

Allied Health Leadership-development Program



DEMENTIA
TRAINING
STUDY CENTRES

Facilitator Resource Notes

An initiative of the Queensland Dementia Training Study Centre
developed in collaboration with the Western Australian Dementia Training Study Centre

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Contents

Introduction 1

Aims and Objectives..... 3

Dementia..... 4

Diagnosis and Assessment12

Strategies and interventions32

Evaluating interventions34

References.....36

Resources40

Introduction

Dementia Training Study Centres

In August 2012 Dementia was designated as a National Health Priority Area in recognition of its impact on Australia's population in terms of morbidity and mortality, associated costs and projected rate of growth. In 2011 there was an estimated 298,000 people with dementia in Australia; a figure predicted to triple by 2050 (AIHW 2012).

The Australian government funds five Dementia Training Study Centres (DTSCs) around the country to address the information and education, and workforce development needs as outlined in the National Framework for Action on Dementia. The DTSCs aim to improve the quality of care and support for people with dementia and their families through a range of education and professional development initiatives for current and future health professionals. Each DTSC has specific priority areas; Allied Health is one of Queensland Dementia Training Study Centre's (QLD DTSC) national priority areas. Occupational Therapy (OT), Social Work (SW) and Diversional Therapy (DT) are the initial fields of focus within Allied Health.

The Allied Health Leadership -development Program (AHLP) is an initiative of the QLD DTSC and developed in collaboration with the Western Australian DTSC. In part it builds on a body of OT specific work developed in WA including the *Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice* and the implementation of the Hierarchic Dementia Scale (HDS) as the assessment of choice in that state.

Dementia Training Study Centres
www.dtsc.com.au

Australian Institute of Health and Welfare
www.aihw.gov.au/dementia/

Australian Government
www.livinglongerlivingbetter.gov.au

Facilitator's Resource

AHLP Resources

Facilitator's Resource

The information and resources included here provide the basis for equipping health professionals with dementia-specific knowledge to facilitate learning and leading change on individual and organisation levels through knowledge and skills development, problem solving and change management in

- assessing and planning care
- working through the complexities and challenges
- recognising the possibilities
- acknowledging individual context
- developing a community of practice

Additional resources include:

- HDS Kit and Manual
- HDS Implementation Guide
- Possibility Oriented Care Guide
- DVD: Dr Dolly Dastoor demonstrating the HDS
- DVD: Heather Freegard's seminar on the HDS and planning care
- PowerPoint presentations

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Aims and Objectives

Aim

The aim of the Allied Health Leadership-development Program (AHLP) is to strengthen allied health workforce capacity nationally in the dementia care sector by conducting a program of education, skills development and mentoring for a group of allied and other health professionals to become “dementia champions” who will lead change in practice within their organisations through education and advocacy.

Objectives

Implement/ promote the use of the HDS as a key assessment method to determine functional ability and plan and develop care strategies accordingly by:

Skills development/ education (Leaders or “Champions”)

- HDS
- Possibility oriented care
- Organisational change / reorientation
- Mentoring

Facilitate proliferation (Organisation level dissemination)

- Community of practice
- Education/ support / mentoring

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Dementia

What is dementia?

A life limiting... syndrome...	Dementia is a terminal illness. Palliative approaches to care provide an excellent basis for planning and providing services.	
	A syndrome is a complex of signs and symptoms resulting from a common cause or appearing, in combination, to present a clinical picture of a disease or inherited abnormality. Each sign or symptom can be indicative of other causes however it is the specific combination of signs and symptoms that are indicative.	
due to disease of the brain...	Alzheimer's AD 50%	Disease Atrophy of the brain due to cell loss. Presence of plaques and tangles.
	Vascular Dementia VaD 20%	Reduced blood supply to the brain, eg stroke.
	Dementia with Lewy bodies DLB 15%	Similar to AD but with rapid progression. Presence of abnormal cells
	Fronto-temporal Dementia FTD 5%	Rounded and tangled bundles of proteins in brain tissue. Early onset (30-40 Years)
	Parkinson's Disease PD 3-4%	CNS loss of neurotransmitter dopamine
	Huntington's Disease HD <3%	Hereditary disorder of CNS
	Creutzfeldt-Jakob disease CJD <3%	Swelling and loss of brain cells. Abnormal prion deposits
in which there is impairment...	As the disease progresses abilities decrease and limitations increase. However it must always be remembered that even in the later stages of the disease trajectory there will be remaining abilities.	
of a sufficient level to disrupt the person's previous ...	Dementia is a functional diagnosis in that it is not a specific cognitive score that defines whether someone has the disease. Rather changes are measured against the person's previous abilities. For example, a genius with dementia may function at a higher level than a person with learning difficulties without dementia.	

