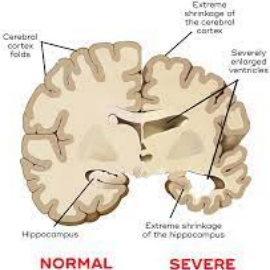


DEMENTIA STANDARD OPERATING PROTOCOL FOR OCCUPATIONAL THERAPISTS (OT)

Compiled by A. Camp and S. Birkhead for the Occupational Therapy Association of South Africa, March 2024

Note: This protocol should be read in conjunction with Occupational Therapy Standards of Practice document to comply with professional standards and facility-specific protocols.

INTRODUCTION	DEFINITIONS
 <p>The diagram illustrates the difference between a normal brain and a brain affected by severe dementia. On the left, labeled 'NORMAL', the brain shows well-defined cerebral cortex folds and a healthy hippocampus. On the right, labeled 'SEVERE', the brain shows extreme shrinkage of the cerebral cortex, severely enlarged ventricles, and extreme shrinkage of the hippocampus.</p>	<p>Dementia is the umbrella term for a number of neurological conditions, of which the major symptom is the decline in brain function due to physical changes in the brain. Dementia is categorised as a Neurocognitive Disorder (NCD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). It is a progressive disease and is not curable, though in some types/causes, it is not a terminal disease. The NCD category encompasses the group of disorders that the primary clinical deficit is in cognitive function, which is acquired rather than developmental. Impairment may occur in attention, planning, inhibition, learning, memory, language, visual perception, spatial skills, social skills or other cognitive functions.</p>
	DSM-5
<p>MINOR</p>	<p>A minor neurocognitive disorder referred to as <i>Prodromal Disease or Mild Cognitive Disorder (MCI)</i> and is defined by the following criteria:</p> <ul style="list-style-type: none"> evidence of modest cognitive decline from a previous level of performance in one or more of the domains listed below, based on the concerns of the individual, a knowledgeable informant or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of one and two standard deviations below appropriate norms (i.e. between the third and sixteenth percentiles) on formal testing or equivalent clinical evaluation.

<p>MAJOR</p>	<ul style="list-style-type: none"> • The cognitive deficits are insufficient to interfere with independence (for example instrumental activities of daily living such as complex tasks such as paying bills or managing medications, are preserved), but greater effort, compensatory strategies, or accommodation may be required to maintain independence. • The cognitive deficits do not occur exclusively in the context of a delirium. • The cognitive deficits are not primarily attributable to another mental disorder (for example major depressive disorder and schizophrenia). <p>A major neurocognitive disorder is defined by the following:</p> <ul style="list-style-type: none"> • There is evidence of substantial cognitive decline from a previous level of performance in one or more of the domains listed below, based on the concerns of the individual, a knowledgeable informant, or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of two or more standard deviations below appropriate norms (i.e. below the third percentile) on formal testing or equivalent clinical evaluation. • The cognitive deficits are sufficient to interfere with independence (i.e. requiring minimal assistance with instrumental activities of daily living). • The cognitive deficits do not occur exclusively in the context of a delirium. • The cognitive deficits are not primarily attributable to another mental disorder (for example major depressive disorder and schizophrenia).
<p>SIX AFFECTED DOMAINS ACCORDING TO THE DSM 5</p>	<ul style="list-style-type: none"> • Complex attention - involves sustained attention, divided attention, selective attention and information processing speed

Warning signs - Patient has increased difficulty in environments with multiple stimuli (TV, radio, conversation). Has difficulty holding new information in mind (recalling phone numbers or addresses just given or reporting what was just said)

- **Executive ability** - involves planning, decision making, working memory, responding to feedback, error correction, overriding habits and mental flexibility

Warning signs - Patient is unable to perform both familiar and complex tasks and projects (at work and at home). Needs to rely on others to plan instrumental activities of daily living or make decisions. Has problems with abstract thinking, displays loss of initiative as well as poor/decreased judgement

- **Learning and memory** - involves immediate memory, recent memory (free recall, cued recall and recognition memory) and long term memory

Warning signs - Patient repeats self in conversation, often with the same conversation. Cannot keep track of short list of items when shopping or of plans for the day. Requires frequent reminders to orient task at hand, confusion about time and place, and repetitive behaviour

- **Language** - involves expressive language (naming, fluency, grammar and syntax) and receptive language
Warning signs - Patient has significant difficulties with expressive or receptive language. Often uses general terms such as 'that thing' and 'you know what I mean'. With severe impairment may not recall names of closer friends and family

- **Perceptual - Motor** - Visual perception, praxis- involves picking up the telephone, handwriting, using a fork/spoon

Warning signs - Patient has significant difficulties with previously familiar activities (using tools or, driving a motor vehicle) and navigating in familiar environments

	<ul style="list-style-type: none"> • Social cognition - involves recognition of emotions and behavioural regulation, social appropriateness in terms of dress, grooming and topics of conversation <p><i>Warning signs - Patient may have changes in behaviour (shows insensitivity to social standards, or make decisions without regard to safety). Patient usually has little insight into these changes. Becomes socially withdrawn or isolated</i></p> <p>Reference: American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, DC, American Psychiatric Association, 2000.</p>
SYMPTOMS	Symptoms will vary according to the type of dementia. Dementia symptoms may include problems with:
	<ul style="list-style-type: none"> • memory loss • thinking speed • mental sharpness and quickness • language, such as using words incorrectly, or trouble speaking. • understanding • judgement • mood • movement • difficulties doing daily activities. <p>People with dementia can lose interest in their usual activities, and may have <u>problems managing their behaviour or emotions</u>. They may also find social situations difficult and lose interest in <u>relationships and socialising</u>. Aspects of their personality may change, and they may lose empathy (understanding and compassion).</p>

