



# Volunteer Training Handbook

A Person Centred Care Volunteer Training Program



## AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building  
67 Albert Avenue  
Chatswood NSW 2067

PO Box 699 Chatswood NSW 2057

**T** +61 2 9464 4666 **I F** +61 2 9464 4728

**E** [info@aci.nsw.gov.au](mailto:info@aci.nsw.gov.au) | [www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)

SHPN (ACI) 150009

ISBN 978-1-76000-009-7

Further copies of this publication can be obtained from Agency for Clinical Innovation website at: [www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)

**Disclaimer:** Content within this publication was accurate at the time of publication.

This work is copyright. It includes copyright Help Sheets from Alzheimer's Australia and copyright Fact Sheets from Alzheimer's Society UK. It may be reproduced in whole or part for study or training purposes subject to the inclusion of an acknowledgment of the source.

It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above, requires written permission from the Agency for Clinical Innovation.

Published Oct 2016. Next Review 2023. © State of NSW (Agency for Clinical Innovation)

# CONTENTS

Introduction.....	4
Pre Education Questions.....	5
Chapter 1: About the Program and the Volunteer Role .....	6
Chapter 1: Additional reading.....	7
Chapter 2: Understanding Dementia and Delirium .....	12
Chapter 2: Additional reading.....	13
Chapter 3: Communication and Person Centered Care.....	26
Chapter 3: Additional reading.....	27
Chapter 4: Activities for patients .....	31
Chapter 4: Additional reading.....	32
Chapter 5: Understanding behaviours which can occur in patients with dementia and delirium ...	33
Chapter 5: Additional reading.....	39
Chapter 6: Assisting patients with eating and drinking.....	50
Chapter 6: Additional reading.....	51
Chapter 7: Safe walking with patients.....	56
Post Education Questions .....	58
Dementia & Delirium Care Hospital Volunteer Training DVD Evaluation.....	59
Quiz Answers.....	62

# INTRODUCTION

This Volunteer Training Handbook accompanies the Dementia & Delirium Care Hospital Volunteer Training DVD. The purpose of this handbook is to support your learning as you progress through the seven chapters of the DVD training resource.

The seven chapters in the Dementia & Delirium Care Hospital Volunteer Training DVD are:

- Introduction to the program and the volunteer role.
- Understanding dementia and delirium.
- Communication and person centred care.
- Activities for patients.
- Changed behaviours which can occur in patients with dementia and delirium.
- Assisting with eating and drinking.
- Safe walking with patients.

This handbook has seven sections based on each DVD chapter. Each section has additional optional reading. There is also a short quiz for you to complete at the end of each chapter.

The quiz is not a test you will be marked on, it is designed to support you in your learning as you progress through each chapter of the DVD. Once you have completed the quiz for each chapter you can check the correctness of your answers with answers at the end of the training handbook.

## How to use this DVD resource

There is a lot of information covered in this training DVD and you are not expected to absorb it all at once. It is suggested that you watch one or two chapters at a time, review the reading resources and then complete the quiz before going onto the next chapter. You may even want to watch the DVD more than once. Each person will be different. If you feel you need to keep the DVD longer to view it again do not hesitate to ask the person overseeing your training.

## Evaluation of the DVD

To assist in evaluating the effectiveness of the DVD training resource, a pre and post education questionnaire is included in the handbook to measure your confidence in caring for patients with memory and thinking problems both before and after watching the DVD.

The lift out pre education questionnaire is at the beginning of chapter 1 and the post education questionnaire at the end of chapter 7.

We would also value your feedback on how useful you have found this DVD training resource as well as any suggestions you may have for improvement. For this reason there is also a short evaluation form for you to complete at the end of chapter 7.

*The questionnaires and survey are anonymous.*

*Please return the pre post questionnaire and DVD evaluation form to the person responsible for your training when you return the DVD.*

# PRE EDUCATION QUESTIONS

Date: \_\_\_/\_\_\_/\_\_\_\_\_

Please answer the following questions, by circling the number that best reflects your response.

## 1. How confident are you that you understand what dementia is?

Not confident at all		Moderately confident		Very confident
1	2	3	4	5

## 2. How comfortable do you feel about the idea of spending time with a person with dementia?

Not comfortable at all		Moderately comfortable		Very comfortable
1	2	3	4	5

## 3. Sometimes, when a person with dementia becomes stressed or anxious, they can become upset, angry or aggressive. How confident would you feel interacting with someone with dementia who demonstrated these behaviours?

Very unsure		Moderately confident		Very confident
1	2	3	4	5

## 4. How confident are you that you understand what delirium is?

Not confident at all		Moderately confident		Very confident
1	2	3	4	5

## 5. How comfortable do you feel about the idea of spending time with a person with a delirium?

Not comfortable at all		Moderately comfortable		Very comfortable
1	2	3	4	5

## 6. Sometimes, when a person with a delirium becomes stressed or anxious, they can become upset, angry or aggressive. How confident would you feel interacting with someone with dementia who demonstrated these behaviours?

Very unsure		Moderately confident		Very confident
1	2	3	4	5

## 7. How comfortable do you feel about the idea of spending time with a person with a delirium?

Not confident at all		Moderately confident		Very confident
1	2	3	4	5



# CHAPTER 1: ABOUT THE PROGRAM AND THE VOLUNTEER ROLE

## What this chapter covers

- Overview and purpose of the volunteer program.
- The specific role of the volunteer in supporting patient care.
- Interaction with staff as part of the care team.
- The value of the volunteer role for patients, family carers and staff.
- The types of patient's volunteers will be supporting.
- The process of referral for volunteer support.
- Important considerations such as roles and responsibilities and confidentiality.
- Definition of a volunteer.
- The experience of existing volunteers.

## Additional information/reading included

1. Referral and Eligibility Form.
2. Volunteer Duty Statement.
3. Rights and Responsibilities.
4. Do's and Don'ts for Volunteers.

## Chapter 1 Quiz

Please circle the correct true or false response

1. The types of patients volunteers will be supporting include those who memory and thinking problems.	True	False
2. The volunteer role provides similar support to that of a family carer.	True	False
3. Reading and signing the code of conduct is a requirement for all health service staff and volunteers.	True	False
4. If a referral form has not been completed the volunteer can still provide assistance to the patient.	True	False
5. Maintaining confidentiality relates only to information about the patient.	True	False

**Check your answers with those at the end of the handbook**

# Chapter 1: Additional Reading

## Referral and Eligibility form

<b>Hospital Volunteer Program Referral and eligibility checklist</b>  Date: ___/___/_____  Ward: _____ Room: _____	SURNAME		UNIT NO/UAID	
	FIRST NAMES		DOB	SEX
	AFIX PATIENT LABEL			

### Patients are not suitable and excluded from the program if:

1. The patient has behaviours that would place a volunteer at risk (eg; Hitting out or physical aggression)
2. The patient or carer has declined to have a volunteer visit.

All information below **MUST** be completed to ensure the safety of both the patient and volunteer

### CRITERIA FOR PROGRAM (circle response)

Patient is aged >65 years (or if aboriginal > 45 years) <b>AND</b>	YES	NO
Scored 24/30 or less on SMMSE or 7/10 or less on AMT	YES	NO
<b>OR</b> Patient has a diagnosis of dementia or obvious memory and /thinking problems	YES	NO
<b>OR</b> Is positive for suggested Delirium with Confusion Assessment Method	YES	NO
<b>OR</b> Patient is >65 (> 45 ATSI) <b>AND</b> has one or more of the following delirium risk/precipitation factors		
Please tick: Severe medical illness ( ) Dehydration ( ) Alcohol dependant ( ) Depression ( ) #NOF ( ) Visual impairment ( ) Hearing impairment ( )		
<b>DELIRIUM ALERT</b> has been placed in patients MR folder	YES	<input type="checkbox"/>
<b>CONSENT</b> is required before the allocation of a volunteer. Verbal patient or carer consent obtained <b>NOTE: Where consent cannot be immediately obtained and the patient who meets the referral criteria is in need of urgent volunteer support the NUM/RN in charge can refer to the program pending consent.</b>	YES	<input type="checkbox"/>
Additional information required from nursing staff to advise volunteers on patient requirements. Volunteers cannot accept patients without this information		
<b>Specific suitability considerations;</b> Does the patient have communication difficulties that would prevent them from talking to a volunteer (eg aphasia)	YES	NO
Does the patient require <b>Personal Protective Equipment</b> ?	YES	NO
Is the patient <b>safe to be walked with a volunteer</b> ?	YES	NO
Does the patient need reorientating?	YES	NO
Does the patient need assistance with eating and drinking	YES	NO
If yes- type of assistance: Menu completion ( ) Set up and supervision ( ) Full assist ( )		
Is the patient on <b>thickened fluids</b> ?	YES	NO
Does the patient need <b>fluids encouraged</b> ?	YES	NO
Is the patient on <b>restricted fluids</b> ?	YES	NO
Is the patient on a <b>Fluid Balance Chart</b> ?	YES	NO
Are there any <b>special diet</b> or other needs for this patient that the volunteer should know	YES	NO
IF YES please specify :		

Name: \_\_\_\_\_ Designation: \_\_\_\_\_ Signature: \_\_\_\_\_

Please place completed form in the Volunteer Referral folder **<insert location>**



# Volunteer Duty Statement

## Volunteer Duties

1. Work within the team of nurses and allied health staff in supporting people with dementia and or delirium or those who are at risk of delirium in the hospital.
2. Volunteers will adhere to the roles, responsibilities, procedures and duties of the volunteer program.
3. The volunteer will be assigned patients as allocated in the volunteer referral folder and in consultation with hospital staff.
4. **In the circumstance where information about the patients feeding, fluids and walking needs are not completed in the referral form, volunteers are not to accept patients to the program until the referral form is completed clarifying this.**
5. The volunteer will respect the uniqueness of each patient and their family and will be guided by the care plan needs of the person. Specific duties include:
  - ❖ Sitting with the patient on a one to one basis or in group activity sessions
  - ❖ Assisting with making patients comfortable to support their sleep and rest – this may include adjusting pillows or providing warm drinks or a hand massage or gentle back rub,
  - ❖ Making sure the patient is wearing their glasses and hearing aides and checking that these are clean and working properly.
  - ❖ Talking to the patient about current events and surroundings
  - ❖ Assisting the patient with eating and drinking and when needed regularly offering fluids to drink
  - ❖ Assisting patients with completion of their menus
  - ❖ Accompanying and encouraging the person with walking as advised by the nurses or physiotherapist.
  - ❖ Supporting the person with activities they enjoy such as reading to them, playing cards etc.
  - ❖ Using dementia friendly communication when interacting with the person with dementia.
  - ❖ Communicating any concerns that may arise to the RN in Charge or NUM.
  - ❖ Communicate to the RN in charge and write down any changes that are noticed in the behavior of the patient in the volunteer records

## ROLE RESPONSIBILITIES

### The volunteer is:

1. Responsible for cleaning any activity items used with patients before returning them to the activity resource storage location.
2. To maintain the confidentiality and the privacy of the patient and their family, in the hospital or other relevant places, while working in a voluntary capacity
3. To refer the patient to the staff when a specific situation arises, i.e. with regard to health related questions, and when professional input is required.

