



Quality
Dementia
Care :

**Practice in
Residential
Aged Care
Facilities
for all Staff**



Quality Dementia Care: A Guide to Practice in Residential Aged Care Facilities for all Staff

February 2007

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Preface

The purpose of this paper is to provide all workers (nurses, care workers, activity/lifestyle staff, other care staff, domestic staff, kitchen staff, gardeners etc.) who provide care for older people living with dementia, with practical information to help them deliver best practice person centred care, in a residential setting. The paper may also be useful for staff providing support or care to people living with dementia in the community or for people caring in a voluntary capacity for older family members or friends living with dementia.

A companion document Quality Dementia Care: A Guide to Practice for Managers in Residential Aged Care Facilities addresses the outcomes necessary to deliver quality dementia care and meet the Accreditation Standards in aged care facilities. This information is based on the principles embedded in the Philosophy of Care described in Alzheimer's Australia Quality Dementia Care Position Paper.

These principles are:

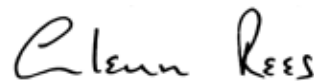
- a philosophical approach that emphasises person centred care;
- a partnership approach between the care providers, the person with dementia and his or her family and carers;
- a professionally based care environment characterised by strong leadership;
- and the adoption of best care practices that reflect the integration of a clear philosophy, current knowledge and applied skills (Alzheimer's Australia, February 2003).

These guidelines are based on the best evidence available and on the long experience of workers and carers who have cared for people living with dementia and supported their families. We are grateful to all those who took part in focus groups and in the Dementia Care Consensus Conference in August 2006 to contribute their experience to this publication. We thank the members of the National Aged Care Alliance for their assistance in organising the Conference in August.

While there are elements of dementia care that will apply generally, there are many areas where difficult judgements are involved about what might be appropriate and what would not, given the unique characteristics of the person being cared for. Ethical issues are subject to complex decision making and are not included in this document as they require individual consideration. This publication contains much information that will assist those caring for a person living with dementia, but professional advice should always be sought if there are doubts about the care provided.

Alzheimer's Australia thanks the Department of Health and Ageing for funding this publication.

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Glenn Rees
National Executive Director
Alzheimer's Australia
February 2007

Introduction

Person centred care principles shape best care practices. Person centred care means knowing the person, what makes them unique, and what is important to them. It means delivering care that puts the person first and is meaningful to the person, not to a group or collective sharing the same environment.

When the person being cared for has dementia there is an even greater need for meeting individual needs because:

- there are many different types and symptoms of dementia that impact differently on individuals, even when those individuals are affected by the same illness;
- the nature of the condition changes as it progresses; and
- every individual is unique, including their history, current circumstances and relationships.
- Because of the alteration in cognition and possible personality change the person can be objectified and devalued losing their 'personhood'.

A focus on individual needs requires continual evaluation of existing strategies and techniques and trialling and assessing new approaches. As the illness trajectory progresses end of life decision making will be necessary. It is preferable this is discussed sensitively with the person and their family through Advanced Care Directives when the person still has the capacity to be involved in the decisions.

About dementia

Why is caring for a person with dementia so different from caring for those without dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's mental and physical capacity. It is a broad term used to describe a loss of memory, intellect,

rationality, social skills and what would be considered normal emotional reactions.

The early signs of dementia are very subtle and vague and may not be immediately obvious. Common symptoms are progressive and frequent memory loss, confusion, personality change, apathy, withdrawal and loss of ability to do everyday tasks.

As the disease progresses it affects people in different ways. As well as the common symptoms above, behaviours can change. Examples of changed behaviours are: wandering, pacing, attention seeking, agitation, depression, aggression and hallucinations.

There are many reasons why a person's behaviour may be changing. Dementia is a result of changes that take place in the brain which affect the person's memory, mood and behaviour. Sometimes the behaviour may be related to these changes taking place in the brain. In other instances, there may be changes occurring in the person's environment, their health or medication that trigger the behaviour. Reluctance to participate in a simple everyday activity such as taking a bath may indicate that the activity has become too challenging for the individual however it could also be that the person is feeling physically unwell at the time or is in pain.

Understanding why someone is behaving in a particular way may help develop ideas about how to provide care. Inter disciplinary team members all contribute to a comprehensive care plan and quality outcomes for the resident.

The following sections provide suggestions of how person centred dementia care can be provided:

1 communication, 2 spiritual, emotional wellbeing, 3 social interaction and lifestyle, 4 personal care, 5 health care, 6 the physical environment, 7 behaviour, 8 abuse, 9 sexuality, and 10 cultural needs.

1. Communication

'Losing the ability to communicate can be one of the most frustrating and difficult problems for people living with dementia and their carers. Each person is unique and the difficulties in communicating thoughts and feelings are very individual" (Alzheimer's Australia Fact Sheet).

Workers and carers will often be able to understand language and problems of expression by using their observation and listening skills. Body language is very important in understanding a message. People with dementia may be able to read unspoken messages from and between workers and carers through their body language, and it is important that body language is consistent with any verbal messages being given.

