

TRANSITIONS IN DEMENTIA CARE

“As the population ages, more of us will be called upon to care for others. So we must understand the importance of recognizing and honouring the intrinsic worth of others, regardless of age or disability. Caring for another human being is sacred work that should have the essence of preserving human dignity at its heart.

This country needs you to be nourished, supported and inspired to give the best care that you can, so let us begin the journey of providing a positive environment for us all. Let us be mindful that we all have our part to play”.

*(Waring A, **The Heart of Care**, Introduction px)*

Caring for a vulnerable person should be a noble calling, inspired by love and affection for the individual and sustained by the support of a caring community. The reality of life as a Carer for most people in South Africa cannot be further removed from this ideal.

INTRODUCTION: THE TERM “CARER”

The fact that there are so many interpretations of the term Carer attests to the complexity of this job that very few people apply for, are trained for or are prepared for. There are different angles from which it can be approached, most importantly one would think being the perception of the person who is on the receiving end of such care.

Christine Bryden, in her book **“Dancing with Dementia”**, says:

“Adopting a sole identity as our care-giver highlights our illness and strips both of us of other identities, we have become care-giver and sufferer, in a relationship of co-dependence...”

In this role, you may feel soon overwhelmed by the multitude of tasks, of remembering for two, of planning and organizing for two, of covering up our deficits, and grieving over our losses, rather than looking for what remains. You can quickly become exhausted, sad, depressed and in despair...

At the same time, if we adopt a sole identity as a sufferer of our illness, we learn helplessness. We lose more function, and show an excess disability...

This will only add to your burden as a Caregiver, and exacerbate the problem for both of us. It will be a downward spiral to disaster. In this situation, we have become co-dependent, needing each other to accept our labels as victim and sufferer for our identities.

Alternatively, we may cover up our deficits and try to act as if we are normal. This too is a form of co-dependency, because we have put your assumed need ahead of our honest need for self-expression. We want to stop you worrying, to stop this downward spiral, and we pretend at normalcy. But as the disease progresses, we can't keep up this pretense, because it becomes impossible and exhausting, and we

become passive and dependent. Suddenly you are faced with the burden we had tried so hard to hold away from you, alone...

We need to move away from labeling ourselves as caregiver and sufferer, towards becoming a care-partnership, in which we accept, collaborate, and adapt to new roles within the journey of dementia.

...in this care-partnership, the person with dementia is at the center of the relationship, not alone as an object to be looked at, as merely a care recipient. Instead, we become an active partner in the circle of care.” (pp. 149-150)

A more clinical interpretation comes from Schultz (2004) from the WHO publication “**DEMENTIA: A PUBLIC HEALTH PRIORITY**”.

“...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time, it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting”.

What might seem like semantics, the word “Caregiver” or “Carer”, by its very nature, implies that someone is in the *giving* position and another person (with deficits) in the *receiving* position, creating and implying an imbalance in the relationship. **The Eden Alternative**, brainchild of Dr. William Thomas, promotes the concept of Care Partnerships, where a relationship is built with the person

living with dementia being at the centre of this negotiated relationship, and in partnership with family, doctors, professionals and community members.

If we truly believe in supporting Care Partners, we should change this imbalance, move away from focusing on only the deficits of people living with dementia, and reconsider the fact that “we view our roles from a paternalistic perspective” as pointed out by Dr. Al Power in his book “**Dementia Beyond Drugs**” (p. 54) True Care Partnerships will only be established if we can look beyond the disease to see the real person. Keady, as paraphrased in “Partnerships in family care” called this “to try and maintain the involvement of the Person living with Dementia as an active agent in the world” (P19) and not just a passive recipient of care. Tom Kitwood, in his book “**Dementia Reconsidered**”, refers to the concept of Personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, trust, and respect.” (p8) The first point of departure would therefore be to educate people in terms of the status given to both people living with dementia and those who care for them. It seems that we are a long way away from that point.

THE AFRICAN REALITY:

The recent 2011 census figures present a startling reality:

1. South Africa covers 1 219 602 km square of the total African continent.
2. The country has a total population of 51 770 560 people, not counting an estimated 5 million illegal immigrants.
3. The total population of South Africa as counted in Census 2011 has

increased by 11.2 million since Census 1996.

