



*Supporting life
to the end*

Heart & Soul



On Listening

Listening is an act of love, an act of caring, a commitment of ourselves to another.

We should listen with every sense—that is, sensitively—if we are responsibly and reverently to participate in the mystery of another human being. Listening is not a one-sided activity.

The other person calls to us in all kinds of ways. He wants to be heard, because to be heard is to be known, and to be known is to live.

Listening should always be two-sided; the speaker respects the listener by trying to speak his meaning clearly and honestly, and the listener respects the speaker by giving his whole attention to what the speaker is trying to say.

In our very listening we have the power to increase or diminish the lives and meanings of the people associated with us.

Reuel L. Howe

**The NurseLink
Foundation Newsletter**

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Rotary Club sponsors Heart&Soul

This edition of Heart&Soul is sponsored by The Rotary Club of Port Adelaide District 9500 South Australia.

NurseLink Foundation gives heartfelt thanks to the Rotary Club of Port Adelaide for supporting our hospice approach to the last phase of life. Our DVD—‘Say it Forward—planning for end of life’ was the catalyst for this support and broached a topic that traditionally is put aside as not being relevant—just yet! The Rotary Club of Port Adelaide is a friendly group of people who share a strong interest in demonstrating the importance of community involvement. They offer a warm invitation to business men and women to join in the planning of community projects that give direction and inspiration. Rotarians all around the world continue to invest in their motto: ‘service above self’ Serving the community locally and internationally is very rewarding as well as providing enjoyable fellowship. The club is open for new memberships. Contact Barry Allison at alliproduct@senet.com.au



In 2010 under the President of Mr. Rod Taylor the Port Adelaide Rotary Club has entered into the following projects:

The international project of providing shelter boxes at a cost of \$1,200 Australian dollars each. Shelter Box is one of the first aid organizations to reach cyclone victims and earthquake victims, delivering shipments of boxes of usually over 700 within a few days and another 1,000 within two weeks of the natural disasters.

This project enables shelter and warmth for up to 10 people for a prolonged period. Each box in size and normally contains a 10 person tent, 10 sleeping bags, a multi fuel cooker and ancillary equipment such as water purification tablets, a torch and batteries, spade, rope, plastic bags etc.

Major fundraising project for the Port Adelaide Rotary Club is the Annual Art Show this Art Show held at the beginning of January each year helps us to continue supporting the community locally and internationally.

For the dates for the next Art Show log on to www.portadelaideartshow.com.au

Twilight seminar for 2010 A Good Death—an emotional and spiritual journey

When: Friday, August 27th 5.30pm welcome refreshment for 6pm start

Where: The Sophia Centre, 225 Cross Rd, Cumberland Park, SA 5041

By: Paul Hammat

Profile: Paul Hammat is State President and National Director of Spiritual Care Australia. He has served for over ten years in Chaplaincy roles in public hospitals, Aged care and SA Police and 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 Counseling Studies at Uni SA and commenced a private practice. He has a commitment to a person-centered approach to the care of individuals, and is a Director of NurseLink Foundation.

About the venue: Sophia is an ecumenical feminist spirituality centre. It was established in 1991 by the Dominical Sisters in a spirit of openness to wisdom where it is found. The building itself is unique and welcoming while the grounds contain areas for meditation and sacred spaces. Travelling South down Cross Rd, cross over Goodwood Rd and watch for the red brick wall of Cabra College. Turn in to the car park on the left and walk the short distance to Sophia which is sheltered by a very large Fig tree.

Unrecognised or hidden grief

(An extract from Book 3 A Passion for Caring Series)

Most of us like to think that we know those close to us pretty well, and if a loved one or colleague were experiencing a significant loss we would know. We like to think we can see the signs or read people well enough to recognize when they are experiencing hard times. However people often carry losses or grief within themselves for whatever reason. Unacknowledged grief may be described as disenfranchised grief.

Disenfranchised grief refers any loss that cannot not openly acknowledged, socially supported, or easily recognised.

