



*The Foundation
for new nursing*

Heart & Soul

**The NurseLink
Foundation Newsletter**

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Principles to live by

*A message from Mother Theresa
How to Deal with the Altruist's Dilemma*

People are often unreasonable, illogical and self-centred:
Forgive them anyway.

If you are kind, people will accuse you of selfish ulterior
motives: Be kind anyway.

If you are successful you will win some false friends and true
enemies: Succeed anyway.

If you are honest and frank, people may cheat you:
Be honest anyway.

What you spend years building, someone could destroy overnight:
Build it anyway.

If you find serenity and happiness, they may be jealous:
Be happy anyway.

The good you do today, people will often forget tomorrow:
Do good anyway.

Give the world the best you have, it may never be enough:
Give the best...you've got it anyway...

You see in the final analysis; it is between you and God or you and
Karma: It was never between you and them anyway.

NurseLink Foundation Ltd
ABN 48 119 525 628

Patrons: Dr Basil Hetzel AC
Mrs Maria Kenda
Mrs Patricia Wynn
Dr Frans de Zwart
Mrs Rosemary de Meyrick
Mr Lewis Barrett AO OBE

Directors: Mrs Joy Nugent
Mr Justin Nugent
Mr Andrew Nugent
Mr John Harley
Mr Paul Hammat

Advisors: Mr Christopher Lee
Dr John Ashfield
Mr Mark Nicholls

Helpful things to do and say when working with the bereaved



Say 'I wish there was something I could say to take away your pain'

'Tell me what you are feeling'—be prepared for a range of feelings including anger, numbness, disbelief, vulnerability, helplessness, sadness, distress

Confirm the person's feelings and encourage them to recall the death or funeral

Be prepared to be comfortable with silence—BE rather than DO

Reassure that tears of distress are normal and indeed beneficial as they release chemicals which act like opioids—'nature's morphine'

Be spontaneous in getting to know the dead person—acknowledge photographs

Get involved, show compassion, empathy—we cannot know how a person feels—a certain amount of self disclosure may be helpful

Acknowledge that head and heart reactions are different

Reinforce that you understand that the person, and what they stood for, is missed—not just someone who had for example cancer and is dead

Confirm that firstly there is a need to survive—then there is a need to grieve and that the hurt will go and leave behind the love and memories

Give people permission to be themselves—understand regression—be non-judgemental and strive to show love

Explain that there is no immediate hurry to remove the body or dispose of the clothes

Confirm that people grieve in their *own way* and *own time* rather than set time limits—limits tend to devalue the person who has died

Confirm the value of anticipatory grief—much 'work' is often done before the death

Offer to be the 'breaker of bad news' rather than allow a loved one to do so—often the blame or feelings of the time get transferred to the person who gave the news

It is OK for the carer to show feelings, cry and become the nurtured for a time. Debriefing in a safe environment is important for all

Before we try to help another, we need to look at our own 'baggage' and heal ourselves—for we cannot give what we do not have ourselves

Acknowledge that hallucinations are normal shortly after the death—for example hearing and seeing the person, smelling their cigarette smoke

Warn people that they may need a contact on special events like anniversaries

Grant News

As part of our Thyne Reid Foundation Grant, advertisements to encourage community nurse practices have been placed in rural newspapers with readerships in Mount Gambier, Millicent, Penola, Clare and Port Lincoln. In addition Joy was invited to speak on the Port Lincoln ABC breakfast session about the packages we are offering. These packages are intended to help nurses take their place alongside other health professionals in private community nurse practices supporting the General Practitioner and offering nursing at home.

The Board wishes to thank the Hotel Care Community Projects which is administered by IGC on behalf of the Australian Hotels Association and Clubs SA for the purchase of three NIKI T34 syringe drivers. These syringe drivers offer palliative care patients the latest in technology for the safe delivery of a subcutaneous infusion for pain relieving medications.

As well as thanking Tessa Colliver from TNT Grant Writing Services we wish to thank Sue Brennan, Rosemary de Meyrick, Dr John Dunn, Dr Basil Hetzel, Christopher Lee, Barbara Magin (Adelaide Northern Division of General Practice) and Martyn Evans who have been most supportive of our work.

New additions to our website's list of publications



This three DVD set is designed to give those involved in caring for the elderly and the dying an appreciation of a person's total needs including the physical, intellectual, emotional and spiritual aspects of the self.

'As the needs of people evolve and

change throughout their lives so must our level of understanding as we strive to give our best supportive care.'

While these DVDs were made from actual case histories in the 1990s they are still relevant today.