4. In the 2001 population census, there were 3,28 million people in the country older than 60.
5. In the 2011 statistics, the number of people over the age of 60 increased to 4 151 760.

In an article **Care for Elderly People with Mental Illness: A Global Problem**, David Skuse (Behavioural and Brain Sciences Unit, Institute of Child Health, London UK) says:

“We often assume that cultural factors in lower-income areas lead to greater respect for, and better care of, the elderly than we experience in many parts of the Western hemisphere. This appears to be a misapprehension, and attitudes towards the elderly are changing as the impact of industrialization increases”

“The article by Drs Clausen and Wilson addresses a wider issue: the prospect of an ageing population in Africa. They point out that health budgets are severely limited for all African countries, and that priority is given to the needs of the younger generations, who are economically active. As the longevity of African adults increases in years to come, it is essential to maintain as high a proportion as possible of the ageing population in economic activity”.

(International Psychiatry Volume 7 Number 2 April 2010)

This sentiment is echoed by Professor Monica Ferreira, Director of The Albertina and Walter Sisulu Institute of Ageing in Africa at the University of Cape Town in her article **“Ageing Policies in Africa”**:

“Africa is the world’s largest and second most populated continent and economically the poorest... With half the population 19 years or younger (United Nations, 2007a), national priorities are issues of the young rather than concerns of the old – among numerous other priorities, such as macroeconomic development and coping with the effects of HIV/AIDS...”

Attempts to define “older persons” in Africa are at variance with international definitions, which are typically chronological and currently use a cut-off age of 60. Such definitions are a poor indicator of being old in Africa, especially in rural agrarian setting where chronological age may not be known and age may be defined in relation with an individual’s functioning, physical appearance and social role transitions”.

“The AIDS epidemic has the potential to affect older persons’ health and well-being in various direct and indirect ways, among others through physical and mental stress, anxiety and burnout from caregiving strains and a greater burden of household work; HIV infection through hands-on caregiving activities; as well as financial demands on older Carers’ income or savings related to the health care costs of their sick off-spring; the provision of material support to their AIDS-ill children and their dependents; funeral costs; and suffering the loss of current and future financial support which the ill child or deceased would have provided”.
(Knodel&Van Landingham, 2000; Legido_Quigley, 2003; WHO 2002f).

In spite of numerous attempts by the South African Government to create a functional Department of Social Development, this has failed miserably to provide for Older People themselves, not to mention Older People who by

default end up as Carers for spouses living with amongst other diseases AIDS, many of whom live with HIV/AIDS related dementia. It must also be noted that Older People will often care for their grandchildren, of their deceased children who died of AIDS, as well as for a spouse, sibling, family member or neighbour. Often Older People's Social Security grant will be used to support an entire family, which means that it would not be in the best interest of the family to seek Longterm Care accommodation for the Older Person, as their Social Grant will be absorbed as part of their rental in the Home.

"HIV-associated dementia and sensory neuropathy, however, continue to be major public health problems, particularly in the developing world where access to antiretroviral medications is poor. As a result, HIV is now becoming one of the leading causes of dementia worldwide along with Alzheimer's disease and vascular dementia."

From: **Journal of NeuroVirology**, 8 (suppl. 2): 115–121, 2002c 2002 Taylor & Francis ISSN 1355–0284/02 \$12.00+.00 DOI: 10.1080/13550280290101094

According to Janette Debora Joubert, in her study "**A Profile of Informal Carers in South Africa**", *"...in 2000, 26.9% of the population were Caregivers according to the definition used. This implies that an estimated 7.4 million persons in the South African population 18 years and older had informal caregiving responsibilities in the year 2000."* In her conclusion, Joubert states that *"The impact of demographic and epidemiological change in South Africa, through the simultaneous effects of population ageing and an intensified, quadruple burden of disease, have brought about changes in the health profile of the population. In turn, these changes have*

affected an increased need for care in the country. In the presence of this increased demand for care, evidence exists that formal public health care services fall short of providing adequate and satisfactory care to those who need care, while, at the same time, spiraling private health care costs place private health services beyond the financial reach of the majority of the population.”