4. To report any changes they notice in the patients to the NUM or RN in charge.
5. To remove themselves from any patients they feel uncomfortable or unsafe with and report this to the RN in charge or NUM
6. To report any hazardous incidents they identify to the NUM or RN in charge and comply with manual handling smart lift practices.
7. To adhere to hand washing and hand hygiene and other required infection control practices (as directed by staff) when visiting patients.
8. To keep a record of time spent, activities conducted the response of patients to those activities, and any other relevant information each shift.
9. To maintain copies of volunteer program documentation.
10. Where relevant, to keep a record and communicate to the RN or NUM the approximate amounts of fluids the patient has while with the volunteer, the level of meal assistance and how much of their meal they ate.
11. To record relevant information about the patients and their behavior in the volunteer record documentation and report any changed behaviour to the RN in charge or NUM
12. Not to attend their shift if they are have a cold, other respiratory infection or are generally unwell.
13. Not to attend their shift if they are suffering from a bout of gastroenteritis. In this circumstance the volunteer should not return to the hospital until 48 hours after their last episode of vomiting or diarrhoea.
14. Try to arrange a substitute for or notify Volunteer Coordinator/s or hospital staff of any unplanned absences
15. To attend supervision, de briefing, ongoing education and support meetings

**As a Hospital Volunteer, I agree to the duties, roles and responsibilities in this duty:**

Signed

\_\_\_\_\_

Signed

\_\_\_\_\_

Name of Volunteer

\_\_\_\_\_

Name of Supervisor/coordinator

\_\_\_\_\_

Date: \_\_\_ / \_\_\_ / \_\_\_\_\_

Date: \_\_\_ / \_\_\_ / \_\_\_\_\_

## Rights and Responsibilities for Volunteers

### **The Volunteer has the right to:**

- Expect orientation to the Service that includes geographic layout, introduction to clients and staff and relevant information. The Volunteer may find benefit in having a "buddy" allocated from the staff to
- ask questions or express concerns.
- Be provided with initial and ongoing training.
- Be regarded as a co-worker in the centre.
- Expect support and guidance from the Volunteer Co-ordinator and staff.
- Be allocated to a suitable assignment, with consideration for personal preference, background experiences and geographic location.
- Be trusted with information that will help in carrying out the assignment.
- Have their ideas heard regarding changes in the service they provide.
- Know whether their work is effective and how it could be improved.
- Indicate when out of pocket expenses are too great.
- Give their side of the case to the Volunteer Co-ordinator and /or staff if there are queries or complaints.
- Take a holiday.
- To have a particular place to put belongings, eg, locker, cupboard or designated shelf space.
- Participate in any meetings and learning opportunities that are organised for volunteers.
- Seek advice when uncertain about the role or task.

### **The Volunteer has the responsibility to:**

- Notify the Volunteer Co-ordinator or staff of absences.
- Provide feedback, suggestions and recommendations regarding the service and thus increase its effectiveness.
- Use reasonable judgement in making decisions where there is no policy. To discuss this with the Volunteer Co-ordinator or staff as soon as possible.
- Be dependable. Do what you have agreed to do. Do not make promises that you cannot keep.
- To be punctual.
- Wear a nametag and uniform is supplied.
- Be a team player.
- Maintain confidentiality.

## Dos and Don'ts: Dementia and Delirium Care with Volunteers

### DO

- Find out about the patients background and personal preferences using the personal profile.
- Communicate and interact with assigned patients
- Talk to assigned patients about current events and surroundings
- Sit with assigned patients one to one and in group activities
- Assist and support assigned patients with therapeutic activities
- Assist assigned patients with completion of their menus
- Assist assigned patients with eating and drinking
- Assist assigned patients with wearing visual and hearing aides
- Report any concerns or changes in the assigned patients to the nurse
- Report any other concerns or worries to the coordinator or NUM
- Keep a record of time spent with assigned patients
- Encourage assigned patients walking as instructed by NUM, RN in charge or Physiotherapist.
- Adhere to confidentiality and privacy of patients
- Adhere to the roles and responsibilities of volunteers

### DON'T

- Assist with or perform any lifting or moving of objects or patients
- Assist assigned patients with walking unless instructed or agreed to by volunteer coordinator or NUM, RN in charge or Physiotherapist
- Assist with care of any other patients that you are not assigned to - always talk with the NUM or RN in charge if you are concerned.
- Assist with duties a nurse might ask you to do that is not in your duty statement
- Assist any other patients (you are not assigned) with feeding or drinking
- Buy food or other items for patients unless permission is obtained from the Nurse Unit Manager (NUM)
- Enter a room where the door is closed without requesting or receiving approval from the NUM or RN in charge.
- Discuss or criticise a patients treatment with them, their carers or relatives
- Discuss any aspects of the patients care outside of the health service.

(ReVive, 2008)

# CHAPTER 2: UNDERSTANDING DEMENTIA AND DELIRIUM

## What this chapter covers

- Dementia is a broad term used to describe a set of symptoms affecting a person's memory, thinking, emotions and their ability to do things they were once always able to do.
- The onset and progression of dementia varies according to the type of dementia but in general it occurs slowly and gradually becomes worse over time.
- Delirium is a common condition affecting mostly older people in hospitals.
- Delirium is different from dementia in that it has a rapid onset. It most often has a medical cause and occurs much more commonly in people with dementia.
- The hospital environment can be quite frightening and stressful for people with dementia and delirium.
- Volunteers can greatly support patients with dementia and delirium and their family carers.

## Additional reading/information

1. Alzheimer's Australia Helpsheet – What is dementia?
2. Brain and Behaviour fact sheet.
3. Delirium family carer brochure.

## Chapter 2 Quiz

Please circle the correct true or false response

1. Dementia can be cured.	True	False
2. Alzheimer's disease is the most common cause for dementia.	True	False
3. Delirium is characterised by a sudden onset of change in a person's mental function.	True	False
4. People with dementia and delirium can be anxious and fearful when in hospital.	True	False
5. It is important for volunteers to notify staff of any changes they notice in a person's mental state behaviour or physical condition.	True	False

**Check your answers with those at the end of the handbook**

## Chapter 2: Additional Reading

ABOUT  
DEMENTIA 1

# WHAT IS DEMENTIA?

This Help Sheet describes dementia, who gets it and some of its most common forms. It describes some early signs of dementia and emphasises the importance of a timely medical diagnosis.

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease.

Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.

Doctors diagnose dementia if two or more cognitive functions are significantly impaired. The cognitive functions affected can include memory, language skills, understanding information, spatial skills, judgement and attention. People with dementia may have difficulty solving problems and controlling their emotions. They may also experience personality changes. The exact symptoms experienced by a person with dementia depend on the areas of the brain that are damaged by the disease causing the dementia.

With many types of dementia, some of the nerve cells in the brain stop functioning, lose connections with other cells, and die. Dementia is usually progressive. This means that the disease gradually spreads through the brain and the person's symptoms get worse over time.

### Who gets dementia?

Dementia can happen to anybody, but the risk increases with age. Most people with dementia are older, but it is important to remember that most older people do not get dementia. It is not a normal part of ageing, but is caused by brain disease. Rarely, people under the age of 65 years develop dementia and this is called 'younger onset dementia'.

There are a few very rare forms of inherited dementia, where a specific gene mutation is known to cause the disease. In most cases of dementia however, these genes are not involved, but people with a family history of dementia do have an increased risk. For more information see the Help Sheet on *About Dementia: Genetics of dementia*.

Certain health and lifestyle factors also appear to play a role in a person's risk of dementia. People with untreated vascular risk factors including high blood pressure have an increased risk, as do those who are less physically and mentally active. Up to date and detailed information about dementia risk factors is available at [mindyourmind.org.au](http://mindyourmind.org.au).

### What causes dementia?

There are many different diseases that cause dementia. In most cases, why people develop these diseases is unknown. Some of the most common forms of dementia are:

#### Alzheimer's disease

Alzheimer's disease is the most common form of dementia, accounting for around two-thirds of cases. It causes a gradual decline in cognitive abilities, often beginning with memory loss.

Alzheimer's disease is characterised by two abnormalities in the brain – amyloid plaques and neurofibrillary tangles. The plaques are abnormal clumps of a protein called beta amyloid. The tangles are bundles of twisted filaments made up of a protein called tau. Plaques and tangles stop communication between nerve cells and cause them to die.

For more information see the Help Sheet on *About Dementia: Alzheimer's disease*.

#### Vascular dementia

Vascular dementia is cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke, or by several mini-strokes occurring over time. These mini-strokes are also called transient ischaemic attacks (TIAs).

Vascular dementia is diagnosed when there is evidence of blood vessel disease in the brain and impaired cognitive function that interferes with daily living. The symptoms of vascular dementia can begin suddenly after a stroke, or may begin gradually as blood vessel disease worsens. The symptoms vary depending on the location and size of brain damage. It may affect just one or a few specific cognitive

[FIGHTDEMENTIA.ORG.AU](http://FIGHTDEMENTIA.ORG.AU) NATIONAL DEMENTIA HELPLINE 1800 100 500

UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA



An Australian Government Initiative

## 1 ABOUT DEMENTIA

functions. Vascular dementia may appear similar to Alzheimer's disease, and a mixture of Alzheimer's disease and vascular dementia is fairly common. For more information see the Help Sheet on *About Dementia: Vascular dementia*.

### Lewy body disease

Lewy body disease is characterised by the presence of Lewy bodies in the brain. Lewy bodies are abnormal clumps of the protein alpha-synuclein that develop inside nerve cells. These abnormalities occur in specific areas of the brain, causing changes in movement, thinking and behaviour. People with Lewy body disease may experience large fluctuations in attention and thinking. They can go from almost normal performance to severe confusion within short periods. Visual hallucinations are also a common symptom.

Three overlapping disorders can be included with Lewy body disease:

- Dementia with Lewy bodies
- Parkinson's disease
- Parkinson's disease dementia

When movement symptoms appear first, Parkinson's disease is often diagnosed. As Parkinson's disease progresses most people develop dementia. When cognitive symptoms appear first, this is diagnosed as dementia with Lewy bodies.

Lewy body disease sometimes co-occurs with Alzheimer's disease and/or vascular dementia. For more information, see the Help Sheets on *Lewy body disease*.

### Frontotemporal dementia

Frontotemporal dementia involves progressive damage to the frontal and/or temporal lobes of the brain. Symptoms often begin when people are in their 50s or 60s and sometimes earlier. There are two main presentations of frontotemporal dementia – frontal (involving behavioural symptoms and personality changes) and temporal (involving language impairments). However, the two often overlap.

Because the frontal lobes of the brain control judgement and social behaviour, people with frontotemporal dementia often have problems maintaining socially appropriate behaviour. They may be rude, neglect normal responsibilities, be compulsive or repetitive, be aggressive, show a lack of inhibition or act impulsively.

There are two main forms of the temporal or language variant of frontotemporal dementia. Semantic dementia involves a gradual loss of the meaning of words, problems finding words and

remembering people's names, and difficulties understanding language. Progressive non-fluent aphasia is less common and affects the ability to speak fluently.

Frontotemporal dementia is sometimes called frontotemporal lobar degeneration or Pick's disease. For more information, see the Help Sheet on *About Dementia: Frontotemporal dementia*, or visit the Frontier research group website [ftdrg.org](http://ftdrg.org).

### Is it dementia?

There are a number of conditions that produce symptoms similar to dementia. These can often be treated. They include some vitamin and hormone deficiencies, depression, medication effects, infections and brain tumours.

It is essential that a medical diagnosis is obtained at an early stage when symptoms first appear to ensure that a person who has a treatable condition is diagnosed and treated correctly. If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information and medication should it be available.

### What are the early signs of dementia?

The early signs of dementia can be very subtle and vague and may not be immediately obvious. Some common symptoms may include:

- Progressive and frequent memory loss
- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to perform everyday tasks

### What can be done to help?

At present there is no cure for most forms of dementia. However, some medications have been found to reduce some symptoms. Support is vital for people with dementia and the help of families, friends and carers can make a positive difference to managing the condition.

### FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [fightdementia.org.au](http://fightdementia.org.au)



For language assistance phone the Telephone Interpreter Service on **131 450**

## Brian and Behaviour Fact Sheet

alzheimers.org.uk

Alzheimer's  
Society

Leading the  
fight against  
dementia

# The brain and behaviour

Alzheimer's disease is a degenerative condition associated with a progressive loss of nerve cells or neurons. The disease gradually pervades most areas of the brain. However, the evolving pattern of damage can vary greatly between different individuals. As a result, each person with the disease may have a complex set of difficulties and experiences that are unique to them.

This factsheet explains which areas of the brain are largely responsible for which skills and abilities, and how the changes in behaviour, memory and thought experienced by people with Alzheimer's may be a direct result of the way the disease has affected the brain.

## Parts of the brain

The brain consists of three main sections: the hindbrain, the midbrain and the forebrain (see Figure 1). The hindbrain and midbrain are mainly concerned with basic life support functions, such as blood pressure and respiration. In contrast, the forebrain is responsible for the majority of higher brain functions, such as memory and language. This factsheet concentrates on the parts of the forebrain.

