

Health Care for Older People

DEMENTIA

Holistic Approach

Sri Lanka Association of Geriatric Medicine
2018

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An attempt to develop and promote multidisciplinary mutual coordination and collaboration among the team involved in care of older patients at various levels in the health and social service sector.

“Teamwork divides the task and multiplies the success.”

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Foreword

Being the President of the Sri Lanka Association of Geriatric Medicine (SLAGM), I am delighted and honoured to write the foreword for the first issue of a series of bulletins “The Health Care for Older People - Holistic Approach” published under the auspices of SLAGM.

In a context where the proportion of community above 60 years of age are exponentially rising globally, owing to ever improving health care facilities adding years to longevity, it is relevant to address different disease patterns and special health needs that go along with ageing process. It is essential for the Ministry of Health which is the supreme body responsible for health care delivery in the country, to concentrate on these needs and to incorporate remedies to upgrade care for elderly.

The care needed for older adults more often involves multidisciplinary teams and discussions at these meetings with all stake holders including patients and care givers often provide satisfactory solutions for many difficulties faced by the elderly.

SLAGM, as a medical professional body committed for elderly medicine, concentrate more on training health care professionals. The Bulletin that will be published biannually will address common medical issues of elderly with the objective of updating the knowledge of members of multidisciplinary team: physicians, medical officers, nurses, physiotherapists, occupational therapists, speech and language therapists and also of social service officers and counsellors. It is our fervent wish that “The Health Care for Older People – Holistic Approach” becomes an essential hand book for officials of the Ministry of Social Services when making decisions on implementation of user friendly social life for elderly community in Sri Lanka.

The first issue addresses all relevant aspects of providing care to elderly with dementia. Safety of demential patients and care giver burnout are such issues that are untouched in Sri Lankan setting that needs attention. It is not uncommon in the country to find abandoned elderly who are taken on media circuses without proper background information causing much embarrassment to the guardian. More often the carers have their own sad story as care provision for dementia patients can be an exhausting task. The bulletin on Dementia highlights intricacies including expenditure and stresses in the care of dementia patients and the need for the Ministry of Social Services to establish free / fee levying institutions at an affordable cost.

“Health care for Older People – Holistic Approach” contains contributions from all relevant members of the Multidisciplinary Team and also from the care giver. I extend my sincere appreciation to the Editorial Board without whom publishing this bulletin would have been impossible.

I, along with the council of the SLAGM, sincerely believe that all relevant professionals along with Sri Lankan community will make maximum use of contents of this publication and join our efforts to create a new era that ensures independent living of older adults.

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Dementia - Overview

Dr Achala Balasuriya

The prevalence of dementia in the world is rising fast with the increase in the ageing population. The estimated current prevalence of dementia is 47.5 million worldwide. The gravity of the problem can be understood when we learn that every 4 seconds one patient is being diagnosed with dementia. Sri Lanka has one of the fastest ageing populations in the region and hence the prevalence of dementia is also rising although we do not have exact figures for the country at the moment.

Most people are now somewhat familiar with the term dementia and for them any form of memory loss is equal to dementia. However it has to be noted that dementia is not a specific disease. It's an overall term that describes a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.

The exact symptoms of dementia can be varied but at least two of the following core mental functions must be significantly impaired to be considered dementia:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception

Signs and symptoms of dementia result when once-healthy neurons (nerve cells) in the brain stop working, lose connections with other brain cells, and die. While everyone loses some neurons as they age, people with dementia experience far greater loss. While dementia is commoner in older people (up to half of all people age 85 or older may have some form of dementia), it cannot be considered a normal part of aging. Many people live into their 90s and beyond without any signs of dementia.

Common clinical features of dementia include

- Recent memory loss - a sign of this might be asking the same question repeatedly.
- Difficulty completing familiar tasks - for example, making a drink or cooking a meal.
- Problems communicating - difficulty with language; forgetting simple words or using the wrong ones.
- Disorientation - getting lost on a previously familiar street, location of

home address

- Problems with abstract thinking - for instance, dealing with money.
- Misplacing things - forgetting the location of everyday items such as keys, or wallets.
- Mood changes - sudden and unexplained changes in outlook or disposition.
- Personality changes - becoming irritable, suspicious or fearful.
- Loss of initiative - showing less interest in starting something or going somewhere.

There are different types of dementias identified. Alzheimer's disease is the commonest type accounting for 80% of the cases. Other types are vascular dementia, Lewy body dementia, Fronto-temporal dementia, Parkinson's disease, mixed dementias, Creutzfeldt -Jakob's disease, normal pressure hydrocephalus , Huntington's disease etc. Each one of these diseases has different aetiologies and loss of memory is common to all.

Alzheimer's disease

This is the most common cause of dementia accounting for 50-75% of dementia cases worldwide. In Alzheimer's disease there is build up of abnormal plaques and tangles in the brain. Alzheimer's disease can be either sporadic or less commonly, familial. Sporadic Alzheimer's disease can affect adults at any age, but usually occurs after age 65 and is the most common form of Alzheimer's disease. Familial Alzheimer's disease is a very rare genetic condition, caused by a mutation in one of several genes. The disease progression is variable and a person may live from 3-20 years with the condition.

Vascular dementia

This is the second most common cause of dementia amounting to 20-30% of the cases. This condition is a result from chronic decreased blood flow to the brain which deprives brain cells of essential nutrients and oxygen thus, often seen in the context of ischaemic heart disease and diabetes. The progression is step wise. Multi-infarct dementia is caused by a number of small strokes, called mini-strokes or Transient Ischaemic Attacks (TIA) which cause damage to critical regions of the brain. Usually the health of people with vascular dementia decline more rapidly than that of people with Alzheimer's disease. Often they die from a heart attack or a major stroke.

Frontotemporal dementia (FTD)

This accounts for around 5-10% of dementia cases. No single pathology has been identified while the disease caused by the degeneration of cells in the brain's frontal or temporal lobes. Usually seen in people between 40 and 65 years of age and is a significant cause of dementia in younger people. Pick's disease is a type of FTD named after the German neurologist who first described it in 1892. Pick's disease affects the frontal lobes, and sometime the temporal lobe of the brain. If the temporal lobe is damaged, memory is more likely to be affected. General life expectancy is two to fifteen years, with an average of six to twelve years.