1.1 General points

- Consider the difficulties of communicating with a person of a different cultural background and language other than English.
- Check if there are sensory loss issues, e.g. hearing or vision impairment, that would impede communication and use aids where appropriate, e.g. spectacles, hearing aids, etc.
- Consider other health conditions that may impact on communication, e.g. confusion due to medication, pain, hunger, thirst, etc.
- Avoid background noise when talking to the person.
- Introduce yourself by name, remain calm and speak gently and clearly.
- Sit still at the eye level of the person so they can see your face.
- Keep sentences short and simple, focussing on one idea at a time.
- Allow plenty of time for responses.
- Do not interrupt the person or finish their sentence for them before they have completed their response.
- Address the person by name.
- Treat the person with respect and involve them in the conversation even if they do not seem to understand. Never talk in front of a person as though they were not there.
- Ensure all carers use the same approach to reduce confusion.
- Non verbal communication such as touching, hugging, smiling may be appropriate depending on the individuals preferences and cultural acceptance.

- The use of humour can, when used appropriately and with caution create positive and enjoyable interactions.
- Ask the family how the person usually responds and be aware of any words that may trigger certain communication e.g. the use of a pet's name may trigger emotional upsets so should be avoided.

1.2 Orientation

- Validate the reality of the person. They may be operating in their time not yours. Challenging the person's reality may only lead to conflict. Responding to them by asking for more information about the topic or by diverting away to another topic may be more helpful than contradicting.
- Use orienting names whenever you can, e.g. 'your son Jack is coming' or 'John is coming'.
- Use notice boards or place notes in an appropriate place to provide information and daily events.
- Ensure name badges for workers and carers use large clear print.
- Be specific in direction and demonstrate what you are requesting if possible, e.g. 'It is time for lunch', not 'Do you want your lunch?'
- Limit choices: ask 'Do you want to wear the lovely red dress today?' not 'what do you want to wear today?'
- Do not try to make the person remember, e.g. 'You know the way to your room don't you?' This sets up expectations that may not be realised and only causes anxiety.
- Keep directions positive rather than negative, e.g. ask the person to 'stand up', rather than say 'don't sit down'.

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2.

Spiritual and Emotional Well Being

Person centred care means knowing the person. This includes knowing what is meaningful in their lives and what promotes their self worth, dignity and respect. Valuing the person as a unique individual means being non-judgmental, rejecting ageist or sexist language and views, and recognising the person exists in the context of their family and community.

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2.1 Spiritual care

- Spiritual care is not confined to religious beliefs and observance, although religion may be an important part of the person's spiritual needs.
- There are many different ways to express spirituality, e.g. meditating, listening to music, praying, walking in the garden etc., and people living with dementia should be encouraged to express themselves in their own unique way if possible.
- The use of icons or symbols can be an important part of the person's life and bring reminders of their faith or beliefs and these should be accommodated if possible.
- Attendance at church or religious ceremonies or contact with previous spiritual community should be available and organised if required.
- Music is often a reminder of meaningful events or practices, especially hymns or cultural music and should be available.
- Expressing spirituality through art, dance or poetry is often possible and should be considered and encouraged where appropriate.
- The opportunity to touch puppies, kittens, plant flowers, or watch the changes in the garden or weather can be a pleasurable experience and should be encouraged where appropriate.
- Outings to ethno-specific social clubs, attending exhibitions and cultural events can be important avenues for enjoyment, and if so, should be provided.

2.2 Emotional well being

- People have a need to express sadness, joy or disappointment, including people living with dementia, and expression of these feelings should be supported.
- A comprehensive personal history should indicate who has been a major support person and this relationship should be encouraged if possible.
- Continual sad moods may indicate depression and should be referred to a clinician.
- Anger and resentment may be present as a reaction to the loss of cognitive function and should be understood and the person given an opportunity to work through their feelings.
- The presence and/or reminders of loved ones may enhance the person's well being and the use of photographs or small personal items should be accommodated.
- A person's attachment to an object, e.g. a piece of clothing, handbag or soft toy, may be a 'security blanket' and should be accepted and respected.
- Some people enjoy human touch and others do not. Assessment should be made to determine the degree to which the use of touch and intrusion into personal space causes distress.
- Being well groomed and comfortable generally assists well being and effort should be made to achieve this for each individual.

3.

Social Interaction and Lifestyle

The importance of a comprehensive social and leisure history cannot be overstated. To know the person and their preferred lifestyle means gathering information about their leisure activities, friends, clubs, work, religious preferences, intimate relationships, hobbies, and what is meaningful in their lives. This can take time to gather and requires input from family and others as well as asking the person themselves.

The social interaction between people living with dementia and the people in their environment is extremely important. Non verbal communication is often as important as verbal in imparting feelings of self worth.

Cultural differences must be recognised and appropriate activities planned.

3.1 Family interaction

- Family members or significant others should be encouraged to participate and share in the resident's leisure and social experiences, e.g. outings, happy hours, meals.
- Visitors in a residential facility should be made welcome at any time throughout the day.
- Workers and carers should communicate regularly with the person's family about their care.
- Family should be encouraged to celebrate special events with food or ceremonies, e.g. birthdays, religious days.
- Families should be encouraged to bring pets and other special items from home to visit with the resident/client.
- Referral for counselling should be available for family members if required.
- Intergenerational programs should be available as they can be of benefit to people who enjoy the company of younger age groups.