In terms of support for Care Partners in South Africa, one will have to start by creating awareness on a national level. Whilst the academic theory of the life course of a care partner might be very real, this life course in South Africa is greatly affected by issues of poverty, a lack of resources, cultural diversity, and language barriers. Just looking at the last point – South Africa has the following official languages:

Afrikaans; English; IsiNdebele; IsiXhosa; IsiZulu; Sepedi; Sesotho; Setswana; SiSwati; Tshivenda and Xitsonga. About 5 million illegal immigrants speak their own different languages. It is interesting to note that the word *dementia* is only part of the Afrikaans and English languages – none of the other official languages has a word for the disease. Considering the saying “words make worlds” one can firmly assume that the reality of dementia does not exist in the world of the majority of the people in South Africa, other than it being a type of ‘madness’.

Another ‘witchcraft’ killing in KZN (Local news article from Mercury Newspaper)

June 20 2012 at 08:30am

By Lungelo Mkamba

An elderly woman and her two grandchildren in Ngwavuma, Zululand, were burnt to death by community members who accused the pensioner of being a witch, Social Development MEC Weziwe Thusi confirmed on Tuesday.

Thusi said she had dispatched a social worker to the family of 72-year-old Thokozile Tembe, and Slindile, 11, and Sphesihle Mnguni, three.

The MEC condemned the incident, saying it was a “cold-blooded killing”, possibly motivated by the strange behaviour of the old lady who could have been showing early signs of senile dementia.

“It is a tragedy that we continue to lose our people in this way,” she said.

“As the government, we are doing our best to raise awareness about abuse of the elderly, but, clearly, we have to step up our efforts if our people are still not getting the message.”

Thusi urged communities to learn about conditions that afflicted the elderly, like Alzheimer’s disease and senile dementia.

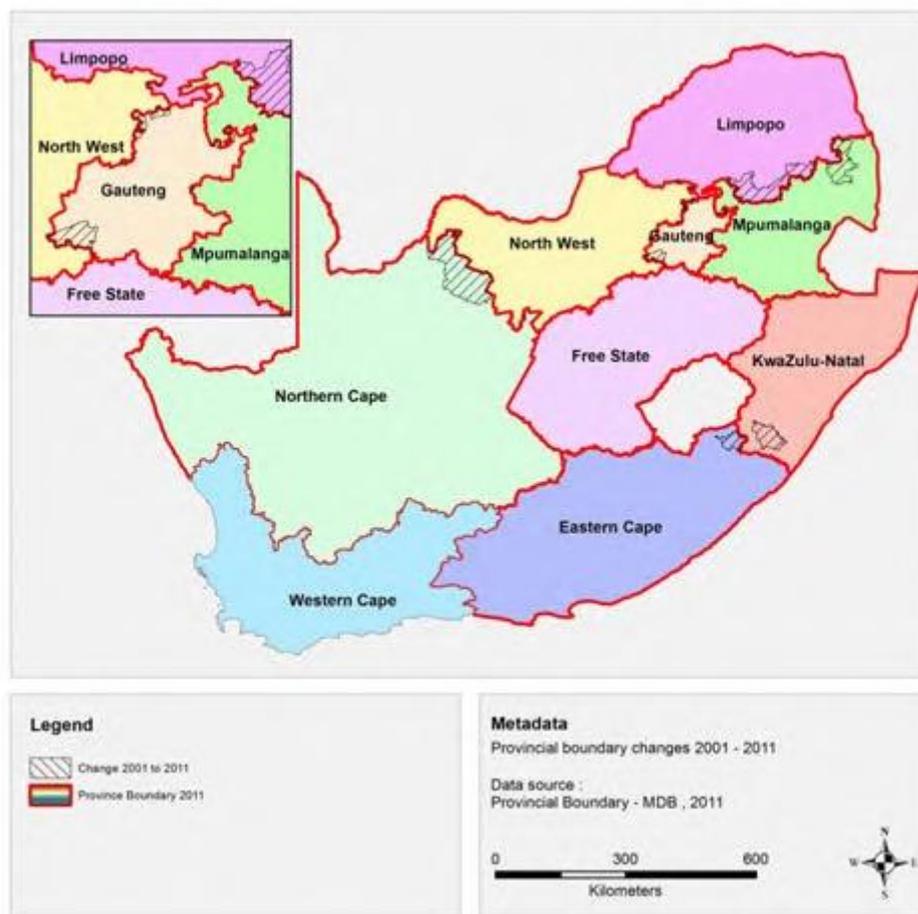
“Conditions such as dementia leave older people confused and unaware of their surroundings,” she said.

