



Facilitator Training Manual

A Person Centred Care Group Training Course
for Hospital Volunteers



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SHPN (ACI) 150008

ISBN 978-1-76000008-0

Further copies of this publication can be obtained from Agency for Clinical Innovation website at: www.aci.health.nsw.gov.au

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Published Oct 2016. Next Review 2025. © State of NSW (Agency for Clinical Innovation)

Dementia and Delirium Care Hospital Volunteer Training

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ACKNOWLEDGEMENTS

This facilitator training manual has been written by Cath Bateman, Southern NSW Local Health District Dementia Delirium CNC. The contents of this manual, has built on the Bega Hospital Dementia Delirium Volunteer Training Program. This original training program was developed in partnership with Barbra Williams, Regional Manager with Alzheimer's Australia NSW.

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The Agency for Clinical Innovation (ACI) is the primary agency in NSW for promoting innovation, engaging clinicians and designing and implementing new models of care.

The Network Manager of the ACI Aged Health Network has overseen the development of this resource. The following members of the ACI consultative committee are acknowledged for their consultation and contribution to this and the video training resource.

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INTRODUCTION

This facilitator training manual forms part of a suite of resources commissioned by the Agency for Clinical Innovation to support the implementation of a volunteer program to support patients with dementia and delirium in hospital. The purpose of this resource is to facilitate the training of volunteers for the Dementia and Delirium Care with Volunteers Program in NSW Health Services.

The implementation guide provides a framework and procedural resources for establishment of the volunteer program. The training resource provides the structure and training resources to support initial and ongoing volunteer training.

There are two components of the Dementia and Delirium Care with Volunteers training resource.

1. The facilitator training manual for conducting the initial and ongoing group volunteer training programs. The training program incorporates eight training sessions. These 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
- Commencing as a volunteer

2. A video training resource. Dementia & Delirium Care Hospital Volunteer Training. This is designed to provide the necessary training for individual volunteers who wish to join the program outside a group training program. It will primarily be used once a program has commenced as volunteers completing this training resource will then buddy up with existing volunteers to learn about the specific health service procedures for the program. The video resource is also designed to complement the group training program or to substitute a group training session/s a volunteer may have been unable to attend. Sections of the video training resource have been embedded into the facilitator training manual PowerPoint sessions.

It is suggested that volunteer training handbooks which include the structure of your program and separated session handouts are made up for participants prior to the training program. This way the handouts are organised and can be referred to during the session.

HOW TO USE THIS FACILITATOR TRAINING MANUAL

An overview of the contents and the time frame for the conduct of each of the eight training sessions is listed in the program outline. Individual health services will need to consider how they will structure the training. For example: whether the training will be run over 4 half days or two full days etc. This will depend on availability of volunteers, presenters and a venue.

Each section contains the key message, materials or resources needed, the activity guides, handouts and facilitator notes for that session. The PowerPoint presentations incorporate narrative notes to guide the trainer through the PowerPoint presentation and activities. Some sessions include video clips or the option of using relevant sections from the video training resource. **NOTE: The DirectX Video Acceleration for WMV Files needs to be turned off for the media files to play correctly. If the video clips are pixilated or do not play properly: Right click on the video. Select More Options then select Performance then untick 'Turn on DirectX Video Acceleration for WMV files' - 4th box under DVD and video play back section. Then click Apply.**

Web links to other relevant resources to support the education for that session are also included. Facilitators will need to ensure they have internet access to use these links.

The purpose of this training resource is to ensure the session learning objectives and key points are covered. It is not meant to be didactic or prescriptive. Approaches to conducting the training will be dependent on the experience of the trainer and the demographics of volunteers undergoing the training. Facilitators conducting the training may wish to vary or individualise the narrative for the PowerPoint presentation. The introductory and communication activities are based on the authors experience in conducting training programs. Some facilitators using this resource may choose to vary or change these activities based on their experience as well as the volunteer demographics. The most important thing is that the volunteers attending the training are engaged, have fun and enjoy it!

The training program is comprehensive with a number of activities, so having variation or two facilitators can be beneficial. As with the original program development, partnerships with dementia advisory services or organisations such as Alzheimer's Australia NSW can support a co facilitation approach.

Session 6 *Assisting patients with eating and drinking* should be conducted by a Speech Pathologist and a dietitian. Likewise Session 7 *Safe walking with patients*, should be conducted by a physiotherapist. In smaller sites where allied health clinicians may not be readily available, Chapters 6 and 7 of the video training resource can be used instead.

The manual is divided into the eight sections for each training session.

Session 1: About the program and volunteer role: In this session services will need to discuss and provide information on the structure of your training program at slide 3. At the start of the session volunteers are asked to complete a one page pre education care confidence survey. The same post survey is completed in session 8.

Session 1 includes the option of playing a practical example of the volunteer referral process from the video training resource or playing the whole chapter. Playing the whole chapter provides a visual overview of the volunteer role and reinforces the learning objectives for the session.

Session 2: Understanding dementia and delirium: In the PowerPoint presentation there is a link to the Alzheimer's Australia web site and a video training resource on the European Delirium Association web site, so internet access will be required to use these links. Session 2 also incorporates the carer interview from the video training resource.

Session 3: Communication and person centred care: In this session a practical guide to completing the personal profile is incorporated from the video training resource.

Session 4: Activities for patients: In this session there is the option of either showing chapter 4 of the video resource and/or conducting a practical activity using the personal profile.

Session 5: Understanding behaviours which can occur in patients with dementia and delirium. In this session a video interview with existing volunteers is included to support learning and volunteer confidence. An activity in this session uses Vision Australia macular degeneration and cataract cardboard glasses which will need to be ordered.

Session 6: Assisting patients with eating and drinking. Ideally this session should be jointly provided by a speech pathologist and dietitian if available or alternatively a speech pathologist with another trainer. Internet access will be required to access links to the YouTube training resources.

The practical example of assisting patients with eating drinking from the video training resource is to be used to compliment this session.

Session 7: Safe walking with patients. This session should be provided by a physiotherapist. The practical example of a volunteer walking with patients and other safety considerations from the video training resource can also be used.

Session 8: Commencing as a volunteer. This session provides an overview of the program procedures including the documentation and reporting lines for your service.

There is no PowerPoint presentation for this session. Services will need to consider how they will structure and run this session. Services will also need to consider whether orientation of the group to the ward/facility will be incorporated in this session or separately. Evaluation and volunteer certificate presentation is in this session.

Symbols used in this manual and within the PowerPoint presentations:



PowerPoint slide presentation



Question mark symbol for questions and brainstorming



Handouts



Symbol identifying a group activity

PROGRAM OUTLINE

SESSION 1: About the Program and Volunteer Role

Time frame for Session 1 :

Due to introductions the time frame for this session will be dependent on the number of participants. For less than 10 participants allow 90 minutes. Greater than 10 participants allow 120 minutes.

- Pre training care confidence survey.

- Welcome and introductions.

- Overview of the program.

 - The concept of person centred care.

 - Types of patient's volunteers will be supporting.

 - The referral process.

- The volunteer duty statement.

- Roles and Responsibilities.

- Confidentiality.

- Rosters, vaccination, mandatory education.

- Summary.

SESSION 2: Understanding Dementia and Delirium

Time frame for Session 2 : 90 minutes

- Overview of Session.

- What is Dementia?

- What is Delirium?

- The Volunteer Role.

- The Carer Experience.

- Summary.

SESSION 3:

Communication and Person Centred Care

Time Frame for Session 3 : 90 minutes

Overview of session.

Person Centred Care and the personal profile.

Communicating with the person with dementia.

Communication exercises.

Summary.

SESSION 4:

Activities for Patients

Time Frame for Session 4 : 60 minutes

Overview of session.

Activities: what are they and why are they important?

Using the personal profile to select appropriate activities.

A range of activity resources for the person in hospital.

Chapter 4: Activities video resource.

Using touch – hand and foot massage.

Summary.

SESSION 5:

Understanding Behaviours which can occur in Patients with Dementia and Deliriums

Time Frame for Session 4 : 90 minutes

Overview of session.

Behaviours that can occur in patients with dementia and delirium.

Understanding common causes or triggers for behaviours.

Safety considerations.

Volunteer experiences.

Practical exercises.

Summary.

SESSION 6:

Assisting Patients with Eating and Drinking

Time frame for session: 120 minutes

Overview of session.

Introduction.

Normal and disordered swallowing.

Safe positioning for eating and drinking.

Texture modified food and fluids.

Undernourishment and dehydration.

Case studies.

Summary.

SESSION 7:

Safe Walking with Patients

Time frame for session: 45 minutes

Overview of session.

Terminology.

Walking aids.

Safe walking with patients.

Safety considerations:

What to do if a patient loses balance?

What to do if a patient has fallen?

Summary.

SESSION 8: Commencing as a Volunteer

Time frame for session: 120 minutes

Overview of session.

The volunteer procedures.

Documentation and reporting.

Orientation to the ward.

Discussion and Summary.

Post care confidence survey.

Evaluation.

Presentation of certificates.

DEMENTIA AND DELIRIUM CARE HOSPITAL VOLUNTEER TRAINING : DAY 1

Session 1 Introduction to the Program	
9.30am - 10.30am	<ul style="list-style-type: none"> Welcome and introductions. Overview, aim and objectives of the volunteer program. Person Centred Care. Roles and responsibilities. Code of Conduct, Confidentiality. Types of patients volunteers will be working with. The volunteer duty statement. Identifying you as volunteers. Rostering.
10.30am -11am	Morning Tea
Session 2 Understanding Dementia and Delirium	
11am - 12.30pm	<ul style="list-style-type: none"> Dementia and Delirium. Delirium prevention. Carer interview.
12.30pm - 1.15pm	Lunch
Session 3 Communication and Person Centred Care	
1.15pm - 2.45pm	<ul style="list-style-type: none"> Communication. Person centred care and the personal profile.
2.45pm - 3pm	Short afternoon break
Session 4 Activities for Patients	
3pm - 4pm	<ul style="list-style-type: none"> What are activities. Why are activities important. Resources available for activities. Practical exercises. Hand and foot massage.
4pm - 4.15pm	Summing up

DEMENTIA AND DELIRIUM CARE HOSPITAL VOLUNTEER TRAINING : DAY 2

8.45am - 9am	Welcome & Review of Day 1
Session 5	Understanding behaviours that can occur in patients with dementia and delirium
9am - 10.30am	<ul style="list-style-type: none"> • Overview of behaviours. • Common triggers for behaviours in hospital. • Your role as a volunteer in responding to behaviours that can occur. • Practical exercises.
10.30am - 11am	Morning tea
Session 6	Assisting Patients with Eating and Drinking
11am - 1pm	<ul style="list-style-type: none"> • Malnourishment & dehydration. • Practical and safety considerations when assisting a patient with eating and drinking. • Modified textured food and fluids.
1pm - 1.30pm	Lunch
Session 7	Safe Walking with Patients
1.30pm - 2.15pm	<ul style="list-style-type: none"> • Common aids and walking terms. • Practical and safety considerations.
Session 8	Commencing as a Volunteer
3pm - 4.15pm	<ul style="list-style-type: none"> • Procedures and reporting. • Documentation. • Buddying up. • Rosters and shift commencement. • Orientation Mandatory training. • Staff vaccinations. • T-Shirts. • Volunteer meetings.
4.15pm - 4.45pm	Certificates and evaluations

SESSION 1: ABOUT THE PROGRAM AND THE VOLUNTEER ROLE

Key Messages

- 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.

Resources

- Laptop and projector.
- Whiteboard and whiteboard markers.
- Health service volunteer handbook.
- Roster if available.
- Pre training questionnaire.
- Sign on sheet.
- Small exercise or note book for participants.
- Biros.

Handouts

- PowerPoint slide.
- **Handout 1:** Referral and Eligibility Form.
- **Handout 2:** Rights and Responsibilities.
- **Handout 3:** Do's and Don'ts for Volunteers.

Session overview

1. Welcome and Introductions

- Facilitators introduce themselves and background.
- House keeping.
- Volunteer introductions.
- Distribute volunteer folder.

2. Overview of the training structure and the volunteer program

- Facilitators introduce themselves and background.
- House keeping.
- Volunteer introductions.
- Distribute volunteer folder.

3. Other aspects of the volunteer role

- Health service volunteer handbook.
- Roles and responsibilities.
- Code of Conduct.
- Do's and Don'ts for volunteers.
- Mandatory education.
- Vaccination.
- Rostering.
- Reporting.
- Volunteer meetings.

SESSION 1: PRESENTATION OUTLINE

- **Participants sign on.** The sign on sheet will need to be kept for training records.
- Volunteers are provided with a small spiral bound note book (10x7.5cm) and a biro. Existing volunteers find the pocket note book is a useful and practical tool to record what rooms/wards their patients are located in or the amounts of food and fluids consumed by patients. This information is then conveyed to staff. It is also a practical welcome gesture. For NSW health facilities the note books can be ordered on IProcurement under NSW Health Store item number: 510482.
- **Pre education questionnaire.** Ask volunteers to complete the pre education questionnaire. Explain there are no right or wrong answers and they will be asked to complete the same questionnaire at the end of the training. The purpose of the questionnaire is to determine the effectiveness of the training in improving their confidence.

Additional reading/information

- Facilitator/s warmly welcomes the group and thanks them for choosing to volunteer for this important patient support volunteer program. Thanks the group for their commitment of time in undergoing the training. Facilitator communicates how it is hoped that the group enjoys the learning experience, getting to know the other members of the group and their future volunteer role.
- Before starting, facilitator requests that the group either turn off their mobile phones or change to silent setting.
- Provide information about toilets/fire exits and comfort needs such as adjusting heating or cooling if anyone is too hot or cold.
- Facilitator/s provide self-introduction, background and what drew them to the area of aged or dementia care.



Show **Session 1 PowerPoint**.

Slide 2: Introductions.

Now it's time to find out about participants. Ask participants to talk in pairs and get to know each other.

- Prompts:
- What have you done in the past?
- What prompted you to apply to join the program?
- What do you enjoy doing the most?
- Participants then take it in turns to introduce the person they have just interviewed.

Slide 3: Overview of the training structure and the volunteer program.

- Provide an overview of the structure you have set for your training program: when breaks will be, encourage participant's interaction and questions.
- Discuss training evaluation and provide evaluation form.
- Discuss and provide volunteer training handbooks.


Slide 4: Talk to points about the aim of the program.

Slides 5-7: Refer and talk to PowerPoint slide notes.

Slide 8: The volunteer role. This is an animated slide: The PowerPoint slide notes will guide the transition.

Slide 9: Refer and talk to PowerPoint slide notes. Provide **Handout 1: Referral and Eligibility Form** and talk through the form. You may need to substitute training manual handout for the form your service has adapted.

