

Caring for a person living with dementia: Every day living



For carers

alzheimer'swa
the dementia experts

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Safety, risk and independence

Taking risks and making our own choices in life is very important to our sense of self-mastery, control, self-worth and self-esteem. It also helps to reinforce our independence. However, for a person living with dementia this right to make a choice and take risk is often taken away.

Supporting a person to continue to do the things they want to do such as going for walks, making their own food and drinks, and participating in other activities is possible by discussing potential risks with the person, reducing risk where possible, and accepting there will always be risk.

Tips:

- » Communicate openly with the person about your concerns for their wellbeing.
- » Enable the person to make choices where possible. How can the person be supported to undertake the chosen activity

so that it can be as safe as possible without taking away the pleasure of that chosen activity? For example, if a person with dementia likes to take long walks suggest someone walks with them, know the usual route they take and how long it takes, and suggest they carry identification and a GPS device.

- » Always ask yourself what the potential harm is if you stop a person taking risks. How could it negatively impact on their emotional wellbeing and quality of life?
- » What has the person's response to risk been in the past? Were they a risk taker or a cautious person? This will help you to understand if the risk is something you should be concerned about.
- » Consider what your life might be like if you were not allowed to take everyday risks such as handling hot drinks, walking in rugged terrain or exploring new places. How would that make you feel?

Frank

Frank is a 70 year old man living with dementia. He is unsteady on his feet and recently fell while getting up out of his lounge chair. Frank has always enjoyed walking and it has played an important role in his life and his wellbeing. He particularly enjoys walking outdoors and being in touch with nature. Frank can feel irritable and depressed if he does not walk and get his daily dose of fresh air.

Frank has recently moved in to residential aged care and staff are concerned he will fall and hurt himself if he walks outside independently. They also worry because he has dementia and think he might get lost. Frank has been attempting to go outside for his walk but staff insist it is too dangerous for him now.

A decision was made that Frank could not go outside for his walks. Frank's state of wellbeing started to decrease and he began staying in his room for most of the day. Frank doesn't understand why he can't go outside for a walk.

If Frank was given all the information what do you think he would choose?

To meet the needs of Frank and of the home, the staff could talk openly to Frank about their concerns for his physical wellbeing, and the potential for injury, and give him a choice to stay inside or go for a walk in a mutually agreed outside area.

Assistive products and technology

There is a large range of assistive products available to purchase that can assist a person with dementia to complete everyday tasks and maintain their independence.

Every day living

Items such as:

- » One touch radios
- » Easy to use universal TV remotes
- » Simple to use mobile phones
- » Safety irons
- » Easy pour kettles
- » Shower chairs.

Prompts and reminders

Items such as:

- » Bluetooth trackers for important items
- » Whistle key finder
- » Orientation signs
- » Easy to read clocks
- » Timers and reminders
- » Medication packs.

Safety

Items such as:

- » Sensor lights
- » Flood detectors
- » Phone locating apps
- » GPS phones, watches, pendants
- » Emergency ID pendants, bracelets.

Assistive technology sheets are available to download from alzheimerswa.org.au (search assistive technology help sheets).

Apps

There are a number of apps available to download on your smart phone that can be useful.

Driving

Dementia can affect a person's ability to drive safely. A diagnosis of dementia does not mean a person must stop driving immediately, however due to the progressive nature of the disease they will need to stop driving at some point in the future.

It is mandatory to report a diagnosis of dementia to the WA Department of Transport if the person is still driving. This can be done by calling 13 11 56 or visiting transport.wa.gov.au/licensing/report-a-medical-condition.asp

The person living with dementia may need to be assessed by their GP or they may need to undertake a driving assessment. Once the assessment is complete a conditional licence will be issued, which is valid for 12 months. Some restrictions may be placed on the person such as driving only at certain times or below certain speeds. After 12 months, the person will be reassessed. The diagnosis will not be printed on the licence.

Please see the driving help sheet available for download from alzheimerswa.org.au/driving

Travelling

General tips for travelling:

- » Always try a short trip first to gauge the person's reaction to being away from their home and familiar environment
- » Encourage the person to carry identification or a GPS device in case they get lost
- » Leave a light on overnight when staying in new places, such as a hotel room.

Tips for travelling overseas:

- » Advise the airline that a person with dementia is travelling with them
 - » Consider requesting seats close to the toilet or on an aisle
 - » Show the person how the toilet works
- » Allow additional time for stopovers, especially when travelling through different time zones.

When not to travel (signs a person may not cope with travel):

- » If they always want to go home when out on short trips
- » If they are easily upset in unfamiliar surroundings.

Physical needs

Eating and nutrition

When caring for a person living with dementia you may become concerned about whether they are eating enough of the right types of food, and whether they are getting enough fluids.

Forgetting to eat, loss of appetite, and problems with chewing and swallowing can affect whether a person living with dementia is eating enough.

