

Dementia Framework Guide 2023

Principles and practice guide for Whiddon Care Services



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Overview

Inspiring dementia friendly communities

Whiddon's current strategic plan (2020–2025) acknowledges the recent industry changes that align with the new Aged Care Standards released in 2019, as well as the national focus on the need for improved wellbeing and care models that deliver enhanced outcomes for residents receiving aged care services. Whiddon's strategic outcomes aim at underpinning core values that include innovation, ageing well and creatively, along with evidence-based care.

The purpose of the Dementia Framework is to provide a scaffold to enable Whiddon to integrate dementiafriendly principles in the provision of care services that align with their values and relationship-based care approach, where later life remains meaningful and filled with purpose.

This guideline highlights evidence-based policy and practice that integrates with the MyLife care model and promotes dementia-friendly environments that aim to enable and better support the Person Living with Dementia (PLwD).

In addition, it fosters a dementia-friendly culture, along with dementia-friendly language and activities, and helps to reduce community stigma around the condition and the impact of people living with it. Research shows that 70%-80% of people living in residential aged care experience cognitive change. Dementia Australia reports that in 2021 estimates of almost 1.6 million people were involved in the care of PLwD with approximately 70% of people diagnosed with dementia living in the community. Aged care providers have the responsibility of ensuring their employees have the skills to create social and physical environments that support people with dementia and other cognitive disorders, to live well

Within a dementia-friendly organisation, a relationship and person-centred based model places the PLwD at the centre of a circle, with direct care staff in the innermost ring beside the PLwD. This enhances the thinking that decisions and policies are intended to support autonomy wellness and enablement and reinforces to employees that their role is not to attend or take over tasks, but to share and enable.

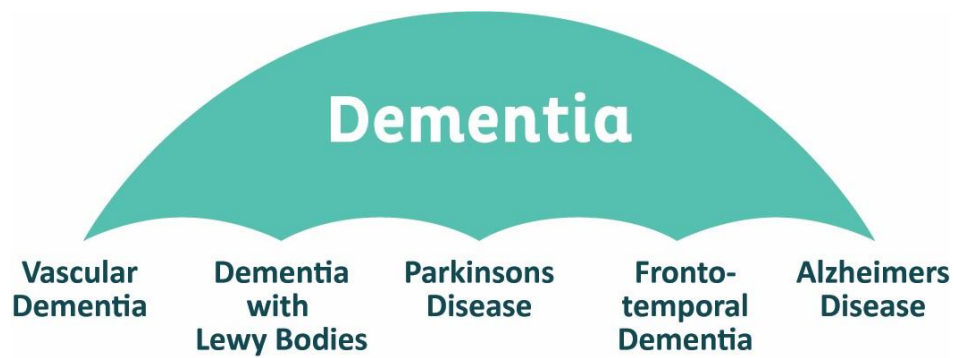
Understanding dementia

Dementia is an umbrella term describing a number of conditions that cause deterioration of brain function.

There are numerous types of dementia including Alzheimer's disease, vascular dementia, Fronto-temporal dementia and Lewy Body Progressive dementia. Symptoms, severity, and progression vary with the type of dementia, along with the impact of other disease processes. Symptoms include memory impairment, changes to executive thinking such as insight, planning and judgement, personality changes, alteration in perception and orientation, changes in social awareness and language abilities.

As dementia progresses, dependence on carers increases. Physical and cognitive function deteriorate often impacting relationships and carer stress of the primary and secondary care givers. There is no cure for dementia currently. Treatment used to help manage includes ensuring good sleep patterns, regular exercise and rest periods, and monitoring medications. Additionally, supporting and maintaining social and community connections, and encouraging respite and support for carers are priorities, along with safe living environments.

There are over 100 diseases that may cause dementia. The diagram below lists the most common causes.

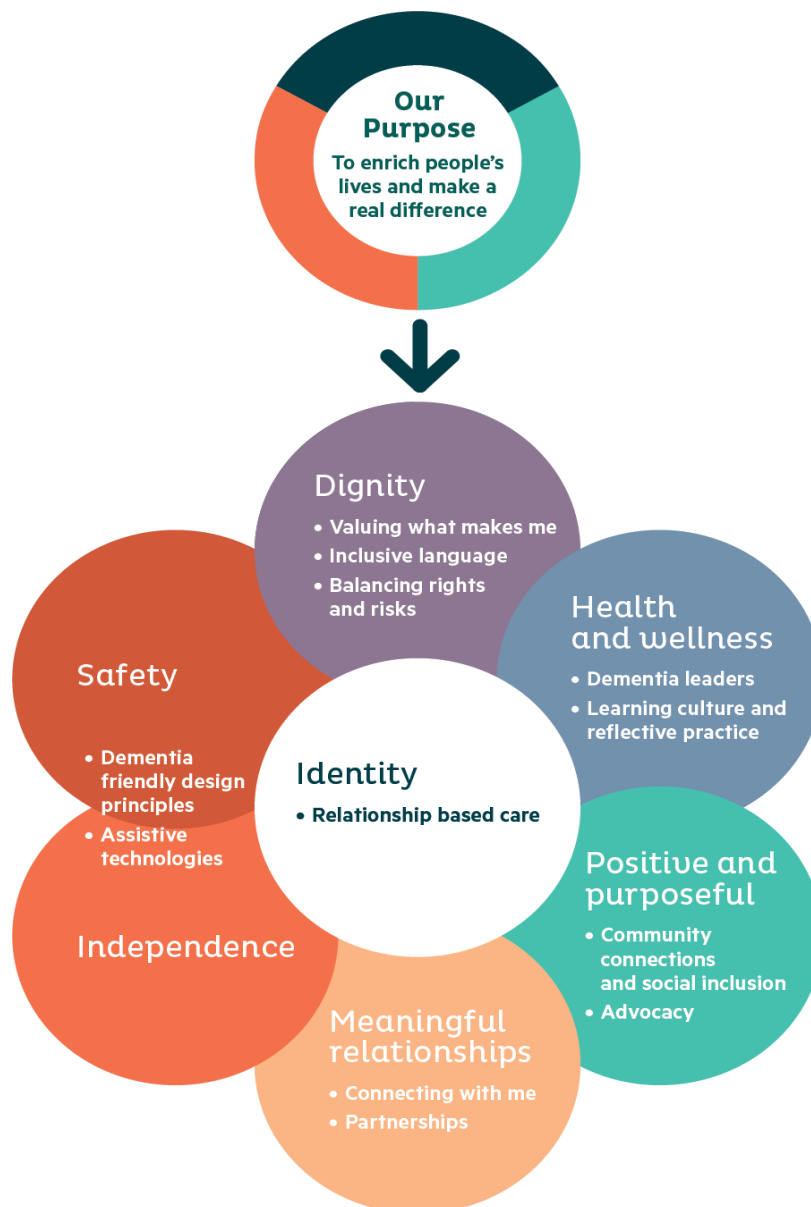


Whiddon MyLife and dementia care

Supporting our employees and communities to improve outcomes for PLWD and their families, the Framework informs strategies and initiatives that shapes an approach that enhances the lives of those in our care who are living with dementia.

