



*Putting heart
and soul into care*

Heart & Soul

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The Song of Another Nightingale

Rosemary de Meyrick.

Margaret Rymill (nee Cudmore) was a gracious and gifted woman. Kind and charming, her attributes were clearly shown when she became Lady Mayoress of Adelaide in the fifties. Margaret was an accomplished painter and her flower paintings (reproduced in the book 'Lady Rymill's Flower Paintings') are quite beautiful.

In 1990 my mother phoned Joy Nugent, to make arrangements for the day when she would need nursing. She was impressed by Joy's cheerful, sympathetic home assessment interview. All my mother's preferences and wishes were noted down. It was so reassuring to know that Joy and her nurses were only a phone call away if they were needed suddenly. Together they sorted out the practical changes to the house for an invalid—shower chair, bathroom handles, and so on. Over the next few years, they kept in touch and became friends, and Joy became a confidante to whom my mother could speak of all and anything on her mind.

NurseLink Foundation Ltd
ABN 48 119 525 628

Patrons: Dr Basil Hetzel AC
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Mrs Rosemary de Meyrick

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‘Hope is not the conviction that something will turn out well, but the certainty that something will make sense, regardless of how it turns out.’

Vaclav Havel

The Song of Another Nightingale (Continued from page 1)

It was in May 2004 that my mother called me—‘I think you’d better come.’ She knew her body was failing and did not want to be rushed to hospital, with life-saving gear tacked all over her. It was to be a quiet family affair, and so she made her arrangements. She always intended to die peacefully at home in her own bed with her family and cat nearby, in the care of Joy’s wonderful nurses.

My mother and I speculated about death. What did we believe happened after death, the great unknown? Was it the end of everything, or would we be together again one day, with everyone we loved? We were both certain we had a soul, and it would go somewhere. ‘Well, I will just settle up in a pine tree’, announced my mother with a twinkle in her eye, a remark so like her. It was lovely to be able to discuss this daunting subject from time to time with Joy and her experienced nurses, trained to support patients in Joy’s special way.

One afternoon my mother decided to say farewell to her garden. My husband and I helped her onto her Gopher, and we walked very slowly beside her around her beloved garden. She looked carefully at everything. ‘That was nice’ she said afterwards, not at all distressed. It was a little ceremony, you could see that—what a strong brave soul she had. She also looked around the room where she had done her beautiful paintings. Another afternoon, with the last of her strength she got out of bed to sit and watch the Danish Royal Wedding on television. That beautiful rose-decorated wedding was like a shared vision of hope, so regal and spiritual.

There were many kind attentions from wonderful nurses and carers, hairdressing, manicure, massage and medication, with the clean sheets and night-dresses that make for comfort and peace. But the kindest of all was sympathetic companionship, as we prepared ourselves for those last moments.

I was sitting beside my mother one day as she lay asleep, when Joy tiptoed into the bedroom for a visit. ‘Joy’ she murmured with a little smile, recognising her presence in the room although her eyes were closed.


One evening our doctor knew this would be the last of her home visits. Jane Alderman leaned over and kissed my mother’s forehead gently, an unspoken tribute to the quiet courage of a remarkable woman. As my mother slipped into her last unconsciousness, our Anglican minister John Stephenson blessed her. During the night Joy was called by the night nurse. When I woke at 7am I was surprised—dear Joy had whizzed up the freeway at 4am to be with us. We sat beside my mother as she took her very last, peaceful breath. What a marvellous support system it had been. Joy’s wealth of experience, her gift of listening with sympathetic understanding, transformed what could have been an agonising nightmare, into a time of acceptance and spiritual strength.

Joy started the Mary Potter Foundation at Calvary Hospital, and now NurseLink has become a registered charity. With the support of fund-raising volunteers, home nursing will become more affordable and widely known. A lifetime of research and experience in the care of the aged and dying goes into her training classes for nurses at 196 Hutt St. Joy’s very special books on practical nursing reflect a cosmic spiritual view embracing everyone, no matter what their different attitudes and cultures—even accommodating pine trees! How wonderful it would be if many more people could be comforted in this way, in the darkest hours we will all face one day.

I share with others who experience this wonderful nursing, immense gratitude for the song of a rare bird we might well call ‘another Nightingale.’

Rosemary de Meyrick.