Slide 10: What do you believe are important qualities for volunteers to have?

-  **Brainstorm activity:** Ask the group “what they think are important qualities for a volunteer to have”. As they suggest things roughly group onto attitudes, knowledge, skills. Write up on the board and discuss as relevant.

Slides 11-12: Refer and talk to PowerPoint slide notes.

Slide 13: Refer and talk to PowerPoint slide notes.

Refer to **Handout 2 : Rights and Responsibilities.**

- **NOTE:** Different LHDs or services may have individualised Volunteer Rights and Responsibilities Forms. There also may be varying requirements as to whether these are to be signed by volunteers. This needs to be considered in relation to training. In addition the process may vary in relation to when volunteers sign the code of conduct. This may occur as part of training or with the volunteer coordinator outside the training program.

Slide 14: Refer and talk to PowerPoint slide notes. Each health service will have their generic volunteer manual or handbook. This can be discussed in this slide. Provide and go through **Handout 3 : Do’s and Don’ts.**

Each service will need to individualise discussion related to the other points for:

- Shifts.
- Mandatory training and vaccination.
- Rosters.
- Volunteer support for when the program is first commencing.
- Buddying support for when program is in place.
- Reporting and volunteer meetings.

Slide 15:  **Brainstorm:** The rewards of volunteering. Refer to PowerPoint notes for suggested prompts.

Slide 16: D & D Chapter 1 video resource can be played. This provides a visual overview of the volunteer role and the referral process and reinforces the learning objectives from session 1.

Slide 17: Questions the group may have.

PRE EDUCATION QUESTIONS

Site: _____

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

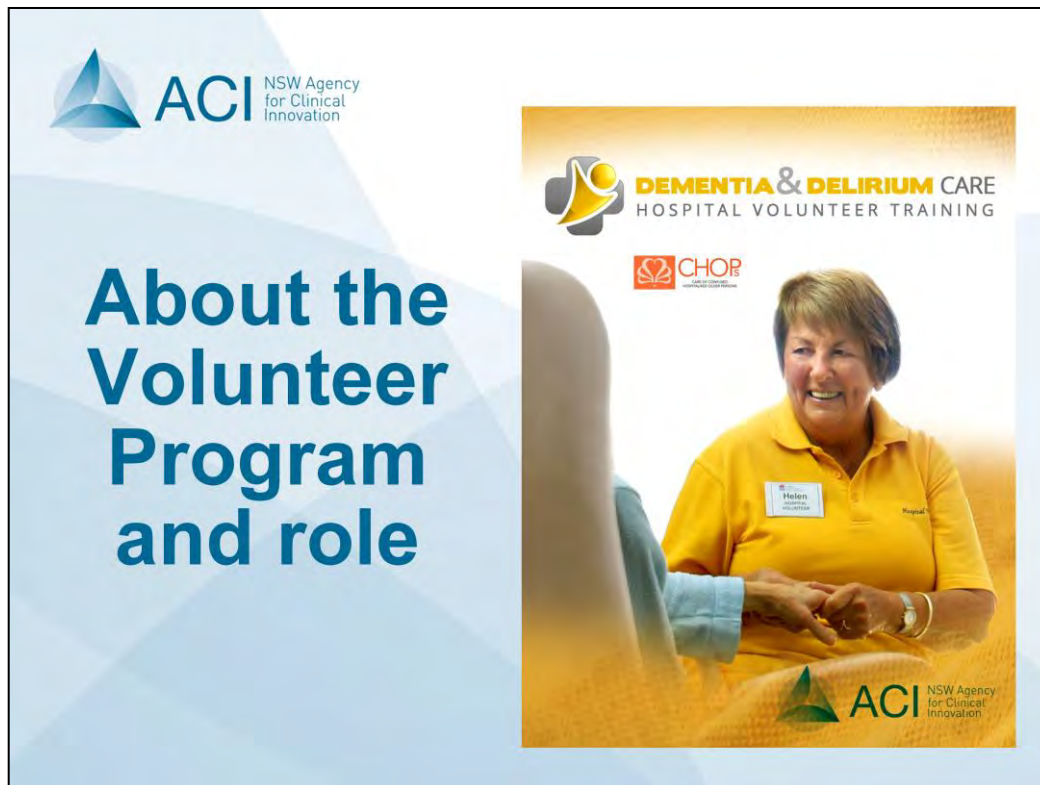
6. Sometimes, when a person with a delirium becomes stressed or anxious, they can become upset, angry or aggressive. How confident would you feel interacting with someone with dementia who demonstrated these behaviours?

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

SESSION 1: POWERPOINT SLIDES WITH NOTES



Introductions

- About us
- About you - Talk with the person next to you and ask:
 - What have you done in the past?
 - What prompted you to apply to join the program?
 - What do you enjoy doing the most?



Facilitator/s welcomes the group and provides self-introduction and their background and what drew them to the area of aged or dementia care.

Provide general house keeping

Participants

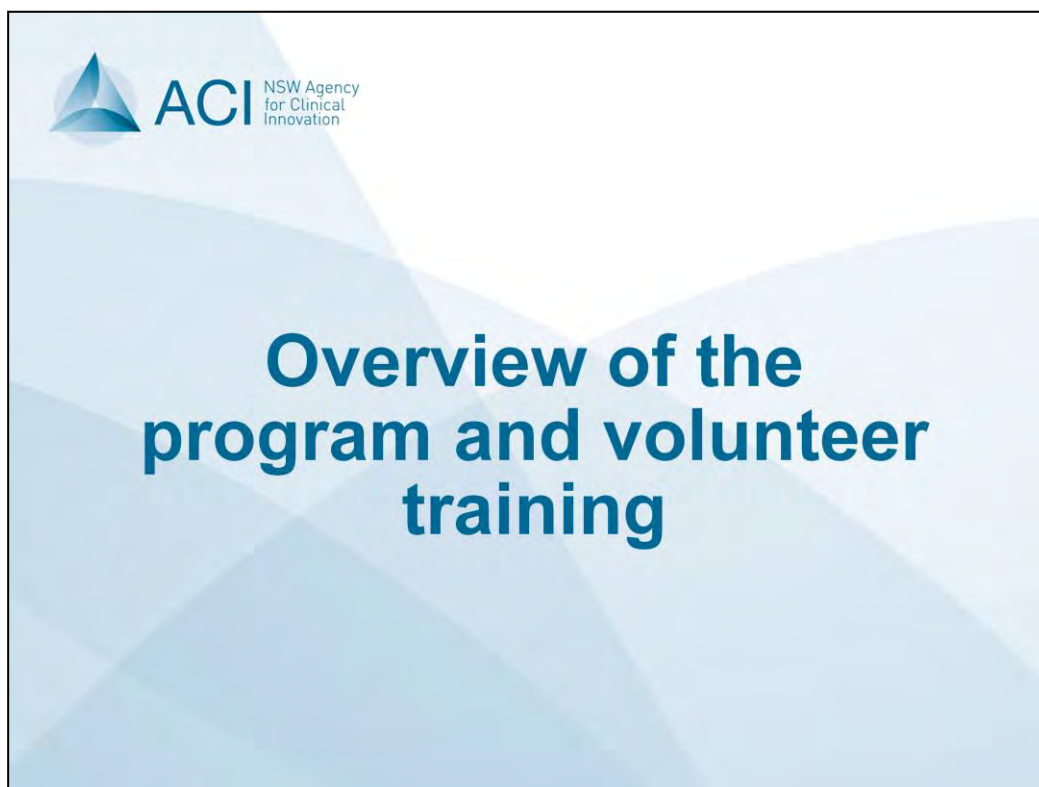
Ask participants to talk in pairs and get to know each other. Prompts:

What have you done in the past?

What prompted you to apply to join the program?

What do you enjoy doing the most?

Participants then take it in turns to introduce the person they have just interviewed.



Facility to add and discuss how they plan to structure the training program.
e.g

Time frame each day.

What sessions will be provided on what days.

When breaks will be

Who the other presenters will be

Encourage participants to ask questions and let you know if they are too hot
or too cold

Attendance sheet

Aim of the program

To support:

1. Emotional security and physical wellbeing of patients with dementia and delirium.
2. Patients who are at high risk of delirium by undertaking preventive activities with them



Talk to points

Why people with dementia and delirium?

- Hospital can be frightening for people who have memory and thinking problems
- A busy, noisy and unfamiliar environment
- Staff are busy and rushed
- Risk and safety issues
- The particular emotional and physical care needs of these patients
- Family carers not always available



Suggested notes:

Admission to the hospital environment can be quite frightening for anyone and potentially even more so for someone who is confused with memory and thinking problems. Not only are they unwell, they have also been removed from their familiar home and people and admitted to a busy noisy unfamiliar place. Imagine what that would be like, an unfamiliar environment and you can't make sense of it. You might be frightened too!

A person may be confused because they have dementia, a disease of the brain. An older person may also be confused because they are unwell. This confusion usually goes away as they get better. This is known as delirium. Information about dementia and delirium will be covered in the next chapter. The experience of delirium, in its own right, can also be a frightening for many people.

Because of their confusion, people with dementia and delirium can be quite fearful and vulnerable when in hospital and unable to express their needs. They are not thinking clearly and that places them at risk, eg getting out of bed to go to the toilet when they are too unsteady on their feet, therefore having a fall or not recognising food so they don't eat.

The volunteer program is designed to assist these patients by providing both emotional support and practical assistance and together these can help prevent delirium

Person Centred Care

- Puts the person and their individual needs and preferences at the centred of their care
- It recognises that people with memory and thinking problems still have emotions and feelings just as you or I would.
- Focuses on gaining an understanding of the person – their background and personal preferences
- Communication and interaction based on this understanding



Person centred care puts the person, their individual needs and preferences at the centre of their care. Although someone with memory and thinking problems might not be making sense, might not be able to tell us what the problem for them is, underneath all of this they have feelings that need to be recognised and acknowledged. In other words people with memory and thinking problems still have emotions and feelings and respond to the way they are treated or feel just as you or I would.

An essential part of the program and providing person centred care is gaining an understanding of the person, their background, personal preferences and activities or interests which provide them with enjoyment. This is done through the completion of a person profile with the patient and or their carer. Gaining this information can greatly assist the volunteer in their communication and interaction with patients and you will learn more about this in session 3

Types of patients you will be supporting

- Patients with memory and thinking problems
- Severely ill
- Dehydrated
- Have vision and/or hearing impairment
- Need help with eating and drinking
- Other older patients staff are concerned about who may be at risk.



You have heard the terms dementia and delirium. These cause memory and thinking problems. There are also people with memory and thinking problems who come into hospital who may not yet have a diagnosis of dementia.

Other patients you will be supporting are older people who are *at risk* of becoming confused.

This can be someone who is severely unwell. They may have just had surgery – particularly those who have had surgery after fracturing their hip, they may be dehydrated or have poor vision and/or hearing.

There are also older people in hospital who require assistance with eating and drinking OR who have special feeding requirements

Confused patients can also be at risk, especially of having a fall. Having that extra set of eyes to notice the patient reaching for an item beyond their arm's length, reassuring voice or simple company to walk up and down the corridor can be invaluable to the patient and the staff.



The volunteer role is similar to what a family carer would be doing if they were supporting the care of their loved one of family member when they are in hospital. In this way the volunteer program can be very supportive to carers as they can feel reassured knowing there is someone there to provide the extra care to their loved one when they are not able to be there.

The volunteers on the program have a specific duty statement. A copy of this is in your handbook. These duties include:

Gaining an understanding of the patient's background and family, their personal preferences and activities they enjoy from either the person or their family

Sitting and talking with patients on a one to one basis

Using appropriate touch or giving gentle hand and foot massage **CLICK**

Supporting the patient with activities they enjoy such as reading to them, playing cards etc. **CLICK**

The practical ways volunteers support patients are:

Setting up or assisting patients with eating and drinking and when needed regularly offering fluids to drink. Assisting patients with completion of their menus

Encouraging patients to walk when it is safe and walking with them when it is safe for a volunteer to do.

Making sure the patient is wearing their glasses and hearing aides and checking that these are clean and working properly

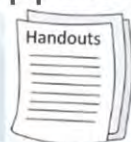
Supporting orientation by regularly reminding patients of where they are and what time it is **CLICK**.

This picture shows a volunteer interacting with a patient.

Volunteers as part of the care team



- Referral process
- Communication with staff
- Communication between volunteers
- Support for family carers



Referral and Eligibility Form



Volunteers in this program are seen as partners in care and a valued member of the care team. Nursing or allied health staff are responsible for identifying appropriate patients for volunteer care and referring these patients to the volunteer program. A referral form is completed by staff. The information on the referral form informs the volunteer of the particular support the patient needs as well as what is safe for the volunteer to do and not to do with the patient. The referral process ensures that the volunteer support is safe for both the patient and the volunteer.

Communication with staff about any changes or concerns you as a volunteer may have is very important. In particular, when assisting patients with eating and drinking, you will need to inform staff about how much the food and fluid the patient has had. This will be covered in more detail in session 6.

In addition to a referral process there is also a communication process between volunteers. This is where volunteers can document their interactions with patients and other information that will assist the next volunteer in their role.

Lastly as was discussed earlier, you have an important role in supporting family carers when they are not able to be with their loved one.

Provide or refer to Handout 1_Referral and Eligibility Form



**What do you believe are
important qualities for
volunteers to have?**



Ask participants “what they think are important qualities for a volunteer to have”. Write responses up on the board and discuss as relevant.

As they suggest things roughly group onto attitudes, knowledge, skills.

Definition of a volunteer

Formal volunteering is an activity which takes place through not for profit organisations or projects and is undertaken:

- to be of benefit to the community and the volunteer;
- of the volunteer's own free will and without coercion;
- for no financial payment; and in designated volunteer positions only

(Volunteering Australia, 2009)



Read out definition

And also:

NSW Health defines “staff” as

*“...any person working in a permanent, temporary, casual, termed appointment or honorary capacity within NSW Health. It includes **volunteers**, patient advocates, contractors, visiting practitioners, students, consultants and researchers performing work within NSW Health facilities.”*

- Volunteers are therefore required to adhere to relevant NSW Health policies and guidelines

NSW Health Code of Conduct [Policy, PD2005_626, page 8],



Read through the Ministry of Health definition of staff

So you can see that volunteers are one category of staff. Although we tend to think of 'paid staff' as staff, you can see there are various staff roles.

As for all staff you are required to comply with NSW Health policies and guidelines. For eg, Before starting as a health service volunteer you will have undergone a National Criminal Record check as part of your recruitment. As a health service volunteer you will be required to undergo additional mandatory education and receive necessary vaccinations. These are requirements for all NSW staff and volunteers.