Our MyLife model of care and twelve dementia care principles

The following diagram shows how the twelve dementia care principles will work to achieve the outcomes in our MyLife Model of Care.



Twelve dementia care principles

Below are the twelve evidence-based principles for guiding dementia care at Whiddon. Ideally, Whiddon services are implementing all twelve of the principles.

Dementia Care leaders

The role of our Dementia Care Leaders is to support employees to transform their understanding of what it is like to live with dementia. This occurs through mentoring and sharing knowledge, experience and wisdom. Dementia Care Leaders are supported to strengthen their knowledge, maintain awareness of new programs and best practice, and take up opportunities that raise awareness, reduce stigma and support families and carers. Toolbox talks in this guidebook are good resources that can be used by the Dementia Care Leaders through resident and client case studies and reflective practice that are meaningful for our workforce.

Learning culture and reflective practice

It is recognised that integrated learning is extremely effective in changing cultures. Aligning opportunistic training with case studies or short videos (see the resource page for websites), has seen proven outcomes. **Toolbox Talk** handouts are aimed at assisting Dementia Care Leaders, or senior Clinical Leads, to facilitate reflective practice sessions. These give employees opportunities to provide feedback and problem-solve, as well as to provide consistency and share best practice. The Training Matrix included in the Framework helps Managers to improve knowledge and develop confidence in their teams, to better support care and services for those residents and clients living with dementia.

RBC is the approach that all staff, not just the care **teams, are** asked to adopt at Whiddon, as we recognise that all resident/staff interactions have value. It has key elements to promote relationship building between residents and staff. By consistently rostering staff to work in the same areas and allocating staff members to be a MyLife Buddy for residents, we intentionally spent time getting to know and understand each resident and their lived experience. RBC allows connections to be built and supported, which is so important in supporting the identity and dignity for PLWD. Staff recognise the important of consistency and meeting individual routines, likes and needs. RBC as a care approach puts the focus on truly building trust with our residents and helping to provide an emotionally secure environment.

Partnerships

Whiddon acknowledges the benefits of nurturing external partnerships that support continuous improvement processes through research and evaluation. Support from Dementia Services, Psychological Service programs, local TAFE and Dementia Training Australia are key to tapping into external expertise and resources.

Balancing risks and rights

Autonomy and independence at varying stages of dementia can be supported through reviewing their environment, being responsive to retained abilities, reducing over stimulation and using evidence-based strategies and learnings as everyday practice. Rather than restricting freedom, knowing the person and connecting with their history and unique life experiences, better supports quality of life and allows the joy of past activities to be shared.

Relationship based and social care

A key to exemplary dementia care, is a committed team who really understand each residents' and clients' needs and draws on each other's strengths and talents to make everyday matter for the PLwD. This results in a psychosocial care model where all employees are aware of the person's unique needs, share in care responsibilities, and participate in social and leisure programs that are right for the PLwD, and flexible enough to meet the person's daily needs. An ability to respond to, adapt and change care approaches are essential expectations in all employee roles. The Top Tips document on social and leisure programs in the DSU/MSWs gives examples of the types of activities that can be used. Ensuring that all employees have baseline knowledge of 'Understanding dementia' as well as appreciating the importance of RBC, provides a foundation of confidence and empathy and . Where employees are allocated to Memory Support Wings, increased training as per the Training Matrix is provided, and dedicated rostering maximised.

Community connections and social inclusion

One of the key aspects to living with dementia is that the client or resident has usually lost their meaning and role in life, along with other physical or emotional attachments that they may have had. Keeping active in their local community, with extended families where possible, or within the care home's larger community, helps to maintain self-esteem and reduces responsive behaviours caused by frustration, depression and loneliness. There may be links with churches, cultural cooking groups, a Men's Shed, gardening, music or craft groups. By working collaboratively with the client and their families staff can discover what these connections have been and support them or find ways to still engage in an adaptive way.

Advocacy

With increased awareness of a person's needs, employees are expected through Whiddon's relationship-based care approach, to increase advocacy for the PLwD. Many are disadvantaged through reduced comprehension and communication, and employees are able to speak out on their behalf and represent their best interests. This can be, for example, during reflective practice sessions, Toolbox Talks or case conferences.

Inclusive language

The experience of living with dementia or caring for someone with the disease is an individual experience and the language we use must be respectful of their life course. There are cultural influences, not only on approaches to care, but on understanding the disease progression and the emotional impact of behaviours on families. Language needs to be respectful, non-stigmatising, empowering and inclusive, and must respect that the disease does not define the person we care for. Dementia Australia has 'Dementia Language Guidelines' on their website that help guide people in using inclusive and appropriate language, that are applicable in multiple settings.

Connecting with me

The key to connecting to the PLwD is in acknowledging their feelings, building trust and showing empathy. Anxiety symptoms are common in those living with dementia and may be reflected in responsive behaviours

such as pacing, agitation or rejecting care delivery approaches. Understanding how to use validation, or 'stepping into their world', helps to build a sense of security and comfort. Use of consistent messages or 'scripts' reduces confusion and the challenge of reality that is beyond their sense of the present. Reflective practice sessions are good opportunities for staff to develop and trial 'scripts' (see examples in the resources section). for individual residents or clients that support consistency of approach.

Valuing what makes me

Each PLwD has unique life experiences, beliefs, values and perceptions. By using our RBC approach our staff intentionally seek to discover what makes each resident special. By sharing this information, we can then tailor specific activities and support connections that will engage each resident. Partnering with their families or friends is important to understanding these meaningful memories and gaining access to pictures and other memorabilia that has meaning. It is important that these memories spark recognition and do not challenge beyond the PLwD's abilities, therefore, they should be an evolving document that adapts to the progression of the disease.