	<p>A person with dementia may see or hear things that other people do not (<u>hallucinations and hearing voices</u>). Because people with dementia may lose the ability to remember events, or not fully understand their environment or situations, it can seem as if they're not telling the truth or are wilfully ignoring problems. As dementia affects a person's mental abilities, they may find planning and organising difficult. <u>Maintaining their independence</u> may also become a problem. A person with dementia will usually need help from friends or relatives, including help with making decisions. The symptoms of dementia usually become worse over time. In the late stage of dementia, people will not be able to take care of themselves and may lose their ability to communicate.</p>
<p>Classification of Dementia ICD 11</p>	<p><i>Dementia</i> includes the following categories:</p> <ul style="list-style-type: none"> • 6D80 Dementia Due to Alzheimer Disease <ul style="list-style-type: none"> ○ 6D80.0 Dementia Due to Alzheimer Disease with Early Onset ○ 6D80.1 Dementia Due to Alzheimer Disease with Late Onset ○ 6D80.2 Alzheimer Disease Dementia, Mixed Type, with Cerebrovascular Disease ○ 6D80.3 Alzheimer Disease Dementia, Mixed Type, with Other Nonvascular Aetiologies ○ 6D80.Z Dementia Due to Alzheimer Disease, Onset Unknown or Unspecified • 6D81 Dementia Due to Cerebrovascular Disease • 6D82 Dementia Due to Lewy Body Disease • 6D83 Frontotemporal Dementia • 6D84 Dementia Due to Psychoactive Substances Including Medications <ul style="list-style-type: none"> ○ 6D84.0 Dementia Due to Use of Alcohol

- 6D84.1 Dementia Due to Use of Sedatives, Hypnotic or Anxiolytics
- 6D84.2 Dementia Due to Use of Volatile Inhalants
- 6D84.Y Dementia Due to Other Specified Psychoactive Substance
- 6D85 Dementia Due to Diseases Classified Elsewhere
 - 6D85.0 Dementia Due to Parkinson Disease
 - 6D85.1 Dementia Due to Huntington Disease
 - 6D85.2 Dementia Due to Exposure to Heavy Metals and Other Toxins
 - 6D85.3 Dementia Due to Human Immunodeficiency Virus
 - 6D85.4 Dementia Due to Multiple Sclerosis
 - 6D85.5 Dementia Due to Prion Disease
 - 6D85.6 Dementia Due to Normal Pressure Hydrocephalus
 - 6D85.7 Dementia Due to Injury to the Head
 - 6D85.8 Dementia Due to Pellagra
 - 6D85.9 Dementia Due to Down Syndrome
 - 6D85.Y Dementia Due to Other Specified Diseases Classified Elsewhere
- 6D8Y Dementia, Other Specified Cause
- 6D8Z Dementia, Unknown or Unspecified Cause

Each of the above Dementia categories may be described as Mild, Moderate, or Severe. The general CDDR for Dementia also provide guidance on applying each level of the severity specifier.

- XS5W Mild
- XS0T Moderate
- XS25 Severe

Specifiers are also provided for Behavioural or Psychological Disturbances in Dementia that may be used when these are severe enough to represent a focus of clinical intervention. These specifiers are also described below as part of the general CDDR for Dementia. As many Behavioural or Psychological Disturbances specifiers may be applied as necessary to describe the current clinical picture. These specifiers may be applied to all Dementia categories. They include:

- 6D86.0 Psychotic Symptoms in Dementia
- 6D86.1 Mood Symptoms in Dementia
- 6D86.2 Anxiety Symptoms in Dementia
- 6D86.3 Apathy in Dementia
- 6D86.4 Agitation or Aggression in Dementia
- 6D86.5 Disinhibition in Dementia
- 6D86.6 Wandering in Dementia
- 6D86.Y Other Specified Behavioural or Psychological Disturbances in Dementia
- 6D86.Z Behavioural or Psychological Disturbances in Dementia, Unspecified