They aim to change health professionals' attitudes towards the way we care for those who are facing death through illness or old age.

DVD 1: Perspectives on Palliative Care

DVD 2: Interweaving Palliative Care and Funeral Planning

DVD 3: A Guide for the Practice of Gerontology and Palliative Care



In 'New Nursing' Joy Nugent writes of her inspiration to return to nursing at the age of 48 years and of the models that best describe her view of caring beyond physical needs to meet the needs of the patient and their families—especially at the end of life.

She also give snapshots of the life of Florence

Nightingale whose writings in her later years confirm a world view that Joy feels makes sense to her.

With the best of intentions

Clare Dunne

With the best of intentions
You withheld the truth
So I could live a lie.

With the best of intentions
You tried to spare me pain
Only to give me more.

With the best of intentions
You taught me to live
In a way that I died.

With the best of intentions
I didn't speak
and lost us both in silence.

With the best of intentions
We secure our lives so tightly
We don't live them.

With the best of intentions
We meet
But never know each other.

With the best of intentions
We are not
What we are.



Preparing to be a Carer

By Joy Nugent

We have to take a long hard look at our own attitude toward death and dying before we can sit quietly, without anxiety, either next to a person who is dying or with a bereaved person. We need to walk with people through their journey and not take over their journey for them. Care always takes place within the context of a relationship. It requires compassion, the giving of unconditional love, positive energy, being oneself, being genuine, showing respect and prizing the person.

‘Care’ is a much better word than ‘help’. A person may say that they do not want anyone to ‘help’ them, but they will usually accept all the *care* that is available. ‘Help’ suggests that you *know* more than they do, that you are more *together* than they are, that you will load them down with all *your* good *advice* and that you will do things *differently* for them.

When a person needs someone to care for them they will be looking for a person who can be a ‘co-carer’. This is someone who will listen to them and will not *know what is best for them* but will recognise the person and appreciate them as a unique person. It is not appropriate for a carer to go to another person

with ‘maps and guidelines’ and all the wonderful things that they have just learned in a course that they have just completed.

The carer brings themselves to their work. That is why they need to ‘brush up’ their own lives before attempting to ‘brush up’ the lives of another. It is not possible to give away something that a carer does not have him/herself. For example, if a carer is reluctant to look at the grief and loss in their own life, the benefit to another will be in direct proportion to the level of self-awareness of their own grief and loss. If a carer is unable to appreciate their own gifted personality, it will be difficult for them to appreciate the uniqueness of the bereaved person.

By understanding and being in touch with their own personal experience, the carer will know not to say, I know how you feel, because it is not possible for another human being to *know* how another person feels. It is appreciated when a person tries to *understand* how the other person is feeling, or to know how they would feel if they were in their position. Most of all they will want a carer who will ‘listen’ to them, not with their head but with their heart. Listening is a *spiritual* as well as a *physical* activity.

Carers' contribution

Care-givers are often family members, but others may volunteer to assist in care, without having any specific training in the comprehensive work of palliative care. A major role can be to facilitate emotional support for both patient and family members, helping communication, listening to fears and feelings, offering 'sitting' so that the family can get out for a few hours, above all offering time, which busy professionals can rarely spare in quantity. This quiet friendship facilitates confidence in both patients and home carers, and also provides the palliative care team with an additional 'listening ear' on the situation, often able to report difficulties, which need to be addressed.

Quote from Emeritus Professor Ian Maddocks NurseLink Book 2 in the series 'A Passion for Caring' 2004

See, in your mind's eye, a person with dignity and worth, even if their 'now' living conditions are not the best. See beyond the chaos and see the real person rather than their surroundings. There may be times when the carer is just needed to *'be'* there, not to *do* anything apart from being *calm* and *peaceful* and not doing anything except being in *the person's* space and understanding *their* needs.

It is also necessary for the carer to set boundaries in the relationship and to be able to say 'no' to unreasonable demands or emotional manipulations. Honesty is usually appreciated rather than a 'yes' being followed by an excuse at a later date. It is also important for the person being cared for to be able to say 'no', without the fear of being deserted and without offence being taken. There is a real poverty in any relationship if either person is not comfortable in saying 'no'.