NOTE: Different LHD's or services may have individualised Volunteer Rights and Responsibilities Forms. There also may be varying requirements as to whether these are to be signed by volunteers. This needs to be considered in relation to training. In addition the process may vary in relation to when volunteers sign the code of conduct. This may occur as part of training or with the volunteer coordinator outside the training program.

Important considerations

- Roles and responsibilities
- Code of Conduct
- Confidentiality
- Insurance
- Your support & looking after yourself
– Employee Assistance Program



Although volunteers are not covered by awards or workplace agreements, you do have both rights and responsibilities.

Provide of copy of **Handout 2 – Rights and Responsibilities** or refer to its location in the training handbook

Go through the rights and responsibilities.

Discuss if your service requires that volunteers are to sign a Rights and Responsibilities statement

The NSW Ministry of Health has a code of conduct which applies to all staff and volunteers. It is a requirement that the code of conduct is read and signed by volunteers. The standards in the code of conduct are:

- Promote a positive work environment
- Demonstrate honesty and integrity
- Act professionally and ethically
- Use official resources lawfully, efficiently and only as authorised
- Maintain the security of confidential and/or sensitive official information
- Maintain professional relationships with patients.

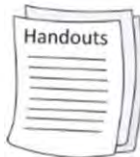
The code of conduct includes confidentiality. As you would understand confidentiality and privacy of patient personal information is a very important aspect of the volunteer role. The requirements of a volunteer related to privacy and confidentiality is no different to the requirement for staff. While serving as a health service volunteer you are responsible for maintaining the privacy and confidentiality of all personal information you are privy to. This can include, information involving patients, families, staff or the general health service business.

Discuss Volunteer injury cover and insurance by your service. Within MoH Volunteers are covered by Public Liability Insurance

Finally talk about how important it is for volunteers to seek support from the volunteer coordinator or other designated person to if they experience any problems or challenges in their role. As health care volunteers you have access to the Employee Assistance Program (EAP) should you require counselling support. Discuss the EAP and provide or refer to the brochure

Program and volunteer role

- Procedures – discussed in session 8
- Health service volunteer handbook
- Dos and Don'ts
- Shifts & Rosters
- Mandatory training & vaccination
- Buddying or initial volunteer support
- Reporting and Volunteer meetings
- Uniform



Dos and Don'ts



- Specific procedures for volunteers and staff have been written for the program and we will go through these in detail in the last session.
- If your service has one, refer to the health service volunteer handbook
- Provide and go through **Handout 3 Dos and Don'ts**. This summarises what the volunteer can and cannot do for both staff and volunteers. This is to ensure the both the safety of you in role and of the patients you will be supporting. As we go through the training different aspects of this will be emphasised.
- Discuss the intended volunteer shift structure at your facility and the date/week the volunteers will commence their shifts.
- Discuss the intended or organised rostering system for volunteers
- Discuss mandatory training arrangements and dates of training.
- Discuss volunteer vaccination
- If this is the first volunteer training program, discuss planned support arrangements for volunteers when they commence their shifts following training
- For subsequent volunteer training discuss buddy shift arrangements
- Discuss who volunteers report to and determine a date for the first volunteer network meeting following commencement of the volunteers
- Discuss how volunteer will be identified and supply of the uniform



Rewards of volunteering?



Now we have been through some of the more formal procedures of the program, what do you think may be some of the rewards of volunteering?

What do you anticipate you will get out of this experience?

Suggested prompts

Tell me more about that feeling of satisfaction?

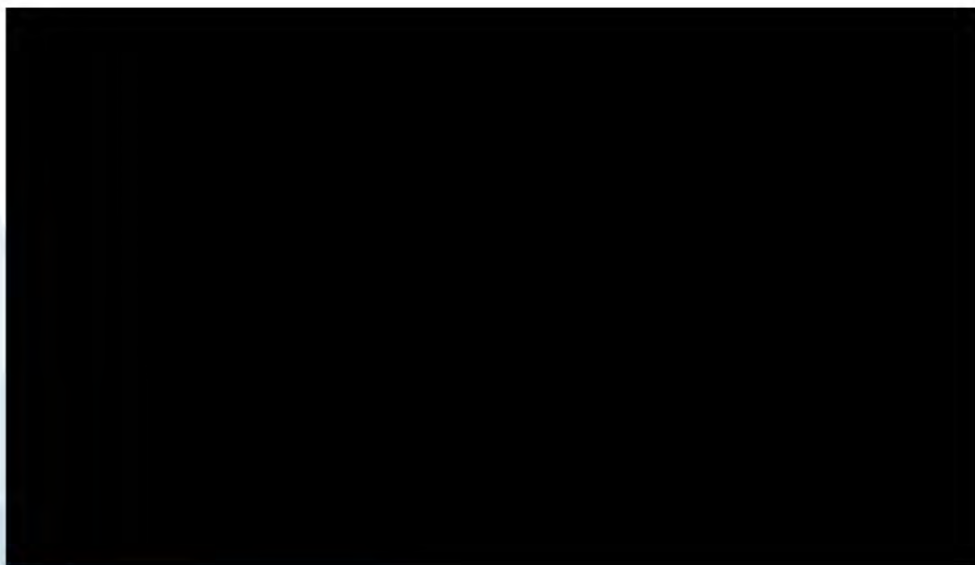
What is the satisfaction related to?

So you will learn new skills – what will that then make possible for you? And then, what will that make possible?

Do you think that this might change your thinking? About what?

You can see that you have many anticipated rewards in common, this is something we will be checking in with as the program develops. It's important to have an idea of what your expectations are because if expectations remain vague then it is sometimes more difficult for volunteers to be satisfied. And your satisfaction is important to us!

An overview of the volunteer role



The following short film summarises what this session has covered. It incorporates practical examples of the volunteer role and duties, the experiences of some existing volunteers and provides an example of the referral process. The referral process shows the nurse discussing a patient she is referring to the volunteer program.

The volunteer also talks with the nurse about the needs of existing patients who have already been referred to the program

Any Questions?



Again, thank you for choosing this program to volunteer with. We are excited about what you will each bring to the program, to help the patients, to give reassurance to the family members/ carers and also you support the staff.

Time for a break and stretch



SESSION 1: POWERPOINT HANDOUTS

Agency for Clinical Innovation



Introductions

- About us
- About you - Talk with the person next to you and ask:
 - What have you done in the past?
 - What prompted you to apply to join the program?
 - What do you enjoy doing the most?



Aim of the program

To support:

1. Emotional security and physical wellbeing of patients with dementia and delirium.
2. Patients who are at high risk of delirium by undertaking preventive activities with them



Why people with dementia and delirium?

- Hospital can be frightening for people who have memory and thinking problems
- A busy, noisy and unfamiliar environment
- Staff are busy and rushed
- Risk and safety issues
- The particular emotional and physical care needs of these patients
- Family carers not always available



Person Centred Care

- Puts the person and their individual needs and preferences at the centred of their care
- It recognises that people with memory and thinking problems still have emotions and feelings just as you or I would.
- Focuses on gaining an understanding of the person – their background and personal preferences
- Communication and interaction based on this understanding



Agency for Clinical Innovation

Types of patients you will be supporting

- Patients with memory and thinking problems
- Severely ill
- Dehydrated
- Have vision and/or hearing impairment
- Need help with eating and drinking
- Other older patients staff are concerned about who may be at risk.



Volunteers as part of the care team

- Referral process
- Communication with staff
- Communication between volunteers
- Support for family carers



Referral and Eligibility Form



What do you believe are important qualities for volunteers to have?



Definition of a volunteer

Formal volunteering is an activity which takes place through not for profit organisations or projects and is undertaken:

- to be of benefit to the community and the volunteer;
- of the volunteer's own free will and without coercion;
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(Volunteering Australia, 2009)



And also:

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Agency for Clinical Innovation

Important considerations

- Roles and responsibilities
- Code of Conduct
- Confidentiality
- Insurance
- Your support & looking after yourself
– Employee Assistance Program



Program and volunteer role

- Procedures – [discussed in session 8](#)
- Health service volunteer handbook
- Dos and Don'ts
- Shifts & Rosters
- Mandatory training & vaccination
- Buddying or initial volunteer support
- Reporting and Volunteer meetings
- Uniform



Dos and Don'ts



Rewards of volunteering?



Any Questions?



REFERRAL AND ELIGIBILITY FORM

Hospital Volunteer Program Referral and eligibility checklist 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) AND	YES	NO
Scored 24/30 or less on SMMSE or 7/10 or less on AMT	YES	NO
OR Patient has a diagnosis of dementia or obvious memory and /thinking problems	YES	NO
OR Is positive for suggested Delirium with Confusion Assessment Method	YES	NO
OR Patient is >65 (> 45 ATSI) AND 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 ()		
DELIRIUM ALERT has been placed in patients MR folder	YES	<input type="checkbox"/>
CONSENT is required before the allocation of a volunteer. Verbal patient or carer consent obtained 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.	YES	<input type="checkbox"/>
Additional information required from nursing staff to advise volunteers on patient requirements. Volunteers cannot accept patients without this information		
Specific suitability considerations; Does the patient have communication difficulties that would prevent them from talking to a volunteer (eg aphasia)	YES	NO
Does the patient require Personal Protective Equipment ?	YES	NO
Is the patient safe to be walked with a volunteer ?	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 thickened fluids ?	YES	NO
Does the patient need fluids encouraged ?	YES	NO
Is the patient on restricted fluids ?	YES	NO
Is the patient on a Fluid Balance Chart ?	YES	NO
Are there any special diet 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		

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.

DO'S AND DON'TS FOR 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.

SESSION 2: UNDERSTANDING DEMENTIA AND DELIRIUM

Key Messages

- 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.
- There is no cure for dementia.
- 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.

Resources

- Laptop and projector.
- Whiteboard.

Handouts

- PowerPoint handout.
- **Handout 1:** Alzheimer's Australia Helpsheet – What is Dementia?
- **Handout 2:** Brain and Behaviour fact sheet.
- **Handout 3:** Delirium Family Carer Brochure.
- **Handout 4:** Delirium Prevention Strategies.

Session overview

- Learning outcomes.
- What is Dementia?
- What is Delirium?
- The patient experience.
- The volunteer role in supporting patients.
- Reporting concerns or changes with a patient.
- The carer experience.

SESSION 2: PRESENTATION OUTLINE



Show **Session 2 PowerPoint**.

Slide 2: Provide overview of learning outcomes.

Slide 3: A lighter side to the reality of memory loss.

Slide 4: Dementia.

Slide 4: Ask participants what they think dementia is. Discuss feedback.

Slide 5: What is Dementia? Refer and talk to PowerPoint notes. Provide or refer to **Handout 1: Alzheimer's Australia Help Sheet: What is Dementia?**

Slide 6: Common causes of dementia. Refer and talk to PowerPoint notes.

Slide 7: Talk to title slide and refer to or provide **Handout 2: Alzheimer's UK Brain and Behaviour fact sheet.**

Slide 8: Refer and talk to PowerPoint notes and discuss different lobes of the brain and their function.

Slide 9: Refer and talk to PowerPoint notes.



Ask for participant feedback in identifying people who have had dementia. Prompts and answers are in the PowerPoint notes.

Slide 10: Refer and talk to PowerPoint notes.



Slide 11: Ask for participant feedback in identifying people who have had dementia. Prompts and answers are in the PowerPoint notes.

Slides 12-14: Refer and talk to PowerPoint notes.



Slide 15: Ask the participants: why they think a carer may feel this way? And why a person with dementia may feel this way? Write answers on the whiteboard and discuss. The purpose is to think about the impact on the person with dementia and their carer as well as to show that dementia is not something visible in a person.



Slide 16: **Brainstorm:** how the hospital environment could impact on a person with dementia and discuss as per PowerPoint notes.

Slide 17: Click on the link and show Alzheimer's Australia Web site and how to access help sheets.
<http://www.dementiadaily.org.au>

Slide 18: Short break and stretch. Encourage participants to stand up, have a stretch and get a drink if needed before the second part of the session on delirium.



Slide 19: Ask participants what they understand by the term delirium and discuss.

Slides 20-22: Refer and talk to PowerPoint notes.

Slide 23: Refer and talk to or provide **Handout 3: ACI Delirium information brochure.**

Slides 24-32: Refer and talk to PowerPoint notes.

Slide 33: Click on link and show video. The Patient Experience:

<http://www.europeandeliriumassociation.com/delirium-information/health-professionals/patient-experience-of-delirium-teaching-video>



Slide 34: Refer and talk to PowerPoint notes: Questions prompts and discussion post video.

Slide 35: Ways volunteers can support patients.



Refer and talk to PowerPoint notes. Explore with participants ways they think volunteers could support patients with delirium.

Slides 36-37: Refer and talk to notes.

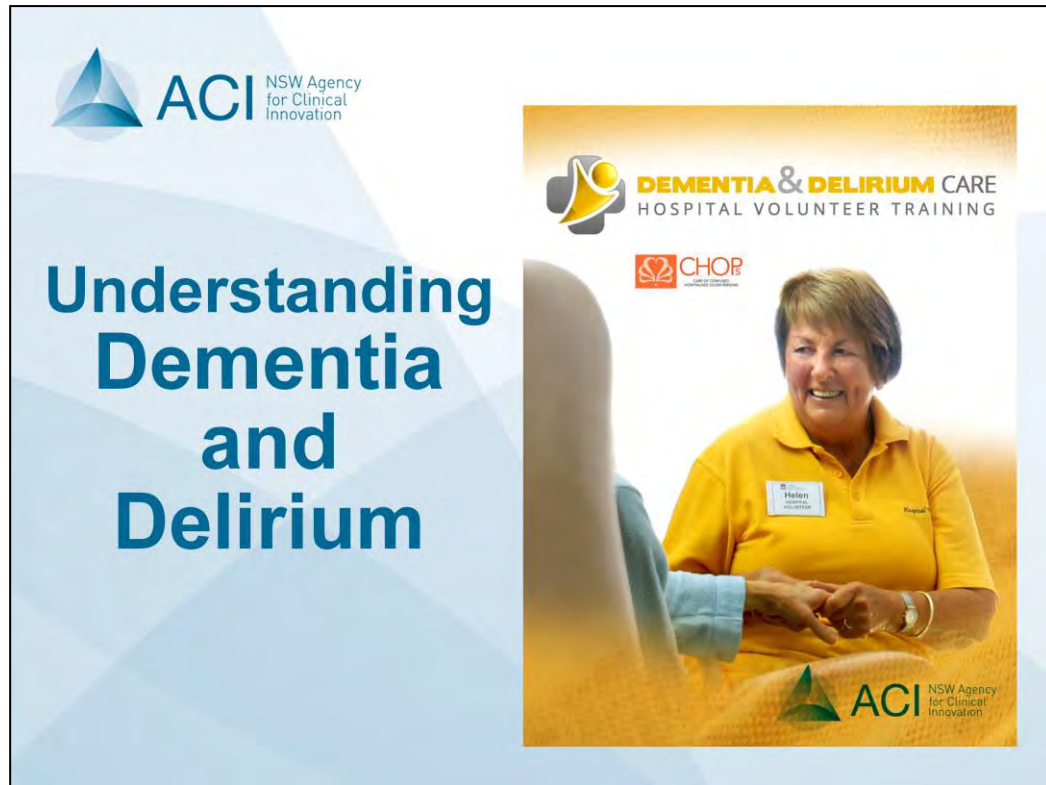
Slides 38-38: Refer and talk to PowerPoint notes. Discuss volunteer reporting if they notice a change or feel unsafe when they are with a patient.