ANATOMY/ PATHOPHYSIOLOGY	<p>Dementias are often grouped by what they have in common. Dementias are progressive.</p> <ul style="list-style-type: none">• Alzheimer's disease: This is the most common cause of dementia. Progressively worsening mental condition. Usually starts with memory loss, language difficulties, poor planning with ADLs, diminishing visual perception, changes in mood, decreased executive function, withdrawal from social interaction. There are different forms of Alzheimer's disease e.g. Young onset Alzheimer's which affects people under the age of 65 (Some even in their 20s and 30s).• Vascular dementia: The most common symptoms of vascular dementia include problems with language (word finding), problem-solving, slowed thinking, and loss of focus and organization. These tend to be more noticeable than memory loss.• Lewy body dementia: Common symptoms include decreased balance, senile tremor, blunted facial features, acting out dreams in sleep and visual hallucinations. Symptoms also include problems with focus and attention.• Frontotemporal lobar degeneration/ dementia: These areas are associated with personality, behaviour and language. Common symptoms affect behaviour, personality, thinking, judgment, language and movement.• Mixed dementia: Patients with mixed dementia can have Alzheimer's disease, vascular dementia and Lewy body dementia.• Parkinson's disease. A percentage of people with Parkinson's disease eventually develop dementia symptoms. When this happens, it's known as Parkinson's disease dementia.
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	<ul style="list-style-type: none"> • HIV-associated dementia. When the HIV virus reaches the brain and causes dementia, symptoms include loss of memory, difficulty thinking, concentrating or speaking clearly, lack of interest in activities and gradual loss of motor skills.
SCOPE OF DOCUMENT	This document pertains to the evidence informed practice for occupational therapists in the assessment and treatment of patients with dementia from mild to severe stages.
PROGRESSION (SEVERITY)	MILD/ EARLY (Stage 1 + 2 of 7 stages)
Mild, Moderate or Severe, according to the degree of neurocognitive and functional impairment, and capacity for independence in activities of daily living.	<p>Dementia is a progressive disease for most of the causes and there are different stage classifications e.g. Stage 1 of the 7-stage model (FAST) refers to no visible cognitive impairment – It can be 10-15 years before the obvious symptoms are noticed. This long period before diagnosis can also be due to denial or the mistaken cause being stress.</p> <p>Patients with Mild Dementia may be able to live independently, but some supervision and/or support is often required. Judgment and problem solving are typically impaired, but social judgment may be preserved. The individual may have difficulty making complex decisions, making plans, and/or handling finances (e.g., calculating change, paying accounts etc). At this stage there may be no medical intervention, and even when diagnosed, people will not present themselves at doctors, clinics, memory clinics or hospitals</p>
	MODERATE/ MIDDLE (Stage 3-5 of 7 stages)
	<p>Patients with Moderate Dementia require supports to function outside the home and only simple household tasks are maintained. They have difficulties with basic activities of daily living, such as dressing and personal hygiene. Moderate Dementia is often characterized by significant memory loss. Judgment and problem solving are typically significantly impaired, and social judgment is often compromised. The individual has increasing difficulty making complex or important decisions and is often easily confused. The individual may have difficulty communicating</p>

	with individuals outside the home without caregiver assistance. Socializing is increasingly difficult as the individual may behave inappropriately.
	SEVERE/ LATE (Stage 6-7 of 7 stages)
	Severe Dementia is typically characterised by severe memory impairment. There is often total disorientation for time and place. The individual is often completely unable to make judgments or solve problems. They may have difficulty understanding what is happening around them and are fully dependent on others for basic personal care in activities such as for bathing, toileting and feeding. Urinary and faecal incontinence may emerge at this stage.
Acute medical management	<ul style="list-style-type: none"> • Co-morbidities e.g. hip fracture/ diabetes/ delirium. • Obtain a baseline of all aspects affected (physical, cognitive, emotional, social, psychological etc.) <p>TESTS the doctors/ specialists use for dementia diagnosis.</p> <ul style="list-style-type: none"> • Brain Scans/PET scans; MRI; Laboratory tests; A variety of cognitive screening tests e.g. MMSE • Medications that can be prescribed in the Early stages of Alzheimer’s disease are mostly cholinesterase inhibitors These are used to address symptoms of the disease and are not a cure: • Donepezil (Mild - Severe stage); Galantamine (Mild – Moderate stage); Rivastigmine (Mild – Moderate stage); Memantine (Moderate – Severe stage) • Medications for sleep, depression and other symptoms may be prescribed but have different effects in the different types of dementia i.e. anti-psychotics, anti-depressants, anti-anxiolytics.
COMPLICATIONS FOR THERAPY	<ul style="list-style-type: none"> • Poor nutrition due to patients not being able to chew and swallow. • Dehydration can cause complications and lead to UTIs. • Aspiration Pneumonia due to trouble swallowing which increases the risk of choking and fluid build-up. Inability to perform self-care tasks, as the dementia gets worse.

	<ul style="list-style-type: none"> • Personal safety challenges in driving, cooking, mobility etc. • Infections that can lead to coma and death can occur in late-stage dementia.
<p>KEY FOCUS AREAS FOR OCCUPATIONAL THERAPY</p>	<ul style="list-style-type: none"> • Reducing behavioral problems (BPSD – Behavioural + Psychological symptoms of dementia) and give a sense of purpose. • Lessening the caregiver’s burden. • Reducing the overall amount of care needed <p>Further:</p> <ul style="list-style-type: none"> • Behaviour - social withdrawal; mood changes; Sleep quality. • Communication – verbal and non-verbal; simplify tasks; improve relationships between carers and patient • Memory – include reminiscence e.g. life stories and sharing memories • Cognitive – disorientation, poor judgement, other executive functions • Safety – risks e.g. falls, fire, lighting • ADLs – Retaining and encourage independence; adapting methods; Assistive devices • Emotion – depression, anxiety, agitation, irritability, lack of confidence • Physical impairments – gait, retardation, sensory, fine motor skills • Perceptual abilities – body awareness; visual and auditory; spatial • Education and support – patient and family; referrals to support groups and other professionals • Enabling the environment – adapting the home; retaining independence • Meaningful engagement – activity profile; work-life balance; stress management; leisure

Table1: Progression features relevant to occupational therapy (based on the disease stage – 3 stage model)