Elisabeth Kubler-Ross (1982) quotes Jung:

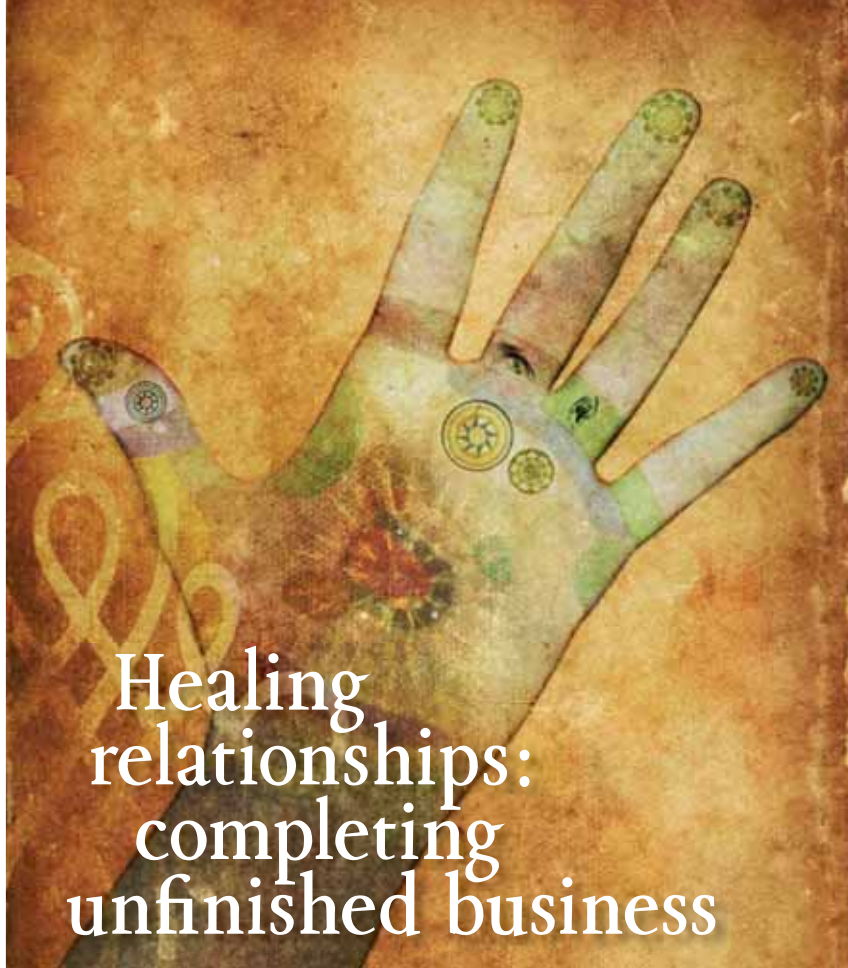
'You cannot apply kindness and understanding to others if you have not applied it to yourself. This is quite serious. We are never sufficient to ourselves. This is the burden that everybody has to carry: to live the life we have got to live. So be kind to the least of your sisters who is yourself.'

C G Jung to Mrs. C., September 24, 1959, Letters II (p 88)

Remember the carer is there, primarily, to meet the other person's needs. It is true that the carer's needs are also met and an awareness of this is essential for a healthy relationship. We all need to be needed. It is part of our very existence, but we need to understand how to meet our own needs and not to expect others to meet them for us. This is where we can get into trouble and feel hurt, rejected and unloved.

Conferences attended

Joy Nugent, our Honorary Managing Director and Nurse Mentor attended the 3rd Australian Conference on Spirituality & Health Integrating Spirituality in the Practice of Health Care held 13-15 July in Elder Hall, Adelaide. Presenters came from the US, South Africa, Thailand and Australia. Topics included: Spirituality and health in later life: aspects of grief among people with dementia by Prof Elizabeth MacKinlay (Canberra); Healing and religious symbols within the clinical context by Prof Siroj Sorajjakool (USA); Staff compassion for oncologic patients extended through music therapy's presence by Assoc Prof Lucanne Magill (Canada); and Making sense of human suffering by Jo Grainger (Melbourne).



Healing relationships: completing unfinished business

Here are some of the common reasons we have 'unfinished business' with people:

- > We're afraid of being hurt again, or of being rejected
- > The other person has already refused to forgive us
- > We feel that what we've done is unforgivable
- > We want to punish the other person with our anger
- > We don't want to let go of our attachment to the person or the past
- > We're afraid to have our part of the problem revealed
- > The other person has gone from our life, or has already died

Christine Longaker in her book, *Facing Death and Finding Hope—a guide to the emotional and spiritual care of the dying* writes that these are natural fears or obstacles to speaking directly with someone about clearing up an old emotional problem. Yet our unfinished business is our responsibility to resolve, and we can finish it whether or not the other person is present or willing to communicate and forgive us.