This can happen in many ways. For example, we may believe that grief is associated only with loss through death. Such a belief fails to recognise that many non-death situations involve loss and can result in grief. Unemployment, migration, moving house, separation and divorce, illness or disability, and other significant changes can lead to feelings of loss and grief.

The losses associated with life stage changes, such as marriage, a child's beginning of school, graduation, children leaving home—the 'empty nest syndrome', and retirement, may not be recognised because we view these events as 'normal'.

Dr. Kenneth J. Doka, Professor of Gerontology at the Graduate School of The College of New Rochelle and Senior Consultant to the Hospice Foundation of America suggests four ways in which grief can remain hidden or unacknowledged:

- **When a relationship is not recognised**
Unrecognised relationships can include those of friends, neighbours, foster parents, work colleagues, step-relations, counsellors and helpers, ex-spouses, unmarried or homosexual partners. The grief experienced due to, for example, a death of one of these relationships may be overlooked or not seen as significant.
- **When a loss is not recognised**
Certain types of losses—such as death of a disabled child, delinquent child, miscarriage, stillbirth, abortion, giving up a child for adoption, death or loss of a pet, dementia—may be seen as less significant than other losses that we think are more 'important'.



- **When the grieving person is not recognised**
Some people may be considered 'not capable' of grieving, and therefore are not recognised as grieving people. These may include children, old people and those who are intellectually disabled.
- **When a death is difficult to publicly accept**
The potential shame and embarrassment associated with some deaths may cause grieving people to avoid support or may cause them to be shunned by others. Such deaths might include suicide, homicide, violent and accidental deaths, AIDS-related deaths, or the loss of someone that is missing but presumed dead.

Yet another type of unrecognised grief can occur in situations of long-term loss, such as chronic illness, drug abuse, addiction or disability. Because such losses are ongoing, we may assume that those in such situations have got over the loss. A Chronic sense of sorrow and or compassion fatigue may arise in such circumstances.

For those who seek to care, counsel or support people who are experiencing disenfranchised grief here are some useful points to remember:

- Identify and acknowledge (in appropriate and sensitive ways) the loss and grief that has remained hidden or which others have ignored. Seek to offer your presence and care in a situation in which many feel alone and unsupported.
- The usual rituals and activities which help the grief process, such as the funeral, may not be available in these circumstances. Developing an appropriate ritual that enables the person to express and act on their grief may be beneficial.
- Unrecognised loss and grief often results in an experience of complicated grief, where our grief process is impeded or stalled. Professional counselling, therapy or group support involvement may be useful options for people.

NurseLink education report

In May NurseLink held a 4 day seminar 'Providing spiritual comfort' for all those supporting people at the end of life.

This seminar was held as it is widely acknowledged that in recent times, counselling and palliative care for those who are dying and grieving has expanded beyond the province of the clergy.

'We all need to tell our story and to understand our story... We need for life to signify, to touch the eternal, to understand the mysterious and to find out who we are.'

Joseph Campbell

The presenters included:

Vidya Kumbhar

Vidya Kumbhar is a compelling and enthusiastic speaker. She holds a Masters Degree in Clinical Psychology, a Bachelors Degree in Education and a Diploma in Counseling and Psychotherapy from India. Vidya has extensive experience in healing through psychotherapy, counseling, yoga, Reiki, and Pranic Healing. She has conducted workshops on Mind Potential, Self Awareness, Self Growth, Creating Empowering Belief Systems, Managing Emotions, Improving Relationships, and Managing Stress.



Paul Hammat, Vidya Kumbhar, Joy Nugent & Christine Hammat.

Emeritus Professor Ian Maddocks AM

Professor Maddocks, a visionary in Palliative Care, was appointed to the Chair of Palliative Care at Flinders University, South Australia in 1987. Until retirement he was the Medical Director of Daw House Hospice, Adelaide and established the International Institute of Hospice Studies based at Daw House Hospice. This teaching unit extends to many parts of Asia including China, Thailand, Vietnam, Malaysia. His teaching materials are highly respected and have been translated widely.