Component	Mild	Moderate	Severe
ADLs	Decreasing ability	Progressive	Progressive
Behavioural Psychological Symptoms (BPSD)	Apathy	Progressive e.g. agitation, anxiety, wandering, hallucinations	Progressive
Cognition	Decreases	Progressive	Progressive
Communication	Word finding, verbal sequencing, deflection, and confabulation	Perseveration, deflection, and confabulation by trying to make sense of a disordered world	Severely decreased synthesis and analysis of everyday information. Non-verbal in the severe stage
Emotion	Denial and blunting; Depression; Anger	Emotional instability ranging from increased instability to apathy and blunted	Catatonic
Memory	Numeric, problem solving affected	Progressive – short term memory increasingly impaired; some long term intact	Progressive – severe loss of short term and long term memory
Orientation	Time disorientation	Time and Place disorientation, and some person	Time, place and person disorientation
Perceptual	Visuo-perceptual difficulties, 3-D, colour contrasts	Visual and auditory hallucinations; sensory integration difficulties e.g. hyper or hyposensitivity; visuo-perceptual	Overall perception affected;

		difficulties e.g. figure ground, body awareness, position in space	
Social	Increased withdrawal from social situations	Isolation	House-bound
Physical factors	Loss of coordination, balance etc.	Progressive – walking deteriorates, poor fine motor dexterity	Progressive- usually bedridden and immobile
Safety	Still drive and work but may get lost;	Safety in the household, stove, electricity, fall risks, poor perception causes greater risks e.g. lighting	Mobility greater impaired and slips and falls, pressure care and positioning and in continue and basic hygiene's
Predictive variables	Finance confusion	Need support, supervision and care in all activities	Palliative and End of Life Care

The Occupational Therapist will

- facilitate the reintegration process and to help the person maintain a healthy physical, mental and emotional state for as long as possible. Family carers can play a vital role in a lot of this process e.g. encourage the person to join OT sessions if reluctant.
- improve Quality of Life in all categories e.g. Relaxation techniques, Physical exercise, Personal activities, Cognitive exercises and Recreational activities.
- teach other professionals to communicate effectively with people living with dementia and caregivers/ refer appropriately/ promote Quality of Life and
- maintain or improve health and wellbeing.

STAGES of OT intervention (Principles underpinning assessment and management.)

There is no acute stage in dementia, but when medical intervention occurs in the Early/Mild stage and a diagnosis is made, this is the point the OT can intervene. Factors OTs can consider for intervention:

- Activity Analysis and grading at all levels
- Patient and family
- Previous patient profile
- Added other ageing conditions and co-morbidities.
- Case management and appropriate referrals to other disciplines
- Sensory integration
- Environment modification
- Education, Assistive Devices and Palliative Care
- OT needs to educate self about local resources in area and respite care availability.
- Quality and routine of sleep (hallucinations, nightmare typical etc.) OT intervention
- Stress and burden of disease assessment and support for carers

ASSESSMENTS, SCREENING TOOLS and OUTCOME MEASURES used by OCCUPATIONAL THERAPISTS

COGNITIVE COMPONENTS
MMSE (MiniMental state exam)
MOCA (Montreal Cognitive assessment)
Rivermead Memory
FAST dementia scale
Kettle Test

FUNCTIONAL COMPONENTS
Modified Barthel Index
APOM Activity performance outcome measure
RUDAS
Barthel
Lawton ADL and IADL test
FIM (Functional Independence Measure)
FAM
VdTMoCA Levels
MENTAL COMPONENT
HAD (Hospital anxiety + depression scale)
Geriatric Depression Scale
QoL-AD
QoL-DEM
Beck Depression Inventory
Canadian Occ Performance Measure COPM
PHYSICAL COMPONENTS
Berg Balance, cerebellar coordination tests
6 minute walk test
Timed Up and Go test
Frailty score measure
PAIN
Abbey Pain Scale for Dementia (Non-verbal)
CAREGIVERS
Caregiver Scale

Caregiver strain index
RETURN TO WORK
COTNAB
WASP
SENSORY PROFILE
Adapted Sensory Processing Profiles

Many aspects can be assessed through clinical examination and observation, doing an activity profile, a person centered questionnaire and interviews to gather collateral information.

TRAINING – OTs need knowledge of the following to offer holistic care throughout the disease process

- Use of creative arts in dementia management - music, art, dance, drama
- Activity resources e.g. Quality Aging, Golden Carers websites
- Grief training (Hospice/Grief training)
- Sleep management for clients with dementia
- Palliative care and End of Life training
- Cultural competency specific to the global south
- Incontinence training and products
- Pressure care training
- Positioning, mobility, physical support and transfers
- Wound care
- Nutritional management
- Dysphagia

- Behavioural and Psychological symptoms management
- Communication skills
- Person Centered Care and other Care Culture Models of change e.g. Eden Alternative
- Knowledge of AI interventions e.g. robotic pets, Apps, Alexa
- Sensory based activities and stimulation including development of MultiSensory Rooms (MSRs)
- Knowledge of animal assisted therapy
- Environmental adaptation for enabling maximum function
- Activity programme development for all functional levels – include physical, cognitive, social, group, individual, spiritual, emotional, creative and ADL activities.
- Validation Therapy (understand the basic principles of it- as that can help to be with them in a moment and validating their feelings and reality in that moment, even if it is different to ours).

Training available

- South African Geriatric Society offer courses each year.
- Geriatric specific CPDs e.g: on OT Link
- Dementia South Africa (DSA)
- Alzheimer's and Dementia SA
- Tapa Snow online training
- University of Tasmania Wicking Dementia MOOC course
- SCiE
- Udemy
- Geratec and Eden Alternative SA

TREATMENT PLANNING (5- stage model)

Treatment planning should be aligned with the functional level or stage that the patient/client is placed on during assessment. The following table describes the symptoms relevant to function and OT intervention through the various stages (S.Birkhead – see references at end)

Note:

- it is difficult to place a person with Alzheimer's disease in a specific stage, as stages may overlap;
- cognitive skills are based on brain structures that help us learn, concentrate, remember and solve problems;
- cognitive impairment refers to difficulties in remembering, learning new things, concentrating or making personal decisions that negatively affect everyday life. It is an inclusive term that describes any characteristic inhibiting cognition, or the thought process. This then leads to other functional difficulties.
- stages provide a shorthand way of understanding the key ways dementia affects the individual as the disease progresses;
- cognisance of each person's individuality, previous life experiences and cultural practices has to be taken.