Consider:

- » Offering their favourite foods
- » Leaving out snacks that are easy to eat
- » Adding sauces to food to increase fluid intake
- » Regularly offering food and drinks
- » Finger food, if cutlery is difficult for the person to use
- » Speaking to your doctor about dietary supplements
- » A dental check up to ensure the person is not experiencing any pain while eating
- » If the person lives alone, try calling to remind them of meal time or arranging an in-home support service to assist with preparation or delivery of meals.

If you have any concerns please consult your GP.

Dental care

Dental care is important for everyone but especially for a person living with dementia if they are unable to communicate, they are uncomfortable or in pain. Changed eating habits in a person with dementia may be an indication of tooth decay that has gone untreated. Dementia may also affect a person's ability to brush their teeth or maintain their dentures.

People with dementia can experience reduction of saliva production due to medications, and also a condition called dry mouth. Saliva production is essential to a healthy mouth and there are products available that may help. Speak to your GP or pharmacist for advice.

Assist a person with their dental care by leaving their toothbrush, toothpaste and mouth rinse on the bathroom benchtop where they can be easily seen.

If you are unsure about what to do, contact your dentist. Many dentists will have experience in caring for a person with dementia.

Dressing

Getting dressed can be a complex task, and may become overwhelming for a person living with dementia.

- » Check that lighting in the wardrobe is bright enough for the person to see clearly
- » If a person is becoming overwhelmed with choice, try putting out one or two outfits for the person to choose from
- » Make the task of independent dressing easier by putting the first item to be put on at the top of the pile, then the next item, and so on

- » Consider a reminder after each step of dressing
- » Pack away extra clothing if they are a distraction
- » Select clothes that are easy to get on and off, without buttons, snaps, hooks or buckles
- » Consider shoes that are slip on, with a non-slip sole.

Many people are used to getting dressed on their own. Losing the ability to dress independently can cause frustration, anger and embarrassment. If this is the case, try to assist from a distance.

Sleeping

A person with dementia may not need as much sleep as before, due to being less active. They may sleep more during the day and less at night, or be unable to tell day from night.

Often, sleeping problems are the result of simple things that you may be able to adjust:

- » Is the room too hot or too cold?
- » Is it clear when it is day time, and when it is night time?
 - » Try opening curtains and blinds during the day to let in natural light, and close them at night to stop distraction or shadows caused by the moon or street lights
- » If a person is disoriented in the dark, try night lights
- » Cover mirrors at night to avoid confusion
- » Is the person getting enough exercise during the day?
- » Try to avoid upsetting activities before going to bed
- » If a person wakes and walks around at night, make sure doors are locked.

Problems with sleeping may be caused by illness, pain, or be a side effect of medications. If you are unsure, contact your GP.

Ensure you are also getting enough sleep at night, and regular rest throughout the day.

Hygiene

Showering or bathing can become difficult for a person living with dementia for many reasons. There are many steps involved in showering or bathing, starting with getting undressed.

- » Try not to rush the person
- » If the tasks are becoming too complex, try breaking down into simple steps
 - » Place soap, washcloth and towel within easy reach
- » A person living with dementia may not like running water on their head, making washing hair a difficult experience
 - » Try to separate hair washing from bathing, or washing from a basin
 - » Try visiting a hairdresser or having one come to your home to help with hair washing
- » Install a hand held shower hose, shower rails or a chair to make it easier to continue using the shower
- » Not everyone is comfortable washing in front of others, create a sense of privacy by closing curtains, blinds and doors
- » Check the room is not too cold for the person and there is enough light to see by, particularly at night
- » Install non-slip flooring to ensure safety.

Continence

People living with dementia can become incontinent for a number of reasons. It is important to rule out possible causes such as infection, constipation, hormonal changes or prostate enlargement first by visiting your GP.

As dementia progresses a person may not recognise they have a full bladder or bowel, they may not remember what to do when this happens, or they may not be able to find or recognise the toilet.

- » Raised toilet seats, contrasting coloured seats and grab rails may all help a person to continue using the toilet independently
- » Ensure lighting is adequate, particularly at night
- » Watch for signs a person needs to use the toilet such as agitation, pulling on clothes or flushed face and gently encourage the person to try using the toilet
- » Consider easy clothing types for the person to pull up, pull down and undo
- » Incontinence can be very stressful for the person living with dementia and their carer. It can also be humiliating and embarrassing for the person experiencing the incontinence.

Seek help as soon as possible. Try calling the Continence Advisory Service on 1800 814 925.

Pain

Dementia itself does not cause pain. A person with dementia can still feel pain, however they may not be able to communicate what they are experiencing.

Pain in a person with dementia may come across as a change in behaviour, crying, sleeping more or a reluctance to move. Use a range of different words when asking a person about their pain (such as sore or uncomfortable) and trying pointing to different parts of the body.

If you are unsure, speak to your GP.



Intimacy

All human beings experience the need to feel closeness and physical contact with others. This contact can be between friends or between partners. An intimate connection with another person can provide a sense of safety and comfort.