Slide 39: [Volunteer support for family carers: Click and show video \(3.5 mins\)](#). Discuss what the group learnt after seeing the video.

Slide 40: Summary points.

Slide 41: Break and stretch - Include if there is to be further session.

SESSION 2: POWERPOINT SLIDES WITH NOTES



Learning Outcomes

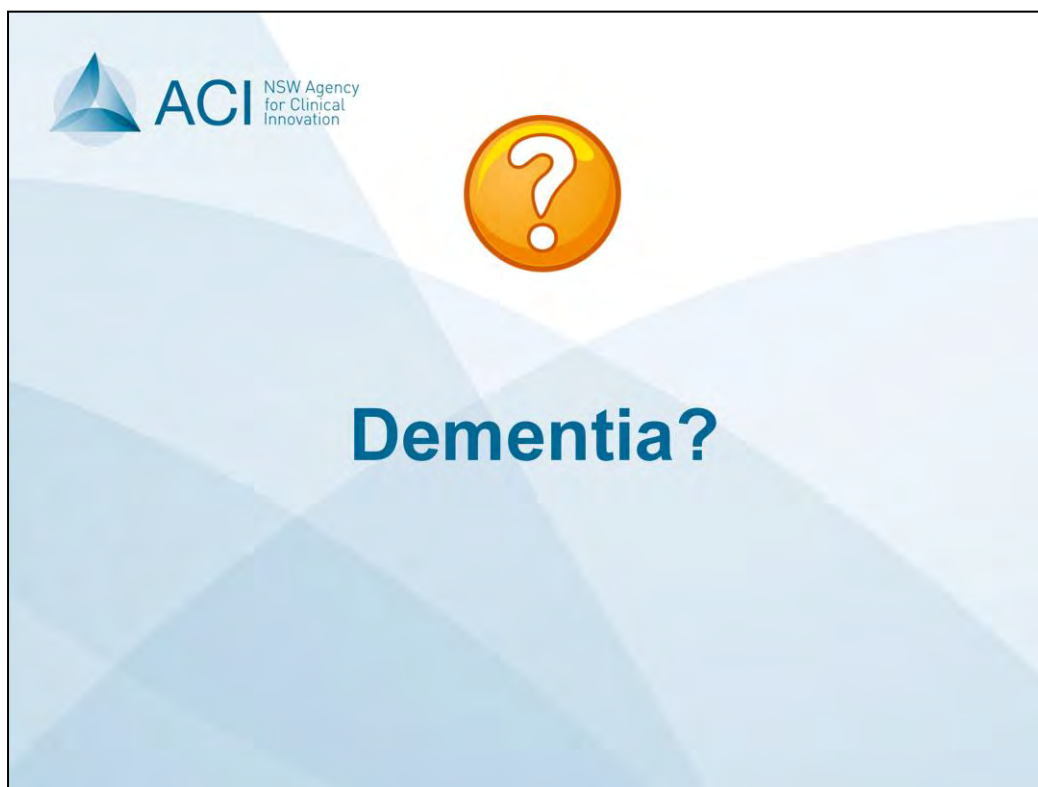
- Learn about dementia and how it affects people
- Learn about delirium – what it is and how it can affect a person
- Understand the difference between dementia and delirium
- Discuss the impact of the hospital environment
- Discover how volunteers can assist people with dementia and delirium



- In this session you will learn about dementia and how it affects people
- You will also learn about delirium, what it is and how it can affect a person and the difference between dementia and delirium
- You will gain an understanding of the impact of the hospital environment on the person with dementia and delirium and how important the volunteer role can be in assisting patients and their family carers



A light side to the reality of memory loss



Ask participants what they understand by the term Dementia?

What is dementia

- An umbrella term used to describe a set of symptoms which can affect a persons
 - Memory
 - Thinking
 - Judgement
 - Language
 - Communication
 - Emotions



Alzheimer's Australia
What is Dementia Help Sheet



- Dementia is what we call an umbrella term used to describe a collection of symptoms which can affect the working of the brain. This can result in changes in a persons thinking, personality, behaviour, judgement, language and communication.
- These changes are progressive and severe enough that they will impact on the person being able to carry out their normal daily tasks or functions.
- Dementia is not a normal part of ageing.
- It is caused by one or a combination of diseases that affect the working of the brain. The onset of dementia is usually slow with the symptoms gradually becoming worse over time
- There are over 70 different causes of dementia

Handout 1: What is Dementia help sheet provides you with additional information

About Dementia Help Sheet

The most common causes are:

1. **Alzheimer's Disease**
2. Vascular dementia
3. Mixed Alzheimer's and Vascular dementia
4. Dementia with Lewy bodies
5. Fronto temporal dementia



As we have said there are many different causes for dementia but the most common causes are:

Alzheimer's Disease – most of you would have heard of Hazel Hawk who had Alzheimer's Disease. This is the most common form of dementia. It is caused by plaques and tangles developing in the brain which progressively damage and destroy nerve cells in the brain.

Vascular Dementia. This is where there are problems with circulation in the brain. A common form of vascular dementia is where mini strokes occur in the brain.

Mixed Alzheimer's Disease and Vascular Dementia. Alzheimer's disease commonly co exists with other forms of dementia most commonly with vascular dementia.

Dementia with Lewy Bodies. This is caused by damage and then death to the nerve cells in the brain caused by abnormal spherical structures called Lewy bodies. The structures are named after a doctor who first wrote about them. Dementia with Lewy bodies can have similar symptoms to Alzheimer's disease and Parkinsons disease.

Fronto-Temporal dementia. In this type of dementia there can be damage to either or both the frontal lobe or the temporal lobe of the brain. This type of dementia can occur more commonly in younger people. Early symptoms often start with a change in the persons behaviour.

We will talk about the lobes of the brain in the next section.

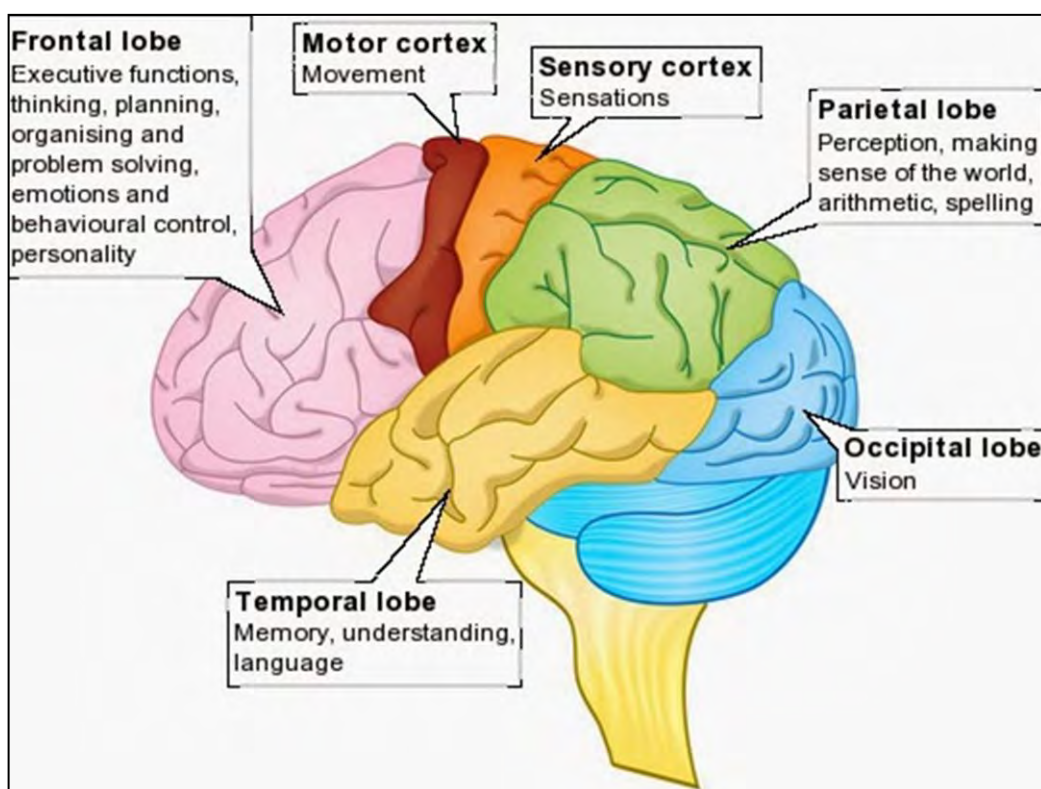


Changes to abilities and behaviour will depend on where damage has occurred in the brain



Brain and behaviour fact sheet

As we have mentioned dementia can affect different areas of the brain



This picture shows the main areas and functions of each side of the Brain. There are 4 main lobes on each side of the brain. In simple terms

- The **parietal lobes** on each side controls our sense of space
- The **frontal lobes** are at the front of our brains. These help to regulate our behaviour
- The **temporal lobes** are responsible for storing new information
- The **occipital lobes** makes sense of the things we see or visual information

The cause of the dementia will most often determine which area or areas of the brain are most affected. For example in Alzheimer's disease, the temporal lobe is commonly the first area affected, so changes are noted most in the persons short term memory. In frontal dementia the frontal lobe of the brain is affected and so changes in the persons personality or behaviour may be the first signs that occur. The area of the brain affected will be dependant of the cause of dementia. In vascular dementia, the area of the brain affected will depend on where the mini strokes have occurred in the brain.

Refer to or handout 2 The Brain and Behaviour fact sheet

Your brain and behaviour fact sheet provides you with additional information on how the brain affects behaviour.

Does anyone have any questions or comments

Dementia



- The biggest predictor of prevalence and incidence rates for dementia is increasing age
- Since the number of people living into their old age in Australia is rising the prevalence of dementia in Australia will rise significantly in the future (WHO 2006)



- The greatest risk factor for having dementia is getting older. So as people are living longer dementia is becoming more common. Since the number of people living into their old age in Australia is rising the prevalence of dementia in Australia is predicted to rise significantly in the future.
- Dementia is the leading cause of disability in people 65 years and older and one of the most common causes of death in Australia (Access economics, 2009)

Ask the group how many of them know or have known someone with dementia? Discuss responses

Dementia in Australia

- 2013: 300,000 people with dementia
- 2050: 900,000 people with dementia
- 1700 new cases per week diagnosed in Australia
- 25,000 people in Australia with dementia are less than 65 years of age
- At age 65: 1 in 12 people have dementia
- At age 80: 1 in 4 people have dementia

AIHW: 2012; Alzheimer's Australia 2013:



These are some of the more recent statistics

- In 2013: There were 300,000 people with dementia
- By 2050: It is predicted 900,000 people will have dementia
- There are 1700 new cases of dementia per week diagnosed in Australia
- 25,000 people in Australia with dementia are less than 65 years of age
- At age 65: 1 in 12 people have dementia
- At age 80: 1 in 4 people have dementia

The greatest risk factor for having dementia is getting older. So as people are living longer dementia is becoming more common. Since the number of people living into their old age in Australia is rising the prevalence of dementia in Australia is predicted to rise significantly in the future.

Ask the group how many of them know or have known someone with dementia? Discuss responses

People who have had dementia?



Dementia does not discriminate. These are just a number of well known people who have been known to have dementia

Ask the group to name people they may know in this slide who have had dementia?

Answers clockwise from top right:

- Iris Murdoch
- Perry Como
- Charles Bronson
- Hazel Hawke

2nd row

- Charlten Heston and Ronald Reagan
- Maggie Thatcher
- Glenn Campbell
- Rita Hayworth

Ask the group do they know of any other famous people who have or have had dementia?

How are people affected?

- Everyone is different. Common symptoms may include:
 - loss of memory
 - problems with thinking and judgement
 - difficulties with tasks of everyday living
 - mood or personality changes



- Each person with dementia will be affected in different ways depending on their individual traits and what area of the brain is affected.
- As mentioned earlier, common symptoms might be
- Loss of memory- there is a saying 'last in, first out' – so initially short term memory is affected but as the disease progresses long term memory is also affected
- Thinking and judgement, so the ability to plan, reason, organise things which is why they have difficulties with tasks of everyday living.
- **Ask group– what do you think 'tasks of everyday living' means?**
Buying, preparing food, eating showering, dressing, toileting, paying bills etc
- As for mood and personality changes – at first the person usually has an idea that they aren't thinking as they would like. The natural response is to become protective of ourselves. Even here, amongst strangers we are a little cautious about what we say. Imagine not wanting to slip up and be found to slip up. Naturally you wouldn't say as much – so people may start to withdraw socially. Or they may become very defensive, so accuse people of stealing their things. Worrying changes your mood. As the disease progresses the person becomes less able to interact and eventually is bedridden, uncomprehending and needing total care.

How is dementia diagnosed?