Dementia-friendly design principles

A well-designed environment can support the PLwD, by enhancing memory through visual aids, reducing over stimulation and stress, providing definition through colour and contrast and creating opportunities for meaningful activities or use of quiet rest spaces. This applies to both residential care and the PLwD's home setting if living in the community. Changes in spatial awareness often occur in dementia, which leads to disorientation and aimless wandering.

The Top Tips table on design principles is included in the resource section of the guide.

Assistive technologies

Communicating effectively in dementia care can be supported by various tools that, for example, can enhance memory, support safe movement or expand opportunities for social engagement.

Supportive aids can be simple items such as day/date clocks, touch lamps, coloured crockery and cutlery. Technical devices such as GPS tracking in watch designs or other wearable devices can reduce carer stress related to risk of exit seeking or wandering. Motion sensors are best practice environmental supports for courtyard and garden doors and bathrooms.

Communication apps are also available for people living with aphasia. Communicaid for example is a communication kit for people with expressive language difficulties and available from Alzheimer's WA in English, Greek and Italian with a CD for templates in other languages.

A Better Visit is a free app that facilitates positive social interactions for people living with dementia in residential care. Other aids that can be helpful include mechanical pets and one touch radios that are loaded with preferred playlists to reduce complexity of manoeuvring choice of stations. Whiddon has a music and dementia program which involves the creation of personal playlists for individuals, which can be listened to on aged friendly headphones. Plans for implementation are in progress.

Training

Appropriate competence in supporting people living with Dementia is integral to the success of this framework. For details regarding these training requirements for each role, please refer to the Learning and Development Policy and the mandatory training matrix. Both can be found [here](#).

Toolbox Talks and reflective practice

Good practice validation ensures that we are in line with evidence-based practice and that clinical tools such as screening and assessment tools, reports and care planning are reflective of our residents' and clients' needs and goals. Our values, policies and practices provide the foundation for our relationship based care model, and integrated workforce learning, and leadership modelling help to maintain commitment and confidence in care delivery.

Tips for delivering Toolboxes and reflective practice sessions

Timeframe: 15-30 minutes

Number of staff: 2–10

Resources:

- Case study/incident form/Toolbox Talk handout
- Whiteboard (and pens) if desired

Things to consider:

- Is this impromptu or planned?
- Consider noticeboard announcement/text message to involved employees • Is it an opportunity to debrief together after an incident?

Key pointers:

- Stay on topic
- Identify a resident/client or event to help visualize the concept
- Pace yourself
- Provide time for questions/clarification if not understood
- Encourage responses
- Follow through with suggestions made
- Encourage ideas for future sessions

Toolbox Talk 1

Responding to persistent or disturbing vocalisation

Learning objectives:

- Increase understanding of cognitive change impacting on vocalisation
- Identify strategies to reduce responsive behaviours in group settings

Think about:

- Is there a sensory loss which may be impacting on understanding the activity? For example: hearing, vision
- Think about what type of vocalisation is occurring? e.g. repetitive questions; disinhibited (inappropriate/antisocial comments); repetitive requests for help – ‘help me, help me’, ‘please nurse, please help me’
- Has their cognition declined lately and they are not coping with the level of engagement required?
- Have they had a fall recently which has increased anxiety?
For example: are they nervous or afraid of falling? Are they affected by glare/lighting/patterns that may be provoking misperception or hallucinations?
- Is there anything in the environment impacting on their vocalisation?
For example: something new/strange; a reflection/glare/noise which they aren’t understanding and can’t explain

People with repetitive/persistent vocalisation often:

- Are experiencing anxiety or fear
- Are physically uncomfortable
- Are lonely or experiencing grief and loss symptoms
- Have frontal lobe changes which impact on emotions and inhibitions

What you can do:

Environment	Communication	Wellbeing
Reposition chair for enhanced vision/hearing	Break the cycle: be firm, focused and repetitive with strategies	Offer pastoral care/volunteer support
Reduce glare and distracting light/shadow	If hurtful comments, introduce mindfulness at beginning of session	Review pain management, discomfort
	Match cognitive/physical acuity in the group	Document changes in ability/participation

Toolbox Talk 2

Promoting wellbeing in people living with anxiety

Learning objectives:

- Increase understanding of the impact of anxiety on everyday activities
- Identify strategies to support the person living with anxiety

Think about:

- When have you been told to do something you were not keen to do?
For example: attend an event; speak at a gathering; swim at the beach with kids when the water is cold
- How did you react?
Avoid discussion; shake your head; walk away; cry; feel nauseous; yell out no! – you became anxious!
- Why did you react like this?
Out of your comfort zone – something new/strange; felt overwhelmed; felt panicked; adjusting to a new environment

People with anxiety often:

- Isolate themselves
- Shadow employees
- Are irritable or impatient
- Are startled easily or report 'palpitations', excessive sweating, sweaty palms
- Carry out certain rituals or obsessive behaviours
- Demonstrate repeated behaviours

They may react because they:

- Have increased heart rate and are frightened about this
- Have had negative/traumatic experiences in the past
- Have a fear of being humiliated or embarrassed
- Experience flashbacks or upsetting dreams
- Are fearful of certain objects (lifts, insects) • Are fearful of something happening to them

What you can do:

Environment	Communication	Wellbeing
Provide a whiteboard in bedroom or kitchen in the home for daily/weekly routines	Maintain consistency, provide structure and routine to their day	Review pain management, discomfort
Increase sensory therapies/activities	Break the cycle of negativity: be firm, focused and repetitive with verbal messages	Identify source of worries
	Source counselling if suitable	

Toolbox Talk 3

Responding to agitated wandering

Learning objectives:

- Identify strategies to determine triggers to restless wandering
- Increase resources and interventions to reduce restlessness

Think about:

- What time is the wandering occurring?
For example: night-time, after bad dreams, or hungry? Sundowning and seeking past roles/duties?
- Is this a new change?
For example: when did it start: consider UTI/anxiety post fall/new visitor?
- Are there key words while wandering?
For example: 'mum', 'mama', 'nurse' (seeking comfort); 'the children' (worries); 'work', 'boss' (roles)

People with agitated/restless wandering routines may:

- Have unresolved pain and feel the need to stretch/move constantly to relieve this
- Have continence issues and not be able to find a toilet easily
- Be confused about time/place
- Be bored or seeking their role
- Be used to walking as part of their routine

What you can do:

Environment	Communication	Wellbeing
Ensure toilet signage is dementiafriendly	Share roles and meaningful tasks	Review pain
Provide tactile items along corridors for diversion	Understand their habits/story	Undertake delirium screen and continence review
Provide increased exercise programs and outdoor activities	Use positive reminiscence and stories	Identify if thirsty or hungry
Use visual memory prompts to help with orientation to time of day or activity/items/room purpose	Create occupational kits for meaningful activities (accountant kit, nursing kit, architect/builders kit)	Review medications
Camouflage exits	Create occupational booklets for reminiscence	Ensure good sleep patterns and rest periods to reduce fatigue in afternoon
Reduce noise, large groups	Create consistent messages	Reduce light and glare to avoid misperception
Remove suitcases from rooms		

Toolbox Talk 4

Understanding sexual disinhibition

Learning objectives:

- Increase understanding of the impact of sensory loss
- Identify strategies to determine triggers to and responses for disinhibited sexual behaviours

Disinhibition is a term describing the poor control of normal socially acceptable emotional or physical responses or actions usually found in people living with brain damage or with drug abuse.

Think about:

- What are the physical or vocal behaviours seen?
For example: fiddling with pants; touching staff or residents? Masturbating in common area? Wandering/shadowing staff or others? Inappropriate questions related to sexuality?
- How did you react?
For example: feel embarrassed? not sure what to say/do – what am I allowed to say to the resident?
- Have there been any other changes to physical or cognitive state recently?
For example: word finding reduced, seem more sedated, craving attention from carers or visitors? Cardiac change with increased heart rate? TIA? change of visitors?

People exhibiting sexual disinhibition may:

- Have urinary problems (retention, dysuria, UTIs)
- Not be able to find a toilet easily
- Have poor skin integrity around groin area
- Be grieving for spouse/companion, have an unmet need or seeking sensory comfort

What you can do:

Environment	Communication	Wellbeing
Ensure toilet signage is dementia-friendly	Maintain consistency, of message: 'I am a nurse here to help you'; 'no, don't touch me like that, that's not right'	Review pain management, discomfort
Ensure room temperature/ clothing layers suit the person	Use diversion – redirect attention through conversation or use an image – be prepared to have something easily accessible, or on the wall nearby ready for distraction	Delirium screen
Provide increased exercise programs and outdoor activities		Ensure clothes are comfortable, not tight
Provide music and dance to increase sensory benefit		Identify if grief or depression impacting on sensory loss
Provide tactile therapy (pet, woodworking, cooking)		Provide aromatherapy oils such as sandalwood or neroli through neck or foot massage

Toolbox Talk 5

Reducing the risk of falls in dementia

Learning objectives:

- Identify triggers for and causes of falls in people living with dementia • Understand and promote strategies to reduce falls and injury through falls

Think about:

- Is there a pattern to a person's falls?
For example: afternoon (could be cardiac/physical fatigue), rising from lying or seated position (hypotensive change)?
- What is their current ability and can this be improved?
For example: sit to stand 'copying' exercises/games; increase walking sessions throughout the day?
- Are there recent changes (clues to determine causes)?
For example: posture; increased skin tears; vision/spatial awareness; BGL changes

People with a new history of falls may:

- Have a change in chronic condition status
- Have experienced a TIA/ CVA

What you can do:

Environment	Communication	Wellbeing
Provide seating along corridors with images on walls opposite to enhance rest stops	Check if anxious or fearful	Undertake delirium screen
Provide tactile items along corridors for diversion and to increase pausing for rest stops	Provide gentle encouragement to move position or rooms for unobtrusive exercise	Review nocturnal sleep pattern
Provide increased exercise/movement programs or games to enhance strength	Offer visual poster of goals for achievements supported by care staff and RNs (e.g. 2 corridors in 6 minutes, etc, twice around garden path in 10 minutes)	Review cardiac/respiratory wellness: monitor random BP, pulse and O2 stats in afternoons – check if hypoxia is causing confusion
Ensure furniture in bedroom provides safe walking props and reduce clutter		Review medications
Provide memory prompt poster for using walking frame		Enhance good sleep patterns and rest periods to reduce fatigue
Camouflage exits		Reduce light and glare to avoid misperception
		Review footwear/non slip socks are in good condition

Toolbox Talk 6

Stimulating engagement in meaningful activities

Learning objectives:

- Increase understanding of the 'half done' approach to meaningful interactions
- Identify strategies that promote interest and reduce apathy

Think about:

- Do all employees know the PLwD's background and story?
For example: is there a Top 5/'My Story' easily available for staff to ensure a person-centred approach?
- Does the environment provide purposeful spaces or cues for engagement?
For example: wall pictures reflect food and dining in a dining zone? Door handles to courtyards or gardens are easily seen and colour defined to encourage outdoor exploration?
- Do they understand what you are trying to do? Setting up 'half complete' activities can provide incentive to be useful or fulfil a role
For example: are they overwhelmed with the task? Is the time of day right for them?
Do the items look too unfamiliar?

What you can do:

Environment	Communication
Provide items of interest on a table/at an activity station and rotate these over the hour with a break in between, e.g. florist box of silk flowers and vases to fill; shoes and polishing items with Dubbin polish on newspaper; socks to match; fishing lures to sort; cloth and water spray bottle to clean tables	Ensure visual and hearing aids are in good working order
Set up a 'work space desk' and use 'occupational kits' and booklets to offer task completion, e.g. accountant / architect/ business person; nurses kit; shopping list and recipe book	Ask for help: 'I'm running behind in my chores'; 'we are having a special visitor today'
Place a musical instrument in sight adjacent to a comfort chair, e.g harmonica, ukelele	Listen to what they are saying: check in if they are 'connected' with you
Fill a sink with warm soapy water and leave crockery for washing	Be flexible and ready to alter the activity if they respond negatively
Leave a broom/rake and a carton in the garden for sweeping/tidying leaves	Start with 'let's go over here..' or 'let's go for a walk...' rather than describe the next step
Use words and pictures for communication cues	Use travel postcards and souvenirs to stimulate positive memories
Create an interactive art wall or board	Allow time for them to copy the task with you

Toolbox Talk 7

Responding to resistance to care delivery

Learning objectives:

- Identify triggers for resistance to care
- Identify strategies to enhance optimum care delivery

Think about:

- Is there a reaction to entering the bathroom?
Think about your response to a new space, e.g. a hotel bathroom
For example: are they afraid of the mirror and who may be in the reflection?
Does it trigger traumatic memories? Are the taps unfamiliar?
- Is there a reaction to the water, or to undressing?
For example: is there hypersensitivity to running water? Are they experiencing neuropathic or vascular pain impacted by water pressure? Are they feeling the cold due to poor circulation? Are they embarrassed or humiliated? Are you compromising their modesty?
- Are they frightened about you, the stranger?
- Do they understand what you are trying to do?
For example: are they overwhelmed with the task? Can they hear you clearly?
Have you used props/visual cues to stimulate memory? Are they used to showers?