TABLE A: Stages of Impairment and Symptoms of Dementia

<i>Mild cognitive decline.</i>	<i>Moderately severe cognitive decline.</i>	<i>Severe cognitive decline.</i>	<i>Very severe cognitive decline.</i>	<i>Terminal stage.</i>
Early-stage Alzheimer's disease can be diagnosed in some with these symptoms. Friends, family or co-	Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At	Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily	This is the final stage of the disease. At this stage, individuals may:	This is the end stage of the disease when the body notably starts shutting

workers notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or during a detailed interview. Common difficulties include:	this stage, individuals may present with:	activities. At this stage, individuals can:		down. Function is limited to:
Recent memory loss at times (<i>forget things such as birthdays, appointments and conversations</i>).	Chronic recent memory loss though long-term memories can be fairly well preserved.	Speak in short sentences but cannot carry out meaningful conversation.	Frequently lose capacity for recognisable speech, although words or phrases may occasionally be uttered.	Mute or few incoherent words.
Mild difficulty with verbal expression.	Increased inability to understand and carry on conversation.	Difficulty with finding one's way. Tend to wander and get lost. Have challenges in planning or solving problems e.g. following a recipe.	Needs help with eating and toileting and there is general incontinence.	Bedridden or wheelchair bound.
Decreased concentration (<i>can only stay focused for a short time</i>).	Difficulty in writing and using objects correctly.	Misidentify persons and objects.	Loses ability to walk without assistance, then the ability to sit without support.	Lose ability to respond to the environment.

Slowed learning and reactions.	Visual-spatial perception problems.	Bladder incontinence. May not care how one looks and may not want to bath.	Loses ability to smile and to hold head up.	Little spontaneous (<i>unplanned</i>) movement.
Some errors in judgement and calculation.	Possible delusions and hallucinations.	Unsteady walk.	Reflexes become abnormal and muscles grow rigid.	Difficulty eating and swallowing.
Is more comfortable with familiar people, things and surroundings. Avoids the unfamiliar.	Do or say the same things repeatedly.	Needs help getting dressed properly; without supervision, may make errors such as putting pyjamas over daytime clothes or shoes on wrong feet ³ . Difficulty fastening buttons and zips etc.	Swallowing is impaired. Increased risk of infection.	Seizures, muscle twitching.
Difficulty with planning, organising and decision making.	May get lost at times, even in the home.	Lose most awareness of recent experiences and events as well as of surroundings.	Lose ability to sit without support and to hold head up	Cachexia (<i>ill conditioned body and mind</i>).
Lack of spontaneity (<i>slow in taking action</i>) and lessening of initiative (<i>can't think for oneself</i>).	Needs reminders or assistance ² to perform activities of daily living.	Remembers personal history imperfectly, although generally remembers own name ³	Lose ability to walk without assistance.	Requires total care.

Starts withdrawing and denies doing anything if confronted ²	Paranoid (<i>suspicious</i>). Accuse people of stealing	Occasionally forgets the name of spouse or primary caregiver, but generally can tell familiar from unfamiliar faces.	Need help with much of daily personal care, including eating or using the toilet.	
Decrease in performance in work and social settings ²	Unable to recall important details such as current address, telephone number, or the name of the college or high school graduated from.	Experiences changes in normal sleep/waking cycle and gets confused between night and day. Mood swings for no obvious reason.	Loses ability to smile. Lives in a state of confusion and lack of awareness of surroundings.	
Word or name-finding problems noticeable to family or close associates.	Become confused about where one is, or about the date, day of the week or season.	Needs help with handling details of toileting (flushing toilet, wiping and disposing of toilet paper properly).		
Reading and only recalling a little of what was read.	Needs help choosing proper clothing for the season or the occasion.	Increasing occurrence of urinary or faecal incontinence.		
Losing or misplacing a valuable object. Decreased knowledge of recent events ³ . Impaired ability to perform	Usually retains substantial knowledge about self and knows own name and the names of spouse or children.	Experiences significant personality changes and behavioural symptoms, including suspiciousness and delusions (for example,		

<p>challenging mental arithmetic³. Reduced memory of personal history³. Decreased capacity to perform complex tasks e.g. marketing, planning dinner for guests or paying bills and managing finances³. May seem subdued and withdrawn, especially in socially or mentally challenging situations³</p>	<p>Difficulty naming objects; finding the right word.</p>	<p>believing that a caregiver is an impostor); hallucinations (seeing or hearing things that are not there); or compulsive, repetitive behaviours such as handwringing or tissue shredding.</p>		
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Table adapted from:

1. A.Ortigara. *Levels of Impairment and Symptoms of Dementia*. The Rush Alzheimer's disease Disease Centre
2. C Eliopoulos. 2001. *Gerontological Nursing*. 5th ed. Lippincott; Philadelphia. P3
3. California Department of Health Care Services, *Community Based Adult Services (CBAS).Guide to Determine Alzheimer's Disease or Dementia Stages for CBAS Screening cognitive impairments (Welfare and Institutions Code section 14522.4)*

TABLE B: Linkage of the levels of creative ability with stage of dementia (Adapted from Sherwood, 2015)

Motivation (VdTMoCA)	Action (VdTMoCA)	Dementia stage
Passive Participation	Norm awareness experimental action	Mild stage dementia
Self-presentation	Constructive explorative action	Moderate stage
Self-differentiation	Destructive action Incidentally constructive action	Severe stage
Tone	Purposeless unplanned action	Terminal stage