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cognitive functional ability in:	The main areas of the brain affected in dementing illnesses are those within the cerebral cortex. Other areas of the brain, for example those involved in movement, vision tend not to be involved.
Memory	Immediate and short term memory loss initially, gradual erosion of other memory over time.
Learning	Because new knowledge erodes quickly or is not retained learning new skills and retaining information makes the developing of new ways of doing things, ie learning, difficult. Tend to rely on habitual actions or previously learnt ways of doing things.
Language	Expression of words to convey meaning. Initially difficulty recalling nouns, then gradual loss of syntax, interpretation of humour or irony. Second language tends to deteriorate earlier but first language also eroding. Not to be confused with communication. People with dementia increasingly rely on use voice cues and body language to communicate.
Comprehension	Reception, interpretation and understanding of language. Difficulty understanding words and syntax. Interprets voice cues and body language.
Concentration	Ability to remain focussed on a task varies in everyone. People with dementia have increasing difficulty filtering irrelevant external stimuli or internal thoughts and ideas.
Abstract thinking	Difficulties with complex cognitive thinking characterised by adaptability, flexibility and use of concepts and generalisations, for example separating now from the past, interpreting mixed messages.
Calculation	Specific form of abstract thinking. Difficulties in this area can be observed in day to day life such as managing money, estimating distance or quantity.
Decision making	Evaluating a range of options for best fit and then selecting one option requires abstract thinking, memory and language. Either/or concrete choices retained for longer as is the ability to know what is not wanted.
Orientation	Awareness of the relationship between self and the physical environment, including time, place, people and purpose requires memory, comprehension, concentration and abstract thinking therefore often impaired with people with cognitive impairment.
Gnosis	Difficulty identifying, interpreting and understanding information received via the senses. Cause of fear.
Praxis	Difficulty with the planning and performance of previously learnt skilled, coordinated movements and actions. Cause of frustration.
Emotional control	In response to stress, frustration or fear associated with misperceptions, etc the person may display mood or feelings inappropriately.
Judgement	Difficulty evaluating one's own performance against an external standard of quality.
Social behaviour	Difficulty moderating one's own behaviour in response to external physical and social environmental cues

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Complexities of Dementia

Complex disease/s

- Normal cognitive function
- Transition to dementia
- Disease trajectory
- Diagnosis
- Death

Complex people

- Vulnerable group
- Multiple health challenges
- Multiple social challenges

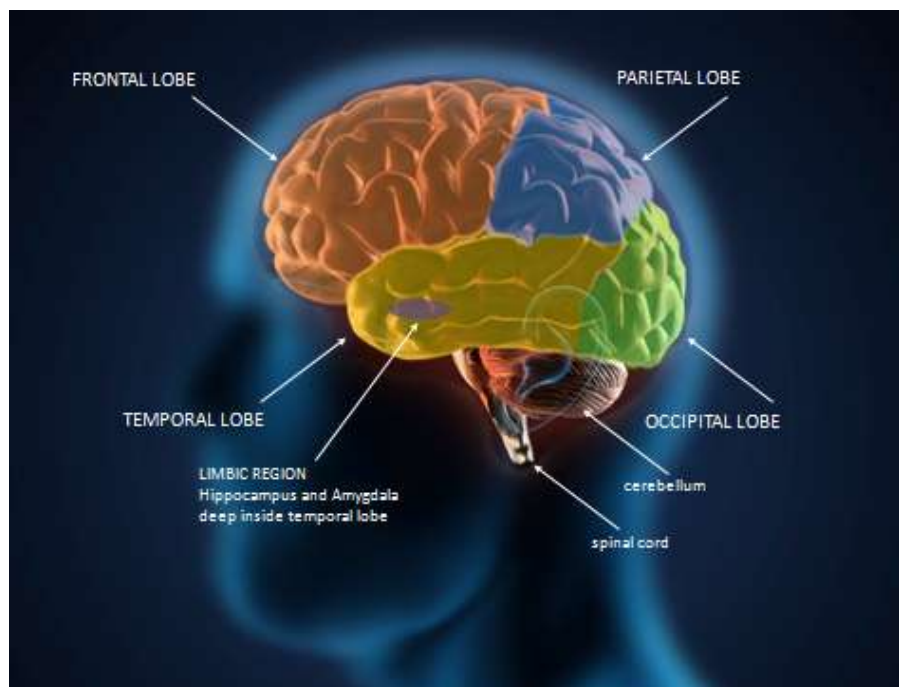
Complex needs

- Social
- Medical
- Ethical
- Legal

Complex care

- Person
- Family

Others



Melbourne Neuropsychiatric Centre (2008); American Health Assistance Foundation (2011); Brain Health and Puzzles (2007); The Brainwaves Centre (2010); Boeree, C. (2009); The Brainwaves Centre (2010), Alzheimer's Australia (2010a) Alzheimer's Australia (2010b)

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How dementia can impact on behaviours

Function	Challenges	Function	Challenges
Memory	<ul style="list-style-type: none"> What has happened What they are doing Where they have been 	Learning	<ul style="list-style-type: none"> Revert to old patterns Use old patterns to solve new problems Mastery of new skills
Language	<ul style="list-style-type: none"> Conversation Needs and wants Word finding Grammar and syntax Writing 	Comprehension	<ul style="list-style-type: none"> Conversation Interpreting what others are saying Following directions Reading
Orientation	<ul style="list-style-type: none"> Appropriate action for time and place 	Abstract thinking Calculation	<ul style="list-style-type: none"> Understand relationships between objects/people Interpret language, eg humour, irony Judging distance Managing money Interpreting sensory information, eg hunger, thirst, pain, taste, smell
Gnosis	<ul style="list-style-type: none"> Perceive object from ground Interpret function/use of objects Interpretation of changes in texture and colour 	Praxis	<ul style="list-style-type: none"> Adapt to new position Follow demonstration Complete familiar tasks/actions Use tools/utensils
Concentration	<ul style="list-style-type: none"> Staying focussed on task Shifting focus to a new action/activity 	Motivation	<ul style="list-style-type: none"> Desire to act Understanding purpose of action Changing actions
Decision making	<ul style="list-style-type: none"> Choose between options Consider past, present and future 	Judgement	<ul style="list-style-type: none"> Foresee consequences of actions Recognise/correct mistakes Determine relative safety of self/others Determine relative success/failure of actions
Social behaviour	<ul style="list-style-type: none"> Interpret the actions of others Waiting and taking turns Interpret environmental cues 	Emotional control	<ul style="list-style-type: none"> Reaction to frustration or fear Over or under- stimulation

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The journey of dementia

This diagram reflects the trajectory of dementia from the perspective of different people and groups of people. It is of course imperfect.