What you can do:

Environment	Communication	Wellbeing
Cover bathroom mirror with a picture if required to reduce misperception	Reduce chatter: keep conversation focused to help their concentration	Provide food and drink before shower/washing
Trial coloured towels and coloured toilet seat and handrails to assist with definition and security	Tell them you are a nurse and you want to help them so they 'don't fall'	Assess if pain is being experienced
Ensure room is warm	Explain tasks in short steps 'I'm going to help you take your shirt off'	Keep upper/lower body warm and covered for dignity (use towel or dignity cape) and minimise nakedness
Warm body wipes before use	Repeat phrases such as 'you're safe, hold the handle here', 'nearly finished'	Provide item to hold while washing (handtowel, cloth)
If available use warm towels	Listen to what they are saying in the bathroom – check on their feelings	Are there any wounds or skin conditions causing discomfort
		Consider avoiding showers and undertaking bedside bathing with bowls of water ('camp wash') – a soapy bowl and clear water for rinsing

Toolbox Talk 8

Misperception and misinterpretation in dementia

Learning objectives:

- Identify difference between misperception/false ideas and hallucinations and delusional thinking (changes in perception)
- Understand causes and interventions to relieve distress

Think about:

- Hallucinations (e.g. visual or auditory): what do you see/hear and what are they interpreting?
For example: reflection of layered blinds may look like a ladder on the floor: can you see the shadows? Who are they seeing in the mirror? Is the dark shadow a hole in the ground?
- Are sounds reported coming from a distant TV? These are often misperception.
- Delusions: what is really happening?
For example: 'they have stolen my money/sold my house'. Their short-term memory does not include these recent events
- Are there recent changes (clues to determine causes)?
For example: is medication being crushed and impacting on taste ('you are poisoning my food'); or increased isolation

People with a history of hallucinations may have:

- Parkinson's disease, Lewy Body dementia or a brain tumour
- Experienced a new TIA/CVA or have changed vision

What you can do:

Environment	Communication	Wellbeing
Ensure lighting is adequate for people with poor vision	Introduce yourself on approach	Undertake delirium screen
Reduce noise and large numbers that impact on concentration	Offer to help them 'search together', or 'remove the problem', then divert to another topic/activity	Check mouth/teeth for decay/other changes
Reduce shadows, bright light and glare	Learn common 'hiding/storing' spaces	Check visual and hearing senses for changes
Cover mirrors	Develop 'scripts'/phrases to use consistently to help reassure, e.g. 'Medicare is paying for your lunch'	Consider if headaches or old glasses are impacting on vision
Ensure outdoor noises are not affecting anxiety Camouflage exits	Ensure staff wear name badges	Review medications
Use colour to increase definition of objects (crockery, cushions, handrails)	Name the object you are using/showing	
Avoid busy patterns on flooring		

Toolbox Talk 9

Responding to paranoid thinking

Learning objectives:

- Increase understanding of contributing triggers to paranoid thoughts • Identify strategies to support the person experiencing fear or suspicion

Think about:

- As memory declines we often compensate for memory gaps creating 'stories' or reasons for changes, lost items etc.
- Is there a sensory change (vision, hearing, taste) which may be impacting on their confusion?
- Is there increased restlessness, agitation or aggression – delirium often triggers anger related to fear, paranoia or hallucinations
- Is there any history of mental health disorders?
- What exactly is being said? Try to identify key words to help solve the problem, e.g. 'poisoned food', 'stealing my things', 'someone coming into my bedroom'
- Where is it easy to hide things as an older person (behind curtains, in pockets, in pillowcases, under mattress, in food containers, the washing machine – anywhere there is a door)
- Has something changed in their environment? Are there new support workers?
- Is there a persistent misperceived fear of a staff member caused by traumatic or negative memories?

People experiencing anxiety related to paranoid thinking often:

- Are misinterpreting the environment
- Are genuinely fearful or mistrusting – this is very real to them
- Are recalling past events/trauma and inserting them into the present • May be unwell (e.g. infection, TIA) and experiencing delirium related behavior

What you can do:

Environment
Communication
Wellbeing

Check their environment for disturbance e.g. tree branch, hitting a window at night, disturbing TV programs or a mirror causing confusion	Acknowledge their concern, reassure, and show interest	Undertake a delirium screen and behaviour assessment; refer to a Geriatrician if required
Reduce glare and distracting light/shadow that creates misperception	Know their history and occupational background	Review vision and hearing function
Learn and document their common hiding places	Ask them to help you 'tidy up' or 'fix up' while you search/review the environment	Review medications that may impact on taste/nausea symptoms
Use labelled containers for memory prompts and structure in their day		Ensure there is no risk to harm or active suicidal ideation
Coordinators review rostering to remove feelings of underlying reserve/insecurity	Write a 'letter' with them to an official to make complaint/request an investigation	Investigate and identify if risk is present

Toolbox Talk 10

Reflective Practice Home Care case study

Supporting the person living with dementia and their carer at home

Learning objectives:

- Increase understanding of the impact of dementia on responsive behaviours
- Identify strategies to reduce confusion for the person living with dementia
- Identify communication strategies that support carers

Case Study: Marjorie and Jack

Marjorie and Jack have been married for 56 years and live together in the family home. Jack has mixed dementia (Alzheimer's disease and vascular dementia). This combination of disorders results in Jack sometimes having insight into his lapsing memory but when he is tired or unwell his awareness and coping skills will impact on memory recall and thought processing. The couple have family members living in nearby suburbs who provide assistance with appointments, maintenance and shopping and they have a Home Care package.*

Marjorie is concerned because Jack sometimes doesn't recognise Marjorie (due to reduced short term memory). He is becoming irritable, and now and then displays added confusion or paranoid thoughts about her being in the house and occasionally Jack has locked the back door refusing to let her into the house. At other times he reverts to past times in their married life when they were both working and can be successfully diverted with positive reminiscence.

