

I know that it has been a very long and intense day and will therefore only deal with a few pertinent issues regarding DEMENTIA

**PRESENTATION TO THE WORKSHOP ON THE SOCIO ECONOMIC RIGHTS OF  
OLDER PERSONS HELD ON THE 22<sup>ND</sup> FEBRUARY 2011  
ROOM 1 C&D, SCHOOL OF PUBLIC HEALTH UNIVERSITY OF WESTERN CAPE**

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**DEMENTIA NEEDS ACTION NOW !!**

Dr Sandra Marais, in research commissioned by the *Directorate Research And Population Development, Western-Cape Department Of Social Development* on “**The Social Wellbeing Of Older Persons In The Western Cape**” it emerges that South Africa has one of the most rapidly ageing populations in Africa, with a particular increase in the 64-70 year age category (May, 2003). In the year 2000 South Africa had the second highest number of older persons on the African continent, being only surpassed by the older population of Nigeria (5.24 million). The 2001 Census found that 7.3% of the total population in South Africa were 60 years or older which is higher than the proportions of almost all other African nations in 2000 and noticeably higher than the 5.1% for the African continent as a whole (Joubert & Bradshaw, 2006).

Dementia affects one person in 20 over the age of 65 and one person in five over the age of 80. About 20% of people over the age of 80 develop dementia, which means that **80% do not**. There are diagnosed cases of early-onset dementia before the age of 65.

The Lancet Medical Journal of December 2005, reports that a new case of dementia arises **every seven seconds** in the developed world and estimates that 24.3 million people currently have dementia with 4.6 million new cases annually. By 2040 the number will have risen to 81.1 million.

The report indicates that there is a great need for community based services, welfare and support for people with dementia and their carers. These new figures show that pressure on governments for dementia services will increase dramatically in the next few years, and that we need to be prepared. There has to be a climate for change in which awareness and education to both policymakers, governments, medical aids, health care professionals, home based carers and also civil societies are encouraged to change their social conscience to include the elderly and more specifically people with dementia.

Dementia is a disease which affects the brain. It will affect memory, thinking and actions – sometimes all at once. It is a progressive disease, which will gradually affect the person with the disease more and more. There are many kinds of dementia. The most common is Alzheimer's disease (about 50-60% of cases) and vascular dementia.

It is no secret that the elderly and more specifically dementia (which includes Alzheimer's disease) is NOT a health care priority as it is in many developed countries in the world. South Africa is plagued with many other social and economic ills including poverty, unemployment not to mention the burden of diseases such as HIV/AIDS, TB, heart conditions etc. to have the added burden of the elderly .....

Dementia especially is not on this agenda for a number of reasons :

- a) It is an illness which is still highly stigmatised, shrouded in myth and in many communities is associated with witchcraft
- b) It is essentially an illness where there greatest risk factor is AGE – we are all aware of South Africa's acknowledgement, service delivery, protection and understanding of the needs of the elderly. The statistics referred to earlier indicate that the growing number of elderly in South Africa is of huge concern – a number of these elderly are vulnerable due to socio-economic conditions and the number raising grandchildren as a result of the loss of their own children to the scourge of HIV/AIDS.
- c) MENTAL ILLNESS in South Africa and the need to address the adequate quality and quantity of mental health care services generally and more

specifically services to older persons let alone conditions which render cognitive and memory impairment.

- d) In most provinces in South Africa it is NGO's who provide services to vulnerable communities. Funding to NGO's which is crucial in providing support, awareness, education, counseling and training is difficult – OLD PEOPLE ARE NOT A SEXY CAUSE and being at the end of your life, and possibly stricken with this illness – what is attractive about that??
- e) Skills shortages are one of the challenges – geriatrics as a career across all disciplines is not as attractive as paediatrics for example.

One developed country however can be a shining example to us in South Africa – Alzheimer's Scotland has successfully developed with the support of the Scottish Parliament and a working group who actively work towards the rights of people with dementia, their families and carers to formulate The Charter of Rights for people with dementia and their Carers in Scotland.

I am going to refer extensively to specific parts of this Charter of Rights as I believe this is possible in South Africa given the political will and support of all involved in mental health, geriatric mental health, families, and people with dementia themselves.

The decline in memory and cognitive abilities experienced by people with dementia and watched helplessly by their families and carers, must in no way diminish their human rights.

To quote from the charter : “dementia is an illness that over time affects the capacity of individuals to make some or all decision about their everyday lives, including their money, health and welfare. It gradually affects their ability to communicate, reason and act in their own interests. The illness severely compromises their ability to protect their own rights; because of this people with dementia are often at greater risk of violence, injury or mental abuse, neglect or negligent treatments, maltreatment or financial exploitation.” We hope that in South Africa the Older Persons Act (2006) will go a long way to protection.

At Dementia SA we know through testimonies which were collected during the public hearings of the Older Persons Bill, and now through own experience of carers in our support groups, community members trying to access a diagnosis or neighbours trying to understand the challenging behaviour of an elderly person in their community etc that there are insufficient services to cater adequately for people with dementia and their carers.

Respite care and treatment for carer burnout is unheard of.

There is insufficient and inadequate safe housing for people with dementia – old aged homes have long waiting lists. The OPA speaks of “community care” but communities have to be educated, made aware of and home based carers and community health care workers trained in order to render the care required.

Mental health care and geriatric services budgets from key Government departments, particularly national departments, and specifically Department of Health are wafer thin.

We in South Africa have not yet developed a social conscience around ageing - we continue to discriminate against the elderly, and particularly those with cognitive and memory impairments.

Quoting from the Scottish Charter of Rights, and we as Dementia SA will **continue to advocate relentlessly for the rights of people with dementia, their families and carers – and hope that we too could have a Charter of Rights to**

- Empower people with dementia and their carers to assert their rights in every part of their daily lives and wherever they are;
- Ensure that those who provide health, social care and other services understand and respect the rights of people with dementia and their carers;
- Ensure the highest quality of service provision to people with dementia and their carers.