It tries to highlight the following:

A person with dementia spends much more of their life without dementia - 50, 60, 70 years compared with 2 – 15. That experience describes them much more than a label or diagnosis. Life stories are essential to understand the person.

Dementia is a life limiting disease

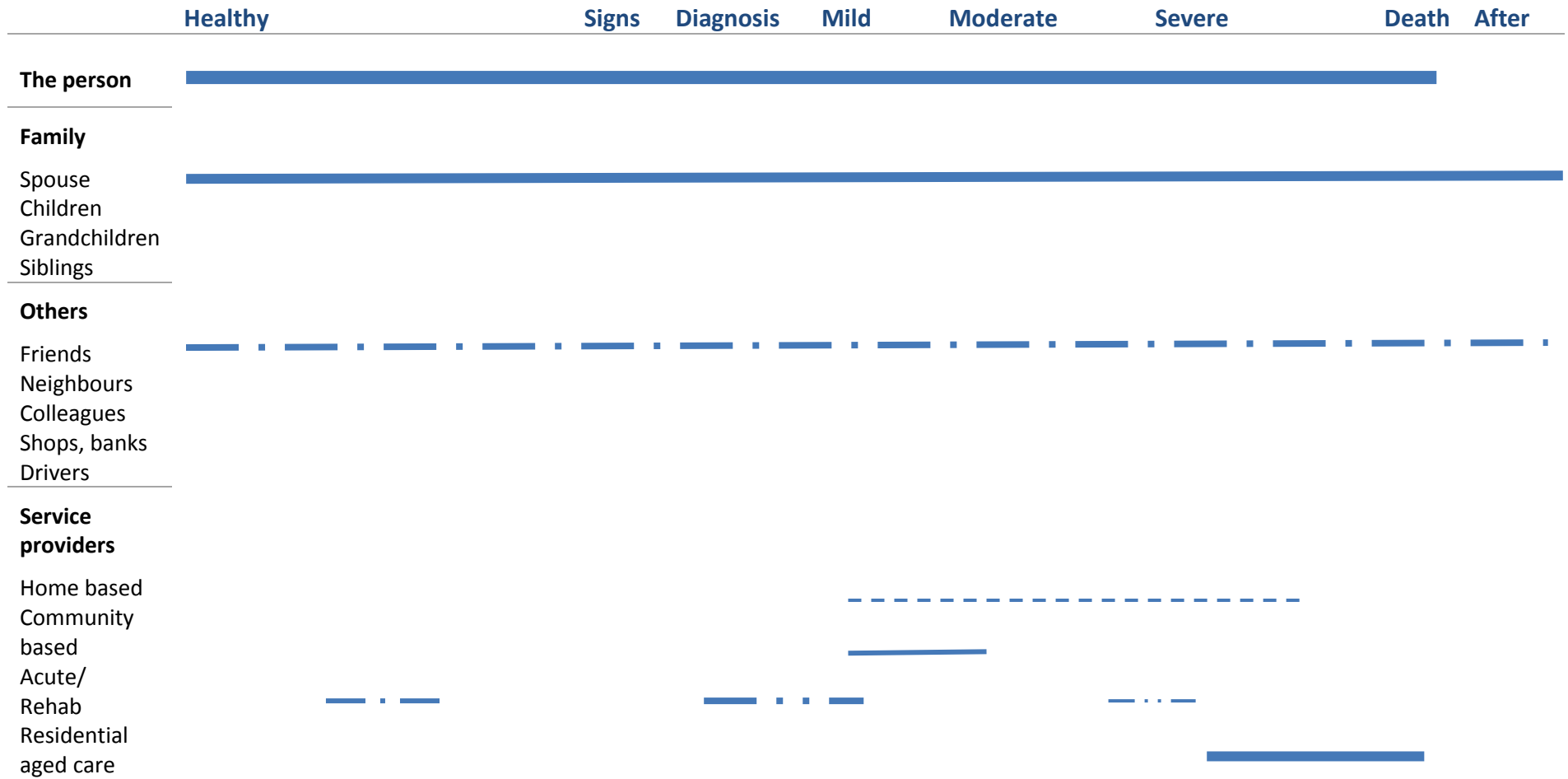
Family members are likely to share the journey with the person with dementia. The degree of experience will vary with the relationship, quality of the relationship and proximity of living. However, all family also experience the period following the death of the person – grief, challenges of picking up a life given up to care,...

Close friends, neighbours, work colleagues may have a closer relationship with the person than some family. Their journey may imitate families or be more fragmented depending on the quality and nature of the relationship.

Regardless of what, when, where and who the caregiver's relationship almost never (perhaps in small close knit communities) covers the full journey. At most the relationship can be measured in terms of 1-2 years; perhaps only in hours or days. The fragmentation of services according to level of need and eligibility, transience of the health workforce, changes in work roles and work load. The care worker cannot fully understand the person's or their family's experience.