Two weeks ago, an elderly woman was found wandering in the Pietermaritzburg CBD and brought to her office.

“We found that she had come into town with her son but walked off and became lost... Does this mean that she is involved in witchcraft? As a society, we must put an end to this abuse.”

The department would provide trauma counselling to the family and neighbours.

Police are investigating the murders. - The Mercury



Considering the realities of Carers in South Africa, one can better understand what Dilworth Anderson (2001) means by “*caring can only be fully understood in its own unique context*”. As complex and diverse as the manifestation of Dementia is, so are the needs and realities of those caring for people living with dementia. These contexts are described as follows in “**Partnerships in Family Care**” (p8)

1. “Socio-cultural context”

Considering the contextual background of Carers and people living with dementia as described above, the socio-cultural complexities have a

major impact on the Care Partnership-relationship. Before support services can be implemented, a national awareness campaign will have to be launched to educate people, in all the different languages, taking into consideration cultural beliefs, customs and rituals, in what dementia is and the effect that it has on the lives of people living with the disease. Support services will have to take cognizance of these idiosyncrasies in dealing with Care Partners in order to build trust.

2. “Structural context”

As mentioned before, Carers in South Africa face a multitude of challenges over and above the challenge of caring. Stigmatization, poverty, lack of resources, lack of education, cultural beliefs, caring for children and Older People, being primary breadwinners, but a few examples of the stress burden of the Carer. Add to this the fact that many Carers themselves are old and not healthy, the structural context is extremely complex. Carers in rural parts of the country will often be miles away from primary healthcare services, will need to walk for hours in the blazing sun to collect medication, will have no access to running water, sanitation or healthy food.

3. “Interpersonal context”

The impact of the quality of relationships before the diagnosis, has been noted to play a major role in the Care Partnership career.

CASE STUDY 1:

In the case of L and S, it was very clear from the “noticing” phase that L was not going to cope with S’s dementia. Her irritation with his confusion early on already was an indication that she was not prepared to take on the role of Carer. Having known them for a period of about ten years before the onset of S’s dementia, it was clear that they were not in a loving, caring relationship. S was always distant as a father and husband, sacrificing a promising career in fear of failure, which he covered up by making the family understand that it was for their sake that he would not take a position in Sweden to further his career. L refused to engage with S’s illness. She made no attempt at understanding what was happening to him, and was persistent in her attempts at “normalizing” the situation, often causing huge stress for S. Going back into L’s history, it became clear that she was never a caring mother either. Her inability to care became very clear when she moved S into a Home very prematurely. (Actually at the first sign of S’s not being able to make it to the toilet on time). L abandoned all responsibility to the professional staff at the home, it suiting her to see them as the experts, hardly giving any input into his care needs.

In the WHO’s document “**DEMENTIA: A public health priority**”, it is interesting to note a quote from Quinn C et al. (The impact of motivation and meaning on the wellbeing of Caregivers of people with dementia: a systematic review from International Psychogeriatrics, 2010) “*Affection is a key motivating factor for Caregivers of people with dementia*”.

CASE STUDY 2:

The lack of affection between L (wife) and J (husband, recently diagnosed and deteriorating very rapidly) was very obvious. In discussion with L, she expressed her deep concern for the fact that she cannot see J as her husband any more – since his diagnosis she finds him repulsive, and describes him as a “cripple”. Although she is shocked and appalled by herself in doing so, she does not seem to be able to get herself to see him as her husband, and a person she loved. The impact that this has on the care relationship is startling. L relays an incident where J became very aggressive because they had to take his car keys away to prevent him from driving. J felt terrible after realizing how he reacted. That night he wanted to make love to L, who could not get herself to be loving towards him, having the image of a “cripple wanting to have sex with me” in her head. This strongly underlines the concept that Kitwood refers to as “personhood” – that status that L gives to J is that of a cripple, not being able to see him as her husband.