NurseLink Foundation ensures the spread of the work which has been Joy’s passion.

A photograph of a hand holding a white daisy flower against a blue sky with white clouds. The hand is positioned in the lower-left quadrant, with the fingers gently cupping the flower. The daisy has a bright yellow center and numerous white petals. The sky is filled with soft, white clouds, creating a serene and uplifting atmosphere.

‘The miracle is not that we do this work, but that we are happy to do it.’

Mother Teresa

‘Grace comes in many forms: illuminated thought, a moment of authority, abundant compassion and courage, the capacity to heal and comfort another, visionary creativity. Grace has many, many forms and grace is meant to be shared, to be distributed to others constantly and under the radar, in silence, invisibly.’

An excerpt from ‘Entering the Castle’ by Caroline Myss.

NurseLink Foundation Seminar at the Hilton

Thank you to Maria Kenda from Kendacraft for sponsoring this event



‘End of life Requests and Conversations.’ Emeritus Professor Ian Maddocks

‘End-of- life situations are not static,’ Professor Maddocks said. ‘Things change, day to day, sometimes hour to hour. What I feel and express today, may be very different tomorrow. Stoicism can collapse into panic, fear evaporate, anxiety evolve into confidence. This is seen not only in patients, but also families and staff and is reflected in their attitudes to each other.’

Professor Maddocks touched on three important words: Control, Respect and Denial. He defined control in terms of being able to maintain a continuing sense of one’s real self, control over bodily functions and control over relationships and important decisions which is progressively lost in many cases.

‘Many persons become confused, some develop dementia and have to allow important decisions to be made for them. That is where respect comes in—another important word. We need to offer a respect that gives maximal opportunity for participation in exchange and expression of wants and feelings,’

For many people today, end-of-life situations are a new and bewildering scene.

‘Denial of the reality of end-of-life is common. More often among family members than patients themselves. A patient may not open up a conversation about end-of-life issues because it goes against all the messages being aired around them—“You’ll beat this”, “You’re looking better today” etc. Or they may be scared. Few of us are good at facing uncomfortable realities until we are forced to, but in end-of-life situations that can lead to a delay until it is too late. And there are many matters of potential importance to discuss.’

Different Types of End-of-Life Conversations

Professor Maddocks suggested that health carers initiate these discussions by asking questions of patients and family: ‘What have you been told?’ ‘How much do you want to know?’ ‘What are you wondering about?’ ‘Is there something that particularly concerns you?’

Legal conversations can be straightforward ones like wills, power of attorney and power of medical attorney documents and complicated ones like advanced directives. ‘It is not easy to be clear about what you might want for yourself ahead of time—situations, ideas and feelings change. Many people wonder about euthanasia, and I think it is a logical and natural consideration for many persons, even if there is no intention of trying to find a quick way out.’

‘There are medical conversations where doctors need to spell out for the patient and family what is likely to be ahead. Prognosis estimation—a point on the calendar—presents great difficulties. It is better to emphasize the compassionate concern of carers. Remember that “We travel one step at a time, but we walk together.” ’

‘This is the time where “Advanced directive” conversations are appropriate. Do you want “everything” done to fight your disease? What does “everything” mean to you?’ said Professor Maddocks, elaborating that a decision to stop treatment is often a wise and compassionate one, but can seem to a patient like an act of abandonment. ‘Remember there is always something to offer, even if only the promise to always be available, to continue to visit the bedside. Such a conversation can be of great importance in assisting decision making when the patient is not competent to spell out detailed wishes.’

‘Kind words can be short and easy to speak, but their echoes are truly endless.’ *Mother Teresa*

Conversations about Emotional, Spiritual and Social Matters

‘Why me, why now?’ ‘Will I suffer, will I cope?’ ‘How long?’ ‘I don’t want to know’—all these emotions benefit from ventilation and exchange to help the patient find a more honest appraisal of his own thoughts and feelings, and hopefully be able to consider ways to accept and deal with them. That means giving space and listening.

‘This leads on to the spiritual—“What matters most to your wellbeing at this time—Your sense of self? Are you focusing on length of life, on the sadness of separation, are you fearing a loss of dignity, major discomfort?”

‘A realistic hope is that I will remain calm, and have enough comfort, and enough clarity of mind to do this last phase well. Not always achieved, but that is what we try for.’