3.2 Activities and leisure programs in residential facilities

- Education for volunteers about dementia and person centred care should be provided.
- Activities offered to the person living with dementia must be within their competency or modified for impairment, e.g. crossword puzzles.
- Daily activity should be planned and recorded on a care plan with the outcomes monitored for suitability and the person's response. Any stress reaction to outings or activity must be noted and the plan amended accordingly.

- Domestic type activity could be encouraged and reminiscences used to promote feelings of worth, e.g. folding linen, setting tables, dusting, watering gardens, etc.
- A range of activities should be provided to meet varying personal competency levels that can alter frequently as the dementia progresses or other health related factors intervene, e.g. music therapy, cooking, art, and sensory experiences.
- Community involvement should be encouraged, e.g. concerts, outings, school children visits, service club involvement, day centre visits, etc.
- People living with dementia should be encouraged and given the opportunity to continue their social roles where possible, e.g. helping others with their work, leading a group activity, planning activities, being the host or hostess, leading the singing, etc.
- Tactile stimulation through craft, touching or feeling items, tasting food items or smelling flowers may be useful in reminiscing and provide pleasure.
- All activity should allow for maximum independence and be paced according to the person's capabilities.
- The introduction of pets may be helpful following an assessment of the person's wishes or allergies and the suitability of the environment. Pets should only be introduced in a residential setting after a thorough assessment is made of their possible impact on other people and staff and only if the pets have been trained to behave in a socially interactive and acceptable manner.
- All lifestyle activity should be fun and encourage pleasant interaction between people. Having fun and sharing stories is a way of bringing meaning to the day.

4. Personal Care

Because people living with dementia may not be able to say what their preferences are in maintaining hygiene, grooming, or eating; nor may they be able to tell workers and carers if they have a sore mouth etc., it is important to observe any change in patterns of daily living. During daily hygiene activities workers and carers have the opportunity to monitor any change in the person's physical appearance, behaviour or responses to care.

Maintaining independence is important and workers and carers should assist to the extent necessary but not take over the task.

Cultural, religious and gender differences may impact on the way personal care needs to be delivered, e.g. an older woman may not appreciate being bathed by a male care worker or cultural beliefs may dictate how certain body areas are touched.

4.1 Personal Hygiene

Preparation for hygiene

- Check that the care plan states the time the person wishes to be bathed or showered and ensure this is observed as far as possible.
- Allow ample time and offer choice (but not so much as to create confusion) when preparing the person for hygiene procedures, e.g. say that you have come to help them have a shower or bath and help them get dressed for the day. If the person is unhappy to do this leave them and return in 10 minutes and try again– the person may have forgotten the previous attempt. Always assume that people will be happy to shower or bathe.
- Maintain the bathroom and water at a suitable temperature.
- Encourage independent action and allow time for the person to do things for themselves as far as possible.
- Resistance to bathing may be reduced by making the bathroom a more friendly place by having music, bubble baths, pictures on the walls, comfortable stools or chairs to sit on whilst undressing, etc.
- Use body wash in preference to soap which may have a drying effect on skin and be difficult to hold when wet.

Observation

- Discreetly observe skin condition during bathing and note any changes, e.g. bruises, skin tears, dry skin or rashes.
- Check hair, finger and toe nails for attention if required.
- Daily observation for bowel movement is important to prevent constipation.
- Report any unusual odours that may indicate an infection.

Reduce anxiety

- Be aware that the process of bathing can be an invasion of personal space and privacy. Preserve modesty by using towels or face washers to cover the person's body and keeping doors shut.
- Talking to the person during hygiene activities and encouraging positive responses will help to allay anxiety.
- Always clearly say if you are going to wash the person's head and never pour water over their face. If hair washing is a problem leave it to the hairdresser or use an alternative such as dry shampoo as this may be more appropriate and less disturbing for the person.
- If possible clean teeth as desired by the person. Ensure the usual personal routine is followed as far as possible. If teeth cleaning becomes an issue a sodium bicarbonate rinse or wet swab stick may be tolerated. Regular dental checkups should be arranged and workers and carers should check gums and teeth daily.

4.2 Meals, Snacks and Drinks

Sometimes people living with dementia are at risk of not eating sufficient nutritious food or drinking enough fluid. Maintaining essential nutrients and fluid intake (minimum 1.5 – 2 litres per day) is very important for health and well being. Often eating habits change over time and workers and carers need to be flexible in offering food and drinks at any time suitable to the person to encourage eating and drinking. Towards the end of life a specific plan to address nutrition and hydration may be necessary. Finger food is often the most satisfactory way of encouraging eating. Meals are a social event and often the most important part of the day for socialising with others. How much the participation with others affects the eating process has to be assessed and appropriate steps taken to balance social needs with nutritional intake. It may be possible to arrange for meal times to be shared with family or friends.

Dining environment

- Create a pleasant dining space. In residential facilities small tables of no more than four settings per table are preferable. Try to ensure the right mix of people at each table. The mix may have to alter as the person living with dementia's needs change.
- Distractions such as loud noise, the television on, too many items on the table, or people moving about the room should be minimised.
- Music may or may not be helpful at mealtimes. Music should be regularly monitored for its impact and changed if necessary.
- Pleasant odours of food cooking are an appetite stimulus and should be encouraged.