TABLE C: Dementia stage and Creative Ability

MILD STAGE NEEDS	MODERATE STAGE NEEDS	SEVERE STAGE NEEDS	VERY SEVERE STAGE NEEDS	TERMINAL STAGE NEEDS
These have been equated to the level of Passive Participation .	These have been equated to the level of Self-presentation .	These have been equated to the levels of Self-presentation and Self-differentiation .	These have been equated to the level of Self-differentiation .	These have been equated to the level of Tone .
<p>Ways to maintain their autonomy (ability to make independent choices) and independence, advice on decisions that need to make regarding forward planning e.g. a will, power of attorney. Participate in decision making on their future, sign relevant documents, guide them on what support is available e.g. Alzheimer's association of South Africa, medications available, benefit of joining a trial. Look at ways to maintain their quality of</p>	<p>The focus in this stage is placed on the person's safety, in that the person's judgment and insight may be so impaired that safety becomes an issue. The person may need assistance if they're going to be engaged in certain activities like cooking, going for a walk, driving. They may need some companionship in that space. Families often struggle to improve the person's quality of life within their home. Knowing the person and how to communicate with them is of</p>	<p>Safety must always be considered but even more so in this stage as the physical symptoms start to appear. The person starts to lose the ability to move around independently by walking or even moving their arms and legs. So, they may get rigidity and they may get complications around muscular and skeletal pain and may get circulation issues because they're unable to move their limbs and body. As their</p>	<p>By this stage the level of care and support is stepped up as areas such as swallowing, continence, mobility, communication and self-help are extremely compromised. 24-hour care is necessary.</p> <p>(OT focus at this stage is mostly on the caregiver e.g. education re transfers/home programme of exercises and improving quality of life. Caregiver support is for stress,</p>	<p>Maintaining a quality of life and comfort to the end of the person's life is essential. The principals of palliative care are practised.</p> <p>(Caregiver support +++)</p>

<p>life/hobbies/interests for as long as possible. Encourage them to maintain their social life or work activities that are meaningful for them.</p> <p>They are compliant with medication if not in denial about diagnosis. Routine must be encouraged as the dementia progresses, but they function independently with use of memory aiding tips. Relationships are maintained and behaviour, including emotions is appropriate, though depression, anger and denial may be prevalent due to diagnosis. They function in familiar activities but may need some intervention as cognitive function declines.</p>	<p>utmost importance as their ability to process information and communicate is extremely difficult.</p> <p>Memory and some language skills may be limited. They will need assistance with some activities e.g. go to dining room for food and not prepare it themselves if in a home.</p> <p>They will exhibit increasing signs of physical or cognitive limitations and will engage in activities that are more supervised and structured.</p> <p>Self-care activities will need some assistance especially with refined forms of care.</p> <p>They can manage 3-4step activities with supervision.</p> <p>They cannot always give a good account of self (emotions and actions) but a full range of</p>	<p>abilities to communicate have deteriorated considerably by this time, they are unable to tell you that they are in pain.</p> <p>Brain activity is poor and sensory perception is disturbed e.g. the person can hear but cannot understand. There is some awareness of surroundings and stimuli. They recognise familiar people though cannot name them and respond to how they make them feel emotionally. Emotional expression is non-verbal e.g. smile. They often hallucinate and are delusional and we need to go into their world. They</p>	<p>depression and exhaustion.)</p> <p>As for the severe stage but with less active response, shorter periods of engagement and less orientation of person. Environmental cues do not always work as the person becomes less mobile and less aware of the environment around them.</p>	<p>They require total care and require sensory input on a one-on-one basis. They are mostly unaware of the environment, others or even self and do not always respond to stimuli. Movement is usually reflexive as are sounds. They may respond to food e.g. chew or swallow when food is put in their mouth.</p>
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<p>They tend to be followers and can get stressed when involved in unfamiliar activities/situations. They can engage in activities they choose to do. Their environment can be adapted to minimise depth perception problems i.e. floor colour is consistent and not too dark. Behavioural issues are minimised by ensuring the right support is experienced. They will start losing independence in certain aspects of function e.g. encouragement to bath regularly or reminder to take medication or may have difficulty learning how to use a new laptop or may start withdrawing from society.</p>	<p>emotions is evident and they express anxiety, fear and aggression when they do not understand the environment or others' behaviour e.g. a carer forcing them to get into the bath. The intensity of the emotion is sometimes incongruent with the stimulus. They often forget where they've put objects or when tasks need to be done but can do chores with encouragement. They tend to be self-centred and social skills deteriorate. They are orientated but need cues e.g. calendar, telephone list, day/night clock, photos and name tags. Signage with pictures and text is useful. They are continent but do not always make it to the toilet on</p>	<p>can follow movements, so demonstration is better than verbal instructions. They are disorientated for time, place and person and have no interest in self-care, though with help may be able to wash their face or hold the face cloth. They can follow 1-2 step instructions of familiar activities with demonstration e.g. shake the maraca or hold the cone and lick to taste the ice cream. Speech is limited but they can do actions they've done all their life e.g. open your mouth to take in food or to swallow. They may mouth an object as a way of discovery so could chew a</p>		
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<p>(Involve the caregivers in goal setting)</p>	<p>time and may need to wear incontinence products as a precaution. They interact with others on a superficial level but make friends and enjoy group participation. Sequence of activity steps needs supervision and attention span is limited. They can use familiar tools and do known tasks with assistance. They need reassurance about the changes as function fades. The environment must enable independence by accommodation loss of sensorimotor skills e.g. colour contrast such as red toilet seats or crockery that helps visual perception. Activities must include aspects of reminiscence.</p>	<p>soft ball and not know what to do with it. They need time to respond. They may not be able to initiate a movement but if familiar they can continue after the carer has moved the body part to do it e.g. putting food in mouth and they can finger feed. They often aren't aware of basic concepts or social norms. Attention span is limited but can extend if the activity is meaningful to them. They can only participate if the carer assists. They will participate in simple activities, especially ADLs, and will benefit from the MSR. With creative thinking, many ordinary</p>		
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	<p>(OT role – selfcare activities, routines, simplification and retraining. Educate the carers on how to do things e.g do WITH, not FOR – if you don't use it, you lose it! Fall prevention; make the home safer e.g. rails; Mental restoration – regular brain training exercises and stimulation; Provide knowledge and awareness about selfcare – give tools needed to live independently and empower them with useful information e.g. where to go to get knowledge and support)</p>	<p>daily tasks can be done with a sensory focus e.g. smelling and feeling toiletries, putting scented foam in the bath, lavender bags into the clothes cupboard, offering different types of tea or coffee, feeling the grass, trees or leaves and smelling the flowers when outside. They're unaware of dangers and if mobile, need constant supervision. Sensory stimuli can stimulate response e.g. music can trigger movement or singing. They need assistance when dancing, walking or catching. They need opportunity to be exposed to sensory stimuli which</p>		
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		<p>might assist them in retrieving a skill e.g. singing the words of a song, but this doesn't always occur. They need objects with which to fiddle e.g. a fidget blanket or could be put in a rocking chair to experience a calming movement.</p>	
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ACTIVITIES IN THERAPY