In these two cases it is clear that a lack of deep affection, not only as a result of years of marriage, but also as a result of really and truly *wanting to be there* for the person living with dementia, completely annihilates the Care Partnership. In both cases also, it became clear that the wives were not able to move out of their roles of being provided **for** to being the provider **of** care. In conversations with both, they made it clear that “they do not want this”. Selfishness prohibited the affection and ability needed for them to step into their partners shoes. Old patterns of resentment

manifested in the relationships that clearly were unresolved and further complicated the Care Partnership.

CASE STUDY 3:

Mary and John started looking after infants of working parents after their retirement. Several small children shared their home for many years. When John became ill and was diagnosed with dementia, Mary took on the role of his Carer with huge affection, but never relinquishing the role of being his wife also. When seeing them again for the first time in about twelve months at the wedding of someone whose child they used to care for, it was remarkable to see how well both of them were looking. On complimenting Mary about how well John seems to be, she was overwhelmed by the fact that someone could think that she is doing “a good job”. Watching them over the weekend at the wedding festivities, it was strikingly clear that Mary saw herself first and foremost as John wife, and not his Carer. John flourished; enjoying himself on the dance floor and chatting to people he had never met. It was clear that theirs was still a marriage, a relationship of mutual affection. In comparison with most of the other couples, John was doing so much better with his disease, which most probably can be attributed at least partly due to the caring relationship.

4. “Personal context”

As already mentioned, the resources available to Carers are extremely limited. The only two organisations in South Africa that provide any form

of support are Alzheimer's SA and Dementia SA. A disagreement between individuals led to a split many years ago, which resulted in the formation of Dementia SA as a "splinter group" of Alzheimer's SA. Whilst both of these organisations have "support groups", these groups are not led by professionals, are informal gatherings where Carers can exchange ideas and comfort one another. In dealing with Carers, it became clear that this does not fill their needs for real support, respite care, education or hope. Newcomers to the support groups have mentioned that they will never go back, as 'the devastating stories they heard from people who have been down the care path put them off forever'. Whilst there would be comfort in sharing stories, the need for professional counselling, provision of care for respite purposes (Carers who can provide short term relief or daycare), training in how to deal with physical care (like falls, incontinence, nutritional needs etc.) and expert advice on medication are desperately needed.

It is clear from my experience of dealing with many Carers of all walks of life, that GP's are simply not a resource for them in most cases, and that they feel "let down" by the lack of support. In many cases one would hear that a diagnosis is made (even that in itself is questionable, considering the lack of training and medical resources in SA), after which the family is told to 'come back in three months time'. For many, this is experienced as a delayed death sentence with which they are sent home. Often the person living with dementia is not part of this verdict given by a GP, and the spouse is left to deal with the full impact of the reality. The stress

levels, physical health, emotional wellbeing and practical realities following this verdict often have a dire impact on the Carer and the person living with the disease.

5. “Temporal context”

The practical implications of transition from ‘wife’ or ‘husband’ to Carer cannot be emphasized enough. For most people, diagnosis brings the beginning of a new life in every aspect of their being.

THE CARE PARTNER LIFECOURSE:

In the book “**Partnerships in Family Care**” reference is made to “A temporal model of caregiving in dementia”, with specific works by Wilson (1989) and Hutchinson (1986) cited.

Within the “temporal context” the stages are defined as “noticing; discounting and normalizing; suspecting; searching for explanations; recasting; taking it on and going through it, and then turning it over” which are referred to earlier on.

DIAGNOSIS:

The challenges for Carers in the SA context become more complex from the starting point where a diagnosis is required. With many people never having

access to a GP at all, those who do have access are often not much better off when considering the level of expertise that can be expected from the average GP trained in SA. On asking Dr. **Sebastiana Z Kalula**, Affiliation Senior Specialist: Internal Medicine and Head of Geriatric Medicine, The Albertina & Walter Sisulu Institute of Ageing in Africa, how much time students in Medicine, in South Africa's largest and oldest School of Medicine spend on Geriatrics, she writes in an email:

"In 2nd year they spend 2 weeks on self-directed learning on topics in geriatrics... Each year there are four lectures given to 4th year medical students...sixth year students also spend one morning in the geriatric clinic... During a research module, about 2-3 students in 3rd year will spend 4 weeks and write a research report on a topic in geriatrics. Post graduate: there is a 3-month rotation through geriatric medicine (not every registrar in their training time has this opportunity as only 4 registrars can rotate through each year)".

