

## Centre for Ageing and Pastoral Studies

### Submission to the Inquiry into the Long term Strategies to Address the Ageing of the Australian Population Over the Next 40 Years.

The Centre for Ageing and Pastoral Studies is a not for profit centre for multi-disciplinary research, education and policy development in ageing, pastoral studies, and related ethical issues.

#### **Issues to bring to notice of Inquiry Implications of an ageing society.**

Over the twentieth century, there have been significant advances in public health and medical technology that have been important factors in the increased life expectancy of all but indigenous Australians. The continuing shift towards an ageing society raises a number of important issues. Given that more people can expect to live longer, and in better physical health, what does this mean for the society as a whole?

Issues of an ageing society:

- Many people reaching retirement age currently may expect to spend one third to one half of their life span in 'retirement'
- There are more healthy older people with valuable work skills being lost to the work force, with the subsequent loss to the community of the benefits of considerable skills and knowledge
- The concept of a defined and short working life that has been dominant during the twentieth century, that may no longer be the best model for work.
- Fewer younger people coming into the workplace will result in a shortage of skilled workers.
- Segregation versus integration across the generations: How can community be built in a new society composed of a higher proportion older people? There is a need for intentional linkages across generations.
- What quality of life can be expected by those growing older? What happens after the long holiday?
- What meaning is there in later life?
- Health needs of older people, including prevention of isolation, in a community where increasing numbers of older people will live alone.
- The ability of society to pay for the services required, both for older people living at home and those in residential care: New models are required

***All the above issues raise the major question: What kind of a society will we be?***

- Will this new society be much like the old, maintaining the same concepts and values regarding work, and what are regarded as appropriate roles for older people?
- Will ageism continue to be an important factor, discriminating against older people?
- Will the new society learn to be a caring society, developing strong links across the generations?
- Will the new society consider and embrace new ways of work and new ways of affirming both younger and older people?

### ***Where will people find meaning?***

It seems that being part of an ageing society may provide both exciting challenges and opportunities for us all, if we are able to look with fresh eyes at the possibilities. We now have added years of life, but for numbers of older people, these added years may have no meaning. Fear of future vulnerability and no longer being in control were major issues for many of the independent living older people interviewed (MacKinlay 2001). Suicide, particularly for older men may be related to this lack of meaning in later life (Hassan 1995; MacKinlay, 2002; Raymond 2002).

Initiatives in positive ageing are important to address these problems, however, positive ageing by itself presently does not go far enough. What is needed is a philosophy that is inclusive of both the weak and the strong in society. While positive ageing, if it is adopted right across society, has much to offer in health promotion and illness prevention, and to promote quality of life, it still does not reach to the heart of what it is to be human. To be fulfilled as a person, it is also necessary to know that you have a place and part in life itself, that your life has mattered and does matter, and that your life still has meaning and purpose in later life.

### ***Spirituality as a necessary part of being human***

There is a growing search within secular society for meaning and for the spiritual, yet many people are unaware of the dimensions of the spiritual. Spirituality is not just the practice of a religion. Spirituality is more than a leisure activity in a nursing home. Spiritual well being is crucial for the well being of society; it is what is needed to address holistic well being for a society and for its members to thrive.

The spiritual dimension is as important as the physical and psychosocial dimensions of being human. (MacKinlay 2001, Swinton, 2001) Spirituality also plays a part in issues of suffering and pain; pain is not only physical, but may also be existential and spiritual. Medicine and nursing, as well as the allied health professions now recognise the spiritual dimension needing care, as well as the body and the mind. There have been enormous gains made in physical and psychosocial care, but there is still much to be done to make headway with spiritual care.

There have been many attempts at definition of the spiritual. One definition, based on doctoral studies (MacKinlay 2001) states the spiritual dimension is:

That which lies at the core of each person's being, an essential dimension which brings meaning to life. It is acknowledged that spirituality is not constituted only by religious practices, but must be understood more broadly, as relationship with God, however God or ultimate meaning is perceived by the person, and in relationship with other people. (MacKinlay 1998, p36)

MacKinlay (1998, 2001a) constructed a model of spiritual tasks of ageing, based on six spiritual tasks of ageing, drawn from themes identified from the data in a study of independent living older people, using the qualitative method of grounded theory. It is suggested that these spiritual tasks of ageing form part of the process of effective ageing, and that these tasks provide support, resilience and protection against many of the losses and disabilities of ageing, including isolation, depression and dementia. These tasks are: to find ultimate meaning in life, to be able to respond to meaning, to

transcend losses and disabilities, to move from provisional to final life meanings, to find intimacy and relationship with God and/or others, and to find hope. A further study (MacKinlay 2001 b) of frail older people, resident in nursing homes confirmed this model.

The spiritual dimension is very much tied to hope: without hope the human being does not survive. With added years of life, we have the potential to be able to live life to the full, in all dimensions of life. Often problems arise for older people who have lost hope and the will to live.

Finding meaning, even in the frailty of age, and in the midst of dementia or depression are critical potentials to aim for in the 21<sup>st</sup> century.