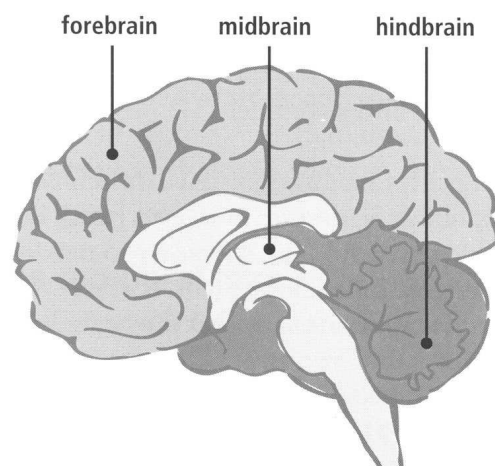


Figure 1: sections of the brain



## The cerebral cortex

The most important part of the forebrain is the cerebral cortex – a thin shell covering the surface of the forebrain. This thin layer is tightly crumpled and folded, to increase its surface area. As a result, the cortex alone contains an astonishing ten billion brain cells (the ‘grey matter’). Beneath this densely packed cortex lie bundles of fibres (the ‘white matter’), which transport information around the cortex and to other brain regions (see Figure 2).

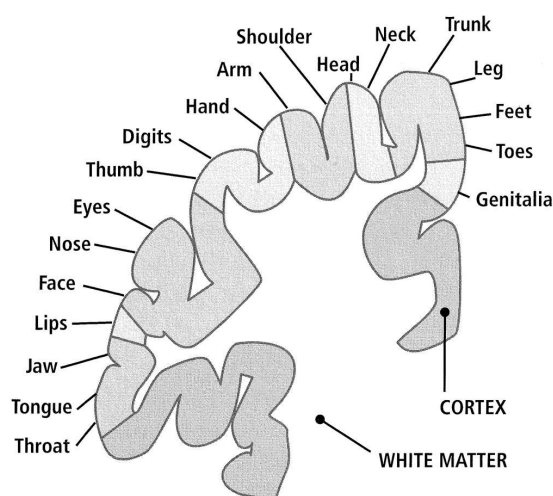


Figure 2: cross section of the motor cortex

## The lobes

To help us describe the different parts of the brain, the forebrain has been divided up into four sections, or ‘lobes’, shown in Figure 3.

- The occipital lobe is located at the back of the brain, and deals primarily with visual information from the eyes.
- The parietal lobe lies in the upper-rear portion of the brain, and is concerned with information about spatial relationships, perception and magnitude.
- The temporal lobe lies beneath the parietal lobe and is involved in memory and language.
- The frontal lobe can be thought of as our ‘executive’ or ‘management’ centre.

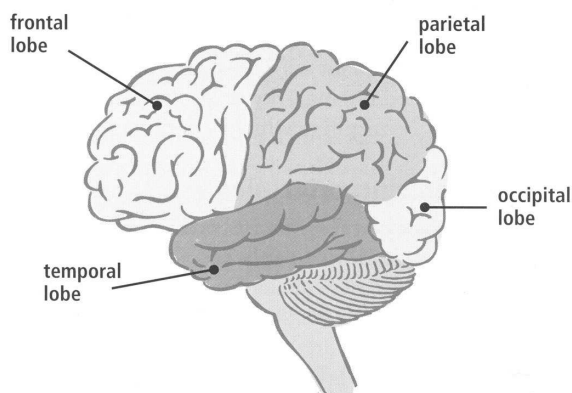


Figure 3: the lobes

## The hemispheres

In addition to being divided into lobes, the brain is also physically divided into two halves or hemispheres: left and right. The hemispheres are not entirely separate – they are connected by a large bundle of fibres that allows them to talk to one another. While these hemispheres look almost identical from the outside, one hemisphere is usually dominant over the other. In all right-handed people, and the majority of left-handed people, it is the left hemisphere that is dominant.

## Organising principles

There are certain principles that appear to govern the organisation of the brain. The division between the hemispheres signals one of these principles: lateralisation. Lateralisation literally means that some functions are best performed by the left side of the brain, while others are mainly supported by the right side. In the human nervous system, the left hemisphere controls the right side of the body and the right hemisphere controls the left side of the body. However, not all functions are shared so equally. For example, language tends to be a function of the dominant hemisphere of the brain (usually the left side), with certain areas involved in language comprehension and language production managed towards the front of the hemisphere.

Some areas of the brain are organised in a map-like order. For example, the motor cortex, which sends movement instructions to the muscles, is organised so that parts of the body that are physically close (such as the hand and the wrist) are controlled by groups of cells that are also near to one another (see Figure 2). Keeping related information in one place in the cortex helps to keep the amount of wiring between cells to a minimum, and so saves on space.

It would be a considerable understatement to say that the structure of the brain is complicated. However, by studying behaviour and cognitive abilities in people with both healthy and damaged brains, scientists have been able to determine the principle functions of different brain areas.

## The occipital lobe

Although the eyes are the source of visual information about the world around us, it is actually the brain that does most of the hard work. The eyes convert sensory information about light into electrical impulses, but these are passed to the brain for interpretation. This division of labour means we have to distinguish between visual acuity and perception.

Visual acuity – the ability to see small objects – is achieved largely by the workings of the eye itself. Perception is achieved by the occipital and parietal lobes, with information about colour, shape and movement being processed separately by the occipital cortex before it is passed on to the parietal lobe for combination into a complete 3D picture of the world.

This means that someone with dementia could have difficulty seeing what an object is, despite both eyes being in perfect condition. However, it is still necessary to maximise their eyesight (for example, with correct prescription spectacles) so that the brain has as much information to work with as possible. For more information, see Factsheet 527, Visuoperceptual difficulties in dementia.

## The parietal lobe

The functions of the parietal lobe are somewhat more diverse, and there is a significant difference between the dominant and non-dominant sides.

**The dominant parietal lobe** (usually the left half) can be thought of as being concerned with things we have to put together into an order or structure. So tasks such as reading and writing, which require putting letters and words together, and calculation, which involves ordering and combining numbers, are critically dependent on the dominant parietal lobe. This side of the parietal lobe has also been heavily implicated in a condition known as apraxia (an impairment of learned purposive movements). ‘Dressing apraxia’ is the form of apraxia most commonly noticed in people with Alzheimer’s disease,

and reflects not only a lack of co-ordination but an actual forgetting of the movements required to achieve a goal (fastening a button, for example).

As if to compound such problems, the dominant parietal lobe is also responsible for our body sense – that is, knowing our left from our right, and sensing where one limb is in relation to the rest of our body.

**The non-dominant parietal lobe** (usually the right half), in contrast, could be thought of as our ‘3D centre’. This part of the parietal lobe receives visual information from the occipital lobe. The function of this area is to combine such information into a 3D representation of the object being viewed. Damage to this area leads to a symptom known as ‘visual agnosia’ – an inability to recognise objects, faces or surroundings. Because visual information is processed separately from other modes of sensation, it is possible for individuals to fail to recognise a familiar face by sight but to know who they are once they speak.

The non-dominant parietal lobe also contributes to our understanding of space but in a different way from its dominant counterpart. While the dominant parietal lobe deals with our body sense or personal space, the non-dominant portion helps us to locate objects in external space, and to calculate the location of objects relative to one another and ourselves (for example, when we are reaching to pick something up).

### **The temporal lobes**

The temporal lobes deal primarily with memory functions. The dominant temporal lobe is specialised for verbal (word-based) memory and the names of objects, while the non-dominant temporal lobe is used for our memory of visual (non-verbal) material, such as faces or scenes.

There are also different types of memory. Episodic memory, as its name suggests, is our memory of events or episodes, which are recorded with a reference to the time when they occurred

(for example: 'I ate eggs for breakfast this morning'). Meanwhile, semantic memory can be thought of as our own encyclopaedia for facts and figures (for example: 'Eggs have a shell, are laid by hens, and can be eaten boiled, scrambled or fried').

In Alzheimer's disease it is the episodic memory that is most commonly damaged. It is not yet clear exactly how or where long-term memories are stored, but it seems that memories are achieved by strengthening the connections between relevant nerve cells. And it does seem clear that some remote or distant memories, such as where one went to school, are stored more deeply than less familiar or recent memories, such as what one did yesterday. This may be because certain poignant or important events have been re-remembered many times over the years, and so are more rehearsed than recent memories. This is why some people with Alzheimer's disease may find it easier to discuss certain often-recalled aspects of their childhood than what has happened that day.

### **The frontal lobe**

The frontal lobe contains several parts, which all act together to form our 'executive' or management' centre. These parts carry out the following activities:

**Planning actions and learning new tasks** – The lateral or outer surfaces of the frontal lobe appear to be critical for organising and planning our actions and learning new tasks. For example, in learning to drive, these brain areas help us put together a very complex sequence of movements that at first seem difficult and clumsy but gradually become more smooth and automatic. For someone with damage to this area, it is like being a learner all over again. Many multi-stage tasks, such as cooking and shopping, become very difficult because the pattern, or plan of action, has been lost.

Damage to these lateral areas can also cause people to get 'stuck' on what they are doing (known as 'perseveration'). As the frontal lobe interacts with many other brain areas, this perseveration may take the form of using the same word over and over again, or taking one piece

of clothing out of a drawer and then unpacking all the other clothes without a specific purpose.

**Motivation** – Moving towards the division between the two hemispheres, the middle portion of the frontal lobe generates our motivation and general impetus. If this part of the brain is affected, people can lose their ‘get up and go’, becoming lethargic and reluctant to get out of bed or perform particular activities. It is important to realise that what some might see as laziness could be a direct consequence of the loss of cells in this area of the brain.

**Regulation of behaviour** – The regulation of our behaviour appears to be governed by a third area of the frontal lobe, the orbitobasal area, which is located in the curvature at the very front of the brain. In healthy people, this part of the brain helps to monitor, control and moderate our behaviour: for example, preventing us from saying something rude if someone has annoyed us. In someone with Alzheimer’s disease, this function may be damaged, which can lead to a failure of inhibition.

### **Other areas and structures**

Many areas of the cerebral cortex are concerned not so much with supporting a specific function, but with integrating and associating the products of surrounding areas. A similar role is played by many structures that lie beneath the cortex, such as the limbic system which, among other things, permits memory and behaviour to influence one another. The limbic system also plays a vital role in the generation of emotions and their interaction with our behaviour.

### **Looking to the future**

It is fascinating to observe and learn about the complex ways in which the components of the brain create and control aspects of our being. If we can combine this knowledge with the ever-increasing technology that permits us to see how a brain affected by Alzheimer’s disease changes, in future we may be able to predict, treat and manage the various symptoms associated with the disease. For now, a greater

appreciation of the relationship between the brain and our behaviour may help people with Alzheimer's disease and those around them to understand and cope with the many changes brought about by the condition.

For details of Alzheimer's Society services in your area, visit [alzheimers.org.uk/localinfo](http://alzheimers.org.uk/localinfo)

For information about a wide range of dementia-related topics, visit [alzheimers.org.uk/factsheets](http://alzheimers.org.uk/factsheets)

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2013. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

### Factsheet 456LP

Last reviewed: November 2010  
Next review due: November 2012

Written and reviewed by: Dr Sebastian Crutch at the Dementia Research Centre, National Hospital for Neurology and Neurosurgery

### Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:  
**0300 222 11 22**

9am–5pm Monday–Friday  
10am–4pm Saturday–Sunday

[alzheimers.org.uk](http://alzheimers.org.uk)

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.



**Alzheimer's Society** | **Leading the fight against dementia**

Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499



# Delirium

**Delirium** is a common medical problem that is characterised by changes in mental function and occurs more often among older people.

When delirium occurs people are confused and may be either very agitated or quiet and drowsy.

The onset of delirium is always sudden.

It usually only lasts for a few days but may persist for longer periods.

It can be a serious condition.

This brochure provides information for people who have experienced delirium and for their family/carers.

## DELIRIUM

If you have any concerns or questions about delirium, talk to your local doctor or ask your hospital staff.

### CONTACTS

**Carers Resource Centres**  
Ph: 1800 242 636

**Aged Care Information Line**  
Ph: 1800 500 853

**National Dementia Helpline**  
Ph: 1800 100 500

**Carers Australia**  
[www.carersaustralia.com.au](http://www.carersaustralia.com.au)

**Alzheimer's Australia**  
[www.alzheimers.org.au](http://www.alzheimers.org.au)



Adapted with permission from Northern NSW Local Health District and Delirium Care Pathways, Department of Health and Aging, Canberra. 2010.

