# *'Utopia'*

## *In*

## *Residential Aged Care Facilities*

## *Hopes and Dreams*

*A Nursing Perspective*

*by*

*Hilda Fitzgerald RN, RM,*
*Postgraduate Diploma in Ageing and Pastoral Studies*
*Currently undertaking study in Postgraduate Diploma in Mental Health Nursing*

*Joan Gavan RN*
*Currently undertaking study in Postgraduate Diploma in Mental Health Nursing*

Caring for Older Australians

The aim of this submission is to highlight the major gaps that we believe are present in the aged care division of the health care system that inhibits the provision of quality health care for the elderly in residential aged care facilities (RACF). As nurses, our vision is for 'Utopia' to be created in RACFs where hopes and dreams of an environment that provides unique and individualised care are a reality which addresses not only the physical and mental health needs of residents, but also includes the cultural, spiritual and palliative aspects that ensure they are safe, valued and respected. While it is acknowledged that the National Health and Hospitals Reform Commission (NHHRC) (2009) has recognised the need to tackle access and equity issues that affect health outcomes for the elderly, it is aimed at those who are able to actively participate in making decisions affecting their future health needs, however, this is not possible for some. Goals are needed to address the service that is offered to the elderly in RACFs, because the present system fails to recognise the individuality and unique needs of residents who reside in these facilities which need to be addressed in order for them to have quality of life, thus violating their human right to accessible and equitable care which they so deserve. Names in this submission have been changed to protect identity.

In 1516, Sir Thomas Moore described a fictional Utopia as intentionally ideal communities with perfect systems, to create perfect environments for an ideal society. We argue that by meeting the often complex, holistic needs of the elderly in these facilities, we can aspire to creating a Utopia. A Utopian residential aged care facility is one where older age is respected, where wisdom and truth abound, where the gifts of this community are recognized and valued and welcomed. It would be a place where equality is found, and despair and suffering are accompanied with love and compassion, and where tolerance and care for the other is normal. A place of hopes and dreams where poverty of care does not exist, and wealth is distributed to encompass a holistic concept of the mind and spirit being as important as the body.

**Stella's story**

***Stella wandered the corridors of the RACF, lost, disorientated and refusing to eat. She became painfully thin, and her mental and physical distress was obvious to residents, visitors and staff alike. Senior staff attempted to intervene on behalf of this lady, seeking medical intervention, but due to difficulties with communication and the lack of response from medical sources, Stella constantly refused to be cared for, so her basic needs continued to be unmet in her mental health distress. She was unable to communicate her needs, whimpering her despair instead.***

**Vignette 1.** The inability to provide holistic care within an environment that does not encompass physical, mental, cultural, spiritual and palliative aspects required for holistic care resulted in loss of dignity for this lady. It also highlights how an individual is rendered 'invisible' within a collectivist community.

People who currently enter RACFs are at risk of becoming invisible in the system because they become part of a collectivist community that is stereotyped as a burden to society due to their age and chronic, complex health needs. They become a forgotten generation who once fought wars to protect our country, worked hard to support their families, cared for their own when they were sick or dying, and who volunteered to participate in charity work to help others. These people should be valued and respected even when they become disabled with physical or cognitive impairment which led to an admission to a RACF. These organisations publicise their facilities as being able to provide for the complex health needs of the elderly, however, it is argued that there is a gap between this conceptualisation of what a RACF does and what actually happens for residents and their families.

Among residents in RACFs, there is a high prevalence of confusion, incontinence, malnutrition, immobility and falls, secondary to a range of disabling conditions such as cerebrovascular disease, neurodegenerative diseases such as Alzheimer's and Parkinson's disease, severe arthritis, and cardiorespiratory failure compounded frequently by depression and sensory impairments (Hayes & Martin, 2004). The increasing dependency and nursing care needed by older persons with significant disability requires a high level of clinical judgement. The risk, complexity, predictability and stability of a resident's care needs identifies that this is an area of health care that requires an abundant source of qualified and skilled nurses to be included in the existing workforce within these areas. Advanced practice nurses (APN) should be included in these areas because they have obtained a higher level of knowledge and skills from postgraduate studies and have

acquired the expertise needed to provide direct comprehensive care of the standard required in order to attain the best outcome for residents in these facilities.