We now need to look beyond the ways of the 20<sup>th</sup> century, to find new ways of being in society. More research is needed in this developing field of the spiritual well being and spiritual care. There is then an urgent need to educate aged care workers so that they are able to provide effective care. Nurses, allied health workers, pastoral carers, chaplains, diversional therapists, and others in aged care need the skills to deal with their own spiritual issues and growth, before they can care effectively for others. For instance, it is difficult to work with people who are dying, without first being in touch with one's own mortality. People experiencing the process of dying need people who are at ease and can walk this journey with them.

Ageing is still too often treated as an illness, rather than as a continuing part of the life cycle. In preparing for an ageing society of the next forty years will require thinking outside the square. It will be essential for caring communities to be established, and to affirm older people too. New models of aged care will be needed.

### **The Centre for Ageing and Pastoral Studies**

The need for this Centre was first perceived within Christian organisations, and its work is conducted in an ecumenical and university setting. It encompasses spirituality across the complete multicultural and multifaith spectrum of Australian society. The Centre was launched by the Federal Minister for Aged Care, in September, 2001.

### **The Centre for Ageing and Pastoral Studies**

Is engaged in investigating ways of finding meaning in later life, and in improving quality of life for older people, and also for those particularly vulnerable older people who experience cognitive disabilities. CAPS is engaged in preparing people to provide effective care, based on sound research.

### **The Centre for Ageing and Pastoral Studies (CAPS) seeks to**

- affirm the integrity and dignity of human beings across the life span
- explore the spiritual dimension of ageing and meaning of life issues in the context of an ageing society
- examine ethical issues related to ageing
- assist people to learn to live in an ageing society
- reduce barriers that may exist between the different age groups of society;
- develop policies related to ageing
- disseminate the findings of its research to all with a professional interest in them and to older people

**Vision**

To instigate a more holistic approach to the planning, delivery and evaluation of aged care in Australia and thus contribute to ensuring more meaningful lives for older people by 2010.

**CAPS core values:**

- the dignity of life across the entire lifespan
- care of the weak and vulnerable
- justice in old age
- the importance of the spiritual dimension in the care of ageing people
- an ecumenical, multifaith and multicultural approach
- applied multi-disciplinary research and education as a vehicle for change
- the enhancement of quality of life for ageing people

**Stakeholder Analysis**

The Centre for Ageing and Pastoral Studies has intentionally positioned itself as an interdisciplinary body at the nexus of health care and pastoral studies. Its purpose in doing so is to bring a wholeness to theory and praxis, and open channels of communication between a range of personnel working with older people. These include clergy, health professionals and older people themselves.

A mix of academic institutions and industry will enable research of practice-based issues and integration of theory and practice in aged care.

This declaration of intent recognises the importance of continued collaboration with other centres in this field, for example, the Centre for Aging, Religion and Spirituality in St. Paul, (CARS) Minnesota, USA.

CAPS recognises that this kind of holistic approach provides not only a rich and broad understanding of issues related to ageing but also special challenges in recognising and meeting the expectations of its stakeholders and constituencies.

**Support from the tertiary education sector**

Universities that have supported CAPS in its development to date are: Charles Sturt University, University of Canberra and Australian Catholic University.

**Support from the Aged Care Industry**

Organisations that provide aged care have an interest in the Centre because it will provide them with ongoing education for their staff and provide access to the latest research to improve aged care, particularly focusing on holistic care and ways of finding meaning in later life.

Specific areas for intervention include: Finding meaning in later life for well older people, to new strategies for holistic care for people with dementia; people who are depressed; frail older people, and issues of the rising levels of suicide in older adults.

CAPS seeks to address these various needs by providing

- consumer input and focus
- policy formulated on the basis of sound research
- educational products relevant to changed trends and changing perceptions
- consultancies

- research findings
- publishing of journals and / or newsletters

**Market segments already identified for services and products of CAPS include:**

- health professionals, including nurses, activity officers, social workers and medical practitioners
- clergy, including chaplains
- pastoral workers
- older people
- families and older people

**Current research being conducted by the Centre:**

***Linkage grant Title: Finding meaning in the experience of dementia: The place of spiritual reminiscence work.***

Researchers: Elizabeth MacKinlay, Corinne Trevitt, Margaret Coady

*Summary:*

This project will use spiritual reminiscence work to study the experience of dementia and the spiritual dimension focussing on how people with dementia find meaning and develop coping strategies. Dementia is a significant issue for an ageing society where estimates of prevalence indicate a rise of 254% from 1995-2041. The greatest challenge to people diagnosed with dementia is their search for meaning leading to the development of effective coping strategies as their memory loss and confusion progresses. Outcomes will impact on persons with dementia, staff and carers, with improved quality of life for all

**Recent research: Title: The Search for Meaning: Quality of life for the person with dementia**

Researchers: Rev'd Dr Elizabeth MacKinlay, Corinne Trevitt, Suzanne Hobart<sup>1</sup>

*Report Summary*

This pilot study examined the process of spiritual reminiscence and how this may be used therapeutically in working with people who have dementia. The project did not examine medical diagnostic processes nor did it address medical treatment of dementia. It sought to refine methodology in research into dementia, a critical area for investigation to improve quality of life for those living with dementia and their carers. The project involved collaboration between the University of Canberra and two industry partners, both aged care providers; Anglican Retirement Community Services, Diocese of Canberra and Goulburn, and Wesley Gardens Aged Care, Belrose.