Dementia with Lewy bodies (DLB)

DLB accounts for less than 5% of dementia cases. It is caused by the degeneration and death of nerve cells in the brain. It is thought that these may contribute to the death of the brain cells. Lewy body disease differs from Alzheimer's disease in that the progression of the disease is usually more rapid. However, like Alzheimer's disease it is a degenerative condition, eventually leading to complete dependence. Death is usually a result of another illness, such as pneumonia or an infection. The average life-span after the onset of symptoms is about seven years.

Identifying the risk factors for dementia

Older age is the most important risk factor for dementia, with prevalence increasing exponentially after the age of 65. Genetics is another non-modifiable risk factor, but the majority of cases are sporadic and likely to result from a combination of genetic and environmental influences.

Factors increasing the risk of developing dementia include smoking, obesity, diabetes, hypertension and high total cholesterol. Higher education and cognitively stimulating activity, regular physical activity, positive life experiences, social activity, moderate alcohol consumption and a healthy diet are associated with lower dementia risk.

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Dementia management in Sri Lanka

Prof Varuni De Silva and Dr Malsha Gunathilake

Comprehensive management of dementia should be done by a multidisciplinary team. This requires considerable time, effort and resources. In Sri Lanka it is challenging to provide comprehensive care with the limited resources available. We discuss the management of a patient with moderately severe dementia due to Alzheimer's disease who presented with behavioural and psychological symptoms (BPSD).

Case presentation

Mr. A a 69 year old male, retired clerk living with his wife, presented with a history of gradual onset, progressive memory impairment for a year and suspiciousness for two months. He suspected that his belongings were stolen by family members. At times he became irritable and verbally aggressive towards his wife. He needed supervision to maintain self-care and other basic activities of daily living. Features did not suggest a vascular etiology or Lewy Body Dementia. He had hypertension which was under control on medications and also had visual impairment. Both the patient and his wife were dependent on his pension of 21000 rupees per month. He owned a land with a house worth 6 million rupees and had a bank account with one million rupees in savings. He did not have any ongoing legal concerns. His wife was his main caretaker and she found it difficult to care for him due to the recent disturbed behavior. She got little support from the two children who were employed and living separately.

Mental state examination showed that the mood was irritable and he had persecutory delusion. He had impaired orientation and could only recall the time of day and the name of the country, but he was orientated in person.

Initial assessment

Although the history is suggestive of dementia in this patient, further cognitive assessment and investigations are needed to establish the diagnosis, identify the subtype if possible, grade the severity and exclude any other brain pathology which could account for the symptoms.

Comprehensive history was obtained from the patient and his wife regarding the course of the disease, risks, behavioural and psychological symptoms of dementia (BPSD), social, financial, legal aspects and physical and psychiatric co-morbidities.

Mental state examination specifically looked for BPSD because nearly 60-

90%of patients experience them. Common BPSD symptoms are depression and psychotic features.

Comprehensive physical examination was performed to assess the cardiovascular state and central nervous system.

Cognitive testing

Most clinicians do not carry out detailed cognitive examination especially when patients present with moderate-severe dementia. It is very important to carry out a detailed cognitive assessment as it provides the patient, family members and the clinician with information regarding the severity of the illness and the cognitive domains which are affected. In the absence of confirmatory biomarkers, cognitive testing remains the best way to confirm the diagnosis. It also helps to monitor progress. MMSE (Mini Mental State examination) and MoCA (Montreal Cognitive Assessment) have been already validated in Sri Lanka. They can be used as bedside tests and take about 10-15 minutes to administer. MoCA is more sensitive than the MMSE in detecting early dementia and it can be downloaded free from www.cgpsl.org.

In this patient MMSE and MoCA were done. He scored 18 in the MMSE and 7 in MoCA.

Functional assessment

Ideally a detailed functional assessment and risk assessment should be carried out by the multidisciplinary team. Functional Activities Questionnaire (FAQ), Katz Index of Independence in Activities of Daily Living, Lawton Instrumental Activities of Daily Living Scale (IADL) are commonly used tools to assess the functioning and they will help to monitor the out-come objectively.

Full blood count, ESR, liver and renal profiles, fasting blood sugar, lipid profile and thyroid profile were done to identify any reversible causes. Blood picture and vitamin B12 levels can be carried out as well.

Neuro imaging

Neuro-imaging is recommended at least once during the assessment specially to look for reversible causes. Even though MRI scan is better, in Sri Lanka a CT scan of brain is an option as MRI scan facilities are limited.

Family education

His family was educated about the nature of illness and BPSD, the role of cognitive enhancers, importance of non-pharmacological interventions and legal aspects.

Cognitive Enhancers

Cognitive enhancers are useful in patients with Alzheimer's dementia, regardless of the severity of the disease. Two cholinesterase inhibitors (ChEI), Donepezil and Rivastigmine are available in Sri Lanka. Unfortunately, they are still not available in the government sector. A month's supply of Donepezil would cost about Rs. 1500-2000.

An ECG was done prior to starting treatment as heart block is a contraindication to starting ChEI. This patient was started on Donepezil 5mg daily. The dose was increased to 10mg daily after one month as he tolerated the drug well. His blood pressure and pulse rate was monitored.

The NMDA receptor antagonists, Memantine is also available in Sri Lanka and would cost about Rs. 2000-4000 a month. It is recommended for moderate to severe Alzheimer's disease. Combination of ChEI and Memantine is used in moderate to severe disease.

Management of BPSD

Non pharmacological management is recommended as first line treatment for BPSD. In this patient with the help of an occupational therapist, behavioural assessment was done followed by behavioral interventions such as distraction methods.

ChEI and Memantine help control BPSD. Family members should be advised to continue these medications even if there is deterioration in cognitive functions. As his symptoms were severe he was started on a small dose of risperidone 0.5mg at night; it was increased to 1 mg twice daily because the behavioural disturbances continued. He was reviewed regularly for the emergence of extra-pyramidal side effects (EPSE). Caregivers were educated about features of neuroleptic malignant syndrome and EPSE as elderly patients are more vulnerable to these.

Antipsychotics have a place in managing psychotic symptoms, agitation and aggression in patients with dementia. The choices are risperidone, aripiprazole, olanzapine and quetiapine. In Lewy body dementia (LBD), quetiapine is preferred. Special care should be taken initiating antipsychotics in patients with LBD as they are hypersensitive to antipsychotics.

