

DEVELOPMENT OF A HOLISTIC APPROACH TO ASSISTING FAMILIES WITH AN ALZHEIMER'S SUFFERER

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INTRODUCTION

Alzheimer's is an irreversible degenerative disease in which brain cells die and are not replaced. It results in progressive impairment of memory, declining cognitive abilities, emotional distress and eventually, death. From an eco-systemic perspective the patient in an illness such as Alzheimer's Disease (AD) is the family rather than the sufferer alone. An intense period of suffering is experienced by all in the caring network as a sufferer progressively loses mental faculties, emotional balance and motor abilities. This demands a more holistic response than simply medical management of the patient. Doctors, however, are often the first professionals to become aware of a patient's declining capacities, and possibly as much through reports by family members as from direct assessment of the patient. Within the evolution of a comprehensive response to AD, then, medical practitioners occupy a gatekeeper role. In tracking the evolution of support services for AD sufferers over a period of time in the Nelson Mandela Metropole, this article gives particular attention to a survey of general practitioners and physicians as well as psychiatrists and neurologists who explored, inter alia, their knowledge and use of support groups as part of treatment plans, and their attitude to a holistic treatment approach.

ALZHEIMER'S DISEASE

Incidence

AD is the most common form of dementia (Cayton, Graham & Warner, 2002). It is estimated that by 2005 about 34 million people globally will suffer a dementia, and that over 70% of these will live in the developing world. In the over-65 age group about 1 in 20 (5%) suffer a dementia, and it is estimated that 50% of these are of the Alzheimer's type. The older a person gets, the more likely he or she is to develop the disease, with the risk increasing at about 1% per year after 65. By the time a person reaches 85 the risk of developing Alzheimer's has risen from 1 in 20 to 1 in 5 (Kaplan & Sadock, 1998).

In South Africa in 2000 the over-65 age group numbers about 2,2 million. It can then be loosely estimated that the country has a population of about 110 000 elderly dementia cases. Of the estimated 1 million people who live in the Nelson Mandela Metropole, about 50 000 are over 65. If the 5% dementia estimate holds true then the number of sufferers in the metropole can be estimated to number about 2500 and AD sufferers 1250.

Clinical nature of Alzheimer's Disease

Alzheimer's Disease (AD) is a dementia. This term is used very specifically by medical practitioners to denote a loss or impairment of mental powers (Mace & Rabins, 1991). According to Alzheimer's South Africa (ASA), ten warning signs of AD can be identified:

- loss of memory;
- difficulty in performing familiar tasks;
- problems with language;

- disorientation in time and space;
- poor or declining judgement;
- problems with abstract thinking;
- misplacing things;
- changes in mood and irritability;
- changes in personality;
- loss of initiative.

Dementia is a symptom rather than a diagnosis (Cayton *et al.*, 2002; Koenig Coste, 2003; Mace & Rabins, 1991). The diagnosis of AD requires systematic exclusion of alternatives such as cerebrovascular disease, Parkinson's or Huntington's, alcohol abuse, trauma-induced mental deterioration, or depressive or schizophrenic disorders. The illness may be categorised in terms of onset (early pre-65 years; late after 65 years) and its clinical presentation (Figure 1). Until recently a definitive diagnosis could only be conducted through a post mortem. However, in recent times more sophisticated (although not definitive) tests have been developed which facilitate a differential diagnosis (Koenig Coste, 2003). In most cases there is evidence of brain atrophy, which can be measured through computed tomography (CT) or magnetic resonance imaging (MRI). It is slightly more common in females than males and very few cases develop before 50 years of age. Cayton *et al.* (2002) distinguish between hereditary and non-hereditary forms of the disease, with the former being defined by early onset (as young as 35) and a history of such early expression of the disease within the family. There is some difference in the literature on the degree to which AD is hereditary, with Cayton *et al.* (2002) suggesting that this form is rare, and other such as Kaplan and Sadocks (1998) proposing that hereditary incidences are higher – with some studies indicating that as many as 40% of AD sufferers have a family history of the disease.