Joy Nugent

Joy is a director of NurseLink Foundation and has been in private nurse practice in the area of aged and palliative care since 1987. She became accredited to use the Myers-Briggs Typology Instrument for understanding the part personality plays in caring for ourselves, patients and their families. She has a Post Graduate Certificate in Bereavement and Palliative Care Counseling from the Adelaide University and has an interest and qualifications in many complementary therapies.

Jeanette Milford

Jeanette Milford is a Senior Music Therapist for Central Northern Adelaide Health Service-Specialist Statewide Mental Health. She has a particular interest in music to support social, emotional and spiritual wellbeing at all stages of the lifespan. Following a



Attendees and presenters at Sophia—including were participants from Broken Hill, NSW and the Barossa Valley.

BA & Diploma in Applied Psychology at Adelaide University, she trained and registered as a music therapist in Melbourne and undertook Masters level coursework in music psychotherapy in Philadelphia. She has extensive experience on using music to support adults adjusting to loss, stress and mental health issues and recently completed a Melbourne University Research Masters degree evaluating the impact of individual music therapy.

Paul Hammat

'See page 2 for Paul's profile'

What the participants said in their evaluations of the course:

- *Found it enjoyable, positive and challenging. The course helped me to see spirituality in a new light. The teachers and presenters were brilliant.*
- *1st class speakers, enjoyed.*
- *Excellent group and lecturers, inspiring.*
- *People may not remember what you said but they will always remember how you made them feel.*
- *Excellent, confidence, self healing, reinforce knowledge.*
- *Tiring at times—Fabulous 4 days, inspiring time—it has left me with many ideas, many possibilities for the future.*

Ideals of hospice care

Emeritus Professor Ian Maddocks began his presentation with reminding us of the hospice ideals for caring for a person who is dying with reference to terms originated by Jan Christian Smuts:

- Patient-centered
- Holistic which means embracing:
 - > the whole person—body, mind and spirit
 - > the whole setting—persons and contexts
 - > the whole time—through to the end
- Unhurried
- Responsive
- Anticipatory
- Continuous

NurseLink Foundation has a commitment to bedside care and is committed to providing training and mentoring that prepares nurses and carers for this special dedicated role. Support for this initiative is being sort widely through grants, donations and bequests.

What is spiritual care?

Paul Hammat had the following to say at the ‘Providing Spiritual Comfort’ seminar referencing award-winning novelist Katherine Govier’s five/six R’s of spiritual care:

Reason and Reflection

A desire to search for, or find, meaning and purpose in one’s life; the will and reason to live; to reflect and meditate on one’s existence (may be enhanced through art, music or literature).

Religion

A means of expressing spirituality through a framework of values and beliefs, often actively pursued in rituals, religious practices and reading of sacred texts: religion might be institutionalized or informal. People are increasingly connecting with spirituality in informal and non institutional ways.

Relationships

A longing to relate to one’s self, others and a deity/higher being (may be expressed via service, love, trust, hope and/or creativity): the appreciation of the environment.

Restoration/Reconciliation

The ability of the spiritual dimension to positively influence the physical aspect of care (certain life events can be detrimental, resulting in spiritual distress)

Paul also drew out attention to the work of the Band R.E.M in acknowledging the universal human experience of hurt and grief. This theme is pointedly expressed by the band in the hit song—Everybody Hurts, Sometime.

Here are the words (below)

REM—Everybody hurts sometime

(Berry/Buck/Mills/Stipe)

When the day is long and the night, the night is yours alone,
When you’re sure you’ve had enough of this life, well hang on
Don’t let yourself go, ‘cause everybody cries and everybody hurts sometimes

Sometimes everything is wrong. Now it’s time to sing along
When your day is night alone, (hold on, hold on)
If you feel like letting go, (hold on)
When you think you’ve had too much of this life, well hang on

‘Cause everybody hurts. Take comfort in your friends
Everybody hurts. Don’t throw your hand. Oh, no. Don’t throw your hand
If you feel like you’re alone, no, no, no, you are not alone

If you’re on your own in this life, the days and nights are long,
When you think you’ve had too much of this life to hang on

Well, everybody hurts sometimes,
Everybody cries. And everybody hurts sometimes
And everybody hurts sometimes. So, hold on, hold on
Hold on, hold on, hold on, hold on, hold on, hold on
Everybody hurts. You are not alone

Report on the success of the DVD

'Say it Forward—preparing for end of life'

Joy reports that she has been invited to: Port Adelaide, Thebarton, North Adelaide, Walkerville, Gawler, Northern York Peninsula, Clare and Golden Grove to date—and there are more invitations. All are very impressed with the knowledgeable presenters and the valuable information regarding the legal documentation required to ensure that the last phase of life has received thought and planning. Joy says that she is stormed with questions and the expression of sensitive feelings.