Marjorie reports feeling very anxious at times and uncertain as to how to respond to Jack when his mood changes.

Think about:

- Is Jack in pain, sleep deprived or unwell? Frequently PLWD seek familiarity when needing relief from discomfort; we often hear someone calling out 'Mum', or 'nurse' which is a natural appeal for support. If Jack is feeling unwell, he may be more confused than normally and thus not recognise the 'older' Marjorie and reject her, seeking out the 'younger Marjorie' who is in his current memory experience.
- If Jack is rejecting Marjorie as his wife, he is still likely to recognise her as someone he vaguely knows or recalls, and carers can take advantage of this positive memory by reassuring she is a friend, or a colleague. The approach needs to be one of reassurance then diversion to reduce the anxiety caused by his confusion.
- The carer/support worker needs to 'step into their world', validate their feelings then use key words or phrases to move their attention to something comforting or familiar.

***Note:** People living with vascular dementia fluctuate in their memory recall and insight which is different to Alzheimer's disease memory decline. They are also at higher risk of experiencing depression. When left untreated, depressive disorders can affect decision-making capacity and memory. This then increases cognitive decline in their dementia presentation.

Strategies:

The key is to sound confident and relaxed, not be overwhelming or too directional in actions or communication. Be familiar with history and hobbies that can be used for distraction and meaningful engagement.

Script examples:

'Jack, it's been a busy day – you're looking a bit tired – how about a cool drink and a snack?'

'Jack – are you feeling a bit crook – how about a drink while I talk to the doctor'

'That bad knee is bothering you again Jack – what about some heat rub/Panadol?'

'The garden's looking a bit dry – I'll help you with the hose'

'Jack, Marjorie has stepped out to take the grandchildren/ children to swimming lessons – she'll be back to fix dinner soon; while she's out let's water the garden and pick some tomatoes for dinner'

It is helpful to identify a relevant story that fits into the family social history and patterns (occupational and social or family patterns, e.g. did their children have music, dance or sport after school; did they mind grandchildren), hobbies or community connections one can chat about (Lions Club, Red Cross volunteering, Sports clubs) that can be used in validating their feelings and setting scenes of reminiscence.

All About Me posters are ideal to include diversionary activities that connect to their familiar history. Ensure these are adapted as the dementia progresses and long-term memory declines.

Marjorie's script examples:

Identify whether he is recognising her or not and use appropriate messages:

'Hi Jack – Marjorie's helping out a friend - she asked me to pop in while you're a bit unwell – I can fix us some lunch'

'Marjorie told me you love a good beef stew – I'll get the shopping sorted and that can be a nice dinner'

If Jack is irritable with Marjorie:

'You know Jack – I've always loved keeping busy, so I'll finish washing up and then let's look at those old photos of our trip to...'

- Is it time to 'step into' Jack's reality if he continually does not recognise Marjorie and thus create separate sleeping arrangements and create a new 'role' for Marjorie? Can she be a sister/sister-in-law, or a daughter come to help?

What you can do:

- Consider Jack's wellbeing and review for recent changes or deterioration in function that may be increasing his confusion or anxiety.
- Coordinator could discuss with Marjorie whether a geriatrician review would be helpful for medication and health status management
- Encourage Marjorie to take part in support groups. Dementia Australia offer online and face to face support as well as education about dementia and the progression of the disease and the impact on caring
- Provide selected Helpsheets from Dementia Australia for the family to read.

Responsive behaviour support script



Date:

Name:

Goal: Reduce restlessness/wandering

Employees need to use these key phrases when seeking cooperation.

Employee script

Setting: Jean hovers around the front door seeking her family and disbelieves careworkers that they visit daily/are coming home soon.

Jean likes to tease/kid with people: learn a few jokes and use these to distract her or suggest she 'come along' to see someone who has some new jokes.

Identify staff who are good at joke telling who are in the care area for the day.

Have some books on jokes in lounge areas.

Collect funny animal photos and place in plastic sleeved folder to use and so she can sit and share with care workers, family or visitors

'Hi Jean. Karen (daughter's name) sent a message. Make sure you've fed the fish today – she doesn't want to see floaters in the fish tank when she comes at 5 o'clock!'

If Jean is in or near her room, point out the time on the clock and the daily message from the family to reassure her.



Top Tips

Principles of a dementia friendly enabling environment

- 1 **Unobtrusively reduce risk** – Maximise a person's abilities, and facilitate unobtrusive secure and safe internal and external spaces
- 2 **Provide a human scale** – Help a person to feel in control – minimise overwhelming spaces, doorways, corridors to reduce confusion
- 3 **Allow people to see and be seen** – Ensure good visual access in a setting that allows the confidence to explore and make choices
- 4 **Reduce unhelpful stimulation** – Manage the amount of sensory stimulation, reducing noise, being aware of light and dark, reflections and shadows
- 5 **Optimise helpful stimulation** – Personalise cues to minimise confusion and to enable decisionmaking; consider auditory, visual, olfactory, and tactile senses in way-finding
- 6 **Support movement and engagement** – Provide indoor and outdoor visually cued pathways that offer points of focus and activities or rest stops
- 7 **Create a familiar place** – Reduce clinical furniture objects and create home settings in clusters with era relevant reminiscence objects/furniture pieces / occupational corners to facilitate learned abilities
- 8 **Provide opportunities to be alone or with others** – Create themed zones to offer alternative active/quiet spaces
- 9 **Provide links to the community** – Maintain connection within the whole community through walks and outings, or participation in groups beyond the MSW
- 10 **Respond to a vision for way of life** – In the residential care setting, determine the care model/philosophy that fits with the building environment and enables staff practices to support the values promoted



Top Tips

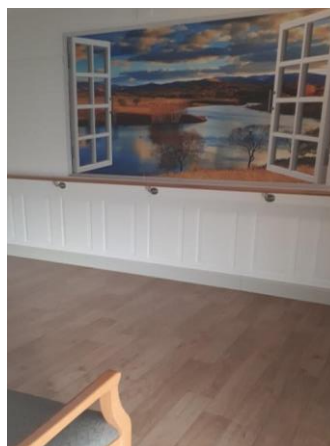
Translation into practice for the dementia environment

These tips apply mainly to the residential setting where Whiddon has control over the environment, however there are principles that can clearly apply to the PLWD's home setting.