FIGURE 1
A HOLISTIC HELPING FRAMEWORK TO ASSIST FAMILIES WITH AN
ALZHEIMER'S SUFFERER THROUGH STAGES OF THE ILLNESS

PATIENT SYMPTOMS: SUFFERER OF ALZHEIMER'S DISEASE					
Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6
<ul style="list-style-type: none"> • Stress • Depression • Forgetfulness • Erratic behaviour • Poor concentration • Easily distracted • Withdrawn • Irritable • Anxious • Denial • Compensation • Rationalisation 	<ul style="list-style-type: none"> • Memory worsens • Gets lost in familiar places • Difficulty in recall • Difficulty in recounting events • Loss of arithmetical abilities • Impaired reasoning • Restlessness • Wandering 	<ul style="list-style-type: none"> • Disorientation: time & place • Disjointed conversation • Repetitious actions • Mood swings • Bewildered in social situations • Aggressive • Volatile • Defensive • Resist bathing & grooming 	<ul style="list-style-type: none"> • Fragmented memory • Impaired communication • Delusions • Hallucinations • Sleep disturbances • Agitation • Scream & cry • Need help walking • Incontinent • Completely dependent 	<ul style="list-style-type: none"> • Bedridden • Doesn't recognize familiar faces • Unable to speak • Pneumonia • Other infections • Coma 	DEATH

TYPICAL FAMILY RESPONSE IN EACH STAGE OF THE ILLNESS

<ul style="list-style-type: none"> Denial Confusion Distress Financial problems Marital stress Lack of information / insight 	<ul style="list-style-type: none"> Anger Frustration Depression Loss Isolation Curtailement of social activities Despair False hopes 	<ul style="list-style-type: none"> Exhaustion Caregiver stress Role reversals Loneliness Loss of companion-ability Burdened with all major decisions Irritable Resentful Shame 	<ul style="list-style-type: none"> Mounting anxiety Feelings of hopelessness Sense of abandonment 	<ul style="list-style-type: none"> Chronic exhaustion Anger & guilt Devastation 	<ul style="list-style-type: none"> Relief Release Guilt Mourning
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HOLISTIC TREATMENT APPROACH

<p>Medical</p> <ul style="list-style-type: none"> Exclude alternatives <p>Legal</p> <ul style="list-style-type: none"> Will & power of attorney <p>Psychosocial</p> <ul style="list-style-type: none"> Information Education Problem-solving Stress management Assertiveness 	<p>Medical</p> <ul style="list-style-type: none"> Medication <p>Legal</p> <ul style="list-style-type: none"> Power of attorney <p>Psychosocial</p> <ul style="list-style-type: none"> Identity bracelets Home safety Service centres Financial mgt assistance Reminiscence therapy Occupational therapy Environmental orientation 	<p>Medical</p> <ul style="list-style-type: none"> Medication Specialized care <p>Legal</p> <ul style="list-style-type: none"> Curator bonis <p>Psychosocial</p> <ul style="list-style-type: none"> Support groups Psychosocial support Day care facility Supervision Stress management Relaxation techniques 	<p>Medical</p> <ul style="list-style-type: none"> Medication Specialized care <p>Legal</p> <ul style="list-style-type: none"> Curator bonis <p>Psychosocial</p> <ul style="list-style-type: none"> Respite through caregivers 	<p>Medical</p> <ul style="list-style-type: none"> Medication Specialized care <p>Legal</p> <ul style="list-style-type: none"> Curator bonis <p>Psychosocial</p> <ul style="list-style-type: none"> Frail care Respite through caregivers 	<p>Medical</p> <ul style="list-style-type: none"> Family <p>Legal</p> <ul style="list-style-type: none"> Assistance with estate <p>Psychosocial</p> <ul style="list-style-type: none"> Bereavement counselling
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Causation is less than certain at this time, although there are indications that acetylcholine (a neurotransmitter) deficiencies and abnormalities in certain genes (ApoE-E4) which affect the body's ability to replace dying cells are associated with AD.

The disease usually progresses slowly, starting with deficits in early memory and then aphasia (deterioration of language function), apraxia (impaired ability to execute motor activities) and agnosia (failure to recognize or identify objects despite intact sensory function). As the patient deteriorates there may be evidence of increased irritability, then personality changes and motor disturbances progressing to a complete inability to attend to personal care, and eventual muteness and total immobility. The average duration of the illness from onset to death is about 9 years.

Support groups: helping clients speak

The first author initiated the first support group for families of Alzheimer's sufferers in the Nelson Mandela Metropole (specifically Port Elizabeth) in 1991. Responding to one family's desire to make contact with others in similar circumstances, medical practitioners were approached for purposes of bridge-building. When this was not successful, a local newspaper picked up the issue, running a comprehensive article on the nature of AD and inviting the public to a meeting on the

disease. Eighty people attended the first meeting in April 1991 – 23 sufferers and 57 interested in learning more about the illness and offering support in various forms.

