness. Psychologically, this old woman had never expressed her guilt and love to her youngest child. At age 48, a mother of five, she bore her sixth child against her will. Furious, she neglected her youngest daughter. She never nursed the child. Stifled guilt and love stayed dormant, locked inside. Now, in the Resolution struggle, the old woman restores her baby. Her arm feels soft, as if it were her baby. Her arm becomes her baby.

Using her mind's eye, she uses a body-part, her arm, to substitute for her baby. The Validation worker understands. The arm is a 'symbol'. In Validation, a symbol is something or someone in present time that substitutes for someone in the past with strong emotional components. This very old woman was never mentally ill. At age 93, she is not suddenly psychotic or deluded, or suffering from a hallucination. There is a good reason behind her behaviour. The diagnosis of a psychosis means that the behaviour is harmful and should be changed. In Resolution, this old woman is healing herself. The Validating caregiver helps. The old woman wants to die feeling that she was a good mother. Her guilt and her love spill. The Validating worker listens with empathy. The old woman is relieved. Her guilt and love have been validated. Painful emotions subside.

Validation is not only a theory, but also a method, with 15 techniques that help the old person release unresolved issues and restore dignity. The Validation techniques are verbal for those who can speak and non-verbal for those who have lost speech. Validation is also a method for forming a group of very old people who are Time-Confused, restoring social roles, verbal behaviours and social controls. Finally, Validation is an attitude of respect for the old person who is diagnosed with a dementia and who struggles to end life in dignity.

*continued overleaf*

Naomi Feil found that reality orientation was unrealistic for them. They ignored her and retreated inward, moving even more to their past. She writes that in 1967, she began to listen to these old people and no longer demanded that they conform to her standards of behaviour; or control their emotions and be always calm and happy. She discovered that they restored the past to resolve it. Old conflicts reared up, shaking them in old age. They struggled to make peace with loved ones. They were ‘cleaning house’ before death. She listened to the tone of their voices, to their unspoken emotions mirrored in their eyes and movements. None had a history of mental illness. All had led productive, useful lives. Adult children confided to her that their 90 year old mothers who complained of men hiding in their beds had often been abused.

Ninety year old men who swore and struck other male residents had often been beaten by their fathers. Those who barely survived the depression accused staff of stealing their clothes and money. The losses of old age triggered memories of earlier losses. These old people were acting out to express emotions they had controlled during a lifetime. Those who had never been loved accused the cook—the mother symbol—of poisoning their food.

Those whose identities were wrapped in their work, who had never learned leisure, used body movements to restore work from the past. Women whose identity was motherhood, who had never learned to be old, used napkins to diaper their children. A former carpenter used his fist as a hammer. With failing speech, these wise old people, labeled ‘demented’, expressed themselves through movements. Case after case, Feil found that there was always a reason behind their movements. When she listened to them closely, acknowledging their anger, fear, or striving for identity, the strong emotions subsided.

They did not know my name or my job, but they knew that I cared. They felt loved. Without words, we shared a ‘validating moment’.

Gradually, she realised that present reality—the day or date—was not important for these old people who were preparing to die. They had a new task to accomplish that was different from middle age striving.

They had to face unfinished business from the past. Behaviour modification techniques, such as distraction, diversion, re-direction did not help these old people. It shut them up.

Unexpressed emotions submerged and gained strength inside. Invalidated, they closed their eyes and withdrew. Gradually, all movement stopped. All speech stopped. They became living dead people. When she used her energy to enter their world, there was connection, and they were no longer alone. One human being, with a strong desire, can enter into the world of another. This entrance is empathy. Empathy is healing. This explains the positive results of

Validation, and why interventions that excluded empathy, such as Reality Orientation, Behaviour Modification, Re-direction or Diversion, did not work.

Human beings must struggle to complete different life tasks from birth to old age. These tasks depend upon the physical, social and psychological development of the human being.

Erik Erikson created a theory

of development. He wrote that we have different tasks to accomplish throughout life. In infancy, we must learn to trust our mother. Otherwise, we learn distrust. In childhood we must learn to follow rules and control our body. If we fail, we are full of shame and guilt. In adolescence, we must learn who we are, separate from our parents. If we never learn who we are, we are afraid to be alone. We exist without an identity. In adulthood, we must learn to face our emotions and be able to express these emotions to those we care about, or we are isolated. In middle age, we must learn to generate new activities when we can no longer perform the old ones, or we stagnate, holding onto outworn roles. In old age, we must review our lives: accept what we are, what we were and what we never accomplished. We must compromise. We must integrate the past and the present, to prepare for the future. In old age, we seek integrity, self-respect. If we succeed, we are glad that we were born, despite physical deterioration and social losses. If we fail, we are in despair.