Area	Suggestion	Related principle
Outdoor paths	<p>Stencilled concreting pathway circuits with contrast edging or at home, edge pathways with beds of flowers.</p> <p>Position seating and points of interest along pathways</p> <p>Paint contrasting colour on steps</p> <p>Suggest ways of making gardens and outdoor areas more dementia friendly in the person's home by applying this principle</p>	Definition against grassed areas assist with reduced vision and perception and direct people to focused areas of interest/rest
Grates in courtyards	Disguise to blend with concrete surfaces or surrounding plants	Contrast of grate appears as a black hole which can create a trip hazard
Small alcoves/room	<p>Establish quiet sensory sitting area</p> <p>Use orientation clock/calendars/label meaning of space</p> <p>Provide music or headphones for use to enhance activity or rest</p>	Quiet zones are useful for people with dementia who are restless or agitated; it also enhances rest stops which reduce fatigue and thus responsive behaviours and provide quiet spaces for visiting families.
Bedroom doors (to corridor) ensuite doors/ common bathroom doors	Paint doors in contrasting colours and use picture signage to identify room use or cupboard storage. Use identifiable toilet signage	<p>Create memory shadow boxes outside each room</p> <p>Strong colours enhance perception in dementia</p> <p>Visual cues enhance memory, communication and ability.</p> <p>Bright large photographs and personal items from the past enhance ownership, security and trust</p>

Store room/ employee only doors	Paint in neutral colour to match walls Use discrete handles/replace with codes and remove “Staff Only” signage	Reduce visual cue which reduces attraction to enter/fiddle with handles/locks
Area	Suggestion	Related principle
Corridors	Use tactile/visually friendly items on walls (hanging silk plants, fabric collages etc), and allocated employee names on a day board. Provide occasional seating for rest stops	Provides sensory stimulation, distraction, conversation starters for employees, and reduces perception of distance becoming ‘tunnelled’. Enhances trust and security.
Bedrooms and ensuites	Review bed position with view to ensuite and toilet signage Consider sensors (various to suit) Consider if mirrors are negative stimuli	Enhances independence within own environment; provides employee cues if movement needs to be detected
Seating and dining	Review colour and contrast tones/use of cushions Position furniture for comfort stops and for balance Coloured tablecloth and mat enhance definition of crockery	Contrast needed to enhance line of sight and perception, enhance recognition

Decals for disguise or wall murals to fit spaces that can be perceived as window views can enhance relaxation or distraction.

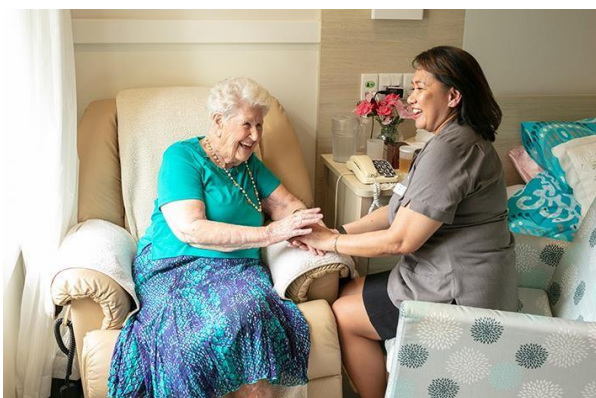




Top Tips

One to one support

- Hang windchimes and suncatchers from trees outside bedroom windows
- Install bird feeders at visible points in gardens
- Facilitate audio books (use your local library)
- Assist a reader holding a book by providing a tabletop bookstand
- Facilitate making family connections through card-making and writing (refer Family Connect Activity information sheet)
- Create a list, the channel and times of regular TV comedies/gender/occupational specific shows for employees or carers to facilitate with ease especially if there are alternative rooms to support concentrated enjoyment
- Develop exercise programs and use a scorecard on a small whiteboard or chart in the bedroom so that residents or clients can see their progress (more details on 'Keeping Fit' information page)
- Promote a Charity project a person can contribute pieces to, e.g. knittersguildnsw.org.au/charity; or knittingforcharity.com/find_your_niche_among_these_great_australian_knitting_charit.html (lists multiple charities that seek donations from rug squares to beanies and trauma teddies)
- Laminated drawing starters: use dry marking pens to allow residents to finish the drawings
- Use trolleys to distribute 'kits' for those isolated in rooms in residential care settings
- Encourage creative work such as helping to make fiddle mats or gel bags
- Make use of digital resources available according to likes and preferences – some suggestions are on website page such as concerts, living museum tours
- In residential care homes, if able, use streaming of movies/documentaries or videos from community organisations through the home's TV, (check with your IT department), e.g. ask your local day care centre to make a video of the children singing and dancing if they were regular visitors to the home





Top Tips

Keeping fit!

Where increased isolation occurs, the PLWD is at major risk of losing their mobility function. This impacts on continence, joint pain and dignity. An end result of this is an increased risk of withdrawal and mood changes, with an increased reliance on manual handling support. In the home care setting this reliance increases the burden of care and the likelihood of earlier entry into residential care.

All employees have a role to play in motivating residents and clients to maintain their physical function, and in promoting a 'do with you' approach rather than 'do for you' at all times.

Using scales, where residents and clients receive a score and maintain this score or improve it, can be a great talking point for families either face to face or on phone calls or video calls, as well as encouragement by staff.

To further increase wellbeing in the residential setting, a 'scorecard' of residents involved at the nurses' stations encourages social interaction and encouragement by care employees.

Our conversations with residents and clients about strength and 'keeping moving' need to be a part of daily care, using positive reminiscence within the conversation.

For example:

'When the bus trips start up again, you'll want to make sure you can get up and down the steps okay, so let's just keep those knees working'

'I know how much you like going out with your grandson for fish 'n' chips – so we need to make sure you can get in and out of his car when he comes to see you'

'Let's do the exercise together – I don't get much time to do this at home'





Top Tips

Writing to 'connect'

Location: Anywhere

Time frame: 10 – 30 minutes

Number of people: 1:1 or small group at a table

Resources required

Paper/cards, postcards, bright coloured pens, stencils, accessories such as stickers, stamps or ribbons, photos of resident from bus trip or events (retain small kits ready to go – this can be a resident or client activity for any time with any carer).