By 1999 about 300 family members representing 150 diagnosed AD sufferers had participated in group meetings. By 2004 this had expanded to 500 family members representing 300 AD sufferers.

Apart from offering participants mutual support, the support groups provide a rich source of information and learning both from each other and from professionals interested in providing assistance to them. Through the years participants in support groups were asked to identify their core needs and these were systematically collected and prioritised. The following were identified, in order of priority:

- appropriate assessment and diagnosis of AD;
- respite care – short-term and day care;
- appropriate nursing at frail-care facilities;
- home-based care / nursing;
- occupational therapy;
- legal services;
- recreational facilities.

These findings triggered several other questions. Which group of professionals was most likely to come into contact with AD patients and their families at early stages of the disease? How did this group respond? What resources existed in the metropole to assist AD sufferers and their families? Discussion in groups indicated that most had confided in, or brought symptoms of the disease to the attention of, their doctors in the first instance. On this basis a survey of medical practitioners in the region was undertaken. A model of stages of progression of the disease was developed to guide the investigation – at what stage typically did patients present themselves, or did family members seek diagnosis and treatment? What tests were used for purposes of a differential diagnosis? What was the incidence of AD in local doctors' caseloads? What awareness was there of support groups and what were the attitudes towards their use? Was there interest in developing a holistic treatment approach?

A five-stage model: conceptualising and initiating a holistic response

Drawing on a 'phases model' reflected in the March 1999 publication of Harvard Women's Health Watch, and carried now in Harvard Medical School's official 'Guide to Alzheimer's Disease' a five stage model was developed (Growdon, 2002). The top row in Figure 1 reflects the major stages of the illness in five major phases preceding death. The second row proposes typical family responses in each of the phases. The deterioration of the Alzheimer's patient is often confusing and irritating for family members in the first instance, generating marital and familial stress. As the patient and family become increasingly aware of the illness this is often accompanied by fear, depression and frustration. Social activities become curtailed, the family becomes increasingly isolated and family members become exhausted with the strain of caring, and then angry, resentful and guilty over their own responses. Financial problems may be experienced. Caring family members experience a loss of companionship and must endure a 'living loss' as the patient steadily loses an ability to relate to them and finally even recognition of them before dying. They report a sense of abandonment, feelings of hopelessness and fear, and an overall exhaustion as they realize they are in a struggle that cannot be won, and which the patient is not even ultimately conscious of.

Medical practitioners as bridge builders: research findings

Medical practitioners were identified as an important source of information regarding the incidence and treatment of Alzheimer's Disease. In 1999 a survey of 60 doctors (including 15 in traditionally black and coloured areas) in the Port Elizabeth-Uitenhage area was undertaken to ascertain:

- the number of Alzheimer's patients currently on their books;
- the standard procedures followed to arrive at a diagnosis of AD;
- the common symptoms presented by both the patient and the family;
- levels of awareness of community resources;
- response to the idea of a holistic treatment approach.

Research findings

Of the 60 medical practitioners in private practice approached, 37 completed the questionnaires (a 62% response rate). Unfortunately not all respondents did so thoroughly, so not all findings are complete. Nevertheless some important findings emerged (Table 1).

TABLE 1
FINDINGS FROM A 1999 SURVEY OF MEDICAL PRACTITIONERS IN THE NELSON MANDELA METROPOLE ON THE INCIDENCE OF ALZHEIMER'S PATIENTS AND AWARENESS AND USE OF SUPPORT GROUPS

	Neurologists & Psychiatrists	General Practitioners & Physicians	Comments
Total in Nelson Mandela Metropole	7	222	
Sample	6 (86%)	54 (24%)	Including 15 in traditionally black and coloured areas
Respondents	4 (67%)	33 (61%)	Unfortunately only one doctor servicing traditionally black and coloured areas responded, resulting in a skew in data collection toward the white population.
No. with Alzheimer's Disease patients	4 (100%)	23 (63%)	
Patient loads			
Number of current patients	30	73	
Average per practitioner	7,5	2,7	
Projected number of patients in NMM based on average patient loads	53	600	Only half the expected number: may reflect poor diagnoses, skewness in sampling.
Admission & diagnostic indicators			
Number of new patients in last 12 months	41	47	Suggests neurologists and psychiatrists see patients in later stages of the disease and experience a higher mortality rate
Number using three or more exclusionary tests	2 (33%)	13 (39%)	
Awareness & use of support groups			
No. aware of support groups	2 (33%)	20 (61%)	Indicates need for an education campaign
Of those aware number who refer to support groups	2 (100%)	10 (50%)	Indicates possible doubts about the efficacy of support groups
Number indicating they would use a holistic, one-stop system	4 (100%)	33 (100%)	Strong support indicated