Many of the activities listed below have been tried and tested by the author and allocated to the different levels of creative ability, but included are ideas suggested by fellow occupational therapists and in literature. (Perrin et al, (2008); (Kalsy–Lillico S, (2014); Dodd (2015))

Passive Participation activities (Independent/Possibly recently diagnosed i.e. mild stage dementia)

Board games, dice and card games as well as quizzes and puzzles. Discussions about people, places and events. Relaxation techniques can be taught to manage the stress of the diagnosis or massage or aromatherapy activities. Arts and crafts that are meaningful e.g. painting, drawing, colouring in, sewing, card-making, flower arranging or pottery. Cooking and baking are possible as well as the planning and shopping required. Sports are enjoyed. End-product activities are better. Use visual planners and cues to structure activities/day.

Self-presentation activities (Moderate stage dementia)

Music – play something that resonates, is liked by the person and has a good bass and beat. They can sing or dance to the music and could still participate in music quizzes especially if incorporating reminiscing e.g. guess the performer. Arts and crafts with end products are possible

with assistance from carers/volunteers e.g. paper crafts, mosaic, pottery, themed objects such as birthday gift bags, beadwork, colouring, knitting and needlework. Exercises such as chair gym, Ageless Grace or sports for seniors, including walking or games e.g. bowling, indoor ball games or target games such as darts (perhaps with magnetic heads). Reminiscence activities including sensory quizzes e.g. smell quiz, writing life stories or making photo scrapbooks. Familiar prayers can be said/hymns sung. ADL activities especially baking tasks or recipes not requiring a stove e.g. fruit salad or fridge tart. Cognitive games such as dominoes, bingo, easier level word and number games, dice games and simple quizzes.

Self-differentiation activities (Advanced/Frail care/Severe dementia/Self-differentiation)

Music – play something that resonates, is liked by the person and has a good bass and beat. Humming along to popular tunes, radio jingles or TV adverts is good. Any activity that stimulates laughing is encouraged. Let them ‘fidget’ with tactile objects such as aprons, mats and cushions made for sensory stimulation. A rocking chair is useful for calming and reducing anxiety. Dancing, even if done in a chair, swaying and rocking in time to music, is good but if the person can be supported in standing, is even better. Simple crafts can be done such as painting with fingers or doing prints e.g. paint a butterfly shape cut from bubble-wrap and press a blank page to ‘lift’ the design. Multi-sensory environments are useful for individual exploration using stimuli such as lights, sounds, smells, taste, items to touch and for movement. They love to rummage in bags. Massage of hands and feet is a good activity. They can do simple, one-step cooking tasks, such as mixing ingredients, peeling food and tasting! One-step gardening tasks, such as watering plants, digging pots or picking fruit or leaves. One-step daily living tasks, such as plumping up cushions, dusting or wiping the table. Walks, even if in a wheelchair are preferable along routes that are circular, with focus points. Stacking and folding items such as clothes, papers and magazines can engage them. Soft weighted toys and dolls are comforting and touch can help anxious feelings. Bubbles and balloons can remind people of fun but be aware not to choose child-like toys or games.

Tone activities (Total care/palliative/terminal stage)

GOAL SETTING (3 stage model)

MILD

- Maintenance and strengthen components of the patient physically (**be independent**)
- Balance (with awareness of turning challenges) * Note that Balance is an overt indicator across age groups
- Gait and Mobility (and bed mobility)
- Maintaining and/or achieving functional Independence
- Memory Books to maintain memory (multiple memory books e.g. family history book etc.)
- Introduction of technology where possible e.g. calendars and alarms etc.
- Introduction of support groups for patient and family members possibly separately (building early care giver/family resilience)

MODERATE (Maintenance)

- Maintain functional strength as much as possible.
- Emotional and psychological incorporated
- Cognitive stimulation all the time e.g. suduko, cross words, reading, outings etc.
- Family and patient- regular routines to help anchor their reality orientation
- Enabling the environment e.g. safety and accessibility (signage, orientation in the environment etc.)
- Modify their environment e.g. grab rails, contrast signage etc.
- Reminiscence books/Life history/photos/music books
- Sensory blankets
- Introduction to life post death for family at end of moderate to severe stages