The average GP will come away with four hours of formal tuition in a six-year degree, plus two weeks of "self directed learning". Only two or three students will spend a further four weeks on research in Geriatrics. More startling is that there is no training for Nurses in Gerontology or Geriatrics. None of the 23 tertiary education establishments offer any education in Gerontology in any of its faculties.

In 'small town' SA the GP is often seen as the highest authority – many local jokes attest to this referring to the GP in a small town as God. When the 'highest

authority' does not recognize or validate the symptoms, is dismissive about the anguish of the spouse or family member who is sent home and asked to return in three months time, the agony of all concerned can hardly be imagined. Self doubt on the part of the spouse who is worried about her loved one's behaviour, anxiety of the person living with dementia not being able to understand what is happening, emotional turmoil, shame and angst must be intolerable. What most often happens is that the person living with dementia will deteriorate at a much faster rate as a result.

Whilst for many in this country there is not the 'luxury' of a diagnosis, there must be a point where roles are taken on and a new journey begins, yet this is difficult to define. In the 2010 Umhlaba Development Services Report to the South African Department of Social Development, it is confirmed that only 2% of the older population can be accommodated in Long Term Care Facilities in South Africa. During the Apartheid Government very few homes were built in disadvantaged areas. Currently, of the 2% of the older population in Long Term Care, 98% are still white. This means that the Care career for most people in South Africa will be a lifelong journey, with no chance of a Nursing Home placement at any point in the journey, or any form of respite.

It is the experience of the author that many residents in longterm care who staff labels as living with dementia, have never had a proper medical diagnosis. Even for those who can afford to seek professional help, there are no PET scan or Bio Marker Tracer equipment in SA, according to Dr. **Felix Potochnik**, Head of the Psychogeriatric Unit of Tygerberg and Stikland Hospitals and Program Manager

of the Old Age Psychiatry Portfolio for the Associated Psychiatric Hospitals, Provincial Government Western Cape and lecturer in the Department of Psychiatry. In practice it has been found that Residents with chronic urinary tract infection have been misdiagnosed by GP's as persons living with dementia. As a result of the total lack of education, both Carers and families will take the word of the GP and accept that their loved one is living with dementia.

MOVE INTO A CARE FACILITY:

For those who have the luxury of transferring their family member to a Care Home, chances are that it is the beginning of a new nightmare. The conflict "social psychology" that Kitwood refers to in his book "**Dementia Reconsidered, The Person Comes First**" (pp 46-47). Family members are mostly not included in the Care Planning Process; whilst in many cases they have been caring for their loved one for many years. Some family members, as was the case with L in the earlier case study, prefer to abdicate all responsibility to the professional staff to ease their own burden. This is used as an 'excuse' that the person living with dementia is now in the best place with people who know what is best for them. The fact that there is very little interaction from the spouse/family member might mean that the person living with dementia will end up being just another patient for whom only the basic physical care needs will be met.

As quoted in “**Partnerships in Family Care**”, “*Creating partnerships with Carers will require a considerable reorientation of professional practice, with a move away from the ‘unshakeable conviction’ in the superiority of professional knowledge*”. (Brandon and Jack 1997). Again the concept of a Care Partnership should be encouraged – where everyone involved with the person living with dementia is part of the partnership, with the person him/herself being at the centre of the relationship. In the training offered by the author families, residents, care staff and everyone involved in the care team are part of creating a Life Story Care Plan, in order for the Resident to have a sense of continuity, dignity, purpose, autonomy, fulfillment and ultimately quality of life. This has resulted in family Carers being far more open to participate, share their knowledge and be part of the holistic care team than before. Families feel supported when they realize that professional Carers are interested in the person that they are and the role that they play in the life of the person living with dementia.