Christine Longaker suggests that in order to release our own heavy baggage of anger, attachment, or guilt, and to be free from our painful memories there is a simple exercise we can all do. And it is not necessary to meet with the other person to finish with our emotional burden and release it.

This is the essence of what she suggests:

Sit quietly and find in your heart the willingness to communicate your problem one last time and let go of it. Also establish your willingness to really feel heard and to listen to and hear the other person's perspective on this problem.

Visualise the person sitting in front of you looking exactly the way you remember them but with an important difference. They are now open and receptive and can hear everything you have to say.

Without emotion reflect on all the things that have been difficult for you and imagine you are now telling this problem to the person in front of you.

Take a pen and paper and write down what you have just considered saying. Write out the problem, as responsibly as possible—just stating the facts without any emotion. Remember that you are speaking to the person's open heart.

Now allow the other person to express their side of the problem. Just begin writing and see what happens. Since you have been speaking to their best side and your feelings have been heard, their response may be surprising.

Continue writing both parts of the dialogue until you feel that the hurt has dissolved. Allow yourself to receive the healing love of forgiveness. See the other person leaving and wave goodbye. Wish them well as your connection fades.

The dream of the yellow bird

A true story, as told to William Lamers Jr., MD

My father was a Buddhist, born in Japan, and he told me many times that he wanted to live to be one hundred years old. My mother had died many years ago. When my father was eighty-one I was finally able to persuade him to come to live with my wife and me. We were childless; my father was a welcome addition to our home. He helped us in many ways. At last we were a family.

Several times over the years my father had told me of a dream in which he was a bird, soaring high over the countryside. He'd float high in the air over hills and fields and rivers until he came to such a beautiful land that he knew it must be heaven.

He told me that each time he had this dream he would wake himself up because it was not yet time to die. He was not yet one hundred.

One night as I came up the stairs to go to bed I noticed my father seated at his desk, writing. He was so intent with his writing that I did not disturb him to say 'Goodnight'.

The next day when my wife returned from work, father was not to be found downstairs. I found him up where he had died peacefully in his own bed. He was ninety-one at the time. Despite the fact that we had been able to provide him with a home for ten years and had given him all our attention and love, I felt guilty that I had not been with my father when he died. He had been alone. He did not say 'Goodbye'. I didn't have a chance to tell him one last time how much I loved him. I thought I'd never be able to forgive myself for not being with him at the time of his death.

Eventually, I remembered that I had seen him at his desk the night before he died. I searched through the desk and found among his papers a letter addressed to me and my wife in which he told us that he knew he was dying and that he was going to 'finish the dream'. He thanked us for taking care of him and told us that he loved us.

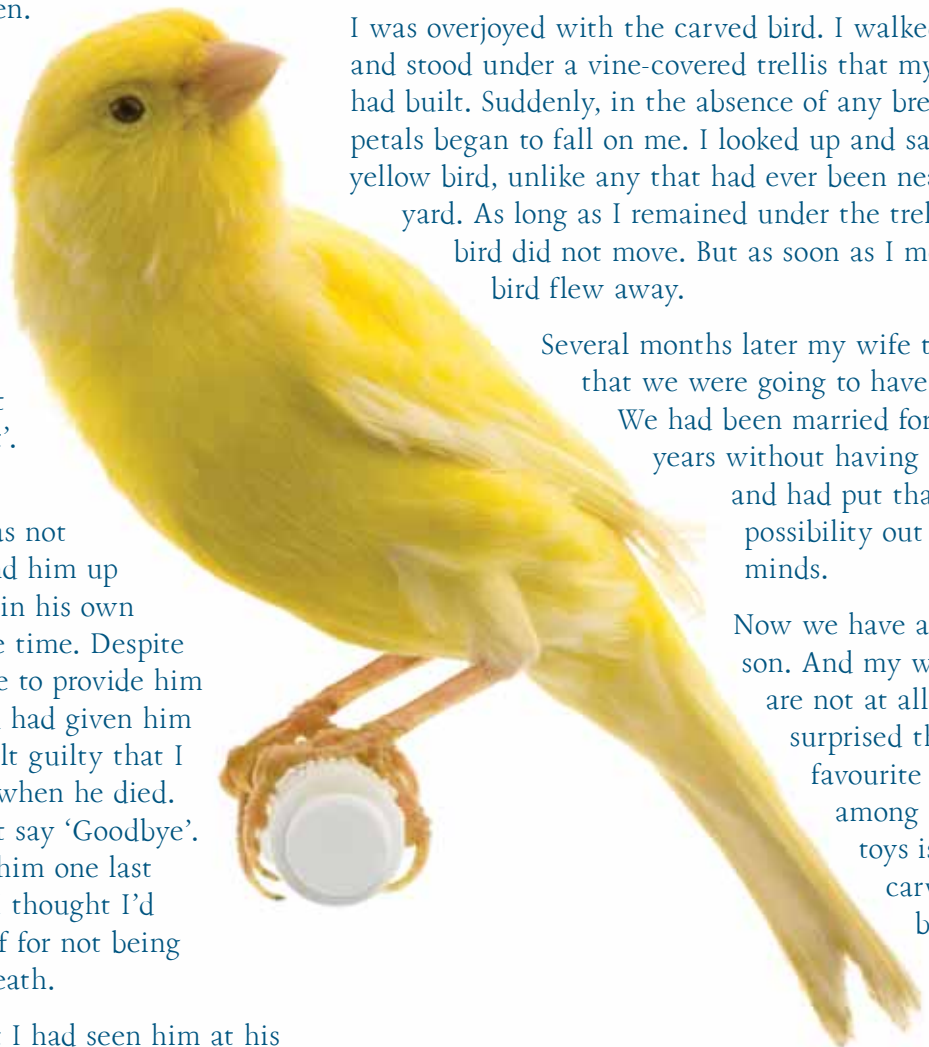
Even after finding the letter I was still sad and felt badly that I had not been with him in his final hours. I needed to do something to relieve my distress. So I went shopping in hopes that I might find something that would commemorate my father.