This brochure has been produced as part of the Care of Confused Hospitalised Older Persons program (CHOPS).

HSS011\_075-02

## DELIRIUM

### How can you help care for someone with delirium?

It is reassuring for people with delirium to see familiar people. Visit as often as you can and try to be available to help with their care.

Encourage other family members or friends to help as well.

- Speak slowly in a clear voice when talking to someone who has delirium. Identify both yourself and the person by name.
- Encourage and assist someone with delirium to have adequate food and fluids.
- Knowing the time of day can reduce confusion. Remind them where they are, and what day and time it is. Open the curtains in their room.
- Visual or hearing impairment can make their confusion worse. If someone with delirium usually wears glasses or hearing aids, help them to put them on.
- If someone with delirium is agitated or aggressive, do not try to restrain them. If they want to walk around, let them, but try to make sure that they are safe from falling and that the area is free from hazards.
- Bring personal mementos that help remind the person of home, such as photos, their dressing gown, radio or CD/tape player with favourite music.
- Let staff know any special personal information that may help calm and orient someone with delirium, such as, the names of family and friends, hobbies, significant events etc.

## DELIRIUM

### ■ Who is at risk of developing delirium?

People who:

- are very sick
- have dementia
- are 70 years of age or more
- suffer from depression
- have poor eyesight
- are taking multiple medications
- are having a surgical procedure eg heart or hip surgery.

### ■ What are the symptoms of delirium?

People with delirium may:

- appear confused and forgetful
- be unable to pay attention
- be different from their normal selves
- be either very agitated or quiet and withdrawn or sleepy
- be unsure of the time of day or where they are
- have changes to their sleeping habits, such as staying awake at night and being drowsy during the daytime
- feel fearful, upset, irritable, angry or sad
- see things that are not there, but that seem very real to them
- lose control of their bladders or bowels.

### ■ How common is delirium?

About one-fifth of older people admitted to hospital, and close to half of the residents in aged care facilities will experience delirium at some stage of their care.

### ■ What causes delirium?

Common causes of delirium in older people include:

- infection (including urinary tract infection in males or females)
- multiple physical illnesses
- constipation
- dehydration/malnutrition
- severe pain
- medications, including 'over-the-counter' medicines
- heavy alcohol consumption
- withdrawal from alcohol or medication, particularly sleeping pills.

### ■ How does delirium start?

The symptoms happen very quickly, usually over hours or days. A person's behaviour can also fluctuate during the course of a single day.

Delirium is sometimes mistaken for dementia or depression, so it is important for family/friends to notify medical/nursing staff of any sudden change in a person's mental state.

### ■ How long does delirium last?

Delirium usually only lasts for a few days but sometimes it will continue for weeks or even months. If delirium is not resolved quickly, it can lead to serious complications such as falls, pressure ulcers, longer lengths of stay in hospital, and even death.

### ■ Will delirium recur?

People who have experienced delirium do have a higher risk of experiencing delirium again.

### ■ How is delirium treated?

Delirium is generally associated with an underlying physical illness. However it is not always possible to identify the cause. Staff will do a thorough medical assessment to look for and treat the underlying cause of the delirium.

Treatment also includes reducing the risk of complications and lessening symptoms.

### Role of family and carers

- Family members/carers can provide valuable information to the staff caring for the person with delirium.
- It is important to notify staff of any sudden change in a person's mental or physical condition.

# CHAPTER 3: COMMUNICATION AND PERSON CENTRED CARE

## What this chapter covers

- The presence of dementia progressively impacts on the person's ability to communicate.
- There are a number of ways to support effective communication between a volunteer and the person with dementia.
- Person centred care puts the person at the centre of their care. It respects the uniqueness of the person, their individual values and preferences.
- Gaining information about the persons background and personal preferences can greatly support communication and person centred care.
- Communication with family carers or others who know the person is essential in gathering information to support person centered care.
- Family carers may disclose information to a volunteer that is important for staff to know.

## Additional reading/information

1. Alzheimer's Australia Help sheet – Communication.
2. The Personal Profile.

## Chapter 3 Quiz

Please circle the correct true or false response

1. Dementia can affect a person's ability to communicate .	True	False
2. People with dementia may not be able to recognise familiar objects such as a cup or spoon.	True	False
3. People with dementia don't have emotions and feelings.	True	False
4. Providing person centred care involves gaining an understanding of the person, their background, personal preferences.	True	False
5. Completion of a person profile can greatly support volunteers in their communication with patients.	True	False

***Check your answers with those at the end of the handbook***

## Chapter 3: Additional Reading

### Communication Help Sheet

CARING FOR SOMEONE  
WITH DEMENTIA

1

# COMMUNICATION

**This Help Sheet explains some of the changes in communication that occur as a result of dementia and suggests ways that families and carers can help. It also includes some personal tips on communication written by a person with dementia.**

Losing the ability to communicate can be one of the most frustrating and difficult problems for people with dementia, their families and carers. As the illness progresses, a person with dementia experiences a gradual lessening of their ability to communicate. They find it more and more difficult to express themselves clearly and to understand what others say.

#### Some changes in communication

Each person with dementia is unique and difficulties in communicating thoughts and feelings are very individual. There are many causes of dementia, each affecting the brain in different ways.

#### Some changes you might notice include:

- Difficulty in finding a word. A related word might be given instead of one they cannot remember
- They may speak fluently, but not make sense
- They may not be able to understand what you are saying or only be able to grasp part of it
- Writing and reading skills may also deteriorate
- They may lose the normal social conventions of conversations and interrupt or ignore a speaker, or fail to respond when spoken to
- They may have difficulty expressing emotions appropriately

#### Where to begin

It is important to check that hearing and eyesight are not impaired. Glasses or a hearing aid may help some people. Check that hearing aids are functioning correctly and glasses are cleaned regularly.

#### Remember

#### Communication is made up of three parts:

- 55% is body language which is the message we give out by our facial expression, posture and gestures
- 38% is the tone and pitch of our voice
- 7% is the words we use

These statistics highlight the importance of how families and carers present themselves to a person with dementia. Negative body language such as sighs and raised eyebrows can be easily picked up.

#### What to try

##### Caring attitude

People retain their feelings and emotions even though they may not understand what is being said, so it is important to always maintain their dignity and self esteem. Be flexible and always allow plenty of time for a response. Where appropriate, use touch to keep the person's attention and to communicate feelings of warmth and affection.

##### Ways of talking

- Remain calm and talk in a gentle, matter of fact way
- Keep sentences short and simple, focusing on one idea at a time
- Always allow plenty of time for what you have said to be understood
- It can be helpful to use orienting names whenever you can, such as "Your son Jack"

##### Body language

You may need to use hand gestures and facial expressions to make yourself understood. Pointing or demonstrating can help. Touching and holding their hand may help keep their attention and show that you care. A warm smile and shared laughter can often communicate more than words can.

**FIGHTDEMENTIA.ORG.AU NATIONAL DEMENTIA HELPLINE 1800 100 500**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**

This help sheet is funded by the Australian Government under the National Dementia Support Program

## 1

**CARING FOR SOMEONE WITH DEMENTIA****The right environment**

- Try to avoid competing noises such as TV or radio
- If you stay still while talking you will be easier to follow, especially if you stay in the person's line of vision
- Maintain regular routines to help minimise confusion and assist communication
- It is much less confusing if everyone uses the same approach. Repeating the message in exactly the same way is important for all the family and all carers

**What NOT to do**

- Don't argue. It will only make the situation worse
- Don't order the person around
- Don't tell them what they can't do. Instead state what they can do
- Don't be condescending. A condescending tone of voice can be picked up, even if the words are not understood
- Don't ask a lot of direct questions that rely on a good memory
- Don't talk about people in front of them as if they are not there

Adapted from *Understanding difficult behaviours*, by Anne Robinson, Beth Spencer and Laurie White.

**Tips from a person with dementia**

Christine Bryden (Boden) was diagnosed with dementia at age 46, and has shared a number of her insights about ways that families and friends can help a person with dementia. Christine is also the author of a number of publications, including *Who will I be when I die?*, the first book written by an Australian with dementia.

Christine provides these tips for communicating with a person with dementia:

- Give us time to speak, wait for us to search around that untidy heap on the floor of the brain for the word we want to use. Try not to finish our sentences. Just listen, and don't let us feel embarrassed if we lose the thread of what we say
- Don't rush us into something because we can't think or speak fast enough to let you know whether we agree. Try to give us time to respond – to let you know whether we really want to do it
- When you want to talk to us, think of some way to do this without questions that can alarm us or make us feel uncomfortable. If we have forgotten something special that happened recently, don't assume it wasn't special for us too. Just give us a gentle prompt – we may just be momentarily blank
- Don't try too hard though to help us remember something that just happened. If it never registered we are never going to be able to recall it
- Avoid background noise if you can. If the TV is on, mute it first
- If children are underfoot remember we will get tired very easily and find it very hard to concentrate on talking and listening as well. Maybe one child at a time and without background noise would be best
- Maybe ear plugs for a visit to shopping centres, or other noisy places

**FURTHER INFORMATION**

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [fightdementia.org.au](http://fightdementia.org.au)



For language assistance phone the Translating and Interpreting Service on **131 450**

## PERSONAL PROFILE FOR VOLUNTEER TO COMPLETE WITH PATIENT AND/OR CARER

Patients Name: \_\_\_\_\_

Patients preferred name? \_\_\_\_\_

Where do you live now?: \_\_\_\_\_

Where have you lived most of your life?: \_\_\_\_\_

**Family details:** eg: spouse, partner, children, grandchildren, siblings.

Name	Relationship	Town they live in

**Other close friends/ neighbours /carers:**

Name	Relationship	Town they live in

Do you have a pet? Y / N

If Yes Type of Pet? \_\_\_\_\_ Name of pet \_\_\_\_\_

Favourite Food: \_\_\_\_\_

Any special diet needs (eg diabetic, gluten free, pureed) \_\_\_\_\_

Favorite drink: tea / coffee / Milo / milk / other : \_\_\_\_\_

Preferences on how drink is made: eg Milk and sugar: \_\_\_\_\_

## Life Experiences

War service: \_\_\_\_\_

Main occupation (past and/or present): \_\_\_\_\_

Clubs and Associations: \_\_\_\_\_

Travel or holidays enjoyed: \_\_\_\_\_

**Activities/interests:** (please circle)

**Sport:** Golf / bowls / bridge / fishing / swimming / lifesaving / football / hockey / tai chi / horse riding / cricket / horse racing / Other: please state: \_\_\_\_\_

**Other interests:**

Gardening / needlework / knitting / painting or drawing / pottery / cards / cooking / stamp collecting / singing / dancing / musical instrument / other – please state: \_\_\_\_\_

**Favourite type of Music:**

Country / classical / opera / jazz / rock and roll / folk / pop / brass bands / other – please state: \_\_\_\_\_

**Favourite type of movies:**

Westerns/ musicals / old movies / romances / comedy / documentaries / wildlife / sporting / drama's / murder mystery / other – please state: \_\_\_\_\_

**Favourite TV Programs**

Live shows / police shows / news / current affairs / comedy / documentaries /

Other – please state: \_\_\_\_\_

**Preferred Radio station:** ABC / Radio National / 2EC / other: \_\_\_\_\_

**Reading**

Enjoys reading? Yes / No    Able to read independently? Yes / No

Needs glasses to read? Yes / No    Would like someone to read to them? Yes / No

Type of reading preferred: magazines / books / newspaper / Other – please state: \_\_\_\_\_

**Other Physical considerations:** (please circle)

Hearing problems / hearing aid with patient / can walk independently or alone/ uses a walking stick / uses a walking frame / uses a walker / difficulty with communication / Other – please state: \_\_\_\_\_

Anything else you would like us to know? \_\_\_\_\_

Volunteer completing form: \_\_\_\_\_ Date \_\_\_/\_\_\_/\_\_\_

# CHAPTER 4: ACTIVITIES FOR PATIENTS

## What this chapter covers

- Knowing the person, their background and past experience, their interests and hobbies and who and what is important to them assists in identifying meaningful activities.
- Communication and one to one interaction is an important part of activities.
- Interacting and participating in activities with patients can be very rewarding for volunteers.
- People with dementia and delirium in hospital are unwell so their ability to concentrate and engage in activities is limited.