Personal preferences

- Catering staff or meal providers need to be aware of and respond to personal preferences.
- Workers and care staff should know the drink and snack preferences of each person in their care.
- Families and friends should be made welcome to join in refreshments or meals or bring food to share.
- People living with dementia should be encouraged to plan their own meals, e.g. a salad bar or trolley could be provided so they can choose meal items.
- Culturally appropriate food should be offered where possible.

Presentation

- Tables should be set with minimal extra items and crockery should be appropriate for adults. It is not necessary to use plastic or unfamiliar crockery that people would not necessarily normally use.

- Meals should be served in an attractive manner with portions according to the appetite of the person.
- At meal times serve food one course at a time and arrange food in such a way that portions are separate.
- Soup can be served in mugs rather than bowls for easier handling.
- Present food on plain plates against a plain but contrasting cloth or place mat.
- Presentation of food should be user friendly for people with dementia, e.g. finger food, plates with raised edges, spoons with easy grip handles, non-slip place mats etc.
- Food and drinks should be served at an appropriate temperature.
- Drinks should be offered frequently through the day and encouraged during activities.
- In hot weather frozen ice blocks or drinks with flavoured ice may encourage extra fluid intake. This depends on the likes and dislikes of the person.

Timing

- People living with dementia should be given enough time to eat and enjoy their meals.
- Meals should be available outside set meal times.
- The person's preferred snacks and drinks should be easily available outside meal times.

4.3 Exercise

The importance of mobility and using the joints of the body cannot be over emphasised. Older people who remain sitting for long periods are likely to exacerbate arthritis and joint stiffness as well as the deconditioning of muscles leading to loss of muscle strength. This may result in falls and circulation problems.

Exercise programs need to be carefully assessed for people living with dementia as they can be frightened of movement in case they lose their balance and fall. This often results in them resisting participation.

Freedom to walk safely inside and outside not only gives pleasure and the feeling of home but also ensures exercise.

Accompanying the person on walks not only helps mobility but can also be a social event.

Planned exercise

- Exercise programs should be offered daily. These programs should be as active as possible. Incorporating exercises into normal daily activities is generally the most effective, e.g. when dressing, showering, toileting, etc. Daily walking for gardening, shopping, or housework tasks may be considered exercise and can be planned as such.
- Regular group classes for exercise to music or Tai Chi, etc., are very beneficial and can be arranged through day care or activity programs.
- Group activity such as walks to see flowers, etc., may encourage people to exercise.
- If a physiotherapy program is in place, it should be followed.
- Risk assessment for falls should be noted and observations recorded.
- Correctly fitting shoes appropriate for indoor and outdoor activity should be worn.

- The wearing of hip protector garments for those people who are at increased risk of falls should be encouraged as much as possible.
- The use of correct, user friendly mobility aids should be encouraged.
- Non ambulant people can still participate in movement, e.g. wheel chair dancing, craft and other activities to move muscles and joints.
- Passive exercises should be used with caution and only on people who can no longer perform active movement. Workers and carers need to be shown how to perform passive exercises by a physiotherapist to avoid causing pain or joint damage.
- The focus should be on the person's ability, praising small achievements to raise their self esteem.

Sensory Loss

Older people living with dementia may have vision or hearing impairment that adds to their confusion and disorientation. Regular assessment of vision and hearing may be difficult as the person may not respond to questions or indicate an appropriate response. However, appointments should be made for vision and hearing services if required and family support may be required to accompany the person for assessment.

Use of aids

- Regular checks for visual changes should be undertaken. The use of bi or trifocal spectacles may not be appropriate for people living with dementia whilst single lenses may improve their ability to see and move without falling.
- Correct use of spectacles and hearing aids should be followed and workers and carers should know what spectacles are for, e.g. long sight, short sight etc., and how to adjust hearing aids.
- All aids must be kept clean, in good working order and stored in an appropriate secure place when not in use.

- Natural light should be used for reading or lamps adjusted to shine over the shoulder if required.
- Workers and carers should ensure all aids are fitted properly should the person wish to wear them, before attempting to communicate.

Cues for sensory loss

- The person living with dementia may not remember their vision loss and have trouble adjusting on a daily basis to their environment.
- Contrast colours may be useful in promoting sharper edges to doors, furniture or environmental cues.
- Workers and carers should ensure corridors are free from clutter and have shadow free lighting that removes the possibility of frightening dark corners and reduces the risk of falls.

5. Health Care

Because of the range of health problems older people living with dementia may have, workers and carers have the responsibility to detect changes in health early and report these to clinicians so that timely interventions can be made. Observational skills are important, as the person may not be able to communicate how they feel or if they are ill. Detecting pain or headache may be difficult but must be considered whenever a change in behaviour is present.

Understanding the impact of cultural and religious beliefs about health and treatment interventions will impact on how health care is delivered.