Professor Maddocks said that at funerals he finds himself wondering what his will be like: ‘Is it my business, or for those who remain after me to decide? Like most of the matters on which we have touched, I see it as healthy for a consideration of the funeral to be raised with each of us who will, as individuals, face the end-of-life. Nothing is more certain.’

In concluding, Professor Maddocks expressed his hope that guests would take home the following message: ‘What you say to a person close to death and/ or to an attending family, is of much less consequence than how well you have heard what they have to say. Listening is more important than talking.’



Margaret Lee, Judy Hole, Kym Bonython and Bardie Simpson attending ‘The Lawyer, The Magician and Dinner’ function held in April at the Queen Adelaide Club

The emotions and feelings experienced during the ‘Four Phases of Transition’

After major life disruptions such as living with a chronic illness, addiction and sexual abuse, feelings are generated and my research shows that these feelings may fall into 4 phases. I have called them ‘The Four Phases of Transition’.

Major life disruption often causes great suffering but the shift in the person’s attitude and perspective can mean they view their suffering as providing a deeper understanding of themselves, God and others. Support and continuity of identity that comes from faith and the knowledge of a continuous spiritual dimension in the midst of disruption in other dimensions of the person’s life, can provide great comfort and integrity in a time when life in other dimensions may be “falling apart”. The person can even feel integrated and at peace with their situation and within themselves, in the midst of the turmoil of transition.

The Four Phases of Transition (1,2)

All humans have thoughts, feelings and attitudes that go on inside one’s head about one’s current experiences. These thoughts and feelings give rise to emotions such as love, fear, anger, hatred, sadness, sorrow, which need to be recognized, acknowledged and, if possible, named. Those emotions can trigger within people particular behaviours and responses that are based on past reactions when similar emotions were triggered under different circumstances. In the case of survivors of past abuse/ trauma, their life experiences have taught them to respond in ways that may have been helpful during childhood, but may be less useful in the context of their adult lives.

Our behaviours always have consequences, whether the consequences have been anticipated or deliberated. These consequences impact upon other people, situations, or on us. Some consequences can be anticipated and some are unintended. Regardless of the consequence, each person experiences or deals with the direct or indirect impacts of their behaviours. This process goes on within each person’s head all day, every day.

People modify their behaviours by the reactions and the results their behaviours provide. They can become confused if the outcomes of interactions are not what they anticipated them to be. When people spend time reflecting, praying, contemplating possible ways forward they often can see more appropriate choices they can employ in future behaviours. They then choose to respond and action those choices to obtain different outcomes under similar circumstances. Such reflection and prayerful contemplation facilitates the important life function of maintaining and nurturing a coherent sense of identity or self, within changing and ambiguous life circumstances. Additionally it enables the person to draw upon their spirituality and faith to gain a sense of direction and continuity that enables them to live until they die, and to die in peace.

Nurses who facilitate this process are putting heart and soul into care.

Antonia van Loon RN PhD

Dr Antonia (Anne) van Loon is a senior research fellow with the Royal District Nursing Service Research Unit. Anne enjoys research that facilitates positive outcomes for participants and researchers while promoting values of social justice, equity, community development and capacity building. Her most recent work has been with people who are marginalized and disenfranchised within our community. Her work with survivors of child sexual abuse (CSA) resulted in two books to help CSA survivors and their workers with the transition process. These books can be downloaded free from the RDNS website www.rdns.org.au

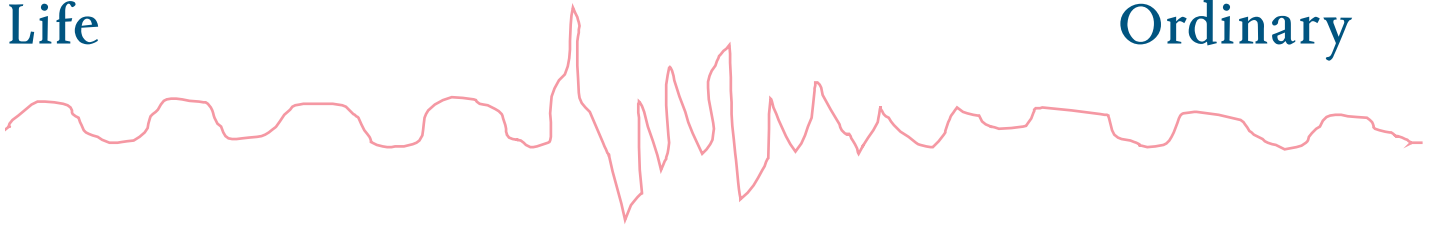


Familiar Life

Ending

Limbo

Becoming Ordinary



The graphic represents movement occurring during each phase of the transition process. Disruption changes familiar life patterns and forces the person into a limbo period where they must make sense of the changes so they can relocate new ways to live and be in the world and shift their sense of identity.