**Mrs. Brown's story**

***An enrolled nurse (EN) and an assistant in nursing (AIN) were allocated to work night shift in the dementia specific ward of an aged care facility which contained thirty six residents but one of the residents, Mrs. Brown was unable to sleep and was wandering about the ward disrupting the other residents. She was unsteady on her feet and the busy nurses tried to observe her closely. However, due to the pressure of caring for other residents, they were unable to watch her all the time and she had a fall and required transportation to hospital where she underwent surgery for a hip fracture and subsequently died of complications. It was later revealed that Mrs.Brown had a previous history of mental illness which indicated that she may have experienced an exacerbation of psychotic symptoms***.

**Vignette 2.** The above incident could have been prevented if an APN was accessible to provide assessment and early intervention.

Advanced practice nurses as leaders have a vital role in facilitating specialisation which allows residents to be treated as individuals with unique needs. In aged care, this is vital to ensure their rights are respected and they receive safe and effective care to enable them to live fulfilling and harmonious lives in a RACF. Including APNs in the aged care workforce is imperative to assist with meeting the goals of retaining and increasing the existing workforce so that the projected rising demands of an aging population can be met. Unless the current workforce is professionally respected and remunerated for the care they provide to the elderly, the exit of nurses from this sector will continue. Retention of aged care workers in this environment requires they be more supported. This can be provided at the 'coalface' for nursing staff by APNs through the dissemination of specialised knowledge that will enhance the quality of nursing practice provided. The value of nursing staff will also be acknowledged in their respective roles and recognises the high level of care that needs to be provided.

**Mr. Xanas's story**

***A carer with Certificate 3 qualifications was rostered on night duty, and allocated as the most suitable person to care for 20 persons in a dementia unit. An RN was in the RACF and along with 2 other carers was at the time receiving handover for 85 other residents on 2 different levels of the building. The carer of the dementia wing received verbal and written handover from another carer who had been in charge of the previous shift and stated that everyone was alright, same as usual, except Mr. Xanas. "He has been a bit off tonight, but he is in bed and settled." Mr. Xanas was well known in the unit for having unstable insulin dependant diabetes, complicated by advanced dementia. The carer on night duty was reassured that the residents were settled as stated on handover and decided to deal with a resident who needed assistance with toileting. The carer then attended to mandatory facility policy expectations of checking the safety of every resident and security of the dementia unit. This inspection was carried out during which Mr. Xanas was found lying on the bathroom floor and had obviously been there for several hours, because he was cold and unconscious. A call to the RN who was on another floor in the facility was made, with a subsequent call made for ambulance assistance. First aid was applied and Mr. Xanas survived but spent weeks in hospital to assess and treat his diabetes.***

**Vignette 3.** This scenario highlights the risk and safety issues that occur from inadequate knowledge and expertise relating to the care needs of these residents. It is essential that nursing practice is regulated to ensure that a high standard of care is provided.

Codes, standards and policies are used to regulate nursing practice and provide clarity on the scope of practice for enrolled nurses and registered nurses, however, the regulations do not require that nurses employed in RACFs should be able to demonstrate special knowledge, skills or expertise in the types of health and social care needs likely to be present in residents (Hayes & Martin, 2004). Nurses are increasingly being substituted by unqualified and unlicensed healthcare workers such as nursing assistants who are less expensive to employ, leading to a lower level of safety and quality of care which places these vulnerable people at risk (Australian Nursing Federation (ANF), 2009). It also places healthcare workers in a position of having to practise beyond their level of competence due to a lack of specialised skill and knowledge in the care required thus placing them at risk of unethical practice and legal liability.

It is essential that health care workers in RACFs be regulated to ensure a high standard of care is delivered to the residents and to ensure that these workers are also protected. Nurses have a moral and legal obligation to provide safe and effective care to their residents and the supervision of unregulated workers in the provision of resident care is demanding work, particularly when those workers have various levels of qualification. The elderly in RACFs are not deserving of substandard care, nor are the nurses deserving of such lack of recognition and respect for the type of work they do for our elderly citizens. Why are our elderly allowed to exist in this environment rather than a flourishing 'Utopian' environment they so deserve?