I went to an art store. Nothing interested me. Finally, in desperation, the sales lady said they had just received a new shipment from Japan. It had not yet been opened. The first thing she removed from the box was a soapstone carving of a bird. I knew immediately that it was the right thing, bought it and brought it home.

I was overjoyed with the carved bird. I walked outside and stood under a vine-covered trellis that my father had built. Suddenly, in the absence of any breeze, petals began to fall on me. I looked up and saw a yellow bird, unlike any that had ever been near our yard. As long as I remained under the trellis the bird did not move. But as soon as I moved, the bird flew away.

Several months later my wife told me that we were going to have a baby. We had been married for many years without having children and had put that possibility out of our minds.

Now we have a child, a son. And my wife and I are not at all surprised that his favourite object among all his toys is the carved stone bird.



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.

New board members

John Harley and Paul Hammat were welcomed as new directors of NurseLink Foundation Limited at a General Meeting on July 13th 2009.

John Harley has been a practising solicitor for 40 years, the last nine of which were spent whilst he held the position of Public Advocate in SA. He has been involved in this area as an adviser to private clients when they have been considering executing advance directives, as a guardian making end-of-life decisions for others and in formulating public policy and law reform.

He is a member of the Human Research Ethics Committee of Calvary Hospital and of the RAH Treatment Ethics Committee. He is also an Hon. Consultant to the Legal Services Commission and a consultant to the Community Business Bureau.

Paul Hammat is Executive Officer of a committee overseeing Chaplaincy in public institutions in South Australia. Paul has served for over ten years in chaplaincy roles in public hospitals, aged care and with SA Police. Paul has a passion for engaging with people in times of crisis or in personal growth. To extend his skills in these endeavours Paul has completed a Masters in Social Science Counselling Studies at Uni SA and has commenced private practice counselling. Paul has a commitment to a person-centred approach to the care of individuals and has an interest in systems and systems theory. Paul has worked as a chaplain with a focus upon palliative care, rehabilitation services and staff support and care.

Fundraising and education

We welcome members and their friends to our Twilight Seminar for 2009. 'Getting our Act Together—Pitfalls and Safeguards for End-of-Life Care' will be held on 27th August at St Andrew's Anglican Church Hall, Walkerville. Our public education is aimed at breaking down the taboos frequently attached to end-of-life preparations.

July 20th was the start of our fifth 5 day course in palliative care. Course participants came from many rural areas and there was much interest in the support packages offered by the Foundation for nurses to start their own community nurse practices.

Specifically designed courses for volunteers and carers have been requested by Gawler and the Barossa Valley. We wish to thank Emeritus Professor Ian Maddocks, Sharonne Price, Paul Hammat, Penny Roe, John Harley, Nigel Langes and Joy Nugent for their contribution to our education programs.

The NurseLink Foundation newsletter **Heart&Soul** will be published four times a year. The next edition will be released in Spring 2009.

If you would like to receive our newsletter, or have something you would like to contribute, send us your details:

email
queries@nurselinkfoundation.com.au
tel 8232 0211 or *fax* 8232 3923

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

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