- History from family
- Memory tests
- Investigations to exclude other causes



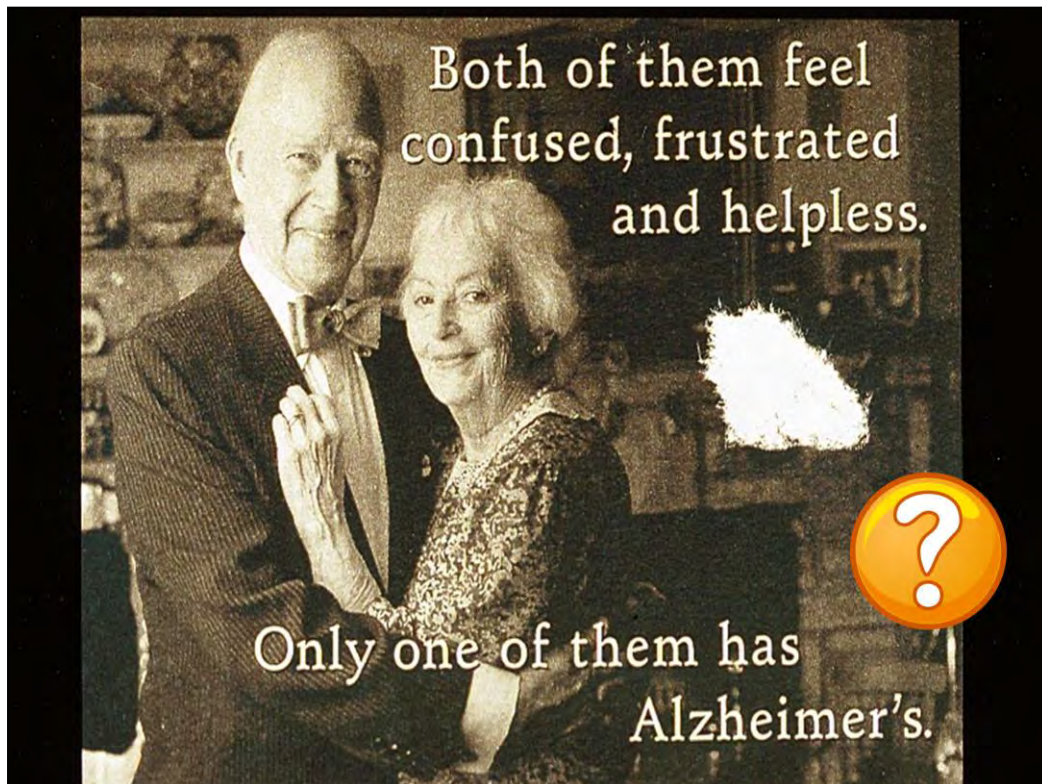
- Dementia is diagnosed through the combination of gaining a history from the family, memory and thinking tests, medical assessment and investigations.
- There are other causes for problems with a person's memory and thinking. These can include treatable causes such as delirium or depression, so it is important that proper assessment occurs so that any treatable causes can be addressed.
- There are people living with dementia who have not yet been diagnosed. These patients can sometimes be admitted to hospital for other reasons and this is where their dementia may be first identified.

How is dementia treated?

- No cure
- Some medication can slow progress
- Information and support for the person with dementia and their family.
- Carer support



- There is currently no cure for dementia. Available medications can reduce symptoms and improve the quality of life in some people, but they do not stop the progress of the disease.
- The important considerations are the quality of life for the person with dementia and the support for their family or carer



Both carer and the person with dementia can feel helpless, frustrated and confused

Ask the participants:

1. why they think a carer may feel this way?
2. Why a person with dementia may feel this way?

Write answers on the whiteboard and discuss

The purpose is to think about the impact on the person with dementia and their carer as well as to show that you cannot tell that a person has dementia by looking at them.

The impact of the hospital environment



Ask the group how they think the hospital environment may impact on the person with dementia and write answers on white board.

Some prompts are:

- Unfamiliar
- Noise
- Rushed staff
- Their illness or surgery
- Their eating and drinking
- Remembering instructions or recognising things for what they are. Eg a cup

Familiarity and routine are important for people with dementia. It can be quite stressful and frightening for the person with dementia when they are removed from the familiar home environment and people they know and admitted to the strange noisy and rushed hospital environment. On top of that they are unwell and may have people caring for them who do not understand that they cannot remember things or communicate properly. All these things can result in the person becoming more confused, disorientated and distressed when they go into hospital. Having their carer or someone who understands their needs and can spend time with them is very important in their care.

Ask have any of the participants ever been in hospital? If yes discuss their experience

Alzheimer's Australia information and resources

<http://www.dementiadaily.org.au/>



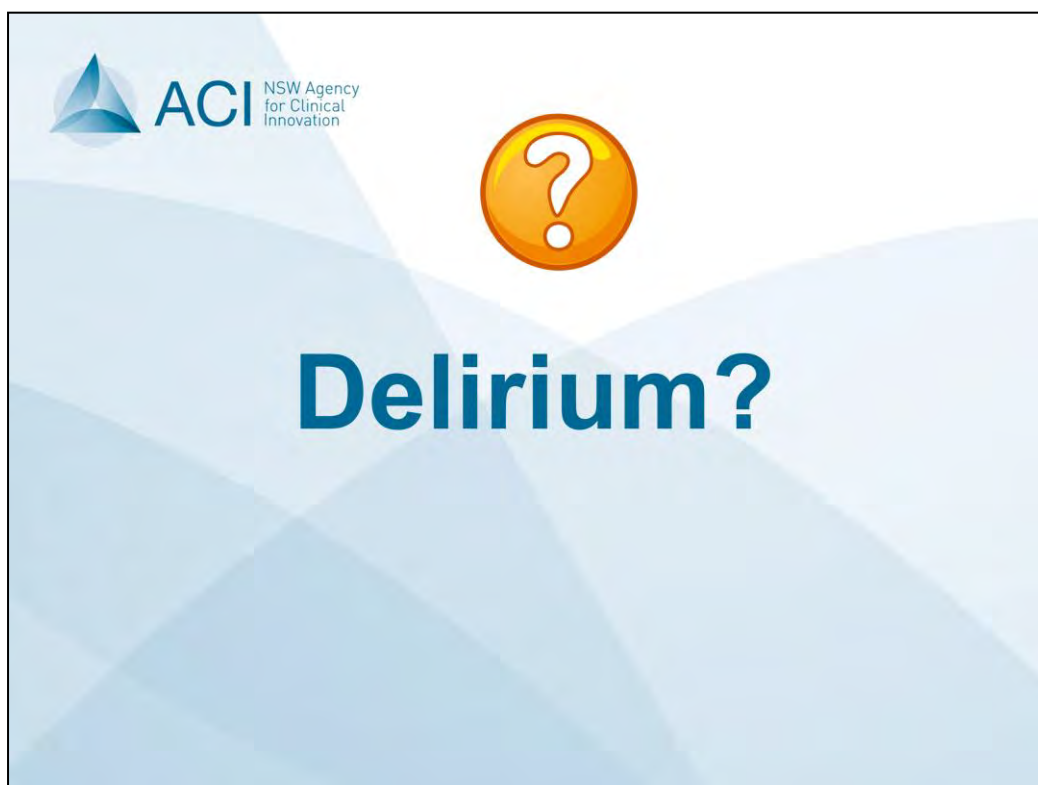
The Alzheimer's Australia web site has a number of helpful resources including a range of information help sheets about the different types of dementia, care considerations and supports available

Click on the web link to show participants how to access the site and help sheets

Time for a break or stretch



Encourage participants to stand up, have a stretch and get a drink if needed before the second part of the session on Delirium.



Ask participants what they understand by the term delirium?

Discuss responses

What is Delirium?

- Delirium is a serious medical condition characterised by **sudden** changes in:
 - Memory and orientation
 - Thinking
 - Behaviour
 - Ability to do things
- A common condition in hospitals
- It is more common older people and is much more common in dementia



- Delirium is a common medical problem that is characterised by sudden changes in a person's mental and physical function or behaviour. This is different to dementia where the onset is gradual with the dementia becoming progressively worse over time.
- The onset of delirium is always sudden and usually usually over hours or days. It will often only last for a few days but can often persist for longer periods particularly if the person has dementia as well.
- Families will notice that the person has not been their normal self.
- The changes often fluctuate in that the person may be better early in the day and then becomes more confused as the day goes on or they may become more sleepy.
- When a person presents to hospital with confusion, it can sometimes be mistakenly assumed that they have dementia.
- Delirium can occur at any age where there is serious illness but it occurs more often amongst older people. It is also much more common in people who have a diagnosed or undiagnosed dementia. This is because their brain is already compromised from the dementing illness and does not have the reserve to cope with the effects of illness and other causes for delirium.
- Delirium is a serious condition in older people and is common in hospitals.

Symptoms of delirium

- Appear confused and forgetful
- Be unable to pay attention or concentrate
- Be either very agitated or quiet and withdrawn or sleepy
- Be unsure of the time of day or where they are
- Be different from their usual selves



Talk through slide and allow time to read through themselves.

In summary, a person with delirium will be different from their usual selves

Symptoms of delirium cont:

- Have changes to their sleeping
- Feel fearful, upset, irritable angry or sad.
- See or things that are not there but seem very real to them called Hallucinations
- Believe that something is occurring that is not – called delusions



ACI Delirium patient and family carer information brochure



People commonly have changes to their sleeping habits such as staying awake at night and being drowsy during the day.

They may experience things that are not there but seem very real to them called Hallucinations. Usually visual, sometimes auditory. Can be very distressing to the patients, some even know that what they are seeing/ hearing is not real – that is also upsetting..

Delusions – are fixed and firm ideas not based in reality. Eg, The patient might think that the medications the nurses are giving them are given with the intention to poison them. We will discuss this a bit more later.

refer to Handout 3 ACI Delirium information brochure

Who is susceptible to developing delirium?

People who:

- Have dementia
- Are very sick
- Are aged 70 or greater
- Have poor eyesight or hearing
- Suffer from depression
- Are taking multiple medications
- Are having a surgical procedure in particular heart or hip surgery



- People who are 70 years of age or greater, if you have been into a main hospital medical ward recently you would have seen that the majority of patients in hospital would have been older than 65.
- As we have discussed people who already have dementia are at greater risk for developing delirium. In addition people who are very sick, have poor eyesight or hearing, suffer from depression, are taking multiple medications or are having a surgical procedure in particular heart or hip surgery are also at greater risk for developing delirium.
- In summary, you can see why so many of the older people admitted to hospital experience delirium. Not all will, but they are certainly at a very high risk. Your actions as volunteers not only help reduce the risk, you can provide reassurance by your calm quiet presence as well as helping with practical things like eating, hearing aids etc.

How does delirium differ from dementia?

- Delirium occurs suddenly
- Dementia typically has a slow progressive onset
- People with dementia or who already have memory and thinking problems are much more susceptible to developing delirium.



- Delirium differs from Dementia in that it comes on suddenly, over hours to days
- As we have covered, dementia does not occur suddenly, it usually has a slow progressive onset, more like over a number of months and family make comments like, 'yeah Mum is getting forgetful and she repeats herself a bit now'. Sometimes it is only when you draw their attention to things like repetitive conversations that the family become aware of the changes.
- However delirium commonly occurs in people who already have dementia or existing memory and thinking problems. When this occurs delirium is sometimes harder to detect. People who know the person will be the first to notice the change from their normal self or the sudden onset of new or changed behaviours or other changes such as the person becoming sleepy, lethargic and confused.

Types of delirium

There are three different types of delirium

1. Hyperactive
2. Hypoactive
3. Mixed hyperactive and hypoactive



There are three different types of Delirium

- The first one is called Hyperactive delirium. This is where the person is agitated and unsettled most of the time. They may be continually pulling at things or trying to get out of bed or become combative. For example: patients with hyperactive delirium may see frightening things (hallucinations) or falsely believe that staff are out to hurt them called Delusions. Because of this they can be very fearful and anxious and may try to resist care or escape. If the person feels threatened by what they are seeing or believing they may constantly be on guard or become aggressive because they think others are going to hurt them. In this type of delirium, the person often poses a risk to themselves or sometime others.
- The second type of delirium is called hypoactive delirium. This is where the person is drowsy, lethargic or sleepy most of the time. It is this type of patient who is more at risk of becoming more unwell because they sit quietly in the bed or chair and forget to eat or drink. This is a common type of delirium that can often be missed.
- The third type is mixed hyperactive and hypoactive where the person fluctuated between the two types of delirium.

How common is delirium?

- Approx 20% of older people admitted to hospital
- Very common in palliative care, intensive care
- More than 50% people from Nursing Homes



- About one fifth of older people admitted to hospital will experience delirium at some stage of their care but this can vary depending on risk factors.
- It is very common in palliative care and intensive care.
- Over half of patients admitted to hospital from nursing homes, because so many HN residents have dementia and as we have said, having dementia puts you at higher risk of delirium

What causes delirium?

Common causes of delirium include:

- ▲ Severe illness
- ▲ Infection
- ▲ Constipation
- ▲ Severe pain
- ▲ Medications
- ▲ Dehydration/malnutrition
- ▲ Withdrawal from alcohol or medication, particularly sleeping pills



There are many different causes for delirium. More often there is a combination of causes. Some of the most common causes are:

- Severe illness
- Infections – most common ones are bladder, chest, wounds eg leg ulcers
- Constipation
- Pain
- Medications – many of the necessary medication that older people take may cause confusion. When you add together a number of these there is a multiplier effect and therefore the risk of delirium increases substantially
- Dehydration and malnutrition
- Withdrawal from alcohol or medication – particularly sleeping pills

How long does delirium last?

- This depends on the cause or causes
- If the cause can be found and treated, the delirium will resolve in hours or days
- When this is not the case, delirium can sometimes last for weeks or months



- If the cause can be easily identified and treated the delirium will usually only last for a few days but sometimes it will continue for weeks or even months.
- In this circumstance the person is in hospital longer and more vulnerable to developing serious complications such as falls, pressure sores or even death.

Treatment for delirium

- Finding and treating the cause or causes
- Allaying the persons fear and anxiety
- Ensuring they are eating and drinking
- Making sure they get enough sleep
- Wearing their glasses or hearing aids



- Treatment for delirium usually consists of finding and treating the underlying medical causes of the condition and reducing the risk of complications. This involves staff conducting a thorough assessment and investigations. In some situations it can be difficult to find or treat the cause.
- In all situations, many things can be done to support the person with delirium and assist in allaying their fear and anxiety. This is where volunteers are really important. In particular to ensure the person is wearing their glasses and hearing aids and encouraging and supporting their eating and drinking.

What the people who have experienced delirium say

- Fear, anxiety or terror – often related to hallucinations
- Feeling threatened
- Hopelessness, loneliness and depression
- Not being heard or understood
- Not being able to tell night from day
- Dreamlike state



- As we have discussed, some patients with delirium may see frightening things (hallucinations) or falsely believe that staff are out to hurt them which is called a Delusion. Because of this they can be very fearful and anxious and may try to resist care or escape. If the person feels threatened by what they are seeing or believing they may constantly be on guard or become aggressive because they feel threatened and think others are going to hurt them.
- On the other hand some patients have said they feel like they are in a dreamlike state and can be drowsy and lethargic. It is this type of patient who is more at risk of becoming more unwell because they sit quietly in the bed or chair and forget to move around or eat or drink.
- While volunteers will not be assigned patients who are aggressive, many patients will be fearful and this is where volunteer support can be very reassuring.

What patients found helpful

- Familiar people
- Reassurance that they were safe
- Calmness
- Information about what was happening and why



- In some circumstances, patients can remember their experience after the delirium has resolved and this can be very upsetting for them if they have seen or experienced frightening things. Interviews with patients who can remember their delirium experience after their delirium has identified a number of things that they found calming and helpful during their delirium.