Things to consider

Approaching a resident or client to understand their desire to connect with family in this way and assuring them you are a 'helper'.

Step 1

Source equipment from resource box

Step 2

Ensure the person has clear writing space

Step 3

Provide choices: card type, colour, stencils, ideas, decorations

Step 4

Kick start the activity to prompt enablement

Step 5

Engage in reminiscence: memories of childhood/birthdays etc

Step 6

Check if item to be mailed and hand over to RAO or to family responsible

Variation to the activity

Add a photo of an event they have been to in the community at the home, or artwork undertaken, as a gift.



Top Tips

Adjustment into the residential care setting – helping families and residents

Being prepared

Whiddon's relationship based care model strongly supports caring partnerships with our families. As the carer for the PLwD, you are our key to successfully delivering person centred care.

It is an emotional time for families and where you can share information, cultural and spiritual preferences, memories, likes, dislikes and past occupations and activities, we are keen to listen.

Setting the scene

It is helpful to recreate familiarity in the bedroom and bathroom settings. This will enhance night-time settling or rest periods during the day. Here are some suggestions:

- Familiar patterned bedspread or blanket
- Favourite pillow
- Religious icons or pictures
- Family photos with names and places labelled
- Favourite armchair if suitable for current ability (the physiotherapist can help with this decision making)
- Remove suitcases (negative cues for leaving)
- If appropriate for past occupation/hobby provide a small desk for guided activities with familiar accessories

Clothing hints

- Loose fitting tops make it easier to dress quickly
- Avoid 'busy' patterned clothing
- If comfortable with stretch pants/trousers, use of these eases continence support
- Check clothing for correct season: rotate as necessary

Visiting tips

- Write postcards together
- Bring in a pet (arrange with Manager for requirements)
- Play familiar board games together or with other residents • Browse through travel books if it was a past activity



Top Tips

Website tips

dementiaaustralia.org.au

dementiaresearch.org.au/resources

dementialearning.org.au

Try 'A Better Visit' app for families

goldencarers.com.au

Membership required for full benefit

thelanternproject.com.au

Resources, videos and newsletters promoting good nutrition and collaborative discussions about resident involvement in their meals in aged care

enablingenvironments.com.au

Information and visual resources for the residential aged care setting that supports enablement and wellbeing for people living with dementia wisdomactivities.com.au

boxndice.com.au

Multiple resources and ideas for programs

eldac.com.au

Information, guidance and resources to support palliative care and advance care planning

health.gov.au/initiatives-and-programs/community-visitors-scheme-cvs

Australian Government funded scheme for volunteer visits to older people in RAC to provide friendship and companionship experiencing loneliness or isolation

visionaustralia.org.au

Vision Australia has numerous podcasts on Vision Australia Radio; tabletop bookstands, jumbo print word and sudoku books sydneylivingmuseums.com.au

sydneyoperahouse.com.au

Digital programs, stories, video clips



Top Tips

Supporting wellbeing in dementia in the home

Early concerns

- Changes in mood or communication, progressive memory loss, confusion about how to do usual activities

Seeking help

- Help the family to make a list of any changes and when they first noticed them
- Encourage an appointment with the GP about their concerns and ask for a wellness check (cardiac, endocrine, respiratory, bladder, bowel, medication review). The GP Practice Nurse may undertake an assessment (advised by the GP)
- Encourage a visit to a Geriatrician for diagnosis confirmation or detailed recommendations and support (referral from GP required)

Key messages

- Behaviours in dementia are often communication attempts or reactions to something the PLwD is confused about – we call these ‘responsive behaviours’
- Changes to the health of the PLwD or their environment can trigger a negative response but can be reversed if the health problem is resolved – it’s important to keep in touch with the GP to help monitor any chronic conditions
- Avoid information overload: verbal messages may not be retained well and forgetting these can cause embarrassment to the PLwD
- Encourage the family carer to use simple body language to provide direction, or to prompt action by having the PLwD copy the action rather than repeating instructions
- Ensure snacks and drinks are offered frequently throughout the day to reduce responsive behaviours caused by unmet needs such as thirst or hunger
- Use signage for memory prompts such as on kitchen cupboards, or a toilet door and day/date clocks
- It is essential for carers to have respite from the PLwD – communication and behaviours can be very repetitive and cause frustration and fatigue for the carer
- Ensure you have resources to divert the PLwD while visiting to allow for ‘time out’ for their carer
- Speak to your Coordinator re concerns about carer fatigue
- Provide Dementia Australia Helpsheets on related topics
- Promote Respite programs and Day Centre programs building from small time periods to enhance new relationships and trust
- Encourage access to support groups or counsellors such as through Dementia Australia



Top Tips

Supporting PLwD and carers who are LGBTQI

The physical and psychological effects of dementia are unique to an individual. Our responses to any illness, our culture and spirituality, our social supports, relationships and occupational histories, as well as the type of dementia diagnosed will all have an impact on how a person and their carer copes with the progression of dementia.

Our clients who recognise as LGBTQI may have experienced social stigma, isolation, family conflict or psychological trauma and this in turn may impact on responsive behaviours or heightened emotional distress during the progression of dementia.

Think about

- What is their role in the relationship and what binds them together?
- Has isolation been a part of living together or is there a strong connection to their community?
- Grief and loss – carers undergo ‘active mourning’ while caring for PLwD as they watch changes – it might be personality, or reversal of role dependency or loss of function at different stages
- Is their concerns if it has been a young relationship and the fear that with short term memory loss the PLwD will forget their partner/spouse early in the disease progression?

What you can do

- Ensure access to the Carer Gateway for support for care partners
- Access resources and references from the Sexual Health and Ageing program [Valscape](#) that promotes delivery of LGBTQI inclusive aged care
- Support special occasions that celebrate the LGBTQI community
- Ensure chosen name, gender and pronouns are consistent and well documented on care plans
- Respect choice regarding desired level of privacy about gender history, physical characteristics, sexuality and relationships including choices about key persons in relation to decision-making
- On outings ensure preferred access to public toilets is known by care staff

Whiddon
Award-winning care