5.1 Pain

Signs of Pain

- Pain is often difficult to detect by others and may not be voiced by the person living with dementia.
- The use of scales such as the Abbey Pain Scale can be useful in assessing people for pain.
- Ask about pain and where it may be. Any change in behaviour may indicate pain, e.g. not moving when the person usually moves easily.
- Other behaviours such as aggression or an increase in aggression, restlessness or agitation may indicate pain.
- Holding a part of the body, e.g. the head or knee, may indicate headache or joint pain.
- Grimacing, moaning or crying when moving or altering position is another indicator.
- Reluctance to raise arms for dressing may indicate pain or discomfort.
- Reluctance to walk when the person usually walks, even if only a short distance.
- Change of facial expression to portray misery and/or anxiety can also indicate pain.

Pain Management

- All pain, particularly if it persists or increases in intensity should be investigated.
- Try to identify what is causing the pain and the present location.
- If possible find out how pain has been managed before and what worked best.

- Offer understanding and reassure the person that you know they are uncomfortable or in pain.
- Appropriate use of hot or cold packs over joints may relieve pain.
- Massage over sore areas may also assist.
- Relaxation techniques may help, e.g. music, soothing talking, warm water therapy, etc.
- Medication as prescribed and observation of effect is important.
- A simple change of position may help to relieve pain.

5.2 Incontinence

There are many causes of incontinence, many of which are treatable. Assessment of the reason for incontinence is important before strategies can be used to promote continence. Both urinary and faecal incontinence is embarrassing and raises the potential for skin breakdown and infection.

Strategies to promote continence

- Following assessment and clinical investigation a plan to promote continence must be written.
- Make sure the toilet is easily identifiable and easy to use, e.g. raised seat, handrails and paper within reach. A coloured toilet seat on white bowl may assist recognition.
- A small light over the toilet visible from the bed or a night-light left on in an appropriate position is helpful at night.
- Clothing should be easy to unfasten quickly if necessary, e.g. a velcro or elastic waist band.
- The person should be observed for signs of distress, fidgeting or calling out that may indicate a need for the toilet.

- Daily fluid intake of 2 litres should be encouraged to flush the bladder. Concentrated urine through dehydration increases the urge to urinate and makes incontinence worse.
- The use of the toilet at a routine time each day for bowel movement should be promoted. The person's usual bowel elimination habits should be obtained if possible.
- Ensure privacy in the toilet whilst being on hand to offer assistance if required.

Managing incontinence

If the above measures and regular toileting do not improve incontinence a clinical assessment and development of a continence plan, including the use of aids may be necessary:

- Mattress protectors are essential.
- Continence aids such as pads must be used according to the needs of the person. A light pad during the day may be all that is needed and a night pad appropriate for the volume of urine may be required.
- If the person keeps removing the pad a body suit may be helpful to keep it in place.
- Daily checks on the condition of the person's skin must be done and barrier cream used on the perineum and buttocks to prevent excoriation.
- Sometimes flexibility in the use of receptacles, such as buckets for men, may keep the person dry.
- Unexpected or sudden faecal incontinence must be checked by a clinician to ensure there is no impaction or constipation present.

5.3 Sleep

Often people living with dementia have difficulty sleeping. There may be many reasons why a person living with dementia has difficulty sleeping including pain, anxiety, fear or other discomfort. Because other people are asleep, workers and carers may become concerned that the person will waken others. If the person does not settle it would be preferable to offer some activity that will not disturb others.

Establishing sleep pattern in residential facilities

- The person should be asked about their sleep patterns or family members asked as necessary.
- The room should not be darkened until it is time to go to bed, e.g. do not close the curtains when it is still light outside unless it is time to go to bed.
- Triggers that wake the person, e.g. noise, pain, nightmares, toilet needs, etc. should be observed, noted and avoided if possible.
- Be familiar with the person's usual sleep patterns and observe these if possible, e.g. the time the person usually went to sleep.
- The person should be asked if they are having trouble sleeping and what can you do to help.
- A lightened or darkened room as appropriate and privacy should be provided.

Strategies to induce sleep

- Remind the person it is now dark and time for sleep.
- Offer hot drinks or food.
- Check the temperature of the room and bed for comfort.
- Quiet music may alleviate loneliness.

- A nap after lunch could be introduced to reduce over tiredness or stimulation at night time.
- Put day clothes away out of sight as they may act as a cue to get up.
- Check with the doctor or pharmacist if any prescribed medication may be causing restlessness.
- Give pain relief as prescribed if it is likely that pain is present.
- Sit with the person for comfort to allay fears or anxieties about the dark or shadows that may cause illusions.
- Take the person for a short walk to show them others are asleep and there is no other activity going on.

If sleep is not induced without repeated intervention it may be wiser to allow the person to wander and give them some activity to do until they are ready to rest. Sleeping in a recliner chair closer to the worker or carer's office or room may also relieve abandonment anxiety. Sedation should only be used as a last resort due to the additional complications that can arise from its use, e.g. increased confusion or an increased risk of falls.

5.4 Medication

Often the person living with dementia is prescribed medication to improve cognition, mood or depression or in an attempt to manage behaviours of concern such as aggression. A past history of mental health problems or treatment for an illness may necessitate medication. All medication has the potential for side effects. Observation may detect changes in behaviour or appearance that may indicate a drug related side effect. Any deviations from normal must be reported to a clinician or a supervisor. Every effort must be made to reduce the risk of medication interactions because of taking too many medications, e.g. polypharmacy.