Optimization of the physical health

Vascular risk factors should be minimized and visual and hearing impairment should be corrected to improve quality of life. This patient was referred to an ophthalmologist as he had visual impairment due to bilateral cataracts.

Non-pharmacological strategies

Physical exercise, socialization and regular routines were recommended as this improves quality of life and reduces boredom and behaviour problems. Tasks which are cognitively stimulating such as reading, board games and puzzle making were recommended. These activities should be tailored according to the patient's interest and abilities. In in-patient units and day units these activities can be carried out in groups. Reminiscence therapy which includes looking at old photographs was tried with help of his family. Reality orientation with calendars and clocks was done.

A home visit was planned to assess his home environment and identify areas which needed modification. This helps to minimize risks to the patient. Following the baseline functional assessment interventions were planned to make his daily activities as independent and as safe as possible.

Support to caregivers

Care giver assessment is an important aspect of management. His wife was assessed to see whether she was coping well and if there was any evidence of stress or depression. She was educated regarding stress management strategies. In Sri Lanka the family looks after patients with dementia as there are very few residential and day facilities which take care of such patients. Patients living around Colombo can attend the day center of the Sri Lanka Alzheimer's Foundation. This provides a respite for caregivers. It is important that the whole family contributes to the management as often a single carer is burdened with the task of looking after such patients.

A family meeting was held with his two children and they were encouraged to provide respite for their mother during weekends.

Legal aspects

As long as individuals with dementia have legal capacity they should take part in decision making. However, with disease progression, they will lose their capacity. By giving power-of-attorney before losing capacity the patient can legally authorize others to act on their behalf when they no longer have capacity. Hence it is important to educate both patients and their families about these aspects during the early stage of the disease. Clinician also should assess and document the capacity at the time of decision making when necessary. Living wills are not valid in Sri Lanka.

Our patient's family was educated about the legal aspect and importance of assessing and recording his testamentary capacity before he transfers property.

Follow up

Patients should be followed up regularly. In Sri Lanka families may have difficulty bringing patients to the clinic. A family member can report the progress of the patient but once stable the patient should be seen at least 6 monthly. Cognitive tests should be repeated; initially 3-4 months after initiation of cognitive enhancers and then 6 to 12 monthly. Documentation and maintaining appropriate clinical records are important for future reference.

Pitfalls in prescribing for the elderly with dementia

Dr Madhavi Fonseka and Prof Shehan Williams

Prescribing medicines for elderly people with dementia can be a double edged sword. The pharmacokinetics and pharmacodynamics of most drugs are altered in the elderly leading to higher drug induced problems in general (Royal College of Physicians 1997). These changes in drug handling and actions must be taken into account if treatment is to be effective in the elderly and also to minimize the adverse effects. Those with dementia also have concurrent medical illnesses in most instances. The inadvertent poly pharmacy often due to the involvement of multiple specialists is often detrimental to the patient and leads to iatrogenic complications.

Use of cognitive enhancers

In the management of cognitive symptoms in dementia, acetylcholine esterase inhibitors (AChEI - Donepezil, Rivastigmine and Galantamine) and NMDA receptor antagonist (Memantine) have evidence as cognitive enhancers. Donepezil, Rivastigmine and Memantine are available and used in the Sri Lankan setting. However these are not without risks. Excess cholinergic stimulation can lead to gastrointestinal symptoms and dizziness. These usually occur at the beginning and are dose related and transient. Gastrointestinal symptoms appear to be highest with oral Rivastigmine and this can be minimized when taken with food. Slower titration (minimum interval of one month for Donepezil) will also help increase the tolerability of AChEI. Overall, Donepezil seems to have a lesser side effect profile.

AChEI have a vagotonic effect that can cause bradycardia. Therefore, they have to be used with caution in patients with cardiac conduction disturbances and with concomitant use of medicines that reduce heart rate. A pretreatment mandatory ECG has been recommended in some centers. But a review of the recent literature has showed that the incidence of cardiovascular risk is low and that serious side effects are rare.

With regard to the drug interactions Rivastigmine appears to have the least issues when compared to other AChEIs and therefore may be preferred in patients on multiple medicines.

Compared to AChEI, the side effect profile of Memantine is less. It mainly consists of somnolence, dizziness, and headache and altered liver functions.

Treatment of behavioural and psychological symptoms of dementia (BPSD)

The pharmacological management of BPSD can be very challenging. BPSD symptoms range from sleep disturbance, wandering, agitation, aggression and depression to overt psychosis with delusions and hallucinations. These symptoms are extremely distressing to the patient and to the family. They perhaps cause the most difficulty to the care givers. Physicians are under immense pressure to control these symptoms quickly and therefore prescribe antipsychotics and benzodiazepines in high doses. The guidelines however decree that non-emergency antipsychotic medication should only be used for the treatment of agitation or psychosis in patients with dementia when symptoms are severe; are dangerous; and/or cause significant distress to the patient. According to American Psychiatry Association guidelines, if there is no improvement after one month of antipsychotics it should be tailed off and stopped. If the patient has responded, one should consider tailing off the medication after four months, weighing the risks and benefits as there is increased morbidity and mortality with antipsychotic medication. Furthermore, one has to be extremely cautious in prescribing antipsychotics to patients with Lewy body dementia as it can cause irreversible Parkinsonism, cognitive decline and death due to extreme neuroleptic sensitivity.

Benzodiazepines are best avoided for older people with dementia because these drugs are associated with well-documented harms, including fall-related injuries such as fractures and cognitive worsening. Despite the evidence strongly discouraging benzodiazepines in patients with dementia, it remains a drug that is widely prescribed for BPSD.

Co-morbid medical conditions

Precautions need to be taken when prescribing medicines for physical conditions in dementia patients. They are more susceptible to cognitive side effects which will be mediated via cholinergic, histaminergic and opioid pathways. Drugs with anticholinergic effects will cause cognitive impairment, sedation, delirium and falls which are more prevalent in patients with dementia. Medication with high anticholinergic burden such as Benzhexol, Promethazine and Chlorphenamine are best avoided. The risk of hypotension should always be considered when prescribing anti-hypertensives and often paediatric starting doses may have to be used. For the management of pain, Paracetamol is recommended rather than opioid analgesics.