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Facilitator's Resource

Possibility Oriented Care:

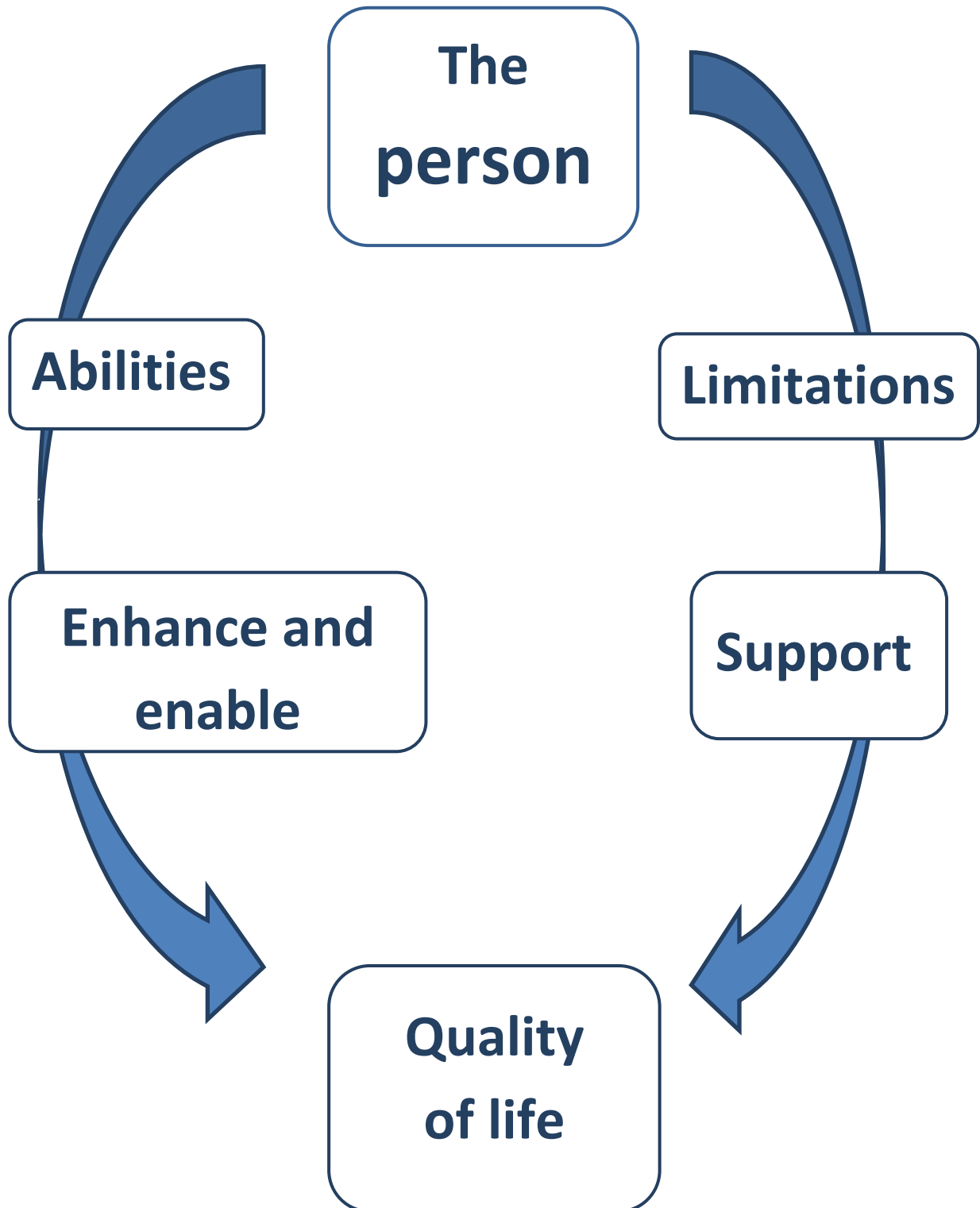
.....is a mindset that encompasses the following:

1. Every person, facility, organisation and health care system has abilities:
 - Knowledge
 - Skills
 - Attitudes
 - Resources
 - Time
2. Every person, facility, organisation and health care system has limitations:
 - Knowledge
 - Skills
 - Attitudes
 - Resources
 - Time
3. It requires persistence and determination to identify abilities
4. Everyone can identify limitations
5. Focussing on limitations alone creates a diminished environment based on control and powerlessness.
6. Focussing on abilities alone creates a chaotic environment with uncontrolled risk and certain failure.
7. Identifying both abilities and limitations enables realistic possibilities for meaning and satisfaction to be envisaged and acted upon.
8. A life lived with opportunity to engage abilities and supported limitations is one of meaning, purpose and satisfaction.

Heather Freegard

Possibility oriented care

Heather Freegard



Diagnosis and Assessment

Why a timely and accurate diagnosis is important

Changes in a person's behaviour are the most common indication that 'something' is amiss and concerns that a person may have dementia arise. There are many possible causes to explain difficulties in cognition and/or changes in behaviour that require careful and systematic investigating. Following a thorough medical and social history, each possible cause has been investigated, eliminated or treated, and changes in behaviour remain, then the diagnosis of probable dementia is reached. In the absence of easily administered or non-invasive tests to positively diagnose dementia careful interpretation of changes in behaviour over time is still the best indicator. Despite the increased knowledge gained from research such as differentiation of types of dementia it still requires an autopsy for a definitive diagnosis.