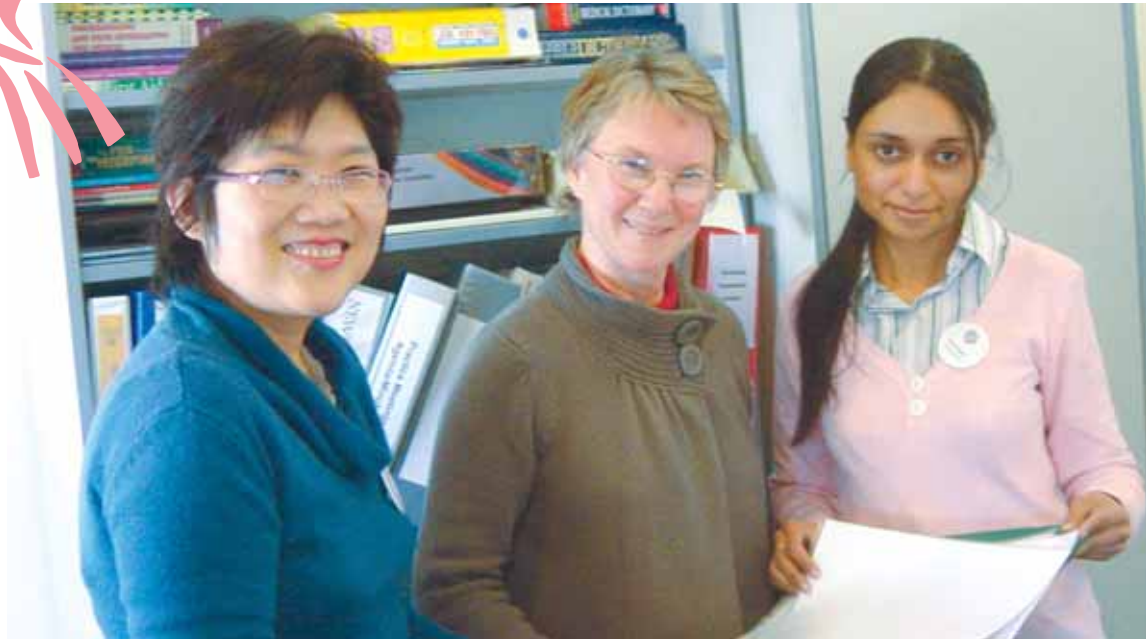
The success of each life task at each age depends on how well we accomplished the earlier task. These life tasks depend upon each other.

**‘Dementia in all its forms shortens life. It is incurable, progressive and terminally life-shortening, and commonly complicated by other illnesses that further threaten life.’**

*Dr. Phil Henscke*



*From left to right:  
Ding Lay Ming and Anne Smith Assistant Case Coordinators  
conferring with Office manager Sangkri Valushamie.*



## Foundation News

In April we welcomed Shankgri as office manager. She has a Bachelor of Business in Management & Marketing. In June Ding joined us as assistant Case Coordinator. Ding initially qualified as a doctor in India before completing a Masters degree in Hospital Administration at UNSW Sydney. These two women from Malaysia are extremely skilful and well qualified to respond to our needs during this time of rapid growth. Anne Smith is a highly qualified palliative care nurse and counsellor who has been with us for some time. Our caring team has grown to over 60. The response to the TV commercial resulted in over 3,000 hits to our new website in the first week!

For those who do not watch commercial TV the clip is available at [www.nurselinkfoundation.com.au](http://www.nurselinkfoundation.com.au)

The packaging of the Tortoise Management System for sale is complete and inquiries are coming from a range of nurses seeking support to set up a community nurse practice. The announcement by the Minister of Health to consider a Medicare Rebate for Nurse Practitioners is encouraging. Firstly we see it important for the Foundation to give support to the nursing profession generally and to highlight the benefits to be gained by personalised nursing in the community—especially for palliative and aged care. We use our nurse practice as a model of holistic care and willingly share our administration systems.

Secondly we seek to give our general members information on end-of-life care and encourage a positive attitude to the last phase of life. Your thoughts and experiences are welcome.

Income for our projects comes from practice surplus, donations, memberships and sales of website products. While our volunteer hours are many we need more. So if you are able to organise a fund raising function, give some time to driving our carers who do not have a car, or provide accommodation or household goods for our beautiful nurses from overseas, please call us on 8232 0211.

# 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 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.

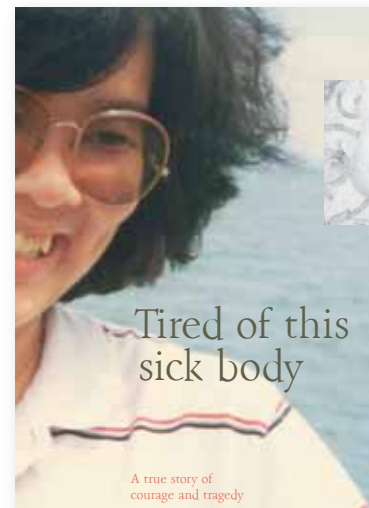
## Works in progress for 2008

Continued development of our new website  
[www.nurselinkfoundation.com.au](http://www.nurselinkfoundation.com.au)



Left: Packaging of software and manuals for a community nurse practice.

Below: Publication of 'Tired of this sick body' book for Sandakan Hospice.



Publication of 'Florence Nightingale in Today's World' for distribution to schools of nursing.

## Changing the way we care

Twycross & Lichter (1993) discuss the issue of appropriate treatment for a patient close to death.

Measures such as cardiac resuscitation, artificial respiration, intravenous infusion, nasogastric tubes and antibiotics are all primarily supportive measures for use in acute-on-chronic illnesses, to assist a patient through the initial period towards recovery of health. To use such measures in patients who are clearly close to death and have no expectation of a return to health is inappropriate and is therefore bad medicine—we have no right or duty, legal or ethical, to prescribe a lingering death. Therapeutic interventions that can best be described as prolonging the distress of the dying are both futile and inappropriate.

*Twycross, R., Lichter, I., (1993). The terminal phase. In: Doyle D., Hanks G., Macdonald N. (eds) The Oxford textbook of palliative medicine. Oxford Medical Publications, Oxford, p653.*

The NurseLink Foundation newsletter **Heart&Soul** will be published four times a year. The next edition will be released in Spring 2008. If you would like to receive our newsletter, or have something you would like to contribute, send us your details:

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