## Additional reading/information

1. Alzheimer's Australia Help sheet – Therapies and Communication.
2. Alzheimer's Australia Help sheet – Activities.
3. List of activity resources.

## Chapter 4 Quiz

Please circle the correct true or false response

1. The information on the patient's personal profile can assist volunteers in deciding on appropriate activities for the patient.	True	False
2. Sitting and talking with patients is not an activity.	True	False
3. Distraction activities can assist with patients who may be unsettled or agitated.	True	False
4. Playing a patient's preferred music is an activity.	True	False
5. Because patients in hospital are unwell, some will be sleepy and not be able to concentrate on activities.	True	False

**Check your answers with those at the end of the handbook**



## Chapter 4: Additional Reading

### Therapies and Communication Help Sheet

CARING FOR SOMEONE WITH DEMENTIA **2**

# THERAPIES AND COMMUNICATION APPROACHES

**This Help Sheet briefly explains three approaches to communicating with people with dementia – Validation Therapy, Music Therapy and Reminiscence. Many families and carers find these approaches helpful in providing support that is respectful and dignified when communication is difficult.**

Communicating effectively with a person who has dementia becomes an increasing challenge as the person progressively loses their memory and their ability to organise and express their thoughts. For many, the loss of recent memory means that the past begins to merge with the present resulting in additional difficulties for family and carers.

A number of alternative communication approaches have been developed which attempt to provide the trust and support so necessary to a person's wellbeing. Many family members and carers will be instinctively using some of them without realising their formal names.

#### Validation Therapy

Validation Therapy advocates that, rather than trying to bring the person with dementia back to our reality, it is more positive to enter their reality. In this way empathy is developed with the person, building trust and a sense of security. This in turn reduces anxiety. Many families and carers report increased benefits for themselves, as well as for the person with dementia, from a reduced number of conflicts and a less stressful environment.

Validation Therapy is based on the idea that once the person has experienced severe short-term memory loss and can no longer employ intellectual thinking or make sense of the present, he or she is likely to go back to the past. This may be in order to resolve unfinished conflicts, relive past experiences or to retreat from the present over which they have little control. Some people will go in and out of the present.

Some family members and carers express concern that validation involves lying to the person with dementia about reality. However a more accurate description is that it avoids challenging their reality.

For instance, if a person with dementia believes that she is waiting for her children, all now middle aged, to return from school, family members and carers who use validation would not argue the point or expect their relative to have insight into their behaviour. They would not correct their beliefs. Rather, the validating approach proposes acknowledging and empathising with the feelings behind the behaviour being expressed. In this way the person's dignity and self-esteem is maintained.

#### Music Therapy

Activities that involve music are another effective way of communicating with a person who has dementia. Often when other skills have gone, the person can still enjoy old familiar songs and tunes. A certain piece of music can unlock memories and feelings. It is important to be prepared to respond to the release of these feelings.

The big advantage of music is that it does not require a long attention span and it can also be a valuable trigger for reminiscing. Knowing a person's musical likes and dislikes is vital for this to be a successful approach.

Music can be used as a formal therapy or simply for enjoyment. It can also help in the management of difficult behaviours. Music therapists have training in the use of music with people with dementia and can address some very complex behaviours.

**FIGHTDEMENTIA.ORG.AU NATIONAL DEMENTIA HELPLINE 1800 100 500**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**

This help sheet is funded by the Australian Government under the National Dementia Support Program

## 2 CARING FOR SOMEONE WITH DEMENTIA

### Reminiscence

Reminiscence is a way of reviewing past events that is usually a very positive and rewarding activity. Even if the person with dementia cannot participate verbally it can still give them pleasure to be involved in reflections on their past. It can also be a means of distraction if the person becomes upset.

While reviewing past events can provide a sense of peace and happiness, it can also stir up painful and sad memories. It is important to be sensitive to the person's reactions if this happens. If their distress seems overwhelming then it is better to use another form of distraction to reduce anxiety.

### *This Is Your Life* book

Making a chronological history of the person with dementia can help with reminiscence and provides information for people who may interact with them. It can also help carers coming in to the home or residential care facility get to know the person and their life. A *This Is Your Life* book is a visual diary, similar to a family photo album. It can include letters, postcards, certificates and other memorabilia.

A large photo album with plastic protective sheets over each page will last indefinitely and can withstand a lot of use.

Each photo needs to be labeled to avoid putting the person with dementia on the spot with questions such as "Who is that?" It is best to limit the information on each page to one topic, and to have a maximum of two or three items on each page.

### The following list may help in getting a book started:

- Full name and preferred name
- Place and date of birth
- Photographs and name of mother, father, brothers and sisters
- Photographs of partner and wedding day
- Photographs, names and birthdays of children and grandchildren
- Photographs of family friends, relatives and pets
- Places lived in
- Schooldays
- Occupation and war service
- Hobbies and interests
- Favourite music
- Holiday snapshots and postcards
- Letter, certificate, diagram of family tree and short stories about specific incidents

This book can provide a great deal of pleasure and pride for a person who may be feeling increasingly bewildered in the present.

### FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [fightdementia.org.au](http://fightdementia.org.au)



For language assistance phone the Translating and Interpreting Service on **131 450**

# Activities Help Sheet

## CARING FOR SOMEONE WITH DEMENTIA 5

# ACTIVITIES

**This Help Sheet provides information about planning and providing appropriate activities for people with dementia.**

### Enjoyment doesn't require memory

Each day there are many things that provide us with purpose and pleasure. For a person with dementia, the need for a good quality of life is not diminished. However, without some assistance from family and carers, their ability to achieve purpose and pleasure is much more difficult.

#### Ideally, activities should:

- Compensate for lost activities
- Promote self esteem
- Maintain residual skills and not involve new learning
- Provide an opportunity for enjoyment, pleasure and social contact
- Be sensitive to the person's cultural background

### Some helpful guidelines when planning activities

#### Consider all that has made the person unique

This means knowing the person's former lifestyle, work history, hobbies, recreational and social interests, travel and significant life events.

#### Activities can re-establish old roles

Make use of skills that have not been forgotten, such as buttering bread, washing up or watering, sweeping and raking in the garden. These are also ways in which a person with dementia can contribute to the household and feel useful. Encourage an area of responsibility no matter how small.

### Activities can give relaxation and pleasure

A person with dementia may enjoy an outing even if they do not remember where they have been. What is important is that the moment is enjoyed, even though the experience may be soon forgotten.

#### Simple and unhurried activities that are meaningful are best

Give the time and space necessary to allow the person to do as much as possible. Focus on one thing at a time. Break down activities into simple, manageable steps. Communicate one instruction at a time.

#### Prepare a safe working area

People with dementia often have difficulty with visual perception and coordination. Ensure that surfaces are uncluttered with few distractions and noise. Good lighting, without glare, individual seat preferences and correct work heights are all important. Using plastic containers might help to avoid breakages.

#### Don't allow activities to reinforce inadequacy or increase stress

Abilities can fluctuate from day to day. Activities can be adapted and tried another time if not successful or enjoyable.

#### Use times to suit the person's best level of functioning

To ensure maximum success when carrying out activities it is best to consider the times of day when the person is at their best. For instance, sometimes walking is best done in the morning or the early afternoon. However for some people who are particularly restless later in the day, a late afternoon walk may be better.

**FIGHTDEMENTIA.ORG.AU NATIONAL DEMENTIA HELPLINE 1800 100 500**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**

This help sheet is funded by the Australian Government under the National Dementia Support Program

## 5

## CARING FOR SOMEONE WITH DEMENTIA

**Don't over stimulate**

Be selective with outings. Avoid crowds, constant movement and noise which many people with dementia find overwhelming.

**Allow an emotional outlet**

For many people, music or contact with babies, children or animals provide positive feelings. Excellent memories of past events are often kept and looking through old photos, memorabilia and books enables the recall of earlier times. The opportunity to relive treasured moments can be deeply satisfying. If reading skills have deteriorated make individual audiotapes. Locate picture books and magazines in the person's areas of interest.

**Include sensory experiences**

Some sensory experiences that may be enjoyed are:

- Hand, neck and foot massage
- Hair brushing
- Smelling fresh flowers or pot pourri
- Using fragrant essential oils
- Stroking an animal or different textured materials
- A visit to a herb farm or a flower show
- Provide a rummage box that contains things that the person has been interested in

**A sense of movement and rhythm is often retained longer than most abilities**

Hire an exercise bike or a walking machine for rainy days. Be spectators or participants at dance classes or walk the dog together. Walkers enjoy the wider world while getting much needed exercise.

**Consistency is important**

It can be helpful to write out an activities care plan if different people are caring for the person. This will ensure that activities are consistent and are suited to the individual needs of a person with dementia.

**Activities play a significant part in the dealing with changed behaviours**

Knowing what helps to calm or divert a person when they are restless or distressed is very important. This can be particularly helpful for respite workers.

**Don't give up**

Mistakes and failures will happen, but don't let the person with dementia feel like a failure. Keep trying.

**FURTHER INFORMATION**

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at **fightdementia.org.au**



For language assistance phone the Translating and Interpreting Service on **131 450**

## List of Activity Resources

### Dementia Delirium Care with Volunteers Patient activity and distraction resource suggestions

Resource	Description
CD players	Small portable CD players, labelled with numbers to allow loan monitoring
Music CD's	A range of music – classical, country, jazz, blues, easy listening, war songs, hymns, Christmas carols. Op shops and donations good sources
Portable DVD players	Need to be labelled and securely stored.
DVD's	A range of DVD's including musicals, old favourites, comedy, documentaries, football and rugby matches, serene scenes such as underwater fish
Games	Large and normal size domino's Large and normal size cards Scrabble Backgammon All need to be able to be wiped over
Crosswords	Easiest to download as A4 sheets that can be copied or photocopy pages of large print crossword books
Drawing or colouring	Coloured pencils Colouring in books or templates. Templates can be downloaded and copied
Magazines and books	A broad range: Gardening, Golf, Cricket, fishing knitting, flowers, history, geography, pets. These can be sourced from donations, op shops and garage sales. A continuing source is needed as often can only be used once.
Laminated A4 pictures	These are useful to generate conversation once you know the person interest. Old or \$2 calendars are a good source. A range of topics such as: Animals, flowers, gardens, scenery, sport etc. The benefit of these is that they can be wiped over and reused.
Rummage or Distraction Items	
Rummage Handbags or boxes - women	Source from op shops or donations. Need to be vinyl or material that can be wiped over for infection control. Fill with different textured materials and items. E.g. small purse, scarfs, bubble wrap, soft material, old keys, squeeze balls
Rummage tool Boxes - Men	Small plastic box filled with large plastic bolts and screws that can be put together, short pieces of tubing, squeeze balls, different textures items
Men's fiddle box	These can be purchased readymade or ask the local wood working group if they would make one. They are coloured wooden boxes with lots of latches and locks to fiddle with
Fiddle rugs, aprons or cushions.	Fiddle aprons can be purchased. However more innovative items are handmade. Local knitters and craft groups or volunteers themselves are happy to

	make them. They involve having different textured materials and fiddle items that can be sown on. They all need to be washable for infection control
Washing basket	A small washing basket filled with items such as handtowels, pillow cases, face washer etc that can be folded
Oxygen Tubing	Can be taped and bandaged over existing IV cannula as a distraction and an alternative to pull at
<b>Other items</b>	
Knitted or crocket rugs	Allows a more homely feel for the bed. They need to be washable
Knitted or soft animals	Patients with more advanced dementia may find comfort with these
A doll	These can also be appropriate for some patients with more advanced dementia
Old Photos' or other memorabilia	This assists with reminiscing
Magnifying sheets	To assist patients who may not have their glasses in reading things
A small whiteboard and whiteboard marker	This can support visual prompts for patients with poor memory and communication
Moisturising cream	To assist with gentle hand or foot massage

# CHAPTER 5: UNDERSTANDING BEHAVIOURS WHICH CAN OCCUR IN PATIENTS WITH DEMENTIA AND DELIRIUM

## What this chapter covers

- Changed behaviours can commonly occur in patients with dementia and delirium in hospital
- There are many reasons or triggers for changed behaviours.
- Gaining an understanding of the person and “putting yourself in their shoes” can greatly assist in understanding the triggers and supporting patients.
- Person profile information can greatly assist volunteers in supporting patients who experience changed behaviours.
- There are a number of practical ways volunteers can assist in settling and calming patients who may have changed behaviours.
- It is important to know and understand what to do in the event that you do feel unsafe with a patient.