Purpose of diagnosis and ongoing assessment

- Rule out reversible causes of cognitive/behaviour changes
- Understand the nature of the disease
- Identify remaining function
- Identify other health concerns
- Assess psychological, social and health impacts on the family and other support systems
- Access appropriate treatment and services
- Anticipate changes
- Address legal and ethical issues
- Research and evaluation

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1.	History :	Family	Social	Medical		
		Stroke Dementia Mental illness...	Family Education Lifestyle Work Leisure Environment Social Support Community involvement Financial security Culture/language Transitions...	Exercise/weight Diet Smoking Alcohol use Head injury Depression Cardiovascular Blood sugar Trauma Medical conditions Mental health...		
2.	Formal cognitive testing	Mental health screen	Structural Imaging	Pharmacologic review	Pathology testing	Environment
	Range and degree of cognitive abilities	Depression and other mental health conditions	Patterns of brain changes and function	Effects of: sedatives, hypnotics, analgesics & antipsychotic medications. Use of other legal and illegal substances	Exclude others causes of cognitive impairment Refer to 16 Ds	Evaluation of social and physical environments to determine if they support or inhibit cognitive function
3.	Reassessment: 4 – 6 months to determine any change					
4.	Diagnosis					

The 16 D's: physical, spiritual and emotional factors of health and well being

Each of the factors listed below can cause decreased cognitive function and cause the person to be confused or behave in ways that are difficult to understand. Once identified and addressed cognitive function is likely to improve regardless of whether a person has, or has not, dementia. It is quite possible that any person, including ourselves, will have one, several or many of these factors at any one time. Most of these factors can be ameliorated or supported in some way. The list has two main sections; physical factors and spiritual/emotional factors. Each factor leaks into all others however the separation allows us to consider all aspects. It also provides clues to how better support the person.

Each factor is expressed by a word beginning with D to aid the reader's focus and memory.

Physical

Deafness
Drugs
Discomfort
Diet
Defecation
Diurnal
Diverse
Delirium
Dementia

Social & Emotional

Dependent
Dysfunctional
Distress
Disorder
Different
Disability
Distraction Depression

Facilitator's Resource

Physical		Social & Emotional	
Deafness	<p>This D represents all sensory impairment; hearing, vision, olfaction, taste, touch and kinaesthetic sense.</p> <p>The senses are the pathways for external information to reach the brain for processing. If the information reaching the brain is incomplete the brain does its best to interpret and understand. Behaviours/responses which arise are likely to be congruent with the message the brain received.</p>	Dependent	<p>Sometimes people are deemed to be less able to act or make decisions than they are just because they are old. This results in carers doing more or making decisions for a person than is necessary.</p> <p>Some older people believe such ageist assumptions and relinquish actions or decisions before they need to</p> <p>If a person requires assistance in daily living or making decisions it can be perceived by the person to be quicker and easier to do 'it' rather than assist the person to maintain independence</p>
Drugs	<p>A very common side effect of many drugs prescribed for elders and people with dementia is confusion.</p> <p>Accidental or deliberate changes to dosage or frequency can cause under or over medication.</p> <p>Over the counter medications and/or 'natural' therapies can negate or multiply the effects of medication</p> <p>Alcohol and other leisure drugs alone or in combination with prescribed and over the counter drugs can also cause confusion.</p>	Dysfunctional	<p>A social environment that is not inclusive, respectful, warm and and/or enabling impedes a person's ability to act or make decisions resulting in behaviours that we cannot understand.</p>
Discomfort	<p>This D refers to the continuum of suffering from discomfort, eg from sitting in one position for too long to agony, eg toothache, broken bone.</p> <p>While people with dementia may not be able to accurately verbalise the location, source and type of pain their behaviours are very indicative, eg withdrawal, wincing, hitting out.</p>	Distress	<p>Links with Distress. Spiritual and emotional pain, for example loss and grief, loss of meaning and purpose are experienced as pain. Spiritual and emotional pain may be expressed as physical pain and physical pain may be expressed in spiritual and emotional forms.</p>

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	<p>cont. Anyone over the age of 70 is likely to have pain somewhere in their body, arthritis, cramp, broken skin.</p> <p>Don't forget spiritual and emotional sources of pain such as isolation, feeling worthless.</p>		
Diet	<p>This D refers to food and fluid intake.</p> <p>Even mild hunger and thirst can cause confusion.</p> <p>Over consumption of food and fluid can likewise cause discomfort and changes to thinking and mood.</p> <p>Intake of inappropriate nutrients can cause confusion.</p>	Disorder	<p>Mental illness was, and remains, stigmatising. Therefore an older person may have a mental illness, either diagnosed or not, that is not disclosed.</p> <p>While rare it is possible for an elder to experience an initial episode in older age.</p>
Defecation	<p>Changes to processes of elimination can cause cognitive changes. Constipation can cause extreme confusion and agitation. Diarrhoea, urinary incontinence or obstruction can also affect a person's cognitive abilities.</p>	Different	<p>Many behaviours and habits have a cultural (in its broadest sense) basis which may seem strange to others.</p>
Diurnal	<p>This D refers to changes to a person's usual sleep – wake cycle.</p> <p>Too much or too little sleep can cause confusion. Changes to the timing of waking can cause disorientation.</p> <p>Poor sleep hygiene resulting in broken sleep can also cause confusion and irritability.</p> <p>Boredom can cause excessive day time sleep resulting in the person not being tired at night.</p> <p>Normal sleep patterns change as a person ages.</p>	Disability	<p>People with limited education and/or a speech impediment can be perceived as being less intelligent than they are. An older person with a language or speech impediment can be perceived to have dementia.</p>