Conclusion

The key to prescribing in the elderly is to have a patient centered approach as opposed to a disease centered approach. Evidence based use of safe medicine, rational polypharmacy, medicine optimization and de-prescribing where indicated, should be embraced to ensure better quality of life for persons with dementia.

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Nursing and care provision for a person with dementia

Ms Kalpani Abhayasinghe

Dementia and caregivers

Dementia is one of the major global public health challenges at present. It has an impact on the lives of the people with dementia, formal (professional caregivers) and informal (family members, friends, neighbours) caregivers as well as the society in general. Over a hundred and fifteen million people worldwide were reported to be living with dementia and it is estimated that formal and informal dementia care worldwide costs over 600 billion dollars annually (World Health Organization, 2015). Whilst care giving for a person with dementia may bring personal gains, psychological satisfaction and sense of accomplishment of duty or responsibility dementia caregivers also face many challenges in relation to unfulfilled psychological, physical, social or financial needs that is relevant to caregiving.

Importance of understanding what it is like to have dementia

Relationships and social environment of a person are central to one's life, regardless of age or mental ability. Living with dementia may have a huge emotional, social, psychological and practical impact on a person. People with dementia experience memory difficulties and problems with thinking which may lead to loss of self-esteem, confidence, independence, social roles and relationships. They are no more capable to carry out favourite activities or hobbies, or everyday skills of daily life.

Dementia patients need round-the-clock support & care, best provided in the comfort of their own home. The most important concept in dementia care giving is empathy and understanding. As caregivers what we need to try and understand is how the person might think and feel, as that can affect their behaviour and empathize about how dysfunctional their cognition can be at times. With their memory loss the person with dementia may experience the world differently, to the people around him. Therefore it is important that the caregiver try to see things from the perspective of the person with dementia, as far as possible.

People with dementia may require long term care, perhaps even in the form of individualized care as the disease progresses. Formal and informal dementia care worldwide costs a staggering 600 billion dollars, thus suggesting a strong

need for all countries to develop national strategies to effectively care for dementia. Managing nutrition and hydration of the patient, attending activities of daily living, pain management, communication and psychological aspects of caring, quality of life and wellbeing of both the patient and caregiver are equally important concerns when providing care for a person with dementia.

Dementia care giving is usually a huge challenge to caregivers. In Sri Lanka most of the care giving is carried out by the family members. It is encouraged a home based person-centered care for people with dementia as it can be an effective way of preventing and managing behavioural and psychological symptoms of dementia. This article intends to provide a practical guidance to those family caregivers who take pain to look after a person with dementia.

How to support a person with dementia?

- Nutrition and hydration

Dementia reduces a person's ability to live independently. However with the right support, they will be able to continue living at home for a long time. With their forgetfulness a person with dementia may stop recognising the hunger and thirst. They may also struggle to recognise the food in front of them, chew or swallow food, handle the plate or cup, use cutlery with their poor physical co-ordination. Further, behaviour problems can result in refusing meal even with help. These factors can result in a limited diet and affect with his nutrition and hydration of the person with dementia. On the contrary, rarely, patients may forget that they actually have taken meals and complain that they were not fed much to the embarrassment of the carer in front of visitors. The caregivers need to try tackling these issues, by making mealtimes enjoyable for the person and including foods that are high in energy and protein. They also must encourage adequate fluid intake. It is also important to be aware of any swallowing difficulties the person experience, additional nutrition requirements and eating and drinking aid if necessary.

Managing Nasogastric tube feeding and PEG feeding are controversial topics as on one hand they will prevent aspiration related complications but on the other hand they will be not tolerated or understood by the patient and may agonizingly prolong the suffering.

- Assist with activities of daily living

As dementia progresses, a person's concentration and co-ordination decreases and they need more help with day today activities. There will be many situations where the caregiver need to physically handle the person with dementia – for

example, to help them in and out of bed, dressing, bathing, going to toilet, or perhaps to lift them up if they have fallen.

A dementia patient might lose recognition of the importance of personal hygiene, forgetting to get dressed. They often resist help because of desire for dignity and autonomy. It is important to note that toileting, washing and dressing are personal and private activities, so it can be hard for them to adjust with having someone help them with this. Personal hygiene is very important especially the patient having difficulties with mobility and incontinence. It can also be challenging for the caregiver to adjust to this level of caring, especially with the relationship to dementia patient, caregivers' age and gender differences. It is helpful to assist them in a positive and open-minded way.

If the person with dementia develops mobility problems, they may benefit from using a wheelchair. As the dementia progresses patients are more at risk of being involved in accidents at home, particularly as the dementia progresses. It's worth taking simple steps to help the person with dementia to navigate their home more easily and safely but try not to make major changes overnight, as this can be alarming or upsetting to the person with dementia. Passive exercises are also important in order to keep them active, reduce co morbidities and to maintain skin integrity.

- Communication

Dementia affects communication of the person to a large extent. Difficulties with communication may cause the dementia patients to lose confidence, self-esteem and ultimately withdraw from social situations. This can be frustrating. It also increases the caregiver burden and stress. If the person finds verbal communication difficult following steps can be utilized to improve the situation. Speaking slowly using simple words and sentences, understanding their behaviour and body language to communicate, (such as gestures, eye contact and facial expressions) are useful techniques. Try to avoid sudden movements and tense facial expressions, as these may cause upset or distress and do not stand too close or stand over the patient when communicating. It may make them feel intimidated. Caregivers may need to listen to the person and give them plenty of time to encourage communication and also to understand the meaning they are trying to convey. The message may be about feelings, not just facts. Non-verbal communication is much helpful to understand their pain and physical needs. Too many open ended questions must be avoided and consider giving the person options of answering questions with a yes or no answer.

- Independence and decision making

A person with dementia may gradually lose their independence and become more reliant on care and support of others around them. At the same time, they often resist the support, get irritable, and may also cause conflicts when caregiver makes the decisions on behalf of them. It is necessary that caregiver facilitate the person to do things for him rather than 'taking over'. People with dementia should be supported to make decisions for them for as long as they can (Mental Capacity Act, 2005). This increases the person's wellbeing and helps to maintain their dignity, confidence and self-esteem, without making them feel helpless or worthless. However, it is necessary to balance the independence of the individual against any safety concerns. It is recommended to do things together rather than 'for them' when offering assistance and focus on things the person can do, rather than those they can't. Caregivers need to be patient, allow plenty of time for tasks and offer reassurance, praise and encourage the patients. Breaking down tasks into smaller, more manageable steps and do things that the person can enjoy is more meaningful.