In a recent experiment conducted by the author, the use of Facebook in a small Home for Residents living with dementia was explored. What was very interesting and unexpected was the positive feedback families gave on being able to 'access' the lives of their parents and grandparents through this medium. The daughter-in-law of one Resident reported that her husband never had a very close relationship with his mother, and that he found it very difficult to communicate with her since she moved into the Home. However, since the Home has been posting her story in the Home on Facebook, the first thing he does when he gets home at night is to check what his mother had done that day, and he now feels connected. Many families want to be involved, yet feel that they have now 'handed over' the care and should not 'interfere'. (Robinson and Thorne 1984; Darbyshire 1987 in "Partnerships in family care"). By giving families access to the day-to-day lives of their loved ones through Facebook, they feel part of the Care Partnership team and have a much more positive attitude towards the Care Team of the Home.

CASE STUDY 4:

Elsa was the Manager of a Care Home for many years. When her husband Charles was diagnosed with Lewy Body Disease, she did not think twice to resign from her job to take care of Charles. As his health deteriorated, she had no other option but to move him to the Care Home where she used to be the manager. It is Elsa's daily ritual to visit Charles at every mealtime, as well as in the afternoon at teatime. Even though Charles no longer communicates verbally or shows any signs of recognizing her at all, she maintains that he is her husband, and that she wants to be there for him and with him. The reaction of most of the nursing staff to Elsa's visits is unfortunately not very positive. In spite of the fact that they have worked with her for years, know her and trust her, it is clear that they feel uncomfortable with her taking care of her husband. It is often observed that staff feels that they are not trusted, and that any effort from the family to assist their loved ones is seen as mistrust and interfering. It can be safely assumed that this must have an impact on the person who is on the receiving end of care, as tensions and disagreements between family and staff often take place in front of the Resident. It was also noted that at times when it is not possible for Elsa to visit her husband, that the staff will not step in, but would have an attitude of not caring, as they do not see Charles as 'their responsibility'.

It is interesting to note how often care staff will complain about family being absent and having 'dumped' their loved one in a Care Home, whilst Safford (1989) as quoted in "**Partnerships in Family Care**" (p187) found that "*studies have consistently produced evidence that relatives in most instances continue to*

care for their relative...” Bridging the gap between the perceptions of Carers and the fear, guilt and anxiety of family will go a long way to improving the health and well-being of persons living with dementia.

In their book “**Broadening the Dementia Debate**”, Bartlett and O’Connor makes the profound statement that “*Oppressive and discriminatory practices often have their foothold in the well-meaning, well-intentioned ideas of those least intending to do harm*”. (p53) Tom Kitwood, in his book “**Dementia Reconsidered: The Person Comes First**” refers to this as a “malignant social psychology” (pp46-47). This can be as true of Family Carers at home as of Professional Carers in a Nursing Home. If there is no support in educating Carers, in guiding them to understand the person behind the disease, care all too often deteriorates into a very negative downward spiral ending up in just the bare essentials of feeding, cleaning and medicating.

The transition to a Nursing Home or Care Home (in SA the terms “Old Age Home” and “Frail Care” are commonly used, which is also indicative of the need for a culture change) is probably the most traumatic experience for both the Care Partners and the person living with dementia. Common practice is that the person living with dementia will be over medicated and physically restrained, which will result in a rapid decline in functionality. For the Care Partners who do have the affection for their loved one, this traumatic experience will inevitably result in the withdrawal from their loved one, and one often hears that Care Partners “say their goodbyes” when a loved one moves into a Care Home. Staff in Care Homes still work 12 hour shifts, are mostly underpaid and carry a heavy

burden in terms of their own socioeconomic circumstances. In spite of this, it is clear through discussions with many Carers over the past year, that most of them develop a real affection for the Residents. The positive impact on care in Homes where **The Eden Alternative** philosophy has been introduced is enough evidence of the need for support for those who give care. It is evident in these Homes that the so-called “Eden Alternative Golden Rule” that says “As Management does unto staff, so staff will do unto the Elders” is indeed a Golden Rule. The investment in education, upliftment, empowerment, skills training and relationship building with and between Carers, residents and families shows a marked improvement in the way that care is delivered. The same will apply in terms of an investment that needs to be made in education and support of family Carers.