Do spread the word to your church groups or any other organisation that would welcome this DVD presentation.

Death and deceit?

The following extract is from The Death of Ivan Ilyich, Penguin Books, 1960, pp.142f

What tormented Ivan Ilyich most was the pretence, the lie, which for some reason they all kept up, that he was merely ill and not dying, and and that he only need stay quiet and carry out the doctor's orders, and then some great change for the better would result.

But he knew that whatever they might do nothing would come of it except still more agonizing suffering and death. And the pretence made him wretched: it tormented him that they refused to admit what they knew and he knew to be a fact, but persisted in lying to him concerning his terrible condition, and wanted him and forced him to be a party to the lie.

Deceit, this deceit enacted over him up to the very eve of his death: this lying which could only degrade the awful, solemn act of his death to the level of their visitings, their curtains, their sturgeon for dinner . . . was horribly painful to Ivan Ilyich. And it was a strange thing—many a time when they were playing their farce for his benefit he was within a hair's breadth of shouting at them: 'Stop lying! You know, and I know, that I am dying. So do at least stop lying about it!'

But he had never had the spirit to do it. The awful, terrible act of his dying was, he saw, reduced by those about him to the level of a fortuitous, disagreeable and rather indecent incident (much in the same way as people behave with someone who goes into a drawing-room smelling unpleasantly)—and this was being done in the name of the very decorum he had served all his life long.

He saw that no one felt for him, because no one was willing even to appreciate his situation.



This photo shows Joy being welcomed by the Clare Rotary Club.

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Membership

As well as general memberships we are welcoming professional memberships from nursing homes and organisations who wish to participate in our Bedside Program and receive our Heart&Soul newsletter.

Please direct anyone who may be interested in either category to our website: www.nurselinkfoundation.com.au for a new member's Application Form or encourage them to contact Christine in the office on 8232 0211 or email: queries@nurselinkfoundation.com.au

Current members who have not paid their annual subscription will receive a Tax Invoice in July.

Thank you to all our members—your support is appreciated.

In restoring and promoting bedside care by nurses

This is a new initiative by NurseLink. Our new brochure to promote this work was sponsored by the Rotary Club of Northern York Peninsula.

The Board wishes to thank this Rotary club most sincerely for supportive palliative care in this way. This brochure has been sent to nursing homes in the Adelaide area. Flora McDonald Lodge which is a nursing home incorporated with Mary MacKillop Care has agreed to be named in a grant application as a nursing home who would welcome this support.

Catherine Willoughby, The Director of Care, says that while they have wonderful nuns and volunteers who take turns to sit by the bed of dying patients during the day time, the extra assistance of a nurse with the skills of nursing, massage and counselling would be most welcome. This care would be offered free of charge for the last nights when the family need a break knowing that someone is maintaining their sense of presence and support.

Volunteers

We welcome Carolyn Byrne to our team of volunteers. Carolyn came to us as we needed a driver for our Palliative Care Nurse Assistants from Nepal to support an elderly woman from their country and her family in Murray Bridge.

The NurseLink Foundation newsletter *Heart&Soul* will be published four times a year. The next edition will be released in Spring 2010. 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.

This newsletter is printed on recycled paper.



Supporting life to the end



NurseLink employs specially trained palliative care nurses and palliative care assistants who provide bedside care for people who are dying. These we offer to you free of charge.

Please call us on 8232 0211 if we can assist you in making this time of life as comfortable and peaceful as possible.

Bedside nursing for a terminally ill patient requires time, knowledge and skills. Sometimes this is more than an organisation or family can provide.