**Harriet's story**

***Harriet was a 68 year old migrant, a heavy smoker with a mental illness, homeless, and no known family who was a much loved resident living in a RACF. Her childlike enthusiasm for life reverberated around the facility, as did her cough. Workers experienced dismay as Harriet's cough worsened, and she was sent to hospital with pneumonia. Late one night a nurse from the hospital rang to inform the facility, as next of kin, that she was concerned for Harriet as her condition had deteriorated. A nurse from the facility visited Harriet, and recognized she was dying, and stayed with her till the early hours, advocated for her to receive much needed palliative medication, prayed and supported her. As news spread around the RACF of Harriet's death, there was visible grief among the residents and especially the staff. It came to light that the Public Trustee was in charged of this lady's affairs, and a private cremation would ordinarily have taken place. As the staff learnt of this, they indicated they would like to support the cremation with a service of some sort. The CEO was approached about this situation when it came to light that most members of staff and residents wished to take part in a service for Harriet. The CEO said "we are not a shop; we can't just shut up shop, we'll just have to have it here." The funeral parlor, the public trustee, the external pastoral people, staff members from the administration through to laundry, catering and nursing care, engaged in funeral preparations. In grand style, in the main lounge of the RACF, a farewell was extended to Harriet. Flowers for her coffin, poetry, songs, hymns and eulogies were written and read by staff who knew her. A truly Utopian, effortless show of care was extended beyond the medical and physical, to include meaningful cultural and spiritually inclusive care for a homeless, mentally ill resident.***

**Vignette 4.** A possibility for all RACFs to adopt an approach that values and respects the elderly.

The approach to adopting palliative care should not be limited to the last days of life (NHMRC, 2006). This approach will address and facilitate an open encompassing attitude of living, despite the realities of death that all residents will face. Adopting and applying the World Health Organisation (WHO), (2003) definition of palliative care is one that is:

"An approach that improves the quality of life of individuals and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Interprofessional collaboration led by the APN can facilitate a palliative approach by coordinating a multidisciplinary team which will include the General Practitioner (GP), palliative care nursing service and other necessary care providers so that focus remains on the best possible pathway for every resident and their family. Barriers around pain medication, uncertainty around treatment options, and appropriate level of care can be minimized to reduce unnecessary distress for the resident and their family and provide appropriate continuity of care.

**Tim's story**

***Tim was Scottish, blind, and with no living family. He had been living in the RACF for many years and was well known for his resilience and will to continue contributing despite his disability. Tim had a stroke which prevented him from gardening, an occupation he thoroughly enjoyed doing at the facility and had done so for many years despite his blindness. Tim resented being unable to function in this capacity anymore and became withdrawn and lonely. Depression crept in but help arrived in the form of a Labrador dog that enabled him to regain an interest in his surroundings and life. However, a further series of strokes found Tim increasingly depressed and angry with his situation, his resilience disappeared and he despaired at his immobility and dependence on others to care for him. He no longer had an interest in religious or spiritual matters and believed God had deserted him and his navy mates in the war. As a result of this, a chaplain from the Duntroon barracks was invited to visit Tim one day, and subsequently became a frequent visitor. A nurse engaged with Tim about his life and family in Scotland, and was able to talk to him about dying and what sort of farewell Scottish people would have when they died. "That's easy," he said, "bagpipes, fruit cake and whiskey." A further stroke saw Tim admitted to hospital where he subsequently died. The RACF engaged the services of a Scottish piper, who volunteered to send Tim off with the bagpipes, fruit cake and whiskey which was consumed by the residents with great gusto, goodbyes said by residents and staff alike and not a dry eye was to be seen.***

**Vignette 5.** Valuing and respecting cultural aspects of a resident's life is an important component of the overall holistic care that should be provided to our elderly so that they can maintain a sense of identity even when they may feel they have lost everything else.

The overarching principle in meeting the cultural and spiritual aspects of life for residents in a RACF is relational to emotional support, independence, privacy, dignity, leisure, interests, culture, religion, choice and decision making, security of tenure and residents rights. In a Utopian RACF, an individual's interests, customs, beliefs, cultural and ethnic backgrounds are valued and fostered. The unique aspects of culture and spirituality that each person brings comes from their own family, practices and beliefs and these influence the behaviour, religious awareness, music, food, clothing, identity and connection within a community. Extensive assessment of residents needs within their culture needs to be done by appropriately skilled staff, so that authentic individual care plans can be developed as a true reflection of the resident. Initial interviews should encompass a cultural and spiritual focus as part of the medical and personal aspects that are required when assessment of funding needs are carried out.