These included:

Having familiar people around

Reassurance that they were safe

Calmness and

Information on what is happening to them and why

So in this way, volunteers and carers can play a valuable role in providing that reassurance, familiarity and calmness that can assist in reducing the fear and anxiety that these patients can experience.

The delirium experience

<http://www.europeandeliriumassociation.com/delirium-information/health-professionals/patient-experience-of-delirium-teaching-video/>



This short video clip shows an interview with a person who has recalled his experienced a delirium and how it affected him.



Do you know anyone who has experienced a delirium?



After showing the video, ask the group what the video clip showed them about the experience of delirium for the man?

How do you think he felt?

What did it say about what was helpful for him?

Ask the group if they know anyone who has experienced a delirium and discuss any responses.



**What are some ways a
volunteer could support a
patient with delirium?**



Having heard about delirium and seen the video, and some of the problems people may face, what do you think that you could do to help them?

Prompts:

If they are frightened, how can you approach them? What tone of voice, body language

If they are confused about where they are, what can you tell them?

Discuss

What the volunteer can do

- Tell the person your name and who you are. Wear you ID badge
- **Be calm** & speak slowly in a clear voice.
- Remind the person of where they are, what day and time it is
- Encourage and assist with eating and drinking
- If the person wears glasses or hearing aids, check they are clean and working and help them put them on



Following the discussion, go through the key ways volunteers can support patients with delirium.

- Tell the person who you are and why you are there. Ensure you are wearing your ID badge. Sometimes it can be helpful to show the person your name on the ID badge as you are explaining who you are. For example. Hello Mrs Smith. My name is Helen and I am a volunteer here to help you with your breakfast.
- Reassure the person that you are there to support them and Speak in a calm clear voice.
- Remind them of where they are. You may need to do this repeatedly.
- Encourage and assist the person with eating and drinking
- Visual or hearing impairment can make their confusion worse. If the person wears glasses or hearing aids, check they are clean and working and help them put them on

What the volunteer can do cont:

- Use available personal belongings
- Gain information from the family carer and or refer to their person profile information.
- Provide reassurance
- Try distraction
- Walk with them, if safe to do so



- Family may have brought in personal things like photos, blankets. Use these to talk to the patient about and people things that are well loved and familiar
- Talk to the family and complete the personal profile to find out information about their background and personal preferences. We will cover this in detail in the next session
- If there are no personal belongings, ask or suggest the family bring in any photos' or personal belongings which may help remind the person of home or things they are familiar with. If the person has a pet, a photo of their pet can assist with communication and talking about this can help allay their anxiety.
- If the person is agitated, try to be reassuring, distraction activities can sometimes assist. We will cover this more in session 4.
- If the person wants to walk or wander. Walk with them. If you are worried about safety or hazards, let the staff know

Compare what points were similar to the what the group fed back in the previous slide 34.

Inform staff if:

- You feel unsafe or do not feel confident remaining with the patient
- If you notice any changes in the person or if the persons behaviour changes while you are with them or over time



ACI Delirium Brochure
for carers



- In any circumstance if you feel unsafe or not confident in supporting the patient who may be agitated – remain calm, leave the room and let staff know.
- As a volunteer you may notice a change in the patients behaviour either over the course of the day or since your last shift. If you notice any changes, such as the person being more sleepy than usual or more confused than they have been, always inform staff.
- If the person has a diagnosis of delirium and the family carers are anxious or concerned. Provide them with a Delirium information brochure and encourage them to talk about their concerns with staff. You can also inform staff that the family are worried, so that staff can talk with them.

What to do if you feel unsafe

- Stay calm
- Leave the room
- Report to staff
- Do not return to the patient until cleared by staff



As we have covered, Volunteers will not be assigned patients who have been assessed by staff as aggressive and a risk to themselves or others.

However if there is any circumstance where you as a volunteer does not feel safe or confident in supporting the care of a patient with dementia or delirium, the most important thing to remember is to

- Stay calm
- Leave the room and report it to staff.
- In this circumstance it would be important not to approach the person again unless cleared by staff

We will talk more about this in session 5

Volunteer support for family carers



As we have discussed volunteers can greatly assist and support concerned family carers in providing the additional support to patients with dementia and delirium when the family are not able to be there.

This short film clip shows an interview with a family carer who's mother had dementia and experienced a delirium while in hospital. In the interview the carer conveys how helpful the volunteer support was for her mother and the family.

In summary: we have covered

- What dementia is and some of the common causes
- The impact of the hospital environment on patients with dementia
- What delirium is, the causes and treatments
- The difference between dementia and delirium
- What the person with delirium may experience
- How volunteers can greatly assist patients and family carers



Talk to the points on screen

Ask if there are any questions

Time for a break and stretch

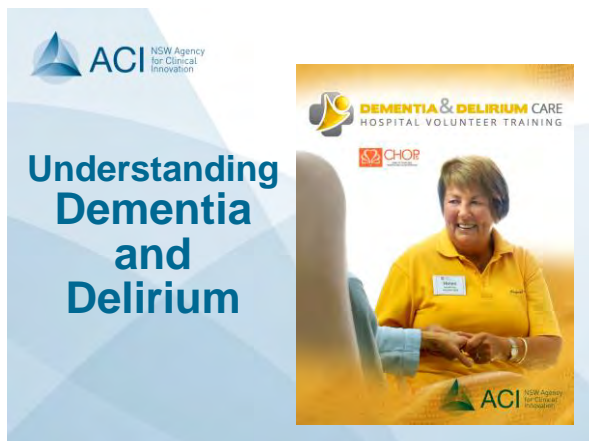


Include if there is to be a follow on session

Encourage participants to stand up, have a stretch and get a drink if needed before the next session

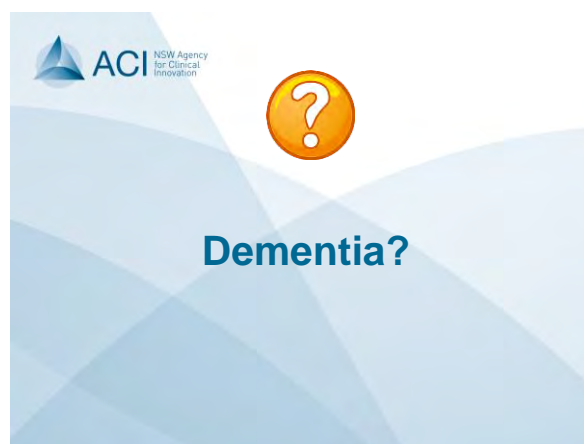
SESSION 2: POWERPOINT SLIDE HANDOUTS

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Learning Outcomes

- Learn about dementia and how it affects people
- Learn about delirium – what it is and how it can affect a person
- Understand the difference between dementia and delirium
- Discuss the impact of the hospital environment
- Discover how volunteers can assist people with dementia and delirium



What is dementia

- An umbrella term used to describe a set of symptoms which can affect a persons
 - Memory
 - Thinking
 - Judgement
 - Language
 - Communication
 - Emotions



Alzheimer's Australia
What is Dementia Help Sheet





The most common causes are:

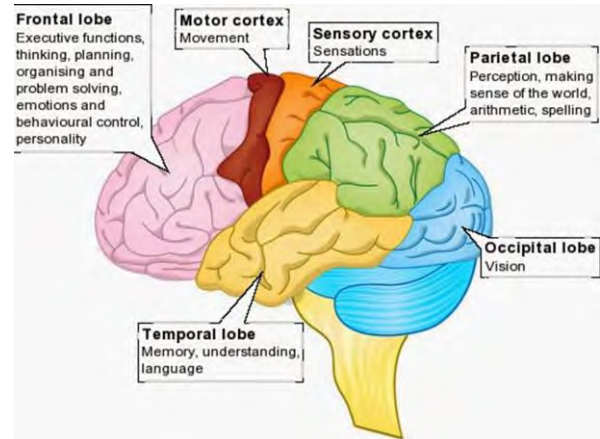
1. Alzheimer's Disease
2. Vascular dementia
3. Mixed Alzheimer's and Vascular dementia
4. Dementia with Lewy bodies
5. Fronto temporal dementia



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 **Changes to abilities and behaviour will depend on where damage has occurred in the brain**

 Brain and behaviour fact sheet



Dementia



- The biggest predictor of prevalence and incidence rates for dementia is increasing age
- Since the number of people living into their old age in Australia is rising the prevalence of dementia in Australia will rise significantly in the future (WHO 2006)



Dementia in Australia

- 2013: 300,000 people with dementia
- 2050: 900,000 people with dementia
- 1700 new cases per week diagnosed in Australia
- 25,000 people in Australia with dementia are less than 65 years of age
- At age 65: 1 in 12 people have dementia
- At age 80: 1 in 4 people have dementia

AIHW: 2012; Alzheimer's Australia 2013:



People who have had dementia?



How are people affected?

- Everyone is different. Common symptoms may include:
 - loss of memory
 - problems with thinking and judgement
 - difficulties with tasks of everyday living
 - mood or personality changes



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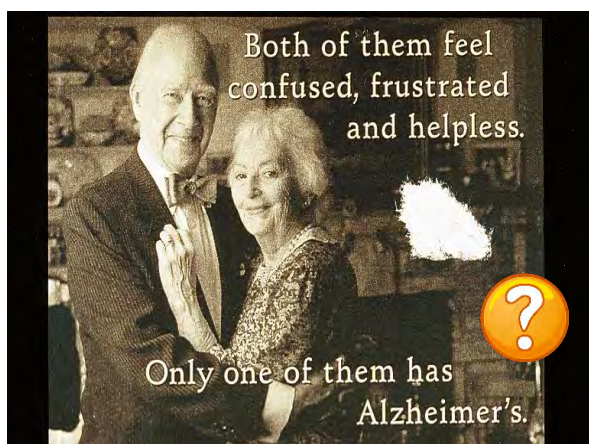
How is dementia diagnosed?

- History from family
- Memory tests
- Investigations to exclude other causes

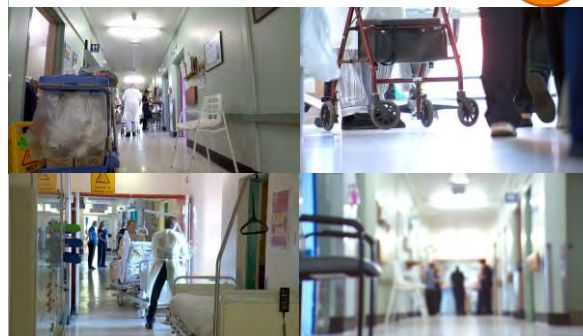


How is dementia treated?

- No cure
- Some medication can slow progress
- Information and support for the person with dementia and their family.
- Carer support



The impact of the hospital environment ?



Alzheimer's Australia information and resources

<http://www.dementiadaily.org.au/>



Time for a break or stretch



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What is Delirium?

- Delirium is a serious medical condition characterised by **sudden** changes in:
 - Memory and orientation
 - Thinking
 - Behaviour
 - Ability to do things
- A common condition in hospitals
- It is more common older people and is much more common in dementia



Symptoms of delirium

- Appear confused and forgetful
- Be unable to pay attention or concentrate
- Be either very agitated or quiet and withdrawn or sleepy
- Be unsure of the time of day or where they are
- Be different from their usual selves



Symptoms of delirium cont:

- Have changes to their sleeping
- Feel fearful, upset, irritable angry or sad.
- See or things that are not there but seem very real to them called Hallucinations
- Believe that something is occurring that is not – called delusions



ACI Delirium patient and family carer information brochure



Who is susceptible to developing delirium?

People who:

- Have dementia
- Are very sick
- Are aged 70 or greater
- Have poor eyesight or hearing
- Suffer from depression
- Are taking multiple medications
- Are having a surgical procedure in particular heart or hip surgery



How does delirium differ from dementia?

- Delirium occurs suddenly
- Dementia typically has a slow progressive onset
- People with dementia or who already have memory and thinking problems are much more susceptible to developing delirium.



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Types of delirium

There are three different types of delirium

1. Hyperactive
2. Hypoactive
3. Mixed hyperactive and hypoactive



How common is delirium?

- Approx 20% of older people admitted to hospital
- Very common in palliative care, intensive care
- More than 50% people from Nursing Homes



What causes delirium?

Common causes of delirium include:

- ▲ Severe illness
- ▲ Infection
- ▲ Constipation
- ▲ Severe pain
- ▲ Medications
- ▲ Dehydration/malnutrition
- ▲ Withdrawal from alcohol or medication, particularly sleeping pills



How long does delirium last?

- This depends on the cause or causes
- If the cause can be found and treated, the delirium will resolve in hours or days
- When this is not the case, delirium can sometimes last for weeks or months



Treatment for delirium

- Finding and treating the cause or causes
- Allaying the persons fear and anxiety
- Ensuring they are eating and drinking
- Making sure they get enough sleep
- Wearing their glasses or hearing aids



What the people who have experienced delirium say

- Fear, anxiety or terror – often related to hallucinations
- Feeling threatened
- Hopelessness, loneliness and depression
- Not being heard or understood
- Not being able to tell night from day
- Dreamlike state



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What patients found helpful

- Familiar people
- Reassurance that they were safe
- Calmness
- Information about what was happening and why



The delirium experience

<http://www.europeandeliriumassociation.com/delirium-information/health-professionals/patient-experience-of-delirium-teaching-video/>



Do you know anyone who has experienced a delirium?



What are some ways a volunteer could support a patient with delirium?



What the volunteer can do

- Tell the person your name and who you are. Wear your ID badge
- **Be calm** & speak slowly in a clear voice.
- Remind the person of where they are, what day and time it is
- Encourage and assist with eating and drinking
- If the person wears glasses or hearing aids, check they are clean and working and help them put them on



What the volunteer can do cont:

- Use available personal belongings
- Gain information from the family carer and or refer to their person profile information.
- Provide reassurance
- Try distraction
- Walk with them, if safe to do so



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Inform staff if:

- You feel unsafe or do not feel confident remaining with the patient
- If you notice any changes in the person or if the persons behaviour changes while you are with them or over time



ACI Delirium Brochure
for carers



What to do if you feel unsafe

- Stay calm
- Leave the room
- Report to staff
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Volunteer support for family carers



In summary: we have covered

- What dementia is and some of the common causes
- The impact of the hospital environment on patients with dementia
- What delirium is, the causes and treatments
- The difference between dementia and delirium
- What the person with delirium may experience
- How volunteers can greatly assist patients and family carers



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.

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

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.

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



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

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.