**Project objectives:**

- Examine how people experience dementia
- Explore how meaning and quality of life can be achieved by and for people who have dementia

---

<sup>1</sup> Elizabeth MacKinlay and Corinne Trevitt, University of Canberra; Suzanne Hobart, Wesley Gardens Aged Care. This project was made possible through a University of Canberra Collaborative Research Grant with research industry partners Anglican Retirement Community Services and Wesley Gardens Aged Care. 2000-01

- Explore the concept of personhood and respect for persons with dementia
- examine strategies used by people who have dementia to overcome social and spiritual isolation
- Explore strategies that may be developed to address dignity of risk and living alone for people with dementia

### **Outcomes of the study**

A model of spiritual tasks of ageing (MacKinlay 2001) was applied once the data had been analysed using a qualitative data program, QSR NUD\*IST. The data fitted the model. The SPSS statistical package was used; the small group size allowed only minimal use of statistical analysis. Single behaviour ratings were measured in the before and after group sessions and these were examined using paired t-tests. There were 12 paired behaviours so a Bonferroni correction was carried out arriving at significant (at .025 one tailed t-test) for happy-content and attentive/responding, did things from own initiative, improving on these scales from before to after the sessions. It is emphasised that the main focus of data collection in this study was the qualitative data.

### **Conclusion and Recommendations**

#### ***Relationship and people who live with dementia***

##### ***Recommendation***

The point of admission to an aged care facility is identified as an important transition time, when these people with dementia may be particularly at risk of isolation. Strategies should be developed to assist new residents to develop relationships with others in the care setting, both staff and residents.

Residential care for people who have dementia should be funded to allow time for connecting with these people, and supporting development of new relationships within the care setting. Physical care is not enough. In fact it is contended that some so-called disruptive behaviours may be reduced when people with dementia *feel* cared for. Other recent studies have shown this too, Bird, (2002)

Further work is needed to develop effective ways of connecting with these people. This is being implemented now in the Linkage Grant (2002-04): *Finding meaning in the experience of dementia: The place of spiritual reminiscence work.*

#### ***Isolation and loneliness***

##### ***Recommendation***

That small group work on spiritual reminiscence may be helpful for reducing feelings of isolation and loneliness amongst these people. The use of this method is being examined further in the current Linkage Grant.

#### ***Communication styles of group facilitators***

This study showed clearly that people with dementia often understand far more than is expected, however, communication is often difficult.

Much can be done to improve the quality of communications for people with dementia; it is a challenge for those working with people with dementia to improve communication skills. As people who have cognitive disabilities find it harder to function on a cognitive basis, it is important to use communication skills geared to maximise their ability to understand.

### **Recommendation**

The training of diversional therapists and activity officers should include skills in group work and facilitating small groups in spiritual reminiscence.

### ***Faith and Hope***

Regardless of whether a person holds a religious faith, hope is central to well being. Those who do not hold a faith also want to have someone listen to them, to be affirmed in their reflections and their own beliefs and values. People with dementia do have beliefs and values, and can express them, given an opportunity.

### **Implications for aged care facilities in providing an environment in which people with dementia can be valued and can flourish.**

The issues raised in this study are at the heart of what it is to be human. People with dementia find it hard at times to communicate effectively. All staff in aged care facilities need to be aware of the kinds of difficulties these people experience and be willing to support them in respectful caring environments.

### **Recommendation**

High priority is given to education of staff in ways that will facilitate appropriate communication skills in aged care staff. This should include nurses, diversional therapists, clergy, social workers, volunteers and all who care for people with dementia.

### **References:**

- Hassan, R. (1995) *Suicide Explained: The Australian Experience*. Melbourne: Melbourne University Press.
- MacKinlay, E. B. (1998) *The Spiritual Dimension of ageing: Meaning in Life, Response to Meaning and Well Being in Ageing*. Unpublished doctoral thesis Melbourne: La Trobe University.
- MacKinlay E. B (2001 a) *The Spiritual Dimension of Ageing*. Jessica Kingsley Publishers, London
- MacKinlay E. B (2001 b) Health, healing and wholeness in frail elderly people. *Journal of Religious Gerontology*, 13 (2) 25-34
- MacKinlay E. B.(ed) (2002) *Mental Health and the Spiritual Dimension in Later Life*. Haworth Press, New York
- MacKinlay E. B. Ellor, J, Pickard, S. (ed) (2001) *Aging, Spirituality and pastoral care: A multinational perspective*. Haworth Press, New York
- Swinton, J. (2001) *Spirituality and Mental Health Care*. Jessica Kingsley Publishers, London

Rev'd Dr Elizabeth MacKinlay

Director

Date: 12 July 2003