## Additional reading/information

1. Alzheimer’s Australia Help sheet – Changed Behaviours.
2. Alzheimer’s Society UK. Unusual Behaviour Fact Sheet.

## Chapter 5 Quiz

Please circle the correct true or false response

1. Onset or change in behaviours can be common in patients with dementia and delirium.	True	False
2. Wandering and agitation are not behaviours.	True	False
3. There can be many causes or triggers for behaviours.	True	False
4. Pain and fear are not causes for changed behaviour.	True	False
5. Gaining an understanding of the person and trying to understand what they might be experiencing are ways volunteers can support patients.	True	False
6. If a volunteer feels unsafe, they should stay calm, leave the room and report what has occurred to staff.	True	False

**Check your answers with those at the end of the handbook**

## Chapter 5: Additional Reading

### Changed Behaviour Help Sheet

#### CHANGED BEHAVIOURS AND DEMENTIA

1

# CHANGED BEHAVIOURS

This Help Sheet looks at some of the common behaviour changes that may occur when a person has dementia. Reasons for the changes and some general guidelines for coping with them are discussed.

Changes in the behaviour of a person with dementia are very common. This may place enormous stress on families and carers. It can be particularly upsetting when someone previously gentle and loving behaves in a strange or aggressive way.

#### Why does behaviour change?

There are many reasons why a person's behaviour may be changing. Dementia is a result of changes that take place in the brain and affects 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. Perhaps an activity, such as taking a bath, is too difficult. Or the person may not be feeling physically well. Dementia affects people in different ways. Understanding why someone is behaving in a particular way may help you with some ideas about how to cope.

#### Where to begin

Always discuss concerns about behaviour changes with the doctor, who will be able to check whether there is a physical illness or discomfort present and provide some advice. The doctor will be able to advise if there is an underlying psychiatric illness.

#### Coping

Coping with changed behaviours can be very difficult, and is often a matter of trial and error. Always remember that the behaviour is not deliberate. Anger and aggression are often directed against family members and carers because they are closest. The behaviour is out of the person's control and they may be quite frightened by it. They need reassurance, even though it may not appear that way.

#### What to try

- A calm, unstressed environment in which the person with dementia follows a familiar routine can help to avoid some difficult behaviours
- Try to keep the environment familiar. People with dementia can become upset if they find themselves

in a strange situation or among a group of unfamiliar people where they feel confused and unable to cope. The frustration caused by being unable to meet other people's expectations may be enough to trigger a change in behaviour

- If a behaviour becomes difficult, it is best not to attempt any form of physical contact such as restraining, leading them away or approaching from behind. It may be better to leave them alone until they have recovered, or call a friend or neighbour for support
- Try not to take it personally
- Try not to use a raised voice
- Avoid punishment. The person may not remember the event and is therefore not able to learn from it
- Speak slowly, in a calm and reassuring voice
- Try not to become provoked or drawn into an argument

#### Aggression

This can be physical, such as hitting out, or verbal such as using abusive language. Aggressive behaviour is usually an expression of anger, fear or frustration.

#### What to try

- The aggression may be due to frustration. For example, locking the door may prevent wandering but may result in increased frustration
- Activity and exercise may help prevent some outbursts
- Approaching the person slowly and in full view may help. Explain what is going to happen in short, clear statements such as "I'm going to help you take your coat off". This may avoid the feeling of being attacked and becoming aggressive as a self-defence response
- Check whether the aggressive behaviour is about getting what the person wants. If so, trying to anticipate their needs may help

**FIGHTDEMENTIA.ORG.AU**    **NATIONAL DEMENTIA HELPLINE 1800 100 500**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**

This help sheet is funded by the Australian Government under the National Dementia Support Program



# 1 CHANGED BEHAVIOURS AND DEMENTIA

## Catastrophic reactions

Some people with dementia over-react to a trivial setback or a minor criticism. This might involve them screaming, shouting, making unreasonable accusations, becoming very agitated or stubborn, or crying or laughing uncontrollably or inappropriately. Alternatively, the person might become withdrawn. This tendency to over-react is part of the disease and is called a catastrophic reaction.

Sometimes a catastrophic reaction is the first indication of the dementia. It may be a passing phase, disappearing as the condition progresses, or it may go on for some time.

### Catastrophic behaviour may be a result of:

- Stress caused by excessive demands of a situation
- Frustration caused by misinterpreted messages
- Another underlying illness

This behaviour can appear very quickly and can make family and carers feel frightened. However, trying to figure out what triggers catastrophic behaviour can sometimes mean that it can be avoided. Keeping a diary may help to identify the circumstances under which they occur. If this isn't possible, you can find ways of dealing with the behaviour quickly and effectively using some of the guidelines listed earlier.

## Hoarding

People with dementia may often appear driven to search for something that they believe is missing, and to hoard things for safekeeping.

### Hoarding behaviours may be caused by:

- Isolation. When a person with dementia is left alone or feels neglected, they may focus completely on themselves. The need to hoard is a common response
- Memories of the past. Events in the present can trigger memories of the past, such as living with brothers and sisters who took their things, or living through the depression or a war with a young family to feed
- Loss. People with dementia continually lose parts of their lives. Losing friends, family, a meaningful role in life, an income and a reliable memory can increase a person's need to hoard
- Fear. A fear of being robbed is another common experience. The person may hide something precious, forget where it has been hidden, and then blame someone for stealing it

### What to try

- Learn the person's usual hiding places and check there first for missing items
- Provide a drawer full of odds and ends for the person to sort out as this can satisfy the need to be busy
- Make sure the person can find their way about, as an inability to recognise the environment may be adding to the problem of hoarding

## Repetitive behaviour

People with dementia may say or ask things over and over. They may also become very clinging and shadow you, even following you to the toilet. These behaviours can be very upsetting and irritating.

### What to try

- If an explanation doesn't help, distraction sometimes works. A walk, food or favourite activity might help
- It may help to acknowledge the feeling expressed. For example "What am I doing today?" may mean that the person is feeling lost and uncertain. A response to this feeling might help
- Do not remind the person that they have already asked the question
- Repetitive movements may be reduced by giving the person something else to do with their hands, such as a soft ball to squeeze or clothes to fold

Based on *Understanding and dealing with challenging behaviour*, Alzheimer Scotland – Action on Dementia

Discuss with the doctor your concerns about behaviour changes, and their impact on you.

The Dementia Behaviour Management Advisory Service (DBMAS) is a national telephone advisory service for families, carers and care workers who are concerned about the behaviours of people with dementia. The service provides confidential advice, assessment, intervention, education and specialised support 24 hours a day, 7 days a week and can be contacted on **1800 699 799**.

## FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [fightdementia.org.au](http://fightdementia.org.au)



For language assistance phone the Translating and Interpreting Service on **131 450**

## Unusal Behaviour Help Sheet

[alzheimers.org.uk](http://alzheimers.org.uk)

**Alzheimer's  
Society** | Leading the  
fight against  
dementia

# Unusual behaviour

---

**As dementia develops, it can cause behaviour changes that can be confusing, irritating or difficult for others to deal with, leaving carers, partners and family members feeling stressed, irritable or helpless. By learning to understand the meaning behind the actions, it can be easier to stay calm and deal effectively with the challenges that arise. This factsheet outlines some typical sorts of unusual behaviour in people with dementia and explains some common causes.**

Each person is an individual, with their own preferences and character traits. However, certain forms of behaviour are particularly common in people with dementia. If the person you are caring for has difficulty expressing him or herself in words, the unusual behaviour may become more extreme. By working out what each behaviour means, and finding ways to overcome the problem, the situation can become more manageable.

## Common types of unusual behaviour

### Repetitive behaviour

People with dementia often carry out the same activity, make the same gesture, or ask the same question repeatedly. Medical professionals sometimes call this 'perseveration'. This repetition may be because the person doesn't remember having done it previously, but it can also be for other reasons, such as boredom.

It is not unusual for a person with dementia to go through the motions of the activity they may previously have carried out at work.

This can indicate a need to be occupied and to feel there is a purpose and structure to their life. Specific types of repetitive behaviour may include:

- **Asking the same question over and over again** – As well as memory loss, this can be due to the person's feelings of insecurity or anxiety about their ability to cope. Try to be tactful and patient, and encourage them to find the answer for themselves. For example, if they keep asking the time, and you know they are able to understand the clock, suggest that they look at the clock themselves. It may help if you to move the clock to a position that is more visible. People with dementia may become anxious about future events such as a visitor arriving, which can lead to repeated questioning. It may help if you don't mention the event until just before it takes place.
- **Repetitive phrases or movements** – This can be due to noisy or stressful surroundings, or boredom. Encourage the person to do something active, such as going for a walk. It can also be a sign of discomfort, so check that the person isn't too hot or cold, hungry, thirsty or constipated. Contact the GP if there is any possibility that the person may be ill or in pain, or experiencing a side-effect of medication.
- **Repetitive actions** – Actions such as repeatedly packing and unpacking a bag, or rearranging the chairs in a room, may relate to a former activity such as travelling or entertaining friends. If so, this may serve as a basis for conversation. Alternatively, it could signify boredom or a need for more contact with people.
- **Repeatedly asking to go home** – This may take place in residential care, or when the person is already at home. It can be a sign of anxiety, insecurity, fear or depression. The concept of 'home' might evoke memories of a time or place where the person felt comfortable or safe, or of a home, family and friends that no longer exist. If the person doesn't recognise their present environment as 'home', then it isn't home for them. Try to understand and acknowledge the person's feelings and reassure them that they are safe and loved.

- **Multiple phone calls** – Some people with dementia phone their loved ones over and over again – particularly in the middle of the night. This can be very frustrating and distressing. The person with dementia may forget that they have already called, or may be insecure or anxious. If you are receiving repeated calls, it may help to get a phone with a number recognition display or an answerphone so you can decide whether you want to answer, and switch mobiles and ringers off at night. You may feel guilty about not answering every call, but it's important to look after yourself and get some rest.

## Restlessness

Some people with dementia experience general restlessness. This can be a sign of hunger, thirst, constipation or pain, or the person may be ill or suffering from the side-effects of medication. Other possibilities are boredom, anger, distress or anxiety, stress due to noisy or busy surroundings, or lack of exercise. It may also be due to changes that have taken place in the brain. If the person seems upset, try to find the reason, give them some reassurance, then try to distract them with an interesting activity, or by involving them in some form of exercise.

- **Pacing up and down** – Pacing may indicate that the person wants to use the toilet but is unable to tell you. Try asking the person whether they need to use the toilet, or lead them towards it. If they are adamant that they want to pace, try to find somewhere they can walk safely. If a person has always been active and walked regularly, they may be feeling frustrated and want some fresh air. Help to choose comfortable clothes and shoes, offer drinks and snacks, check their feet regularly for redness, swellings or blisters, and try to persuade them to rest from time to time.
- **Fidgeting** – Someone with dementia may fidget constantly. As with pacing, try to distract their attention and offer reassurance. Try giving the person something to occupy their hands, such as a soft toy or worry beads, or provide a 'rummage' box containing interesting objects.

## Shouting and screaming

The person may continually call out for someone, shout the same word, or scream or wail over and over again.

- They could be in pain or ill, experiencing difficulties with visual perception or hallucinations, or the behaviour could be a result of brain damage. In these cases, talk to the GP.
- A person with dementia may feel lonely or distressed, if their short term memory is damaged they may not remember that you are in the next room and believe they are alone. They may feel anxious about their failing memory, bored, or stressed by too much noise and bustle.
- If the person shouts out at night, a nightlight in the bedroom may be reassuring.
- Consider how the room looks in the dark. Are there shadows or shapes that cannot be seen when the light is on but that could be misinterpreted and look frightening in the dark?
- If they are calling for someone from their past, try talking to them about this period in their life and respond to the feelings the person is showing. Avoid harsh facts that may cause distress – if the person they are asking for has died, they may not remember this fact and will feel they are hearing it for the first time.

## Lack of inhibition

The person may behave in a way that other people find embarrassing because of their failing memory and general confusion. In a few cases, this may be due to specific damage to the brain. Try to react calmly.