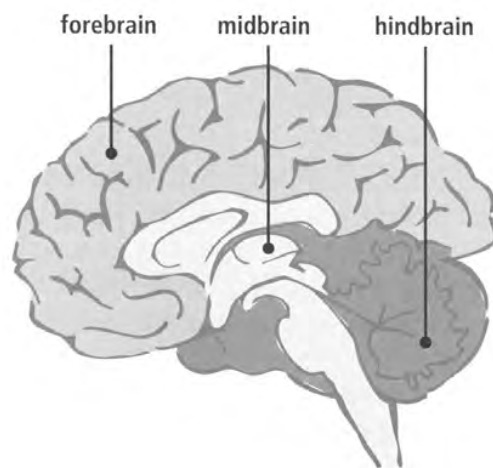


Figure 1: sections of the brain

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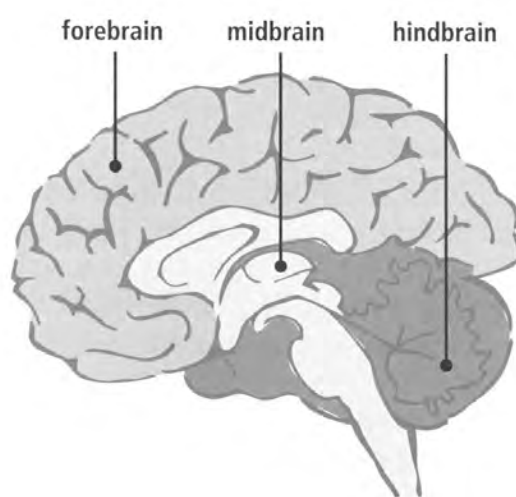


Figure 1: sections of the brain

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

For information about a wide range of dementia-related topics, visit 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.

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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

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



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

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.

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

Alzheimer's Australia

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).

HS011_075-02

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

■ 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.

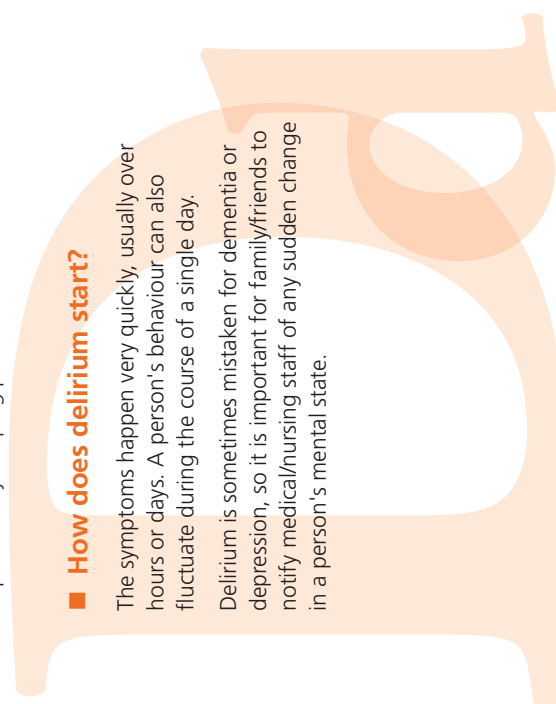
■ How is delirium treated?

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.



You Can Help Prevent Delirium

What is delirium?

Delirium is a sudden confused state of mind. It is a common problem in older people in the hospital. Delirium can be prevented and treated.

What does delirium look like?

People with delirium can act confused and may:

- be restless and upset
- slur their speech
- not make any sense
- act differently
- drift between sleep and wakefulness
- have trouble concentrating
- see and hear imaginary things
- be unaware of surroundings
- mix up days and nights
- be forgetful

What can you do?

Promote Physical Activity



- Avoid using restraints
- Help with sitting and walking
- Talk to the Nurse about how you can help with exercises and safe activities

Promote Healthy Rest and Sleep



- Reduce noise, distractions and unnecessary lighting
- Add comfort with a pillow, blanket, warm drink or back rub
- Avoid sleeping medications when possible

Promote Mental Stimulation



- Arrange for familiar people to visit regularly
- Talk about current events and surroundings
- Read out loud
- Try large print or talking books

Ways to Help

Promote Healthy Eating



- After checking with staff:
 - Encourage and help with eating
 - Offer fluids frequently

Promote Healthy Hearing



- Encourage hearing aids and amplifiers when needed
- Make sure hearing aids are working
- If in doubt, talk to the speech or hearing specialist

Promote Healthy Vision



- Encourage the use of glasses and keep them clean
- Use enough light
- Consider magnify glass or eye exam

Health Promotion and Prevention Really Works!

SESSION 3: COMMUNICATION AND PERSON CENTRED CARE

Key Messages

- 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.

Resources

- Laptop and projector.
- Whiteboard.
- Communication exercises.
 - Instruction exercise 1
 - Instruction exercise 2.
 - Back to back exercise 3.

Handouts

- PowerPoint slides.
- **Handout 1:** Alzheimer's Australia Help sheet : Communication.
- **Handout 2:** The Personal Profile.

Session overview

- Learning outcomes.
- How and why we communicate.
- Common effects of dementia over time.
- Communication tips and strategies.
- Person centred care.
- The personal profile.
- The importance of family carers in gaining personal profile information.
- Disclosure by family carers.
- Completing the personal profile.

SESSION 3: PRESENTATION OUTLINE



Show **Session 3 PowerPoint**.

Slide 2: Provide overview of learning outcomes.

Slide 3: **Brain storm** with participants "Why do we communicate?" Write answers on whiteboard and discuss.

Slide 4: Refer and talk to PowerPoint notes.

Slide 5: Ask participants what are some other ways people communicate other than words. Discuss responses.

Slide 6-9: Refer and talk to PowerPoint notes.

Slide 10: Refer and talk to PowerPoint notes. Refer or provide **Handout 1. Alzheimer's Australia Help Sheet: Communication**.

Slide 11: Refer and talk to PowerPoint notes. **Handout 2: Alzheimer's UK Brain and Behaviour fact sheet.**

Slide 12: Communication activity exercise.

Refer to PowerPoint notes. Select one of the three communication exercises and allow 15- 20 minutes for completion and feedback.

Slide 13: Person centred care.

Slide 10: Refer and talk to PowerPoint notes.

Slides 14-17: Refer and talk to PowerPoint notes.

Slide 17: Refer to or provide **Handout 2. The personal profile**.

Slides 18 - 19: Refer and talk to PowerPoint notes.

Slide 20: [Show PowerPoint video completion of the personal profile \(12 minutes\)](#). Discuss with group.

Slide 21: Provide session summary and ask if there are any questions.

Slide 22: Break and stretch- Include if there is to be further session.

SESSION 3: COMMUNICATION EXERCISES

Instruction Activity 1 **Folding paper**

INSTRUCTIONS

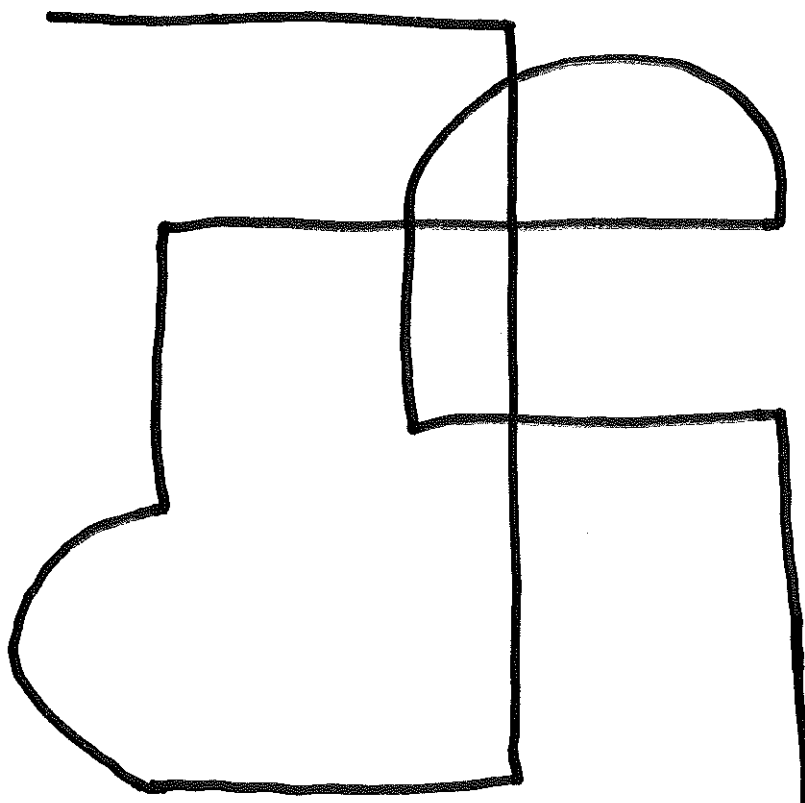
1. Ask participants to close their eyes and follow your instructions. Tell them they are not to ask any questions during the instructions.
2. Give the following directions.
Firstly, fold the sheet in half. Then fold it in half again. Then fold it in half yet again. Tear the right-hand corner off. Turn the sheet over and tear the left-hand corner off.
3. Now get the group to open their eyes and unfold their sheets of paper.

INSTRUCTION EXERCISE 2

Facilitator or selected participant instructs the other participants to complete the drawing below. Ensure that the participants are not able to see the drawing you have. Have it sitting in a folder.

Instruct the participants to complete the drawing. No explanations or use of words such as line or circle is allowed.

Instruct to participants to start with pen on the paper about 5cm from the top then move the pen to the right for 6cm then move the pen wards for 10cm. Move pen 5 cm to the left then curve around to the left. Move the pen straight up for 4 cm the move the pen foe 8 cm to the right. Curve upwards and around and the move down in a straight line for 4 cm. Move the pen right for 5 cm and then move downwards for 4cm.



Instruction Exercise 3

Back to back communication:

Body language and eye contact are the two important aspects of effective communication. This activity has eliminated these two aspects. Two participants for this activity have to sit back-to back. Ask the participants to talk to each other about what they did yesterday.

After the conversation ends gain feedback from the audience.

Ask how this conversation was different from normal conversation.

The main aim behind this activity is to explain the importance of eye contact and body language for effective communication

Effective Communication Activities. Shelly Frost eHow contributor:

http://www.ehow.com/about_5305266_effective-communication-activities.html

SESSION 3: POWERPOINT SLIDES WITH NOTES



Learning outcomes

- Understand how dementia can affect the persons language and communication
- Recognise the importance of tone and body language in communication
- Learn some tips to assist in communicating with the person with dementia
- Learn about person centred care
- Understand the personal profile and how it can assist with communication and person centred care
- How important family carers are in gaining a patients personal profile information
- What to do if carers disclose important information that staff should know





Ask the group:

Why do we communicate?

And write answers up on board, then compare with next slide

Why do we communicate?

- To express our needs or wants
- To respond to the needs of others
- To be part of social interaction with others



Talk through points

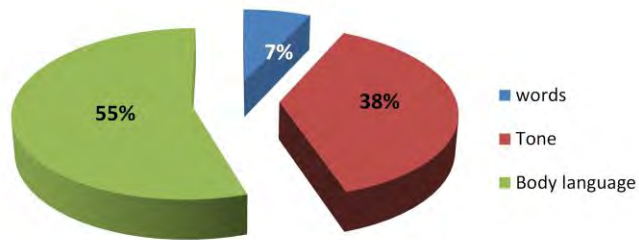
Compare the groups responses from the previous slide



Ask the group what are some of the ways we communicate?

Write their answers up on the board

Communication - More than words:



No, of course I'm not upset!!



Mehrabian, Albert (1971). Silent Messages (1st ed.). Belmont, CA: Wadsworth.



Communication is more than just verbal communication. In fact the use of words accounts for only 7% of our communication. Our body language is the primary way we communicate. This accounts for about 55% of communication and the tone and pitch of our voice accounts for the other 38%. So it is not only what we say, more importantly is HOW we use our body language and the tone of our voice when we are communicating.

People with memory and thinking problems who are unable to communicate their needs or reactions in words will often communicate through their behaviour. If they are frustrated or unhappy, their reaction may be anger or aggression. If they are bored, it may be apathy.

Ask the group if they can give some examples of the use of body language and tone in communication. Discuss their responses

Common effects of dementia over time

- Progressive loss of memory
- Reduced ability to concentrate
- Inability to recognise or name familiar objects
- Difficulty completing multistep tasks
- Difficulty expressing themselves
- Easily overwhelmed



Dementia affects a person's language and communication. Because of the progressive nature of the dementing illness, problems with language and communication tend to gradually become worse over time.

The early communication problems people with dementia experience can include general vagueness and difficulty remembering recent events, instructions and people. As the disease progresses, the person will have difficulty recognising or naming familiar objects. For example, when asked to drink, the person may not recognise a cup. Their vocabulary will decrease and they will have difficulty expressing themselves and following complex instructions. In the more advanced stages, the person is unable to follow any instructions which have multiple steps and will have great difficulty speaking, understanding or reading. In the end stages of dementia, the person is unable to verbally communicate at all.

In supporting the person with dementia, it is important to focus on what the person still can do.

What the person can always do

- Respond to body language, tone of voice and touch
- React to body language and tone of voice
- Experience feelings and emotions



Despite these problems with communication, the person with dementia can still respond and react to tone of voice and body language.

They also still have emotions and feelings and are sensitive to how others communicate with and treat them, no differently to you or I.

Non verbal communication is therefore very important in communicating with the person with dementia.

Communication Tips

- Speak slowly and clearly
- Always introduce yourself
- Use clear simple language
- Don't ask complex questions.
- Be calm and patient and allow time for a response
- Reduce competing noises such as TV



Some important ways volunteers can assist the person with dementia in communication are:

- Speak slowly and clearly
- Always introduce yourself
- Use clear simple language
- Don't ask complex questions. Break questions down. Would you like tea or coffee? Do you have sugar? Would you like milk with you tea?
- Be calm and patient and allow time for a response
- Limit or avoid competing or distracting background noises such as television or radio.

Communication tips cont:

- Have a caring approach & use gentle touch where appropriate
- Be aware of your tone and body language
- Don't argue even if the person is wrong
- Try and understand what the person might be experiencing or feeling
- Communicate at eye level



Alzheimer's Australia Communication
Help sheet



- A caring attitude is important. Often just a gentle touch or holding the person's hand can be more effective than words
- Be aware of your tone and body language
- Don't argue even if the person with dementia is clearly incorrect. Their brain is telling them that what they believe is right
- Try and understand what they might be experiencing or feeling
- Communicate at eye level
- Use words or pictures to assist with communicating

Refer to or provide **Session 3: Handout 1 Alzheimer's Australia Help Sheet - Communication**

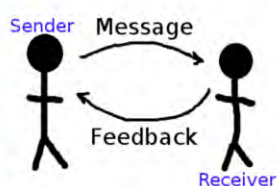
Does anyone have any comments?