Potential medication side effect observations

- Changes in eating or drinking habits.
- Dry mouth and/or cracked dry lips.
- Alteration in walking or moving.
- Mood changes, crying or unhappiness.
- Skin rashes.
- Loss of balance.
- Diarrhoea or constipation.
- Dizziness on moving from a lying to standing position.
- Increased confusion, sedation.
- Headache or blurred vision.
- Slower speech, slurred speech, and vague responses where the person has changed from previous abilities.
- Lack of interest and participation in activity.
- Changes in behaviour, increased anxiety, aggression or resistance to care.
- Rigidity, involuntary tongue or mouth movements.

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6.

The Physical Environment

Person centred care is enhanced by an environment that is conducive to a lifestyle as close as possible to that of being at home. People living with dementia who live in a residential facility ideally need the same amount of space as if they were living at home. The environment in a residential facility must be monitored to provide acceptable levels of noise and stimulation. Freedom and choice of movement through the facility should be possible. Areas of quiet space for reflection and interaction with others are also important.

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6

6.1 Internal spaces in residential facilities

- Personal possessions should be encouraged in personal spaces and communal areas if appropriate.
- Pockets of interest and diversion should be provided.
- Floor coverings and furniture in the residential facility should be home like, comfortable and well maintained.
- Features such as books, sensory equipment, plants and pets should be available to encourage spontaneous participation, interaction, distraction and interest.
- Orientation cues to promote independence and self esteem, e.g. door signs, labels, and pictures to identify particular areas/rooms/items should be used.
- Photos on doors or items of a personal nature on a shelf may help with recognition of bedrooms.
- Signs and labels in other languages should be provided if required.
- Smaller sitting areas should be available to encourage small groups and intimacy.
- Smaller living units should be considered in order to decrease confusion, noise and encourage a home like feel.
- Bedroom areas should be available during the day.
- Interesting window views, e.g. bird baths or feeders should be provided.
- Furniture and fittings should be kept in the same place for continuity and to avoid confusion.
- The use of mirrors that may cause delusions or illusions should be avoided.
- Care should be taken in the choice of paintings, etc., to meet spiritual, emotional or cultural need.

6.2 Outside the building

- Residents should be encouraged to move freely and safely to outside areas.
- Secure areas should be provided for wandering outside.
- Outdoor spaces should be interesting with regular changes throughout the year. Shaded areas should be available for outdoor activities and safe outdoor seating provided.
- Private outdoor areas where families and friends can visit should be provided, e.g. a barbecue area.
- Opportunities for residents to be involved in outdoor activities such as watering the garden or washing the car should be provided.

6.3 Ambience

- Ventilation and temperatures should be kept at a comfortable level as determined by residents, rather than staff.
- A warm, friendly, relaxing and calm environment is required.
- Placement of familiar objects in the person's own personal space should be encouraged.
- Contrasting colours can be used to assist orientation and facilitate independence.
- Design and colour can be used to distinguish staff areas to reduce frustration and confusion.
- Noise in the environment should be kept to a minimum. Staff conversations, radio and television should only be heard by the intended audience.
- The environment should have appropriate lighting and use as much natural light as possible to avoid shadows.

- Shared areas and bedrooms must be kept clean with no odour or carpet stains.
- Public speaking units should not be used to announce events, etc., as they can cause high anxiety and stress.

6.4 Safety

Hygiene and cross infection

- Appropriate measures should be available for toileting hygiene, e.g. disposable wipes and skin moisturiser in bathrooms.
- Food and body fluid spills should be cleaned appropriately and promptly when they occur.
- Staff must wash their hands adequately between resident/client attentions.
- Staff must assist people living with dementia to keep themselves clean, e.g. hand washing and changing clothing.
- People living with dementia should be encouraged to maintain hygiene after using the toilet and before eating.
- Bathrooms should be regularly checked to make sure clean towels are always available and toilets checked for cleanliness and the provision of toilet paper.
- Kitchen spaces should be kept clean and food put away in the appropriate places.

Emergencies

- Staff should be fully trained for evacuation and fire/safety procedures and know the designated safe areas to evacuate to in the event of an emergency.
- Beds of people who are incapacitated must be fitted with evacuation harnesses for removal of the person on the mattress in case of fire.
- Staff should be aware of the limitations that may impact on a resident's capacity to follow instructions in an emergency.
- A list of emergency call numbers should be kept by the telephone for use by the care workers.

Security/risk management

- Policies and procedures on restraint should be clearly followed with a restraint minimization program in place.
- The environment must be kept clear of items that may be dangerous for people in transit, e.g. chairs, trolleys in corridors.
- Assistive technology can be used to support risk management strategies, e.g. bed/door/chair alarms, personal alarms worn by the client.
- The correct and safe use of domestic equipment to assist in activities of daily living should be monitored for safety regularly, e.g. kitchen mixers, vacuums, shavers, etc.
- Rooms/cupboards used to store dangerous goods should be safely locked at all times. Poisons and dangerous goods should be kept in a safe place.
- Medication rooms and trolleys must be locked at all times when not in use or attended by staff.
- All aspects of the environment and all work practices should ensure the safety of the person living with dementia, and workers, carers and others.