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<p>Diverse</p>	<p>This D reminds us to be alert to other medical conditions that could cause decreased cognitive function, eg brain tumour, metabolic disease</p>	<p>Distraction</p>	<p>Doing several things at one, worry, concentrating on a task in a noisy and/or busy external environment can result in a person being forgetful, losing their place in a task or making mistakes.</p>
<p>Delirium</p>	<p>An acute organic mental disorder caused by disturbance of cerebral function resulting from a wide range of metabolic disorders, nutritional and endocrine imbalances, mental or physical shock, ingestion of toxic substances, exhaustion. Reversal of the cause will usually resolve the episode. Untreated delirium can cause permanent loss of function.</p>	<p>Depression</p>	<p>Depression is common within current society and very common in elders residing in residential care. Signs and symptoms in an elder can present in similar ways to dementia. Depression is treatable.</p>
<p>Dementia</p>	<p>The 17th D is Dementia. When all other possible causes of cognitive changes have been accounted for and significant cognitive loss remains, then the diagnosis is Probable Dementia. The type of dementia is usually determined by brain scan and analysis of behaviours.</p> <p>Progressive organic cognitive disorder caused by diseases of the brain. While generally considered irreversible and incurable conditions that cause the decline may be treatable or partially reversible.</p>		

Facilitator's Resource

Person centred approach to assessment

- Respect and value the lifetime lived
- Clarify the purpose of assessment
- Develop a relationship of trust
- Flexibility on approach and method
- Identify abilities and limitations
- Sensitivity to word, voice and body
- Active listening
- Assessment as intervention
- Intervention as assessment
- Identify social matrix
- Use appropriate assessment tools
- Sensitivity to language and culture
- Minimise ethical and legal risks
- Do not interpret the results based on just one assessment

Purpose of assessment

- Form a diagnosis
- Rule out reversible causes of cognitive/behaviour changes
- Understand the nature of the disease
- Identify remaining function
- Identify other health concerns
- Assess psychological and physical impact on the family
- Access appropriate treatment and services
- Evaluate efficacy of interventions
- Measure change over time
- Anticipate changes
- Address legal and ethical issues
- Research and evaluation

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Challenges of assessment

For the person

- Eligibility for service
- Being ready for the appointment
- Examination anxiety
- Relationship of trust with assessment/team
- Fear of failure
- Fear of the consequences of results
- Understanding why assessments are necessary
- Accepting or questioning relevance of particular assessments or items in the assessment
- Disclosure of private and personal information to strangers
- Concern about how the information will be used
- Multiple assessments of same/similar areas
- Fatigue
- New surroundings and people

For the Family/advocate

- Eligibility for service
- Reasonable access to appropriate services (eg location and cost)
- Advocating on behalf of the family member
- Obtaining a timely appointment
- Getting the person ready and to the appointment at the right time and place
- Supporting the stress and anxiety of the person
- Assisting general comfort; distance to walk, eating, drinking, toilet, rest, etc
- Understanding why the assessments are necessary
- Accepting or questioning relevance of particular assessments or items in the assessment
- Disclosure of personal and private information to strangers
- Concern about how the information will be used
- Confronting limitations and abilities of family member
- Concern regarding potential consequences of assessment
- Interpreting and sharing information with the person and other family members

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Challenges of assessment

For the Health professional

- Clarifying the purpose of assessment
- Choosing the most appropriate assessment tool
- Availability and access to assessment tool and consumables
- Facility policy on tools to be used
- Qualified and experienced to use the assessment
- Administering the assessment and interpreting the results accurately
- Sharing the results with person, family and other team members coherently
- Other team member's familiarity with the assessment tool and its results.
- Formulating intervention and treatment options
- Proposing an intervention plan
- Presenting information to person and family to gain informed consent
- Accurately and succinctly recording results, findings and recommendations
- Workload and case load expectations
- Ability to support identified limitations and abilities within the service budget, etc.

For the Service

- Efficiency and effectiveness of service provision
- Budgetary constraints
- Salary and on-costs
- Appropriately qualified staffing
- Adequate staffing levels
- Staff retention/turnover
- Staff development and training required for new assessments
- Managing fads of assessment
- Costs of assessment tools, replacement parts and consumables related to the assessment
- Coping with identified unmet needs

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Challenges of Cognitive Assessment

Ageing

Refer to the 16 Ds (*Page 14*)

Physical

- Deafness
- Drugs
- Discomfort
- Diet
- Defecation
- Diurnal
- Diverse
- Delirium
- Dementia

Social & Emotional

- Dependent
- Dysfunctional
- Distress
- Disorder
- Different
- Disability
- Distraction Depression

Dementia

- Multiple cognitive functions
- Range of cognitive abilities
- Cognitive level does not always indicate function
- Results focus on limitations and losses

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Comparing and evaluating cognitive assessments

Factor	Explanation/examples	Comparison A	Comparison B
Purpose of assessment	What are you trying to determine? What decisions will be influenced by the results? How precise do the results have to be?		
Purpose for which assessment was designed?	Research or clinical Longitudinal Diagnostic Intervention planning Intervention evaluation		
Rigour of design	How was the assessment developed? Experience/qualifications of designer/s? Validity? Reliability?		
Cognitive functions addressed	Number and type of cognitive functions assessed? Which cognitive functions are not addressed?		
Time	How long does it take to administer? Re-test time gap?		
Scoring/rating	How broad or specific can the scoring be? Pass/Fail Likert scale Numerical Subsection scores Total score		
Sensitivity	High or low ceiling? High or low floor?		