Spiritual and pastoral aspects are neglected in the context of the modern health system, as the focus remains on a medical driven system. This contributes to the provision of spiritual care falling through the cracks by a

> "Dominant bio-medical paradigm, underpinned by efficiency driven managerial ethos, and the mystery surrounding the human condition." Kingston(2009 p1).

In a utopian RACF, the human condition will be explored by adopting a spiritual perspective that does not shy away from questions like "what is the reason for my suffering?" "How can I find hope in my pain and loss?" "What is the value of human life as the end of life diminishes the physical body." Spiritual assessment is more than the religion a person may nominate. It involves addressing cultural and spiritual needs with a deep understanding and thorough assessment of each person as a unique being with specific needs and preferences. Quality of care and quality of life can only be truly achieved when they are provided in a way that recognizes the physical, emotional, psychosocial, cultural and spiritual needs of each person (Pringle, 2010). A multicultural population in Australia brings with it a culturally and religiously diverse society, which is having an impact on the delivery of health care. RNs need to be mindful of policy that is multicultural and inclusive and to be aware that opportunities exist for clinical settings and RACFs to offer pastoral care for people of all denominations.

**Nancy's story**

***When Nancy was accepted into a RACF, it was expected, that she would live and enjoy some quality time, despite the progress of her cancer. Nancy spoke and understood limited English. She was very sad because her husband had died two years before, and she had been his full time carer despite her own diagnosis of bowel cancer. Nancy was very accepting of her diagnosis, describing it as 'gods will'. The Ukrainian religious community was contacted after it was noticed by staff that the only possessions N had brought with her to RACF was an Icon of the Virgin Mary. Her condition deteriorated more quickly than expected, but she was stoic despite the pain, and would only accept minimal pain relief. The Ukrainian priest facilitated prayer and ritual for Nancy the evening she died, so she died peacefully as was her wish which had been expressed through her friend who interpreted for her.***

**Vignette 6.** An example of how addressing spiritual aspects in a person's life can provide meaning and dignity at the end of life.

It is time to attend to the inconsistencies of service delivery in RACFs by exposing the flaws that allow RACFs to provide substandard care. As long as RACFs are seen as a commodity in the market place where monetary gains blur the boundaries of care needs, residents and care staff alike will remain invisible and disempowered so that they are forced to become weak links in a chain that binds them together.

We advocate that underlying principles that can be used as a basis to inform Utopian concepts surrounding the physical, mental, palliative, spirituality and cultural aspects of life of those who reside in RACFS are those which we have extracted and adapted from the philosophy of the Eden alternative to be interred into a philosophy of care in RACFs.

1. Loneliness, helplessness and boredom account for the bulk of suffering in a human community.

2. Access must be provided for companionship by human and animal contact.

3. To give care makes one stronger. To receive care gracefully is a pleasure and an art. Both these virtues should be promoted in the daily life of residents in a RACF in order to encourage self respect and independence. It should not be directed by funding tools.

4. Trust in each other allows the pleasure of answering the needs of the moment. When we fill our lives with variety and spontaneity, we honour the world and our place in it.

5. Meaning is the food and water that nourishes the spirit. It strengthens us. The counterfeit of meaning tempts us with hollow promises that in the end always leave us empty and alone.

6. Medical treatment should be the servant of genuine human caring, never its master. Hence the need for the incorporation of psychosocial aspects that allow for the uniqueness of individuals to be addressed equally and appropriately.

An RACF that promotes a Utopian like environment where resources are plentiful and appropriate to allow the complex needs of our elderly residents to be met, will be a showcase of the genuine care that is a constancy at all times. Accreditation processes would be welcomed to show what can be achieved in such an environment that genuinely cares for its residents, by providing an informed and compassionate workforce that is nurtured by the skilled and knowledgeable leadership of advanced practice nurses.

This submission has identified gaps and offered solutions for consideration by the NHHRC aged care inquiry. A goal of providing Utopian aged care for all of our vulnerable elderly residents in RACFs is not a choice, and should not be compromised by substandard delivery of care and limitations of institutional objectives. Our wish list for a "Utopia" in Residential Aged Care Facilities includes recommendations for the employment of an adequate number of APNs per ratio of residents, more RNs within the organisation, and the need for continuous training in multicultural and palliative care delivery.

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