- Emotions and feelings

People with dementia often have less control over expressing their feelings and emotional responses. They get agitated, tearful, overreacting or may appear unusually unenthusiastic in things. These changes are often hard to predict and difficult for carers to deal with. Even in such situations try and avoid harsh criticism or belittling comments. If a patient makes a mistake, try to be as supportive as possible, and try to understand how the person with dementia feels. Though they may be cognitively unsound, one should not dismiss their worries. Look beyond the words whilst listening and showing them empathy is the essential component when providing care for dementia. Strong emotions may also be caused by unmet needs. Try to work out what these needs are and meet them where possible.

Caregivers also can help a person with dementia to feel valued and included by supporting existing relationships and encouraging continued participation in social groups, community activities, religious activities and hobbies. It is important to create a dementia-friendly community in which local people have an understanding of dementia. Caregivers need to have the relevant experience to care for their needs, and support should be sensitive to the person as an individual to guarantee that people with dementia are independent, happy, healthy, and enjoy the life that they deserve for as long as possible.

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Speech and Language Therapy Intervention in Dementia

Ms Saumya Rathnayake

Dementia is a term which describes a set of symptoms, including impairment in memory, mood, cognition, communication, and reasoning and can cause many difficulties in activities of daily living. The World Health Organization's ICD-10 (2010) definition of dementia includes: "disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment". Prevalence of dementia is around 46.8 million worldwide and over 9.9 million new cases of dementia are diagnosed each year worldwide according to the statistics of World Alzheimer Report. Interestingly, 58% percent of people with dementia live in low and middle-income countries, and scientists predict this will be increased to 68% by 2050. Identifying necessary interventional strategies to assist this population is vital, and this article will briefly explain management strategies used by speech and language therapists (SALTs) to improve both communication and swallowing functions of people with dementia.

Types of Dementia and associated communication difficulties

There are over 100 different forms of dementia (WHO, 2010). Speech and Language therapists commonly work with cortical dementias such as Alzheimer's disease and Fronto-Temporal Dementia (Pick's disease) which are associated significantly with language dysfunction. They may have neologisms and difficulties in recalling words.

The sub-cortical dementias such as progressive supra-nuclear palsy affect the motor aspects of speech, while linguistic abilities are preserved. Those clients will have issues with their articulation and prosody of speech. Many Parkinson patients will also manifest such difficulties although patients with post-traumatic encephalopathies and vascular dementias usually have dysarthria with varied language abnormalities. Incoherent verbal output with non-aphasic anomia may commonly be associated with dementia as a result in metabolic encephalopathy. In speech and language therapy dementias are categorized into mild, moderate and severe phases and SALTs specifically work with progressive language defects in dementia named as primary progressive aphasia.

The evidence-based practice of speech and language intervention in dementia

When treating a client with Dementia, Client's psychosocial history, work

and occupational history, environment and other relevant areas will also be analyzed prior to implementing treatment goals. Once the comprehensive analysis is made, the treatment goals are made in collaboration with patients and their families and other health professionals. American Speech and Hearing Association has outlined treatment principles based on WHO disability framework. Treatment will also involve in providing information and education about the patient's condition and current level of competency of the family. The SALTs will utilize strengths and work on weakness related to underlying structures and functions of communication and facilitate the individual's participation in daily activities via communication strategies.

Individualized treatment approaches

There are evidence-based treatment approaches available for an individual with dementia in speech and language therapy. However, these approaches should be analyzed carefully before implementing it in Sri Lankan context due to cultural and linguistic variations. The approaches can be divided as specific and general. Following are a few specific treatment options that had been developed to cater individualized treatment for people with dementia.

The following approaches were selected based on current practice in Sri Lanka. All selected approaches are used by SALTs in Sri Lanka with modification to suit to local context. Although there is no research driven evidence as to how each approach was conducted, empirical data reveals all these are feasible to use in the local setting.

Cognitive stimulating therapy in conversations (CST)

This approach is focused on developing theme-based (topic based) activities helping the person with dementia to be engaged and get involved in the optimal learning environment. This is usually done within a small group and generalized in a safe guided context. Swan et al, (2018) reviewed six studies based on CST which facilitates communication. Results summarized that direct treatment on cognitive training had shown positive outcomes in patient's communication but observed poor outcome in maintaining the achieved skills. This approach helps patient to recognize current topics and systematic method to recall information within the conversation while providing the opportunity to practice conversational skills.

Montessori-Based Treatment (MBT)

Montessori- Based treatment was developed using evidence from Maria Montessori which includes activities based on real-life materials when conducting activities. This involves creating an environment that supports sequenced learning through minimum failure. Each activity will be done in little

components to identify accomplishment in each task. A systematic review by Sheppard and his colleagues (2016) examined the effect of MBT in people with dementia that had been analyzed and results indicated improvement in lower-level cognitive abilities (memory, attention) where no improvement was seen in higher level functions (reasoning, planning).

Reality Orientation and communication (RO)

This approach is used to reduce confusion in orientation and helps clients to communicate issues relevant to the immediate context. Also, this allows clients to understand time, day, place, and person and reinforce the understating of the environment. Study results of O'Connell and Gardner (2007) showed RO had significant benefits in improving orientation and increase independence in dementia.

Reminiscence Therapy (RT)

Uses life history and experiences to initiate and establish conversations and typically this approach uses journals, autobiographies and family trees when facilitating the life stories. A study done with a group of clients to identify the effectiveness of RT was done by Kim et al (2006) and found that RT may contribute to improving cognitive functions.

Alternative and Augmentative Communication (AAC)

When a severe form of dementia presents they will be introduced to alternative methods of communication such as the use of picture books, computer devices or special communication boards. Some form of high tech methods such as “text to speech type apps” are also available. Roset et al, (2017) had done a study on the use of assistive technology to support memory impairment and results suggest that such devices positively impact the daily routine of the individual and helps in assisting many situations.