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Instructions	<p>Are the instructions clear and specific?</p> <p>Are items timed as part of the assessment?</p> <p>What degree of interpretation and/or flexibility is permitted?</p>		
Interpretation of results	<p>What information can be elicited?</p> <p>Inclusion-exclusion criteria</p> <p>Identification of abilities and limitations</p> <p>Identification of care options</p>		
Representation of results	<p>Numerical score</p> <p>Chart</p> <p>Graph</p>		
Language/literacy bias	<p>Does English as a second language affect performance?</p> <p>Does level of education affect performance?</p>		
Age bias	<p>Does being older or younger affect performance?</p>		
Cultural bias	<p>Are the assessment items appropriate for the cultural/ethnic background of the client?</p> <p>If translated into different language is the degree of simplicity/complexity equivalent?</p>		
Acceptance	<p>Is the assessment recognised as valid by colleagues, other health professionals?</p> <p>Do other colleagues or health professionals understand the results and interpretations?</p>		
Qualifications of assessor	<p>Are there restrictions on who can administer the test?</p> <p>Is certification required?</p> <p>Is training available and accessible?</p>		

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Communication

Making sense of what people say

Value the opportunity of interaction

Forget what is wrong with the interaction – in what way is it appropriate?

What other word or words are usually spoken with this one?

Can this word be linked by association?

What link or association could the 'wrong' word be expressing?

Does this make sense if I look beyond what is expressed to the more general category if I mentally add, 'like this in some way'?

What is the person saying about the person, object, event, etc. by giving it or them another name?

Does what the person is saying or doing make sense if we relate it to something or someone in the past?

Does the interaction refer to something or someone in the environment?

Listen carefully for clues that indicate the person's frame of reference?

Does the person's use of voice (rate, pitch, volume, etc.) indicate meaning or emotional state?

Does the person's body language (posture, gesture, facial expression, etc) indicate meaning or emotional state?

Do simple questions requiring 'yes', 'no' or one word answers help clarify?

Is one place or person in this story a combination of places or people from the past and present?

Forget whether the details are true. What value does the story have for the teller?

Is this interaction an opportunity to spend time with the person?

What messages am I sending back?

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Health and wellbeing

Abilities	Factor (D)	Limitations
	Sensory (Deafness)	
	Drugs	
	Pain (Discomfort)	
	Nutrition and hydration (Diet)	
	Elimination (Defecation)	
	Sleep wake cycle (Diurnal)	
	Other medical conditions (Diverse)	
	Delirium	
	Dependence	
	Social environment (Dysfunction)	
	Speech and language (Disability)	
	Concentration/attention (Distraction)	
	Cultural expression (Different)	
	Mental health/illness (Disorder)	
	Spiritual or emotional anguish (Distress)	
	Depression	
	Dementia	

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Excess Disability

Brody (1971, p124) described excess disability as 'the discrepancy that exists when a person's functional incapacity is greater than that warranted by the actual impairment'.

A person with dementia, or not, may or may not:

- Experience one, or more than one, factor at any one time
- Recognise the connection between the cause and their behaviour
- Interpret the situation accurately
- Know how to relieve or resolve the situation
- Appreciate the escalating effect of multiple small inconveniences and discomfort



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External environment

Every external environment can be described using the ten factors listed below. Examples of supportive and fatiguing aspects have been listed to demonstrate.

Supportive	Factor	Fatiguing
Small; homelike; freedom to wander; variety; private and public; appropriate to activity; inside; outside; garden;	Space	Confined; very large; too small; one space with multiple purposes; no choice;
Cues for orientation; adequate; even source; something to walk towards; familiar;	Light Sight	Glare; dim; patterns that break up outlines; bold; distracting patterns; flickering;
Contrast to highlight; tone on tone to camouflage; clear;	Colour	Bland or vivid colours; childish colour schemes;
Purposeful; connection between sound and action; appropriate volume;	Sound	Too many; inappropriate volume; silence; confusion between sound and action; distracting; Constant background noise; monotonous noises;
Familiar; cue memory; pleasant; something to feel, explore and carry;	Texture Touch	Unfamiliar; unpleasant; nothing to feel, explore or carry;
Meaningful; fresh; cues orientation; gentle air movement; comfortable temperature; comfortable humidity;	Air Smell	Clinical; noxious; high pollen count; oppressive; too hot or cold;
Familiar; clear connection between object and use; personal possessions; number appropriate to space; in the right place; orientation cues;	Objects	Strange; unclear connection between object and use; communal use of all objects; absence;
Purposeful; meaningful; appropriate to space; routine; ritual; success oriented; choice;	Activity	Purposeless; overwhelming; no connection between action and environment; childish; demeaning; no choice;
Calm; small in number; accepting; courteous; supportive; family; consistent; choice; familiar;	Social	Sad; angry; too many; no people; no choice; judgemental; demanding; expected to function as a group;
Smile; respectful; wear clear bright colours; neat and tidy; clean; alert; interested; knowledgeable; healthy;	Myself	Frown; disrespectful; unkempt; tired; disinterested; hurried; lack of knowledge; unwell;

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Supportive	Factor	Fatiguing
	Space	
	Light Sight	
	Colour	
	Sound	
	Texture Touch	

Facilitator's Resource

	Air Smell	
	Objects	
	Activity	
	Social	
	Myself	

Facilitator's Resource

Activity

What is activity?

- Activity is everything that happens in 24 hours.
- Activity encompasses work, leisure, self-care and rest
- There is no such thing as 'doing nothing'

Through activity the person can:

- Express sense of self and individuality
- Link the past, present and future
- Focus on abilities
- Make purposeful use of time
- Create a sense of belonging
- Develop and demonstrate competence
- Engage creativity and achievement
- Connect with others and communicate verbally and non-verbally
- Spend physical, emotional and spiritual energy



Facilitator's Resource

Any activity can be adapted to fit a person's abilities and limitations using DRAMAS.