SEVERE (Goals related to how family can care for the patient- total care)

Moving towards basics of palliative care and bodily systems are a priority

- More sensory in this phase for the patient and family
- Environment stimulation and orientation
- Overall wellbeing

TREATMENT MODALITIES

Each dept needs to have access to household familial tasks, areas like cooking, domestic, access to toilet and a basin, ADLS and steps, or area round, outside area, home environment etc. plinth simulate and a bed etc. Many of the activities listed below have been tried and tested by the author and allocated to the different levels of creative ability, but included are ideas suggested by fellow occupational therapists and in literature. (Perrin et al, (2008); (Kalsy–Lillico S, (2014); Dodd (2015))

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Tone activities (Total care/palliative/terminal stage)

At this stage, the input one gives is calming, soothing and directed to the environment as well as the person e.g. no bright lights or stimulating objects on the walls or around the person e.g. moving mobiles. One could even use a dull yellow or blue shaded globe and draw the curtains – though some people respond to sun shining into the room. Candlelight is often used to create a spiritual environment but can also be a focal point to gaze at if they have eyes open. The person usually has eyes closed, so visual stimulation is often ineffective at this stage.

Gentle music that induces calmness, a sense of security e.g. lullaby or gentle religious music or nature music e.g. ocean waves (gentle) or music that the person knows which is known to be soothing for the person, can be used. One could try to use headphones at this stage but do not leave them on all day – 30 minutes maximum and then have a break with no auditory input. Talk to the person, even if it appears they are not listening or responding and do not talk about them or about things unrelated to them e.g. do not have a conversation to your colleague, and especially do not talk in another language that is not familiar to the person.

Touch is important so hold their hand, gentle massage of feet or hands, but again just for short periods and not continuous unless just a light stroking. A sheet or blanket tucked in could give deep pressure which is calming to some but if in Summer, the person may benefit from a light sheet/blanket as they may be hot – could have a fan providing cool air, but in Winter, keep the room warm and cosy. A soft plush toy animal/cushion may be comforting against their skin.

Use smell for making the environment comforting e.g. lavender or camomile or vanilla. This may depend on the person's preferences.

Usually taste has gone but the smell of e.g. mint-flavoured lip ice, may be soothing and can ease digestion even though not ingested.

There is no need for stimulation of physical movement, though if on an air mattress this provides the body with pressure relief. Move the person very carefully and gently when turning or repositioning in bed. Put a cushion between the knees if side-lying and check the blankets are not pushing the feet into plantar-flexion when the person is lying on their back, or raise the feet to keep the heels off the bed by placing a cushion or roll behind the Achilles tendons of the feet.

End stage: Smiling and stroking or cuddling can bring comfort, as can singing to them or rocking them. Sensory items can be put in their hands to squeeze or stroke, but often there is no response. Spray lavender in the room to induce calmness or dim the lights.

ASSISTIVE DEVICES

(be mindful of costs implications and user friendliness with elderly and family)

Mild	Memory aids, driving assessment, accessible and modification of the environment
Moderate	Mobility device, walking frame to seating in a wheelchair. Commode, motion lights, orientation aids calendars, cellphone reminders to take your pills, eating aid or adapted cups and spoons diet modification. Orientation Signage. Incontinence products. Linen and mattress protectors; red crockery, plate guard, (adapted cutlery may be too confusing) mobility aids, contrast strips on the edge of stairs, rails, modified remote control etc.; modified remote; Adapted clothing and other admin; adapted clothing e.g. elasticised pants – no buttons or bands! Cups with a spout.
Severe	Appropriate seating, e.g. raised chairs Pressure mattress and cushions Wheelchair Bed raises, Railings, grab rails Lap trays in wheelchair – postural support, perceptual reference Incontinence support and products; Raised chairs with armrests; Have a contrast colour of carpet to your present one;

CONSUMABLES AND EQUIPMENT NECESSARY FOR OT INTERVENTION

Paper

Magazines

Glue stick

Pens, pencils,

Balls

Balloons

Tea/coffee making items

Basic baking items – flour, sugar butter, eggs, milk

Velcro

Pool noodles (activities, positioning, splinting of hands)

Hand cream (Aqueous cream) sensory input

Sensory kit (ideas to put in – brush, sponge (smooth/rough), bells/whistles, keys, spiky balls, little taste bottles)

Grooming kit – brush/comb/toothbrush/ toothpaste/ face cream, shaving cream, soap, face cloth, bubble bath/ colourants in the bath.

Fidget toys

Equipment

Crockery (plates, glasses) ideally should be contrasted to food/ table eg: red crockery.

CD player/ blue tooth wireless speaker for music

Kettle

Drinking glasses

2 plate cookers

Kitchen utensils for cooking

Basic pots and pans

Microwave
Computer
Laminator
Printer
Wifi
Small fridge
Plinth
Bean bags
Board games
Sheet for games
Basic mobility equipment – wheelchairs, lap trays, transfer board
Broom
Dustpan
Basic sewing – needle and thread

TERMINATION OF TREATMENT

Direct treatment of patient may discontinue but ongoing support and education will continue until death.

(note: there might be indirect intervention e.g. sensory by the caregivers)

OCCUPTIONAL THERAPY in Bereavement support of caregivers and family

- OT would be aware of the need to continue ongoing with family post death – bereavement support/grief counselling.
- Refer to the National OT Palliative Care Protocol
- Palprac.org is a South African based palliative organisation with a wealth of information and support resources for the clinician

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