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7. Behaviour

The person living with dementia may exhibit behaviour which is different to their usual life pattern. These behaviours often cause concern for partners, families, workers and carers. The disease process can alter how the person reacts to others, whilst also having a disinhibiting effect on social behaviour and sexuality.

A person's normal behaviour can change, causing distress to others and possibly harm. Workers and carers should have an understanding of the personality and traits of the person prior to the onset of the disease and the behavioural changes that have occurred as a result of the disease process. Workers and carers should always seek clarification about changes in behaviour in case of undiagnosed delirium, pain, depression or confusion that may be the cause of the behaviour.

7.1 Altered behaviour

- Changes in behaviour may be a result of damage to the brain or have another physiological cause, i.e. pain, and be outside of the person's control.
- The person living with dementia may be frightened by their own behaviour and their inability to control it.
- Some behaviours can be initiated by care workers who do not understand the person and who interact in a way that triggers an inappropriate response.
- Aggression or altered behaviour may be due to frustration, anger or fear. Invasion of personal space may trigger avoidance and anger.
- An assessment should be made to determine what may have triggered the response or behaviour which is causing concern.
- The behaviour should never be aggravated by workers or carers being angry or punishing the person. This will only accelerate the behaviour you are trying to avoid.
- Stress can cause unpleasant reactions as the person feels out of control and cannot regain a sense of self, so stressful situations for them should be avoided if possible.
- Difficult behaviour can sometimes be managed by giving control back to the person by letting the person calm down in a safe environment.
- Adhering to routine, e.g. sitting in the same chair, can be reassuring and assists in orientation.
- Boredom can lead to frustration and anger. Offer some form of activity to defuse the situation can help, e.g. "come and help me make the tea".
- Hallucinations are often present in later stages of dementia and should be reported to a clinician. Seeing or hearing things that are not there is often frightening. Voices or sounds may be heard, people or objects seen and these can cause severe reactions.

- Workers and carers should try to work with the person to reassure and manage their reactions.
 - Shadows, noises, mirrors or objects that could cause disturbances should be avoided where possible.
 - Hoarding, repetitive behaviour, suspicious thoughts, pacing, and other behaviours all require observation, reporting and understanding about what may trigger them and how triggers can be avoided in the future or the behaviour managed appropriately.
 - Anxiety and agitation require an understanding of the reality the person is experiencing and validating this may help to settle them. Talking about the anxiety producing thoughts may help, e.g. the children are due home? How will they come home, by bus? Did you cook special treats for them? A conversation that evolves around the children may reduce anxiety.
- Workers and carers should endeavour to stay calm and seek the assistance of another worker or carer to distract the person if the behaviour persists and becomes difficult to manage. A pre-determined emergency plan should be available if the person's aggression becomes unmanageable.

8. Abuse

Because the person living with dementia may not be able to report physical or psychological abuse, workers and carers must be alert for signs of suspicious changes in behaviour or physical signs that may indicate that the person is being abused.

The behavioural changes associated with dementia and the stress of caring for a person living with dementia may trigger abuse in families with no previous history of abuse.

Abuse can take many forms and includes physical, emotional, psychological, sexual and financial. Staff can contribute to a form of abuse by withholding treatment, placing aids out of reach, removing call bells, treating residents as children, talking about residents in front of them and ignoring the resident's needs.

Any form of abuse is unacceptable and must be reported.

8.1 Observations of possible abuse

- Changes in behaviour toward a particular person, e.g. withdrawing from them; refusing to go with them on outings or to the bedroom or bathroom; emotional responses, such as crying; negative reactions such as anger or expressions of fear; may indicate abuse and should be investigated.
- Bruising, skin tears, disrupted clothing, unexplained bleeding or discharge from any orifice should always be reported.
- Any worries or suspicions must be reported and a plan of action implemented. If in a residential facility, the organisation's policies and procedures should be followed.
- Concerns about financial matters should also be reported.
- Management policies should empower and protect staff in reporting abuse.

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9. Sexuality

People generally have a need to express their sexuality and a sense of love and belonging. Personal relationships are an integral part of being human and people living with dementia may continue to have sexual needs and desires or wish to continue an existing sexual relationship.

- A loving relationship between two people can continue if both are happy to do so.
- Uninhibited sexual behaviour should be discouraged with sensitivity. Uninhibited sexual behaviour may indicate an unmet need for sexual expression and ways of meeting this need appropriately should be explored.
- Ways in which the person's sexual needs could be met should be discussed with their family in a manner which does not cause embarrassment or family conflict.
- In a residential setting, sexual expression may be facilitated by the

provision of privacy, appropriate furnishings, e.g. double bed, and permitting overnight stays.

- Sometimes the person living with dementia forms an attachment to a worker or carer and this may lead to sexual advances being made. The worker or carer should give clear and consistent messages in a calm and kind manner establishing behavioural limits. People living with dementia who form such attachments are vulnerable and workers and carers must never take advantage of or encourage inappropriate sexual advances. If the behaviour persists assessment by a clinical psychologist or psychogeriatrician is required.