- Some people with dementia may undress in public, having forgotten when and where it is appropriate to remove their clothes. If this happens, take the person somewhere private, and check whether they are too hot or are uncomfortable or want to use the toilet.

- Stroking or exposing genitals in public, or apparently inappropriate sexual behaviour, may be a result of the physical damage to the part of the brain that allows us to recognise acceptable social behaviours. If this happens, discourage the person tactfully and try to distract their attention. It is important to remember that having a dementia does not mean a person no longer has physical or sexual needs – simply that inhibitions and social skills may not be functioning. If such behaviour is frequent or persistent, consult the GP.
- Some actions, such as lifting a skirt or fiddling with flies, may not be related to sex at all – it may simply be a sign that the person wants to use the toilet.
- If the person behaves rudely – for example, by insulting people or swearing or spitting – don't attempt to argue or correct the behaviour. Try to distract their attention, and explain to other people later that the behaviour is due to dementia and is not directed at them personally.

### **Night-time waking**

Many people with dementia are restless at night and find it difficult to sleep. Older people often need less sleep than younger people in any case. Dementia can affect people's body clocks so that they may get up in the night, get dressed or even go outside. This can be very worrying – and exhausting – for carers.

- Make sure the person has enough exercise during the day and that they use the toilet before bed.
- Try a walk before bedtime, a warm milky drink and soothing company before they fall asleep.
- If the person wakes up, gently remind them that it is night-time.
- During the light summer months it can feel like daytime even late at night or very early in the morning, so put a clock that shows whether it is am or pm next to the bed and consider darker curtains or blackout blinds.

## Trailing and checking

Living with dementia makes many people feel extremely insecure and anxious. This can result in the person constantly following their carers or loved ones around, or calling out to check where they are. A few moments may seem like hours to a person with dementia, and they may only feel safe if other people are nearby.

- This behaviour can be very difficult to cope with, but try not to speak sharply.
- If you are busy, give the person something absorbing to do – perhaps distraction through a pet, task or activity, or you can hum or sing, or put the radio on.
- Make sure you also find some time for yourself.

## Hiding and losing things

People with dementia sometimes hide things and then forget where they are – or forget that they have hidden them at all. The wish to hide things may be due to feelings of insecurity and a desire to hold on to what little the person still has.

- However impatient you feel, try to be reassuring.
- Don't leave important documents lying around, and make sure you have a spare set of keys.
- Try and find out the person's hiding places so that you can tactfully help find 'missing' items.
- If the person hides food, check hiding places regularly, and discreetly dispose of any perishable items.

## Suspicion

Some people with dementia can become suspicious. If they have mislaid an object they may accuse someone of stealing it, or they may imagine that a friendly neighbour is plotting against them. These

ideas may be due to failing memory, an inability to recognise people, and the need to make sense of what is happening around them.

- If this happens, state calmly what you know to be true, if appropriate, and then reassure and distract the person.
- Try to remember that although the person's interpretation may be wrong, the way the person feels is real.
- Explain to others that they should not take unfounded accusations seriously.
- Don't automatically dismiss the person's suspicions if there is any possibility that they may be true.

### **Sleeplessness and 'sundowning'**

Many people with dementia, especially in the middle stages, experience periods of increased confusion at dusk, with their disorientation continuing throughout the night. These periods of what is known as 'sundowning' usually diminish as the dementia progresses.

Sundowning may be caused by:

- mental and physical tiredness at the end of the day
- reduced lighting and an increase in shadows
- less need for sleep, common among older adults
- an upset 'body clock' with the body mixing up day and night.

See sections on 'Restlessness' and 'Night-time waking' for suggestions on how to deal with the effects of sundowning.

### **Tips: Coping with unusual behaviour**

- Try to remember that the person you are caring for is not being deliberately difficult, their sense of reality may be very different to



yours but very real to them. Dementia can affect a person's ability to use logic and reason so things that may seem obvious to you might appear to be very different for the person with dementia.

- Ask yourself whether the behaviour is really a problem. If the behaviour is linked to a particular activity such as washing or dressing, ask yourself if this task really needs to be done right now or if you could leave it for a while until the person has calmed down.
- Try to put yourself in the person's situation. Imagine how they might be feeling and what they might be trying to express.
- Offer as much reassurance as you can.
- Remember that all behaviour is a means of communication. If you can establish what the person is trying to communicate, you will resolve the problem much more quickly.
- Distract the person with calming activities such as a hand massage, stroking a pet, a drive in the country or by playing their favourite music.
- Try to make sure that you have support for yourself and breaks when you need them.
- Some people find unusual behaviours, particularly a repetitive behaviour, very irritating. If you feel you can't contain your irritation, make an excuse to leave the room for a while.
- If you find the person's behaviour really difficult to deal with, ask for advice from professionals or other carers before you become too stressed. Medication may sometimes be used for these behaviours, but this should be monitored and reviewed very carefully. Ask about the possible side-effects of any drugs so that if they appear you do not automatically assume that the dementia has become worse.
- Remember that it is possible to be the cause of the behaviour through a lack of understanding of what the person is trying to communicate. Try stepping away from the situation, look at the person's body language and try to understand what they might be feeling at that time. Give the person space to calm down and offer reassurance.

For details of Alzheimer's Society services in your area, visit [alzheimers.org.uk/localinfo](http://alzheimers.org.uk/localinfo)

For information about a wide range of dementia-related topics, visit [alzheimers.org.uk/factsheets](http://alzheimers.org.uk/factsheets)

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2013. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

#### Factsheet 525LP

Last updated: November 2010  
Last reviewed: November 2010

Reviewed by: Cathy Baldwin,  
Programme Delivery Manager,  
Knowledge and Learning, Alzheimer's  
Society

Alzheimer's Society would like to thank Janet Keane of the Department of Psychiatry at Oxford University for her help in preparing this factsheet.

This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



#### Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:  
**0300 222 11 22**

9am–5pm Monday–Friday  
10am–4pm Saturday–Sunday

[alzheimers.org.uk](http://alzheimers.org.uk)

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.

**Alzheimer's Society** | Leading the fight against dementia

Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499

# CHAPTER 6: ASSISTING PATIENTS WITH EATING AND DRINKING

## What this chapter covers

- The process for checking the patients name, diet order and fluids on the menu.
- The importance of social engagement , communication and minimising distractions.
- Safety and positioning considerations for assisting patients with meals.
- Identifying and reporting any problems when assisting with feeding.
- The range of different standardised food and fluid textures.
- Communicating food and fluid amounts consumed by patients to staff.

## Additional reading/information

1. Australian Food Standards.
2. Alzheimer's Australia Nutrition Help Sheet.
3. Tips for caring for a patient with swallowing difficulties.
4. Standard Fluid amounts.

## Chapter 6 Quiz

Please circle the correct true or false response

1. Patients with dementia and delirium are at risk of become dehydrated when in hospital.	True	False
2. Coughing, gurgly voice, food residue left in the mouth are not signs of swallowing difficulties.	True	False
3. The 3 types of texture modified fluids are: mildly thick, moderately thick and extremely thick.	True	False
4. It is not important for the volunteer to check the patients menu to ensure it is the correct meal.	True	False
5. Gaining an understanding of the person and trying to understand what they might be experiencing are ways volunteers can support patients.	True	False
6. It is safe for a volunteer to feed a patient when they sleepy or drowsy.	True	False

***Check your answers with those at the end of the handbook***



# Australian Standards for Texture Modified Foods and Fluids



Australian Food Standards  
 Chapter 6: Additional Reading

The provision of thickened fluids and texture modified foods is a routine part of the assessment and management of feeding and swallowing difficulties (dysphagia).

If you need assistance with the level of fluid and food texture modification required, contact your Speech Pathologist.

To find a Speech Pathologist, go to [www.speechpathologyaustralia.org.au](http://www.speechpathologyaustralia.org.au).

If you require support to determine whether a textured modified diet is meeting nutrition and hydration needs, contact your dietitian.

To find an Accredited Practising Dietitian (APD), go to [www.daa.asn.au](http://www.daa.asn.au).

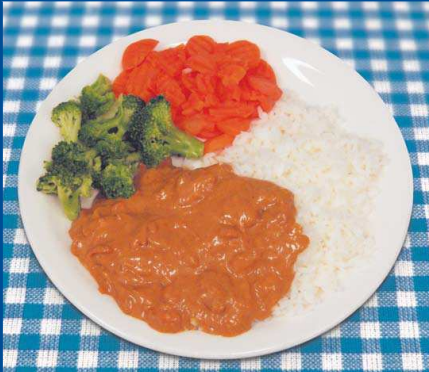


Please contact Novartis on 1800 671 628 or visit [www.novartisnutrition.com.au](http://www.novartisnutrition.com.au) for further information or for copies of this poster.

*This poster is proudly supported by Novartis Medical Nutrition as part of the development of the Australian Standards.*



Novartis Consumer Health Australasia Pty. Ltd. ABN 46 004 535 513  
 Australia 327-333 Police Road, Eastern Building, Mulgrave VIC 3170  
 For further information, please call 1800 671 628 (Australia)  
 or 0800 607 662 (New Zealand). <http://www.novartisnutrition.com>

Fluid	Mildly Thick Level 150	Moderately Thick Level 400	Extremely Thick Level 900
	<p>Fluid runs freely off the spoon but leaves a mild coating on the spoon</p> 	<p>Fluid slowly drips in dollops off the end of the spoon</p> 	<p>Fluid sits on the spoon and does not flow off it</p> 

Food	Texture A Soft	Texture B Minced and Moist	Texture C Smooth Pureed
	<p>Food may be naturally soft or may be cooked or cut to alter its texture</p> 	<p>Food is soft, moist and easily mashed with a fork; lumps are smooth and rounded</p> 	<p>Food is smooth, moist and lump free; may have a grainy quality</p> 

# Nutrition Help Sheet

CARING FOR SOMEONE  
WITH DEMENTIA

13

## NUTRITION

**This Help Sheet discusses the importance of good nutrition, and provides some practical ways that families and carers can ensure that a person with dementia is well nourished.**

### Good nutrition is important

The type of food we eat affects our health and our quality of life. Poorly nourished people get sick more often and recover from injury and illness more slowly. Poor nutrition is a major health problem for many older people.

For people with dementia, maintaining good nutrition presents extra challenges. A person with dementia may:

- Experience a loss of appetite
- Develop an insatiable appetite or a craving for sweets
- Forget to eat and drink
- Forget how to chew or swallow
- Experience a dry mouth, or mouth discomfort
- Be unable to recognise the food and drink they are given

### Daily nutritional balance

The nutritional requirements of someone with dementia will be similar to other people of their age. However some people with dementia experience increased physical activity such as pacing, which means they will need larger amounts of food to prevent them from losing weight.

Dietary guidelines for older Australians recommend:

- Enjoying a wide variety of nutritious foods
- Eating at least three meals every day
- Drinking plenty of water
- Eating plenty of vegetables (including legumes) and fruit
- Eating plenty of cereals, bread and pastas
- Eating a diet low in saturated fats
- Choosing foods low in salt and using salt sparingly

- Including foods high in calcium
- Using added sugars in moderation

### Some common problems

Some people with dementia may forget to eat.

#### What to try

- An alarm clock, or a phone call, may be a useful reminder at mealtimes
- Snacks that are easy to eat and don't need to be refrigerated can be left out where they can be easily seen

Some people with dementia can't or won't prepare meals for themselves. This can be particularly difficult if they are living alone.

#### What to try

- Meals should be shared social occasions whenever possible
- Delivered meals such as meals-on-wheels. However these may not provide all of a person's daily nutritional needs or may not be what the person is used to eating
- Home support to assist with meal preparation, serving and to discretely prompt with eating
- Pre-prepared meals from the supermarket
- Family and friends helping to prepare meals and or eating together
- Preparing large quantities of food, then freezing into meal size amounts
- Home delivered ready-to-eat food from restaurants or fast food outlets
- Eating out. However check first that the person with dementia will be comfortable with the venue and food
- Stocking up on healthy snacks such as yoghurt, cheese or dried fruit that do not need preparation or cooking

**FIGHTDEMENTIA.ORG.AU NATIONAL DEMENTIA HELPLINE 1800 100 500**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**

This help sheet is funded by the Australian Government under the National Dementia Support Program

## 13 CARING FOR SOMEONE WITH DEMENTIA

Alcohol may stimulate the appetite and add to the enjoyment of a meal. However, too much alcohol can replace food and people can run the risk of becoming malnourished. If a person with dementia is a heavy drinker it may be difficult to change their drinking habits.