Communication Partner Training Approaches

Evidenced-based treatment guidelines to practice in speech therapy for people with dementia involves heavily in conducting communication partner training programs. All caregiver training provided support to the family to assist communication, each used a standard program that could be individualized and each provided a means to identify and solve implementation problems. Following is one such program which was used successfully in many contexts including in Sri Lanka. Ripich (1995) and Ripich, Whyke and Niles (1995) had developed this treatment approach and it is named “FOCUSED”.

The FOCUSED strategies included following areas:

F- Functional and Face to face communication

O- Orient to the topic

C- Concrete topics and continuity of the topic

U- Unstick any communication blocks (ignoring the communication blocks)

S- Structure with yes/no and choice questions,

E- Exchange information and encourage information

D- Direct simple and short phrases

After six weeks of two hourly training the effectiveness was measured and observed to have significant improvement (86%) in the use of questions and 87% inter-rater agreement was in communication strategies used by patients. Based on empirical data the above program had been implemented successfully within Sri Lanka.

General activities that can be used to stimulate communication function in people with dementia

When communicating with a person with dementia, it is important to be specific and clear about your feedback to the patient. For an example, communication partner should clearly inform the patient when he or she is non-coherent or uses irrelevant facts during conversation. When the patient is unable to recall words or express wrong words, it is best to help the individual by writing down the word than telling it verbally, because visual pathway is intact compared to auditory pathway in dementia. Further, use of nonverbal language such as gestures and facial expressions could also help with this group of patients as they could easily interpret visual input messages compared to verbal communication methods.

Swallowing impairment in Dementia

Ability to eat and drink is a complex mechanism that is controlled in many neurophysiological stages. However, when patients presented with a severe stage of dementia their ability to take food safely will be compromised due to cognitive impairments. According to the study by Gallagher, 2011 prevalence of dysphagia or swallowing difficulties among patients with dementia is 50% to 75%, and 50% of those patients were aspirating their food and one-third had developed pneumonia as a complication. Therefore managing dysphagia within this group is essential.

Early dysphagia in demential patients are presented similar to any other type

of dysphagia, with signs of aspiration such as cough, noisy swallow, watery eyes and wet voice quality after swallowing. However, many will have impairments in the pre-oral stage of the swallow as well. Some symptoms of pre-oral stage swallow difficulties are difficulty in judging the amount or bolus size of the food, recognizing the temperature of the food or texture of food and or timing the swallow.

A further consequence of dysphagia is that it leads to dehydration, malnutrition and weight loss if timely intervention was inadequate. Speech and Language therapist plays an important role in assessing and managing dysphagia within this group.

Managing dysphagia in Dementia

Management of dysphagia in any degenerative condition or cognitive impairment is done based on three basic principles, safety, nutrition and liquid intake. However, some of the clients in palliative care may receive “risk feeding options” aiming to facilitate quality of life. Diet modifications postural management and alternative feeding methods are used in managing clients when dysphagia is present in dementia. Apart from directly working with the patient, it’s essential to work with a caregiver when managing dysphagia.

Conclusion

Currently, in Sri Lanka there are over 200 qualified SALTs working in both government and private sector. All therapists are trained to work with people with dementia where managing dysphagia is recommended after they received a special clinical training. This article aims to explain how speech and language therapy intervention is used in people with dementia. Communication and dysphagia symptoms may present in dementia in different stages and it is vital to conduct holistic assessment to identify correct treatment approach to maximize the potentials of the individual to improve the quality of life.

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Occupational therapy to care for people with dementia

Mr Suranga Semasinghe

Dementia is an important cause of disability in elderly populations, and typically leads to impairments in the performance of activities of daily living (ADL). The performance of ADL is a key focus of the occupational therapy (OT) intervention process and therefore patients with dementia are commonly referred to OT for ADL screening and appropriate interventions. Besides considering ADL, occupational therapist also explores a patient's participation in enjoyed past-times, social, recreational and leisure activities.

ADL can be divided into two main forms, basic ADL (BADL), such as eating, drinking, bathing, dressing and grooming. Patients with dementia will frequently have problems with these types of BADL. Another form of ADL is known as Instrumental ADL (IADL) and includes more complex and demanding tasks such as shopping, cooking, driving, managing finances, telephone use and other everyday tasks. A wide range of underlying factors such as cognitive, motor, perceptual, mood changes, apathy, and even urinary incontinence, have an impact on ADL performance, and all these aspects of functioning are well recognized and have been studied within the dementia population.

An occupational therapist assesses ADL using various types of assessment. The first stage in the assessment process is to evaluate a patient's own personal priorities in terms of their BADL and IADL performance. The OT will then build on the patient's reported needs and concerns and support the patient to identify any additional, overlooked but important, ADL problems. The next step, ideally, is for an OT to observe motor and process skills, while the patient with dementia is performing BADL or IADL that they are having problems with and want, need, or are expected to do by others.

People with dementia need to see their environment clearly in order to understand directions and be able to use landmarks to help with way finding. It is widely recognized that the building he lives in and the environment can have a significant impact on a person with dementia. The environment can be supportive or it can hasten a person's deterioration.

People with dementia may misinterpret aspects of their environment such as reflections of shiny floors appearing slippery or wet, seeing shadows as objects, seeing objects as shadows, or being unable to distinguish small objects or detail on large objects. These misinterpretations may lead to increased risk of falling, increased dependency on others and lowered life expectancy. Features such as seating, flooring and wall coverings, Lighting and handrails often pose barriers

to people living with dementia.

Excess noise, glare or sensory overload may result in agitation or frequent problem behaviours. Environmental design has a major impact on wellbeing, problem behaviours such as wandering or agitation, activity levels, independence and nutrition.

The following are some examples of how environment can be positively adapted by the OT team in view of making everyday life easier to dementia patient.

Use of colour

Older adults experience difficulty with distinguishing colours. Ageing causes colours to be seen through a yellowing film and it is thought that yellow is the last colour perception to be lost by people with dementia. Colour depth and brightness appear different under different lights. Visual cues can be utilized to aid orientation and maximize a person's function. It is best to use colours from different spectrums. There is a higher incidence of cataracts in older persons, which can also change colour and perception of the environment. Some tips for usage of colour in managing dementia can be as follows.

Remove bold/busy patterns on wallpaper, curtains or floor covering as patterns in carpet can be interpreted as holes, steps etc. It is better to use contrasting colours for walls and doorways to highlight boundaries of each room and colour contrast should be used between furniture and floor, chair seats and table tops and counters, sinks and floors. Using matte paint instead of gloss to reduce glare is recommended. Colour can also be used to highlight or disguise key locations around the home.