10.

Cultural Needs

Meeting the needs of older people from culturally diverse backgrounds can be difficult, especially in a residential setting where there may be many different cultural backgrounds. Often second languages are forgotten so that people with dementia can only communicate in their original first language. In this situation, the use of interpreters is essential to gain a history and an understanding of the person's background. Family members can contribute but the older person may not have shared their concerns with them. To promote the wellbeing of Aboriginal and Torres Strait Islander people contact with their cultural group may be essential.

The impact of dementia on the cultural beliefs of the family should be established, e.g. do they understand it is a disease; do they understand the disease process; do they consider it a mental illness?

- The person's preferred language should be established and clearly documented.
- Daily conversations in the person's preferred language should be conducted by using an interpreter or a worker or carer who speaks the same language; or by using visitor schemes, church groups, clubs or friends.
- Books, including picture books, in the person's preferred language should be available. These are sometimes available in both English and the person's preferred language.
- Any signs or symbols that the person understands should be documented and used by staff to help convey a message, e.g. a sign or picture for toilet or bathroom.
- Labels in the person's preferred language should be used on cupboards or on items the person uses, such as hairbrush, slippers, etc.
- Appropriate therapies, activities or events the person may enjoy should be discussed with their family and participation of the person encouraged.
- Culturally specific events should be recognised and made available, such as posters, food, films, books, or television programs.
- Music the person recognises and enjoys should be made available.
- Post traumatic stress may surface as memory changes and past events remembered. Experience of war, disasters, family abuse or trauma of any kind may cause changes in behaviour: such as hiding when it becomes dark, hoarding items in case of famine, refusing to undress in front of others or lashing out at authority figures. These behaviours need to be understood and managed kindly and sensitively.
- Comfort and reassurance is constantly necessary for people living with dementia who cannot express themselves because of language barriers. They will usually respond to a worker or carer who conveys warmth and empathy and who genuinely tries to understand their concerns.
- Some cultures forbid undressing or bathing in front of others. Privacy should be respected by providing covers and closing doors.

11.

Altered Mental States: Confusion, Depression and Delirium

Confusion is a broad term that has a non-specific meaning. A better, more precise way to assess cognitive and behavioural change is to describe the actual behaviour being observed. There are many causes for changes in the mental state of an older person that exacerbate the dementing process. Drug side effects, circulatory disturbances, fluid imbalance, infections, environmental changes, etc., can lead to an acute confusional state or delirium. Delirium is a short-term brain malfunction caused by a disturbance in the physiology of the brain through a general illness process. The level of confusion can alter rapidly with changes in perception and thinking, emotions and reactions and psychomotor behaviour.

Depression is suspected when the person has lowered mood, loss of interest and enjoyment in life, feelings of hopelessness, despair, sleep disturbance, loss of appetite, apathy or irritability that is a change from their usual state of mind. If these changes persist over two weeks they must be assessed by a mental health professional. Not all episodes of sadness are clinical depression. The fact of losing one's memory and grief over the multiple losses associated with ageing can create sadness. It is when this sadness persists over time that clinical depression is diagnosed.

- Astute observation is the key to understanding mental changes.
- Not all sadness is depression and establishing good relationships with the older person so they can express their fears is often all that is required to assist them to adjust.
- Medication can assist in reducing anxiety and depression but must be monitored closely for other effects.
- Report any alteration to mood, reactions or personality immediately and seek further assessment for correct treatment.

Additional reference material

Internet sites

Alzheimer's Association Australia www.alzheimers.org.au
Arthritis Australia www.arthritisaustralia.com.au
Australian Pain Society www.apsoc.org.au
College of Pharmacy www.vcp.monash.edu.au
Beyondblue (depression) www.beyondblue.org.au
Continence Foundation Australia www.continence.org.au
Palliative Care Australia www.pallcare.org.au
Wound Foundation Australia www.vcp.monash.edu.au

Evidence based guidelines and reviews such as –

www.nicsl.com.au
www.latrobe.edu.au/acebac/board.htm
www.cochrane.org/indexO.htm
www.joannabriggs.edu.au

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Quality Dementia Care Series

1. Practice in Residential Care Facilities for all Staff
2. A Guide to Practice for Managers in Residential Care Facilities

Papers

1. Dementia: A Major Health Problem For Australia
2. Quality Dementia Care
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4. Dementia Terminology Framework
5. Legal Planning and Dementia
6. Dementia: Can It Be Prevented?
7. Palliative Care and Dementia
8. Decision Making In Advance: Reducing Barriers and Improving Access to Advanced Directives for People With Dementia
9. 100 Years of Alzheimer's: Towards a world without dementia
10. Early Diagnosis of Dementia

Reports commissioned from Access Economics

- The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003
Delaying the Onset of Alzheimer's Disease: Projections and Issues, August 2004
Dementia Estimates and Projections: Australian States and Territories, February 2005
Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006
Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home, November 2006

Other Papers

- Dementia Research: A Vision for Australia September 2004
National Consumer Summit on Dementia Communiqué, October 2005
Mind Your Mind: a users guide to dementia risk reduction 2006
Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, November 2006

These documents and others available on www.alzheimers.org.au



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