The accuracy of estimates of Alzheimer's sufferers must be viewed with caution. Patients on the books of neurologists and psychiatrists may also be on the books of the general practitioners and physicians. To limit error the projection of patients has been done on the basis of the average AD patient load of the latter grouping (rather than the specialists). If each carries a patient load of 2,7 Ads, then about 600 diagnosed AD sufferers can be estimated to be on the books of NMM private practitioners – about 50% of those estimated to be sufferers in the area.

There appear to be quite uneven weightings of AD patient loads amongst medical practitioners, suggesting that some doctors attract higher numbers of such patients than others, but also raising questions about the diagnostic sophistication amongst non-specialists in the mental health field. Fewer than 40% of doctors used three or more tests for exclusionary purposes, a finding which strengthens such doubts. Responses to questions as to the stage at which patients were identified were confused and could not be used for this study.

There are some indicators as to when AD sufferers access the care of specialists. The findings reflect a more rapid mortality rate amongst specialists' patients, indicating late access to such care.

Only about 60% of medical practitioners knew about support groups for carers of AD patients, indicating the need for an extensive information / education campaign. However, of greater concern was that, of those who did know about support groups, half did not refer families to them. Questions arose as to whether this reflected perceptions of the quality or usefulness of services offered. Positively, however, the need for and interest in using a holistic, one-stop centre was unanimously confirmed.

Services available in 1999

The Nelson Mandela Metropole has a relatively high density of aged persons (estimated at almost 50 000) and facilities for this group, with at least 20 registered homes for the aged (excluding 10 privately owned retirement villages with frail-care facilities) accommodating over 2000 people. At least 5% of people over 65 are accommodated in frail-care facilities. Cuts in government subsidies had obliged many to look for alternatives, including home care. At the time of the survey such facilities cost in the region of R2500 per month. The minimum fee for home carers was R80 per day, excluding travelling costs and meals, and fees might rise to R150 per day. Organisations such as Algoa Care of the Aged offered counselling and support services to aged people at a nominal fee. Others such as St Johns conducted regular first aid courses for people seeking placement as home carers. At the time 5 home carers were placed in the homes of AD sufferers. Various community centres offered fellowship, entertainment and meals for the over-60s, as well as municipal health clinics, church-affiliated homes and services, and Meals on Wheels.

Only some of these resources could be used by an AD sufferer and then only in the early stages of the disease. As the patient's condition deteriorates, so accessing resources becomes increasingly difficult, contributing to the isolation of the family and stress on immediate carers. Some old age homes indicated a willingness to offer short-term respite services of 7-10 days for Alzheimer's patients to allow families a short break or to look after patients for a few hours once or twice a week to allow time for shopping or respite. Some active elderly people in homes indicated a willingness to care for AD sufferers for brief periods of time.

USING RESEARCH TO BUILD A HOLISTIC 'FAMILY-CENTRED, DISEASE-PACED' SERVICE

A responsive resource system finds its design in the needs of the patient – from an eco-systemic approach, to the family as a whole. In the case of AD, family needs for support rise as the patient inevitably moves into a decline towards death. At the time services were clearly inadequate and fragmented. The helping framework proposed in Figure 1 starts with recognition that AD is progressive and proposes that the patient and the family have very specific needs related to phases of the illness. These require a multi-disciplinary response for both diagnostic and treatment purposes, but one which is focused and accessible. Founding a helping system in the reality of the illness acknowledges that all will be pulled ineluctably down a path dictated by the progressive deterioration of the sufferer. A holistic service would therefore require a '*family-based, disease-paced*' approach. The following were, and are, envisaged (Anstey, 1999):

- twice a month a multi-professional team comprising a medical doctor, social worker, occupational therapist, nursing sister and attorney would make themselves available for a thorough evaluation of patients and their families, and to draw up comprehensive treatment plans;
- an occupational therapist would be responsible for the ongoing assessment and evaluation of the individual needs of sufferers and to draft programmes to meet these;
- a day-care programme for sufferers;
- the provision of short-term respite using available beds in an existing facility with appointment of temporary contract staff;
- venue, facilities and activities would remain as constant as possible to minimise patient confusion;
- ongoing counselling and supportive services would be rendered to the spouse and family members of the Alzheimer's patient, with the emphasis on assisting them to manage their stressed lives more effectively. Counsellors must take responsibility for networking families to specialised medical, legal and financial resources.