Adapting to Stairways

It is advised to paint or glue a narrow contrasting strip on the edge of each step and paint the wall of the stairs in a well contrasting colour. Make sure to keep the stairs illuminated at all times. Installing handrails, securing loose floor coverings, keeping stairways clutter free and utilizing safety gates where applicable are recommended.

Garages, sheds, courtyards

It is needless to say to keep pathways levelled, lit, non-slip with contrasting edges, visible both day and night. Make sure to remove flammable or potentially dangerous items and to remove external locks to ensure the person cannot accidentally lock themselves in. Keeping well fenced courtyard with clearly visible "stop" signs at the boundaries may well be adequate to keep the patient orientated to his yard. The gates may need to be kept secured.

Bathroom

Suitable aids or appliances to assist with bathing e.g., shower chair, grab rails, long handled aids should be installed and ensure adequate lighting is available. The flooring should be made of minimally slippery material and install window coverings to eliminate glare in bathroom. Paint the bathroom door with a bright eye catching colour and you may have to modify doorways for increased accessibility. Install bells or alarms on doors, cabinets and drawers to alert carers remove or change lock on bathroom door. Potentially hazardous items such as bath tubs, electric items may need revision by the OT.

Kitchen and Dining Area

Installing locks on kitchen cupboards and shut off switches on electric or gas lines is an advisable thing to do when a patient with dementia is around. Pasting signs on cupboards or replacing panes with transparent doors to allow easy viewing of contents can be useful. Arranging everyday items in an easily accessible manner can make life easier for the patient.

A diagnosis of dementia does not automatically mean that the person is immediately incapable of caring for themselves. The type of support needed depends on the individual situation, circumstances and their preferences. It may be possible for more family members to become involved in different aspects of the persons' care. If this is not a possibility or if extra assistance is required then community support will be required.

Organized Social Services: An essential need for elderly with dementia in Sri Lanka

Dr Padma S Gunaratne

Dementia is a long-standing neuro-degenerative condition generally observed among elderly. They require assistance of well-organized health care and social services long term. Prevalence of dementia in Sri Lanka is estimated to be approximately 3.8% of the population. This figure is likely to rise further over next several decades along with the exponentially rising elderly population owing to longevity. According to world Alzheimer's Report from the Global Voice on Dementia, less than 50% of patients are given the formal diagnosis of dementia even in developed countries. This figure is estimated to be around 10% in low income countries like Sri Lanka. This is mainly due to lack of diagnostic expertise. In this context, it is essential that we do not miss early presentations of dementia so that the patients could be directed to correct channels of care early. With increasing awareness of rising prevalence, authorities can be lobbied to fortify social services which will be a very timely requirement. This we owe to our patients, as gratitude for their services in the past, to our society.

“Dementia is just forgetfulness”- is a misconception. Memory problems are certainly a component of dementia, but communication, emotional, and behavioral problems are also present more often than not. Problems with language and communication issues are early indicators for many dementia patients. Inability to remember correct words, using wrong words, and not being able to understand other's words are commonly observed in early stages. They may misunderstand and misinterpret simple incidents leading to family problems amongst the loved ones. This will lead to anger, frustration, and depression. As the disease advances, they may only use a set of words that they use regularly, and finally end up with the inability to express their thoughts verbally at all.

Navigation problems and wandering are other common symptoms seen in advanced stages of dementia. Patients may find it difficult to find their way and to attend to their regular activities even in their familiar environment and places of work without being assisted. Being unable to drive in familiar areas, getting lost in your own town, struggling with maps can be very subtle signs in early dementia. In some of the occasions, patients in advanced stages would go astray and encounter falls and accidents in unfamiliar environments, causing worry, grief and guilt for relatives and loved ones.

Furthermore, patients develop behavioural problems and lack of understanding with regard to what is socially acceptable and unacceptable. These disinhibitive behaviours, particularly in undiagnosed patients, may cause severe embarrassment and frustration to their immediate family members.

It is common to attribute symptoms of Dementia as part of aging and this may lead to delay or not arriving at the diagnosis altogether. Elderly with Dementia often co-suffer frailty and multiple medical morbidities. These confounding factors can make it even more difficult to access standard health care. More must be done to help these people to optimize their physical health, maintain their nutrition and hydration, and reduce their risks of falls, accidents, infections, and delirium.

There is evidence that specialist based care for dementia is neither practical nor sustainable in large scale, particularly for developing countries but strengthening primary care to support dementia patients, is quite effective. Therefore, there is a need to strengthen primary health care to absorb the responsibility of taking care of dementia patients. Organizing education programs for primary health care professionals, incorporating dementia care to undergraduate and post graduate education syllabuses and arranging patient based multidisciplinary team meetings are of immense value on this regard.

There is no specific treatment to reverse the symptoms or to arrest the progression of the symptoms for the majority of dementia patients. Given the long-standing course of illness, providing care for dementia is exhausting and distressing for care givers and exuberantly expensive for health care systems. In today's context, where extended family support is disappearing, for a family where both spouses work, either, one person will be forced to give up his/her job or to hire a nurse at a significant expense to give care for the demential patient. In Sri Lanka many problems of dementia patients including these family issues could be supported by well-organized social care services guided by the Ministry of Social Services with the aid of many willing Non-Governmental Organizations. While providing standard health care for patients, organized social services are likely to comfort the patient and ease the burden to caregivers and to the health services in general in the country. From here, this article tries to summarize the types of social services required for dementia patients.

Organized Social services could help dementia patients in many ways. For an organized system, strengthening social services with an adequate number of social service officers who could be allocated to identify and to improve care for dementia patients would be valuable. They should know and have statistics about all dementia patients in their region and should raise alert to the care

givers to have regular, periodic assessments through medical facilities as the needs continue to change with gradual progression of the illness. At the end of each medical and therapist assessment, based on it the social service officer should be able to give them a social care plan based on the disability, financial status, and social status of the patient. The wishes of the patient and the relatives should also be considered when creating the care plan.