Element	Aspects	Description
D ignity	Relevance Age appropriate Risk	
R epetitive	Routine Ritual Familiarity	
A greeable	Task ----- Process Have to- Should do- Want to	
M odifiable	Physical Cognitive	
A daptable	Time Place Person	
S afety	Risk: real or potential Physical social, emotional spiritual cognitive	

Facilitator's Resource

Strategies and interventions

Abilities and Limitations

Name:

Date:

Information based on:

	Abilities	Limitations
Communication Word Voice Body Receptive Expressive Language		
Health and Well-being Physical Emotional Spiritual		
External Environment Physical Social		
Activity 24 hours Past, present, future Work, leisure, rest, self-care Physical, social, cognitive, spiritual, emotional		

Facilitator's Resource

Name:

Date:

	To enhance abilities	To support limitations
Communication		
Health and Well-being		
External Environment		
Activity		

Facilitator's Resource

Evaluating interventions

Characteristics of contentment

Calm and relaxed	Body posture and mood free of tension
Experiences pleasure	Enjoys social or sensory experiences
Tracks with eye	Follows what is happening in the environment
Makes eye contact	Engages with individuals
Helpful	Seeks or is willing to assist others
Responds to sensory input	Appropriately appreciates noxious and pleasant smells, tastes, noises, sights and touch
Enjoys being with others	Is comfortable in the company of others either passively or actively
Alert	Is awake and aware of surroundings
Sleeps well	Sleeps for appropriate length of time Wakes refreshed
Enjoys eating and drinking	Social and physical aspects of eating and drinking are appreciated
Gains satisfaction	A sense of achievement at having accomplished a task or activity or interaction with another
Gives and receives affection	Responds to kindness, fondness positively
Sense of dignity and self-worth	Respects themselves and expects other to show respect
Assertive	Able to make needs known or make choices firmly and politely
Sense of humour	Able to react to situations of absurdity with laughter or smiles

The Characteristics of Contentment are adapted from Kitwood's 'Indicators of Well-being' and Nancy Mace's physiological measures of mental health.

Facilitator's Resource

Characteristics of:

Hopelessness

Contentment

Agitation

Slow Withdrawn	Calm Relaxed	Pacing Restless
Disinterested	Pleasure	Distressed
Avoids eye contact Keeps eyes shut	Tracks with eyes Makes eye contact	Stares
Passive	Helpful	Resistive
Withdraws from or avoids sensory input	Responds appropriately to sensory input	Irritable
Seeks to be alone	Enjoys being with others	Seeks reassurance and attention
Difficulty arousing or engaging	Alert	Cannot rest, watchful
Excessive sleep	Sleeps well	Disturbed, restless sleep
Refuses food and drink	Enjoys eating and drinking	Unable to settle to eat Craves to eat, drink
Boredom	Satisfaction	Frustration
Rejects affection	Gives and receives affection	Demands affection
Expresses feelings of uselessness	Sense of dignity and self-worth	Overly anxious Flustered
Compliant	Assertive	Aggressive
Sad	Sense of humour	Excessive jollity

All emotional responses can be placed on a continuum from low emotion to high emotion. Somewhere in the middle can be perceived as - **the place of contentment.**

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Resources

Dementia Training Study Centres: www.dtsc.com.au

Dementia: Osborne Park Hospital Guide for Occupational Therapists in Clinical Practice
<http://dtsc.com.au/dementia-guide-for-occupational-therapists-in-clinical-practice/>

Understanding the brain and behaviour (DVD) - Alzheimer's Australia, Helen Creasey
This DVD explains the function of different areas of the brain and the impact this may have upon and changes to mood or personality. The changes that are seen relate to damage occurring inside the brain. This DVD explains the function of different areas of the brain and the impact this may have upon behaviour.

Change Theory, Change Management

Kritsonis A. Comparison of Change Theories. *International Journal of Scholarly Academic Intellectual Diversity*; 8:1, 2004-2005.

Kurt Lewin's Change Theory: www.currentnursing.com/nursing_theory/change_theory.html

Adult Learning Styles: www.qotfc.edu.au/resource/index.html?page=65376

Communities of Practice

Communities of Practice Etienne Wenger: <http://www.ewenger.com/theory/>

Building Communities of Practice

<http://www.adb.org/Documents/Information/Knowledge-Solutions/Building-Communities-Practice.pdf>

Community of Practice Design Guide: <http://net.educause.edu/ir/library/pdf/NLI0531.pdf>

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Life Story work

Life Story information and templates

www.dementiauk.org/information-support/life-story-work/

nwf.org.uk/Life_Story_Book_Template.html

Kellett U, Moyle W, McAllister M, King C, Gallagher F. 2010 Life stories and biography: a means of connecting family and staff to people with dementia *Journal of Clinical Nursing*, 19, 1707–17

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Environmental Design and Assistive Technology

Information, links and videos: DTSC (NSW ACT) Wikiversity

http://en.wikiversity.org/wiki/Caregiving_and_dementia/Topics/Environmental_design#External_links

or go to http://en.wikiversity.org/wiki/Caregiving_and_dementia and click on Environmental Design and Assistive Technology under Current Topics

BEAT-D (Built Environment Assessment Tool: Dementia)

University of Wollongong Free App for iPad or iPhone (Download from iTunes) Assess the quality of residential care environments for people with dementia. This app will guide you through the use of the Environmental Audit Tool (© NSW Health), invite you to photograph key parts of the environment and send your data for processing. A report comparing your facility with 56 other facilities and identifying areas for improvement will be emailed to you along with an invitation to discuss the results with an expert in the design of facilities for people with dementia. This service is provided by the NSW/ACT Dementia Training Study Centre which is supported by the Department of Health and Ageing. There is no charge.

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Notes

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Notes