Living and being in the world is predictable and situations are taken for granted.

The current way of living ends. The change event or experience may be chosen or forced, but life is different.

The changes, chosen or forced, become disorientating. This can be a time of disempowerment and suffering. Moving through this phase is facilitated by sense-making activities.

Incorporating changing patterns of being and doing into new ways of living and being. This leads to living life in a way that provides a sense of coherence.

In **Familiar Life** patterns you experience:

- predictability
- identity
- roles
- status
- location
- situation
- security
- relationships
- connections
- acquaintances
- internalized socio-cultural norms
- thoughts, feelings, attitudes within self
- ordinary life

Following an **Ending** you may experience:

- disruption
- difference
- fractured identity
- brokenness
- being over burdened
- displacement
- separation
- disconnection
- uncertainty
- hesitation
- insecurity
- ambiguity
- vulnerability
- inadequacy
- violation
- victimization

During **Limbo** you may experience:

- confusion
- turmoil
- uncertainty
- confrontation
- alienation
- isolation
- loneliness
- self-absorption
- self-pity
- incongruence
- feeling unanchored to life
- betrayal
- powerlessness
- grief & loss
- insecurity
- feeling disenfranchised
- feeling extraordinary
- suffering

In **Becoming Ordinary** you may experience:

- new beginning
- transformation
- growth
- progress
- continuity
- return to ordinary life
- coexisting
- feeling 'normal'
- realignment
- reconstructing
- revising
- revaluing
- reconnecting
- reclaiming
- refining
- reconciling
- return to familiarity
- relocation
- renewal
- mastery
- healing
- resilience
- 'I'm OK!'

References

1. Van Loon AM, Kralik D. *Reclaiming Myself After Child Sexual Abuse*. Adelaide: Royal District Nursing Service Foundation Research Unit, Catherine House, Alcohol Education and Rehabilitation Foundation, 2005b.
2. Kralik D, & van Loon, A.M. *Transition and Theory Building* (Chapter 11). In Koch T, Kralik, D. Eds. *Participatory Action Research in Health Care*. Oxford: Blackwell Science, 2006. pp. 150-163.

New membership application

To become a Member of the Foundation, fill in the form enclosed within this newsletter and send it to us. Please include your membership fee of \$25.00 (GST inclusive).

As a Member of the Foundation you will receive:

- The **Heart&Soul** newsletter sent out in the mail on a quarterly basis
- Opportunities to attend educational programs designed for health professionals and all those interested in learning more about life.
- Information about fund-raising events

The NurseLink Foundation newsletter **Heart&Soul** will be published four times a year. The next edition will be released in August 2007. If you would like to receive our newsletter, or have something you would like to contribute, send us your details:

email
nurselink@nursehomecare.com
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 100% recycled paper.

Preliminary notice of educational seminar

The NurseLink Foundation will be presenting a seminar on 'Understanding Men and Emotions and how they deal with grief' with Guest Speaker John Ashfield PhD. This event will be held in mid August at the The College for Actualising Human Potential, Unit 2, 146 Greenhill Road, Parkside.
Phone 8232 0211 to register your interest.

John Ashfield is the author of 'The Nature of Men: Elements of Male Psychology' and 'Taking Care of Yourself and Your Family - a Resource book for Good Mental Health.' John is currently working in the area of men's health in regional SA.
Enquiries: NurseLink Foundation on 8232 0211

Foundation website

www.nursehomecare.com

Please take time to view our updated website soon to be completed. A palliative care approach, when rehabilitation or cure is not a reality, is costly. It also requires expert medical knowledge, human warmth and vigil as well as machines and comfortable surroundings. Bequests and donations in memory of someone whose life has touched you may be made by Visa, EFT or cheque.