The social service officer should ensure that the patient is safe in his/her own environment. The required adaptations should be provided and carers should be advised to make the patient independent and safe in their own environment for as long as possible. For example, not changing their familiar surroundings, ensuring that the pathways are always well lit, making sure that their room displays a readily visible clock and a calendar and ticking off days on it, supply of daily news paper can be hopeful attempts to fight their declining cognition in the early stages. Not keeping the gates open ajar and keeping the neighbours and the local police informed about the patients' condition could be preparatory steps in the unfortunate event he wanders off. The services of occupational therapists should be sought in making the required decisions. Assistance of volunteer groups in the region could be used to facilitate implementation of certain decisions in relation to the region.

Frailty and malnutrition is common along with infections and delirium in dementia patients. They may need special nutrition, and frequent visits for medical treatment. As such, free access to these basic facilities such as free ambulance services and including concessions for supplementary food should be available for them. . There should be assistance to attend their basic needs of daily living such as washing and grocery shopping, and also to get admission to institutions for long term care when it is no longer safe for the patients to live in their own home environment. These institutional facilities should be made available for both fee levy groups and fee free for deprived community in a self-sustainable manner.

It is a not an uncommon occurrence to come across old parents abandoned or abused by their guardian in our own communities. The majority of these parents are with undiagnosed dementia and care givers are usually ignorant of the existence of such diagnosis and exhausted in providing care for their patient. Worsening matters, the community pressure as neighbours accuse them of abusing their elderly could be a double edged sword and could further spiral down the patient-carer relationship. Even if it is possible for many families to take care of the patient with milder symptoms initially, as the illness progresses, it becomes extremely difficult and expensive to give care . Therefore, it is a basic need to have few institutions dotting the country that

can accommodate dementia patients either free or at an affordable payment. Respite care is another important service that should be available for Dementia patients. Respite care is replacement care which is short-term and has been planned in advance. As mentioned previously, giving care for a Dementia patient is physically and emotionally exhausting for the care giver and can lead to depression and burnout of carer, eventually. Rightfully, there will be occasions where the care giver will wish to leave the patient under the care of someone else for a short period for a break or to attend another important matter. In a well-organized social care service, it is essential to make respite care available for both paid and unpaid streams. The same respite care service such as day care services could be used for patients with other disease entities as well.

Further to all above, amending legislation of the country regarding providing standard care, ensuring rights and preventing abuse of demential patients also will become a relevant topic in near future as in the developed world.

As she was fading away - a doctor's personal experience in caring for her mother with dementia

Dr Tamara Jayanetti

On Women's day 2008, just before midnight, I woke up as the telephone was ringing. My father was at the other end. He said "Duwa, Amma woke up from sleep and finds it difficult to breathe." Since it was an emergency, my husband and I rushed to my parents' residence. My mother was in acute heart failure, probably after a myocardial infarct. She was admitted to CCU and with prompt management, was better by the following morning and recovered gradually.

Again in June she had another episode of acute heart failure from which she recovered after admission to CCU.

My parents aged 82 and 77 years by 2008, have been living in their residence without domestic aid until my mother's first episode of heart failure. Therefore I persuaded them to stay with me as it was not safe for them to live alone.

At the end of the year we moved to our newly built house, with parents. After a few days, my mother had asked my father, "Why are we staying in a 'guest house' without going home?" Gradually my mother started talking about her mother who had died 32 years back. She asked, "Where is my mother? I want to see her." When we said she was dead and gone, my mother used to weep saying, "I didn't know, why you didn't tell me?" Almost every day, sometimes few times a day, she inquired about her mother from everybody at home. Next, she started to write letters to her mother and posted those to the address of her parents' original residence. Then we decided to lie saying that grandmother was sleeping upstairs whenever she inquired.

When her cousins visited, she used to ask the same questions over and over. She became very suspicious about the man-servant we had and frequently complained that he had stolen her jewelry. We realized that she had short term memory loss. The other thing we noticed was that she ate only a very little amount and was never hungry.

As the time passed, we noticed that her forgetfulness was progressing and decided to consult a psychiatrist who started her on medication for dementia. With treatment, the disease progression became slower.

My father was a very good companion throughout and looked after her very well. Three years later, when my father passed away, she denied that it was her husband. Instead, she cried that her father had passed away. Gradually she started to need help for washing, bathing, dressing and feeding.

As the only daughter, it was my duty to look after my parents who brought me up with such love and care and also helped me look after my children. My husband and children were very supportive and helped me all the time.

But at the same time, it was exhausting to do the cooking for the family plus taking care of a demented mother who needed lots of time and patience, while doing a full-time consultant job with on-call duties. I managed to get an assistant from a nursing agency for the day time. Luckily my mother enjoyed an uninterrupted sleep after dinner.

With time, she gradually lost her appetite for food altogether and it was a constant struggle feeding her. She used to call me 'akka' and my husband, 'ayya'. Initially she listened to me (akka) but subsequently she became very stubborn, especially during meals and I had to shout at her many a time which I regret to date. Sometimes when I could not persuade her to eat, I had to seek assistance from my husband or children. Some days she totally refused meals and was on liquids only.

She used to get constipated despite laxatives given and I had to manually evacuate, during which she started screaming. Although she was very thin and emaciated, she had enough strength to resist. Somehow the assistant managed to brush her teeth, bathe her daily, apply moisturizer and keep her clean.

It is always better to keep a full-time caregiver because an elderly patient with dementia needs attention and companionship. As my mother was an English teacher, I advised the caregiver to learn some English from her and bring a workbook along with her. Interestingly, mother enjoyed teaching her and had a good command of language until late in her illness. Mostly she lived in the past and wanted to go home to her residence 'after school' but strangely, she completely forgot about Father, who was her life partner for 54 years.

Most of the evenings, I used to chant 'Pirith' with her after offering 'Buddha pooja' but with time she lost interest in them.

Giving proper care to an elderly with dementia is quite costly -paying a caregiver, providing a special high calorie-high protein diet, medication, wheel chair, diapers, etc. Since I was financially stable and my mother had her pension, it was manageable. As a family we were unable to go on a holiday, local or overseas, even for a few days since 2008. My husband and children had been very supportive and understanding during this difficult period.

Eventually my mother lost the control of bladder and bowel continence. The assistant and I somehow managed without diapers by regularly taking her to the washroom. She gradually deteriorated and passed away very peacefully, over 8 years of battling dementia, at the age of 85 years.

Even though it was exhausting and required so much commitment, in the end, as I look back, I feel an immense happiness in being able to provide my dear mother with the best care possible.

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