STEPS IN DEVELOPING SERVICES FOR 'ALZHEIMER'S FAMILIES'

The idea of a regular one-stop service has proven ambitious in the short term, but many other objectives have been achieved since 1999.

A vigorous campaign of *doctor education* has been undertaken, with information regarding AD and support group services being placed in all medical practitioners' rooms in the metropole.

The number of *support groups* has been expanded. Six such groups now exist in the region (three at the time of the research) and assistance is being provided in establishing others in the neighbouring towns of Port Alfred and Jeffreys Bay.

A salient need identified by families of Alzheimer's sufferers was for *respite services*. In response to this, five aged-care organisations have made their facilities available for short-term care (day care as well as weekend and longer stays). One senior service centre has allocated one day a month to hosting early to middle stage dementia sufferers and their carers for tea and entertainment, and extended an invitation to them to enrol in daily activities and outings.

An eight-hour training workshop on AD and patient management was developed for staff of frail-care centres and was attended by employees from 17 of these (Appendix 1). Between August 2003 and August 2004 four such workshops attended by over 200 people were conducted, on the basis of demand. A further 50 have received specialised information and instruction in management of AD patients over and above the basic home-care course. Five of these were placed in needy frail-care centres for two months for practical training and experience, with one such centre requesting placement of another. A number of carers have been placed in private homes to care for AD sufferers. Two of these carers attend support group meetings and have started a care facility for AD patients, whilst their spouses participate in such meetings.

At the time of writing a standardised national 'Train the Trainer' workshop has been developed within the Services Sector Education and Training Authority (SETA) open to professionals nationally. Both the carer training and SETA training projects have been funded through monies from Lotto and Anglo Gold as well as regional fund-raising activities. Encouragingly, Lotto funds have been generous and ASA is now much better positioned to develop and offer sustainable services into the future.

CONCLUSION

Although there is still much to be done, this article provides a review of the development of a holistic service for families coping with an Alzheimer's sufferer in the Nelson Mandela Metropole. Starting as a response to the needs of one family to locate a support system, support groups have been initiated across the area, doctors have been informed of services, funds raised and training provided to carers to offer respite and support to families in need. For social work practitioners the article seeks not simply to offer insights into the nature of Alzheimer's Disease and its impact on families, but also to indicate how services can be developed on the basis of a series of small practical or action research activities and how support services can be developed off a base of few resources.

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APPENDIX 1

Typical components of a training course for carers of Alzheimer's sufferers

1. The nature of Alzheimer's Disease

- diagnosis
- incidence
- causes
- phases of the illness

2. Management of Alzheimer's Disease

- treatment options
- resources
- support groups

3. Caring for Alzheimer's sufferers: practical skills for respite workers

- *behavioural and environmental manipulation*
 - * limiting ambiguous stimuli: sticking with the familiar, lights on at night, visible and auditory orientation guides
 - * limiting potential for physical harm
- *general medical measures*
 - * comprehensive evaluation
 - * regular review and adjustment of treatment measures
- *communication*
 - * keeping questions simple
 - * use of visual cues
 - * being direct and literal vs abstract
 - * repeat words and phrases
 - * getting attention before communicating
- *nutrition & eating*
 - * understanding why sufferers don't eat: loss of recognition of food, loss of sense of time, inability to swallow, etc.
 - * importance of a meal routine
 - * flexibility with food presentation – respond to the sufferer
 - * creative use of utensils
- *personal hygiene*
 - * sensitivities to water
 - * maintaining patient dignity
- *dressing*
 - * why patients dress inappropriately: forgetting the purpose of clothes, time of day confusion, order of clothing
 - * building a routine into dressing and use of clothes
- *individualising patient care*
 - * use of exercise
 - * pacing the day – reducing pace at dawn and dusk
 - * pacing meals and content of meals during the day
 - * shadowing sufferers to identify times, events, triggers for agitation
 - * use of simple repetitious activities

- *wandering*
 - * getting lost: setting off on a familiar task and losing orientation, seeking for people and places from the past, restlessness
 - * using regular exercise and ensuring accompaniment
- *identifying and stopping abuse of the elderly*
 - * identifying physical and psychological abuse
 - * possible financial abuse
 - * active or passive neglect
 - * appropriate steps

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