ADVANCED DIRECTIVES:

CASE STUDY 5

A friend who wrote the story of his journey with his mother who lived with dementia, recalls *“After 4 years in an old age home, she had a mild stroke. I was away on holiday and got the call from the home, saying she was in the local public hospital. I went there on my return that evening to find a bewildered woman in a wet bed, clutching onto the frame around the bed, not knowing what was going on around her or what happened to her”*.

The concept of an advance directive is not known in Care Homes, and where families do have these, they are ignored most of the time. It is found so often that

families and persons living with dementia would have an attempt at an advance directive, especially when it comes to taking the person to hospital, which will end up in a file in the Sisters' office, and ignored when it is needed. Doctors and nurses in SA are mostly of the opinion that their professional opinion overrides the desires of family in a "medical emergency". (SA law does not allow lasting power of attorney.)

The conflict between professional staff (who rely on their oath more than on their common sense) and families (who are often riddled with guilt) has a devastating effect on the person living with dementia caught in the middle.

The question of "coping" is often raised in conversations with Carers. In "**Partnerships in Family Care**", "The importance of coping" (p133) is discussed and again one is aware of the diversity of emotions and feelings that would be considered 'coping'. The importance of faith (within the SA context) comes up time and time again in conversations across cultures, language and Care Partner relationships as a main source of coping. For many people living in a harsh country like SA coping is a part of surviving on a daily basis, and caring for a family member is just another part of what needs to be done. Many Care Partners in the rural context rely on neighbours, something that is very strong in especially informal settlements where people rely on one another for help in many aspects of daily living. Within the Care Home setting, the question how they are coping is seldom asked of Care Partners, and a pattern of sick leave, absenteeism and staff turnover are the only signs of them not coping. It has been noted that an intervention as simple as a one-day training course, exploring the

role and importance of Care Partners, is a lifeline in terms of giving a coping mechanism. This underlines the statement in **“Partnerships in Family Care”** that states “the ability of Carers to perceive care-giving in a different light is an essential coping approach”. (p137)

In a PhD study, **“FACILITATING CARE: THE EXPERIENCES OF INFORMAL CARERS DURING THE TRANSITION OF ELDERLY DEPENDANTS FROM HOSPITAL TO HOME - A GROUNDED THEORY STUDY”** by June D. Jeggels at the University of Cape Town, SA, most of the experiences that were mentioned above are substantiated. *“I discovered that other researchers have identified similar challenges in the experiences of informal Carers in this country (Orner, 2006; Joubert, 2005; Akintola, 2004; Joubert, et al. 2002). These include the fact that Carers: are not recognized as essential community assets, are not included in the health care systems, need financial and material resources and need the support of family, home-based workers and professionals alike.*

I also concur with the local academics who recommend that Carers be included in the district health system and are given the support and resources they require to become the primary providers of community-based rehabilitation services in this country.

To all the Carers in South Africa who are facilitating care against all odds, I salute you”.

In conclusion, support for family Carers in the transitions of the journey of a loved one living with dementia, needs to start on a macro level (see graph below) before it will be effective on an interpersonal level. The “normal” psychological

growth process and stages can only progress in a system where people are educated, where social support is available and accessible, and where the greater consciousness around dementia is a reality to everyone.



In January 2012, the Republic of Mauritius launched a “**Carer’s Strategy and Action Plan**” (Carer’s strategy and action plan “We care for you”. Policy paper. Port Louis, Mauritius, Ministry of Social Security, National Solidarity, Senior Citizens Welfare and Reform Institutions, 2010, as quoted in the WHO paper on Dementia, a Public Health Priority. It is clear that many countries are realizing the need and acknowledging the wealth of resource that family Caregivers are. As noted earlier, it is interesting that this document also refers to “the need for

more public resources is acknowledged *as the traditional belief in filial piety is increasingly eroded*". (My emphasis). (p77)

SA's quadruple burden of disease (HIV/AIDS, underdevelopment, chronic diseases related to unhealthy lifestyles and injuries) will have a major impact on the lives of Carers in the future. Government and civil society must be awakened to recognize the need for a National Strategy and start empowering and supporting Care Partners across the entire spectrum of care. If this is not made a national priority, the care burden will have a dire effect on the quality of life of those who care as well as those for whom they care.

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