### What to try

- Make sure that they are well nourished
- Discourage drinking on an empty stomach
- Offer drinks other than alcohol
- Water alcohol down

### Finger foods

All food should be able to be eaten with dignity. If a person with dementia is having difficulty with cutlery, finger foods can be a nutritious and easy alternative.

Finger foods are simply foods prepared so that they can be eaten with the fingers. This enables people who would otherwise lose this level of independence to feed themselves.

### What to try

- Prepare a plate of nutritious and attractive food that can be picked up in the fingers
- Make sure that the food is accessible. Put it on a flat plate with no pattern so that the food can be seen clearly. Make sure the plate is in comfortable reaching distance
- Don't use complicated table settings and avoid lots of different cutlery, crockery, glasses, foods and drinks together
- Serve only one plate of food at a time
- Impairment to taste and smell senses can reduce appetite. The preparation of tasty, strongly flavoured and aromatic food may help
- Allow time for the memory to respond
- It may be necessary initially to help fingers to convey the food from the plate to the mouth
- It can help to eat together so that the person with dementia can copy you
- Types of foods served need to take the culture and past eating habits of the person into consideration

### Eating in the later stages of dementia

It is common for people in the later stages of dementia to lose a considerable amount of weight. People may forget how to eat or drink, or may not recognise the food they are given. Some people become unable to swallow properly. Providing nutrition supplements may need to be considered. If a person has swallowing difficulties, or is not consuming food or drink over a significant period of time and their health is affected, nutrition supplements may be considered for consumption other than by mouth.

### Based on:

*Finger foods for independence; For people with Alzheimer's disease and other eating difficulties*, by Lois Newton and Dr Alan Stewart, and *Reduce the risk: A common sense guide to preventing poor nutrition in older people*, by Carolyn Bunney and Rudi Bartl

### Who can help?

A dietician or doctor can advise you about good nutrition. Your local hospital, community health service, Commonwealth Respite and Carelink Centre, or your doctor can put you in touch with a dietician.

Commonwealth Respite and Carelink Centres around Australia provide information about the range of community care programs and services available to help people stay in their own homes. Visit [commcarelink.health.gov.au](http://commcarelink.health.gov.au) or call **1800 052 222**

The Dementia Behaviour Management Advisory Service (DBMAS) is a national telephone advisory service for families, carers and care workers who are concerned about the behaviours of people with dementia. The service provides confidential advice, assessment, intervention, education and specialised support 24 hours a day, 7 days a week and can be contacted on **1800 699 799**.

### FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [fightdementia.org.au](http://fightdementia.org.au)



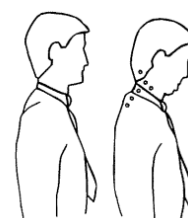
For language assistance phone the Translating and Interpreting Service on **131 450**



## Tips for Caring for a Person with Swallowing Difficulties

### Tips when caring for a patient with swallowing difficulties

1. Is the patient alert and able to concentrate?
2. Is the posture of the patient – upright and chin tucked as below right?
3. Do they have the correct menu to fill and the correct meal tray? Check the menu and tray ticket for the patients name and check that the diet order is correct.



4. Are they getting adequate fluid?  
Most people who aren't on a fluid restriction require 1800-2000ml /day (7-8 cups includes tea, coffee, fruit juice, milk and water)

Fluid for people with dysphagia may be either:

- a) Un modified (regular fluids)
- b) or Thickened:  
Mildly thick (150) nectar like or  
Moderately thick (400) honey like or  
Extremely thick (900) pudding like







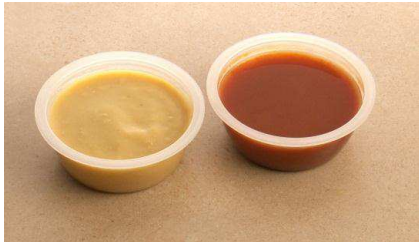


5. Do they need aids or utensils to assist in eating their meal?
6. Ensure that they have good mouth care –
  - a) Mouth is clear after meals
  - b) Mouth care takes place with rinsing and cleaning the mouth and teeth.
  - c) Adequate hydration is also helpful.
7. Record and report –
  - a) Poor oral intake. Good nutrition and good fluid intake assists the body to recuperate.
  - b) Body weight.



# Standard Fluid Amounts

## Standard Fluid Amounts for Volunteer/staff Fluid Balance Chart Documentation

Type of Fluid/container and standard amount	
<p>White ceramic cup = <b>180 mls</b></p> 	<p>Paper cup = <b>200 mls</b></p> 
<p>Thermal tray mugs for hot drinks and clear soup = <b>200mls</b></p> 	<p>Fruit juice in portion control containers (Berri) = <b>110mls</b></p> 
<p>Thickened fruit juice (Flavour Creations) = <b>185 mls</b></p> 	<p>Jelly in portion control containers = <b>120mls</b></p> 
<p>Soup in portion control containers = <b>200mls</b></p> 	<p><b>Other measures</b></p> <p>1 teaspoon = 5ml</p> <p>1 soup spoon = 15ml</p> <p>1 dessert spoon = 15ml</p>

Source: Bega Valley Dietitians. May 2014



# CHAPTER 7: SAFE WALKING WITH PATIENTS

## What this chapter covers

- Encouraging regular walking is beneficial for many patients.
- Terms used to describe patients walking ability.
- The different walking aids that a volunteer may see a patient's using.
- How to prompt patients to stand.
- Safety when walking with patients.
- What to do if a patient becomes unsteady.
- What to do if you find a patient who has fallen.

## Additional reading/information

Nil

## Chapter 7 Quiz

Please circle the correct true or false response

1. Walking frames and walking sticks are the most common types of walking aids volunteers will be involved with.	True	False
2. Volunteers can only walk with patients who are independent or require supervision.	True	False
3. A volunteer can prompt or remind a patient about the right way to get out of a chair but not physically assist.	True	False
4. Encouraging patients to walk regularly when it is safe for the volunteer to do so is an important volunteer role.	True	False
5. If a patient has fallen, a volunteer can help them get up.	True	False
6. Volunteers should always check with staff if they are unsure about anything.	True	False

***Check your answers with those at the end of the handbook***

Congratulations! You have now completed the Dementia & Delirium Care Hospital Volunteer Training DVD.  
Please complete the post education care confidence questionnaire and the training evaluation form.  
Return the completed post education care confidence questionnaire, the evaluation form and the pre education care confidence questionnaire to your volunteer coordinator or person responsible for your training when you return the DVD

# POST EDUCATION QUESTIONS

Please answer the following questions, by circling the number that best reflects your response.

## 1. How confident are you that you understand what dementia is?

Not confident at all		Moderately confident		Very confident
1	2	3	4	5

## 2. How comfortable do you feel about the idea of spending time with a person with dementia?

Not comfortable at all		Moderately comfortable		Very comfortable
1	2	3	4	5

## 3. Sometimes, when a person with dementia becomes stressed or anxious, they can become upset, angry or aggressive. How confident would you feel interacting with someone with dementia who demonstrated these behaviours?

Very unsure		Moderately confident		Very confident
1	2	3	4	5

## 4. How confident are you that you understand what delirium is?

Not confident at all		Moderately confident		Very confident
1	2	3	4	5

## 5. How comfortable do you feel about the idea of spending time with a person with a delirium?

Not comfortable at all		Moderately comfortable		Very comfortable
1	2	3	4	5

## 6. Sometimes, when a person with a delirium becomes stressed or anxious, they can become upset, angry or aggressive. How confident would you feel interacting with someone with dementia who demonstrated these behaviours?

Very unsure		Moderately Confident		Very Confident
1	2	3	4	5

## 7. How comfortable do you feel about the idea of spending time with a person with a delirium?

Not confident at all		Moderately confident		Very confident
1	2	3	4	5



# DEMENTIA & DELIRIUM CARE HOSPITAL VOLUNTEER TRAINING DVD EVALUATION

Your feedback is seen as important. Please circle on the scale of 1-10 how helpful each session of the training program was to you:

**1** = least helpful    **10** = extremely helpful

## Chapter 1: The Volunteer Role

1    2    3    4    5    6    7    8    9    10

## Chapter 2: Dementia and Delirium

1    2    3    4    5    6    7    8    9    10

## Chapter 3: Communication and person centred care

1    2    3    4    5    6    7    8    9    10

## Chapter 4: Activities for patients

1    2    3    4    5    6    7    8    9    10

## Chapter 5: Understanding behaviours in dementia and delirium

1    2    3    4    5    6    7    8    9    10

## Chapter 6: Assisting patients with eating and drinking

1    2    3    4    5    6    7    8    9    10

## Chapter 7: Safe walking with patients

1    2    3    4    5    6    7    8    9    10

**Please circle how you found the training program handouts and resources.**

Not useful

A little useful

Moderately useful

Very useful

**What was the best thing about the training program?**

---

---

---

**What was the worst thing about the training program?**

---

---

---

**What could have made the training program better?**

---

---

---

Thank you for taking the time to complete this feedback.

# QUIZ ANSWERS

Chapter 1	Correct Answer
1. The types of patients volunteers will be supporting include those who memory and thinking problems.	True
2. The volunteer role provides similar support to that of a family carer.	True
3. Reading and signing the code of conduct is a requirement for all health service staff and volunteers.	True
4. If a referral form has not been completed the volunteer can still provide assistance to the patient.	False
5. Maintaining confidentiality relates only to information about the patient.	False

Chapter 2	Correct Answer
1. Dementia can be cured.	False
2. Alzheimer's disease is the most common cause for dementia.	True
3. Delirium is characterised by a sudden onset of change in a person's mental function.	True
4. People with dementia and delirium can be anxious and fearful when in hospital.	True
5. It is important for volunteers to notify staff of any changes they notice in a person's mental state behaviour or physical condition.	True

Chapter 3	Correct Answer
1. Dementia can affect a person's ability to communicate.	True
2. People with dementia may not be able to recognise familiar objects such as a cup or spoon.	True
3. People with dementia don't have emotions and feelings.	False
4. Providing person centred care involves gaining an understanding of the person, their background, personal preferences.	True
5. Completion of a person profile can greatly support volunteers in their communication with patients.	True

Chapter 4	Correct Answer
1. The information on the patient's personal profile can assist volunteers in deciding on appropriate activities for the patient.	True
2. Sitting and talking with patients is not an activity.	False
3. Distraction activities can assist with patients who may be unsettled or agitated.	True
4. Playing a patient's preferred music is an activity.	True
5. Because patients in hospital are unwell, some will be sleepy and not be able to concentrate on activities.	True

Chapter 5	Correct Answer
1. Onset or change in behaviours can be common in patients with dementia and delirium.	True
2. Wandering and agitation are not behaviours.	False
3. There can be many causes or triggers for behaviours.	True
4. Pain and fear are not causes for changed behaviour.	False
5. Gaining an understanding of the person and trying to understand what they might be experiencing are ways volunteers can support patients.	True
6. If a volunteer feels unsafe, they should stay calm, leave the room and report what has occurred to staff.	True

Chapter 6	Correct Answer
1. Patients with dementia and delirium are at risk of become dehydrated when in hospital.	True
2. Coughing, gurgly voice, food residue left in the mouth are not signs of swallowing difficulties.	False
3. The 3 types of texture modified fluids are: mildly thick, moderately thick and extremely thick.	True
4. It is not important for the volunteer to check the patients menu to ensure it is the correct meal.	True
5. Gaining an understanding of the person and trying to understand what they might be experiencing are ways volunteers can support patients.	False
6. It is safe for a volunteer to feed a patient when they sleepy or drowsy.	False



Chapter 7	Correct Answer
1. Walking frames and walking sticks are the most common types of walking aids volunteers will be involved with.	True
2. Volunteers can only walk with patients who are independent or require supervision.	True
3. A volunteer can prompt or remind a patient about the right way to get out of a chair but not physically assist.	True
4. Encouraging patients to walk regularly when it is safe for the volunteer to do so is an important volunteer role.	True
5. If a patient has fallen, a volunteer can help them get up.	False
6. Volunteers should always check with staff if they are unsure about anything.	True