Over time, it may be common for a person living with dementia to lose the closeness of relationships and to feel alone and isolated. The need for closeness and intimacy does not disappear for a person living with dementia. Retaining or developing intimate relationships with others can help a person with dementia to feel connected.

Changes within existing relationships

Dementia can change the nature of intimacy for people in long-term relationships.

Reasons for this may include:

- » Changes in the relationship dynamics, where one partner becomes a carer and the other becomes cared for
- » Confusion, memory loss, recognition issues and disorientation experienced by the person with dementia
- » Increased stress and tiredness experienced by both partners.

Changes to sexual expression

Some people living with dementia may experience changes to how they express themselves sexually. This may be a result of:

- » Emotional reasons: an unmet need such as physical closeness or experiencing feelings of loneliness or isolation

- » Confusion: a person with dementia may confuse their partner with someone else
- » Physiological reasons: dementia can cause a person to lose inhibitions or express themselves in ways that are different to how they used to.

Loss of inhibition, confusion and memory loss can lead to a person living with dementia making unwanted sexual advances toward a person other than their partner. Although this can be confronting for the people involved, it is important to understand the actions of the person living with dementia are symptoms of the disease and do not reflect who they are as a person.

What you can do:

- » Identify possible triggers
- » Modify clothing
- » Diversional approach
- » Activity with hands
- » Increase positive contact
- » Avoid an overreaction that can make the person feel embarrassed or humiliated.

Informed choice

There are often issues regarding a person living with dementia's capacity to make informed choices around sexual intimacy, particularly if they start to express themselves in different ways to how they would have before the diagnosis.

If you are concerned or need support or information, speak to your GP or call Alzheimer's WA on 1300 66 77 88.

Preparing for hospital visits

A hospital admission can cause fear and anxiety in a person with dementia. This can be due to being in an unfamiliar environment, being surrounded by strangers, experiencing an altered routine, or concern about one's own health.

Preparation

Depending on the level of support required you may need to:

- » Ensure the person living with dementia is aware of the hospital admission or visit, this is best coming from a family member or someone the person trusts
 - » Ensure the person living with dementia is involved in the decision making process as much as possible, this can help to reassure the person when they are in an unfamiliar environment
 - » Ask them to assist in preparing and packing clothes, shoes, toiletries
 - » Include a photo, book, blanket or other special item that is important to the person
 - » Provide reassurance, particularly if the person has had a negative experience in hospital previously; either themselves or with a loved one
 - » Ensure the person takes several sets of familiar and comfortable clothes
 - » Label belongings if possible
 - » Pack all medications
 - » Bring familiar pieces for the person's bedside table such as a torch, clock, photo
- » If the person has a personal profile, Advance Health Directive or contacts list, make sure these accompany the person going to hospital. A personal profile can help staff get to know the person quickly and build rapport.

Admission

- » Upon arrival, discretely inform the admissions officer that the person has a diagnosis of dementia
- » Move the person to a quieter part of the admissions area
- » A familiar item, such as a photo or a book, can provide support and reduce anxiety
- » Once admitted and in the hospital room, provide items that offer orientation such as a newspaper, clock, watch, calendar or diary for bedside table
- » Familiarise the person to the hospital surroundings where possible, for example point out the toilet, nurse and nurse's station, name of ward, call bell, water jug and glass. Consider a wayfinding sign for the toilet.

Hospital stay

- » Always involve the person living with dementia in discussions, particularly at the bedside
- » Be mindful of multiple conversations where there is potential for the person to be excluded
- » Have profile page displayed in a prominent place on table
- » Bring to the attention of staff the person's routines and strengths, likes and dislikes, triggers for stress

- » Provide meaningful engagement, where possible and depending on the person's health; music can have a positive and reassuring effect
- » When it is time for you to leave after the person's admission, inform staff in case the person becomes distressed, and reassure them that you will return soon
- » Hospitals can be stimulating environments. It is a good idea for carers to monitor the person with dementia for signs of being upset or distressed. Carers may notice signs of distress before hospital staff.

Wanting to leave hospital prematurely

- » Try to identify the reason why the person wants to leave
- » Focus on the positive experiences of the hospital stay; helping the person get better so they can feel great, time to have a rest or take a break
- » Talk on the phone and visit regularly.

Discharge

- » A person living with dementia may feel anxiety or distress when told they are leaving the hospital
- » Ensure follow up care or services have been organised: these may include reinstatement of health package services, and GP, specialist, allied health or therapy appointments
- » Ensure the hospital provides an up to date medication list, and that medications have been picked up from the pharmacy or will be delivered to the home in a timely manner.



Our Vision

A world where people with dementia and their families are supported and valued on their dementia journey.

Our Philosophy

Dementia is a lived human experience rather than just a biological condition. We therefore embrace and support a holistic, person-centred approach that respects the individuality and the experience of those living with dementia.

Our Purpose

To improve the lived experience of those on the dementia journey through our advocacy, leadership, innovation, education, partnerships and holistic, person-centred care and support, and to support the pursuit of risk reduction, treatment and cure for dementia.

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