Communication

The imparting or exchanging of information by speaking, writing, or using some other medium

Effective Communication

Is when the exchange of information is received as intended by the person imparting it



<http://www.oxforddictionaries.com/>



In simple terms, communication is the imparting or exchange of information between one or more persons using speaking, writing or other medium.

Effective communication is when the message or exchange of information is received as intended by the person imparting it. That is there is no confusion or uncertainty.

This is not always the case as we will see with some activities:

Communication exercise

Activity!



Option of either exercise:

1. Instruction exercise 1: Refer to Communication exercise resources

Give participants a piece of paper. Ask them to close their eyes and follow your instructions. Ask participants to open their eyes when task is finished and compare differences. Compare differences and explore why there may be differences given that everyone was given the same information?

This exercise is used to demonstrate that although everyone was given the same instruction the results are different. Ask the group why that may have been?

Prompts: Only words were used. Participants could not ask any questions to clarify the exercise. They were not able to see.

This exercise emphasises that clear instructions with visual cues are important particularly for people with memory and thinking problems who may not have the ability to clarify instructions

2. Instruction exercise 2: Refer to Communication exercise resources

One participant is given a picture. They are then to explain the drawing of the picture to other members in the group using the same instruction for everyone. Other members of the group are to follow the instructions and draw of the paper provided. Compare differences and explore why there may be differences given that everyone was given the same information?

The instructor gives specific steps to the task using words only. Participants could not ask any questions to clarify the exercise.

Prompts: Only words were used. Participants could not ask any questions to clarify the exercise. They were not able to see what the drawing was.

This exercise emphasises that clear instructions with visual cues are important particularly for people with memory and thinking problems who may not have the ability to clarify instructions

3. Back to back communication: Refer to Communication exercise resources

Body language and eye contact are the two important aspects of effective communication. This activity has eliminated these two aspects. Two participants for this activity have to sit back-to back. Ask the participants to talk to each other about what they did yesterday. After the conversation ends, gain feedback from the audience. Ask how this conversation was different from normal conversation.

The main aim behind this activity is to explain the importance of eye contact and body language for effective communication

Person Centred Care

puts the person at the centre of their care



Person centred care puts the person at the centre of their care. This relies on having respect and understanding of the persons individual values and preferences.

Personhood

“A standing or status that is bestowed on one human being by another in the context of a relationship and social being. It implies recognition, respect and trust”

(Kitwood 1997).

This is a definition of personhood by a well known writer in dementia care. Tom Kitwood transformed the way dementia care is now provided.

The psychological needs of the person with dementia



Kitwood, 1997



Kitwood defined 6 essential psychological care needs for the person with dementia which were depicted in a flower.

These are:

- Inclusion as part of interpersonal relationships
- The need for physical comfort
- A sense of identity
- Meaningful occupation
- Recognition of the specific attachments or bonds the person may have
- LOVE at the centre. Love is a basic human need. While volunteers might not have 'love' for the patients you all have a big heart where compassion, empathy, care and patience are found.

Principles of Person Centred care

- Respect for uniqueness of person
- Knowledge and value of persons past history
- A focus on abilities
- Supporting choice
- Enhancing Communication
- Valuing attachments they may have
- Maintaining social environment



The key principles of person centred dementia care based on these psychological needs are:

- A knowledge and valuing of persons past history
- A respect for the uniqueness of the person
- A focus on their abilities and what they can do
- Supporting their choices and personal preferences
- Valuing the attachments to things or persons they may have
- Supporting positive interactions and activities
- Enhancing Communication

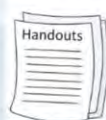
Using a person centred care approach, shifts the focus from the behaviour of the person to a more holistic view of what may be causing or contributing to the behaviour.

It recognises that cognition ability does not determine a persons capacity for emotional well being or ill being. That despite the effects of dementia on the brain, the person still experiences happy and unhappy emotions.

Therefore how people communicate and understand the person in their interpersonal relationships is very important.

The personal profile

- Gaining an understanding of the person
- Their background
- Personal preferences
- What is important to the person
- Activities or other things which give the person meaning and enjoyment



The personal profile



Applying and using the principles of person centred care in the volunteer role can be greatly assisted by using a personal profile.

A personal profile gathers information about the persons past, their family, who and what is important to them and their personal preferences in relation to likes and dislikes.

Completing the personal profile with the family also shows to them how important the individual characteristics of their loved one is and helps send a positive message that their loved one is not just a bed number.

The importance of family carers

- Carers can provide essential information to support person centred care
- The family or carers are often the people who know the person best
- They can provide important information about the persons personality and what is important to them



Because the person with dementia and or delirium has impaired communication and is not always able to provide all of this personal information, interaction and communication with their family carers or others who know them closely is very important. Families will often assist by completing the person profile when the patient is unable to do so.

However, on occasions it is not always possible to complete the profile if the patient is unable to and when the family carer or someone who knows the patient is not available.

Other family carer considerations

- The caring role can be very demanding and exhausting
- Carers may feel confused and not have received information about the effects of dementia and delirium
- Carers may sometimes disclose to a volunteer that they are having difficulties in caring for the person with dementia



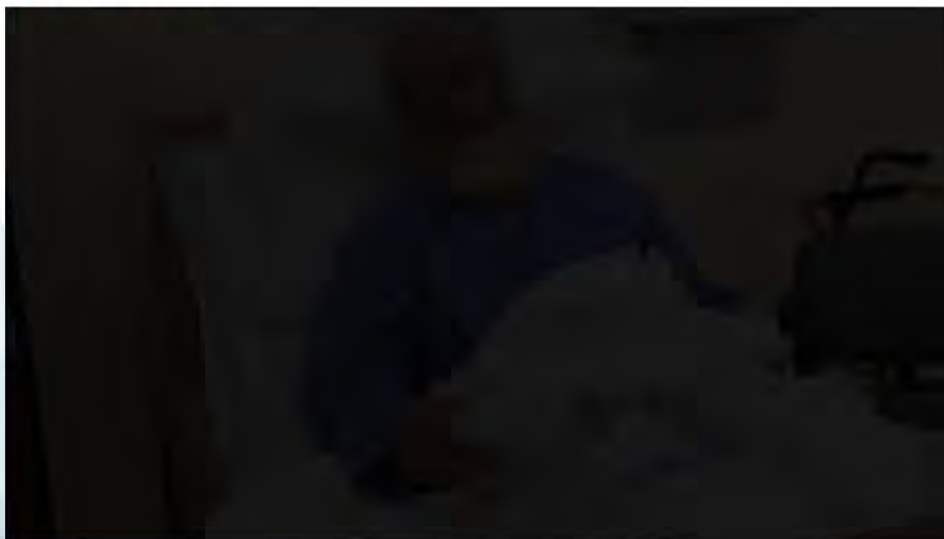
The role of caring for someone with dementia can be particularly demanding for carers.

In the case of delirium, the carer may have been dealing with the persons changed behaviours at home for some days before presenting to hospital and so may be exhausted. This is where the volunteer role can be really supportive to family carers who need a rest and are not able to be there all the time.

In addition because the volunteer has time to spend with patients, a carer may disclose to a volunteer that they are having difficulty managing at home or that they are feeling frustrated by their loved one's behaviour.

In this circumstance it is important to tell the carer that this is important information for the staff to know as they can assist with more information and support. The volunteer then has a role to inform staff of what the carer has disclosed, so that staff can assist the carer with their information and support needs.

Completing the personal profile



This scenario will provide a practical example of a volunteer completing the personal profile with a patient and family carer. In the scenario the carer discloses to the volunteer information which the volunteer then conveys to staff.

Ask participants what they learnt from the video?

Discuss their responses.

In summary

- Dementia can progressively affect the person's language and communication
- Tone and body language are important in the way we communicate
- Person centred care is based on gaining an understanding of the person and their preferences
- The personal profile can positively support communication and person centred care
- Family carers are important in gaining a patient's personal profile information
- Communicating to staff issues that family members may disclose to a volunteer



Talk to points on slide

Ask if there are any questions?

Time for a break and stretch



Include if there is to be a follow on session

Encourage participants to stand up, have a stretch and get a drink if needed before the next session

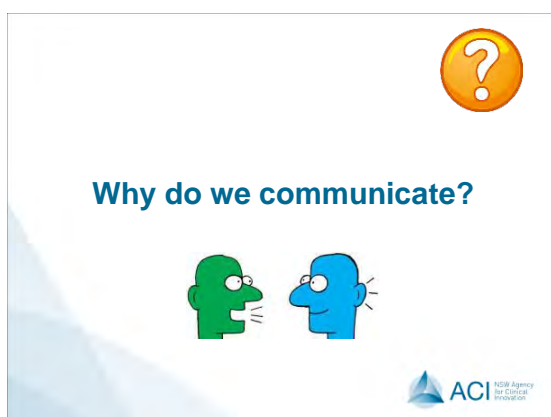
SESSION 3: POWERPOINT HANDOUTS

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Learning outcomes

- Understand how dementia can affect the persons language and communication
- Recognise the importance of tone and body language in communication
- Learn some tips to assist in communicating with the person with dementia
- Learn about person centred care
- Understand the personal profile and how it can assist with communication and person centred care
- How important family carers are in gaining a patients personal profile information
- What to do if carers disclose important information that staff should know

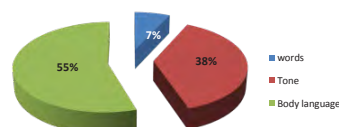


Why do we communicate?

- To express our needs or wants
- To respond to the needs of others
- To be part of social interaction with others



Communication - More than words:



No, of course I'm not upset!!



Mehrabian, Albert (1971). Silent Messages (1st ed.). Belmont, CA: Wadsworth.



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Common effects of dementia over time

- Progressive loss of memory
- Reduced ability to concentrate
- Inability to recognise or name familiar objects
- Difficulty completing multistep tasks
- Difficulty expressing themselves
- Easily overwhelmed



What the person can always do

- Respond to body language, tone of voice and touch
- React to body language and tone of voice
- Experience feelings and emotions



Communication Tips

- Speak slowly and clearly
- Always introduce yourself
- Use clear simple language
- Don't ask complex questions.
- Be calm and patient and allow time for a response
- Reduce competing noises such as TV



Communication tips cont:

- Have a caring approach & use gentle touch where appropriate
- Be aware of your tone and body language
- Don't argue even if the person is wrong
- Try and understand what the person might be experiencing or feeling
- Communicate at eye level



Alzheimer's Australia Communication Help sheet



Communication

The imparting or exchanging of information by speaking, writing, or using some other medium

Effective Communication

Is when the exchange of information is received as intended by the person imparting it



<http://www.oxforddictionaries.com/>



Communication exercise



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Person Centred Care

puts the person at the centre of their care



Personhood

"A standing or status that is bestowed on one human being by another in the context of a relationship and social being. It implies recognition, respect and trust"

(Kitwood 1997).

The psychological needs of the person with dementia



Kitwood, 1997



Principles of Person Centred care

- Respect for uniqueness of person
- Knowledge and value of persons past history
- A focus on abilities
- Supporting choice
- Enhancing Communication
- Valuing attachments they may have
- Maintaining social environment



The personal profile

- Gaining an understanding of the person
- Their background
- Personal preferences
- What is important to the person
- Activities or other things which give the person meaning and enjoyment



The personal profile



The importance of family carers

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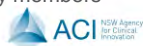


Completing the personal profile



In summary

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- Tone and body language are important in the way we communicate
- Person centred care is based on gaining an understanding of the person and their preferences
- The personal profile can positively support communication and person centred care
- Family carers are important in gaining a patient's personal profile information
- Communicating to staff issues that family members may disclose to a volunteer



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



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**



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 ____/____/____

SESSION 4: ACTIVITIES FOR PATIENTS

Key Messages

- 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.

Resources

- Laptop and projector.
- Whiteboard.
- Personal profile activity
- Moisturising handcream.
- Volunteer Training DVD – Chapter 4: Activities.
- Sample completed personal profiles – three sample profiles are included as examples. Depending on group numbers, facilitators can write up additional fictitious profiles for the exercise.

Handouts

- PowerPoint slides.
- **Handout 1:** Alzheimer's Australia Help sheet : Therapies and Communication.
- **Handout 2:** Alzheimer's Australia Help sheet : Activities.
- **Handout 3:** List of activity resources.

Session overview

- Learning outcomes.
- What are activities?
- Planning activities.
- Tips when undertaking activities.
- Reminiscence.
- Distraction activities.
- Volunteer suggestions for activities.

SESSION 4: PRESENTATION OUTLINE



Show **Session 3 PowerPoint**.

Slide 2: Provide overview of learning outcomes.

Slides 3-5: Refer and talk to PowerPoint notes.

Slide 6: Reminiscence.



Refer and talk to PowerPoint notes: Ask participants what they understand by the term reminiscence and why it could be important for people with dementia.

Slide 7-8: Refer and talk to PowerPoint notes.

Slide 9: Distraction activities: Refer and talk to PowerPoint notes.

Slides 6-9: Refer and talk to PowerPoint notes.

Slide 10: Brain storm with participants ideas they may have for other possible activities for patients.

Slide 11: Refer to or provide **Handouts 1, 2**

Handout 3: List of possible activity resources: Talk through and discuss these resources.



If the program is just starting, this is an opportunity for discussing with the group some possible opportunities for gaining some resources either through fundraising or other service groups.

You will find participants can be very resourceful in their suggestions.

Slide 12: Practical application of activities



Personal Profile activity. Have participants work in groups of two or three. Handout completed person profiles. Ask participants to read through and discuss what possible activities or communication topics they would use with the patient.

Allow 10 mins.

Have each group feedback nominate the person to provide an overview of the persons profile and feedback to the group their suggestions for communication and possible activities.

Three sample profiles are included.



Optional Massage activity: Have group separate into pairs and massage each other hands.

Allow 10mins and explore their experience of touch.

Option of playing [Chapter 4 Activities for Patients video training resource \(13 mins\)](#). This will provide an overview of activities and provide participants with volunteer experiences of using the personal profile to select activities as well as demonstrate a range of activity resources.

Slide 13: Summary points.

SESSION 4: POWERPOINT SLIDES WITH NOTES



Overview

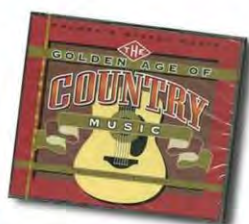
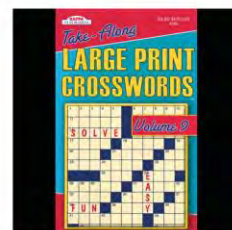
- The personal profile can greatly assist in supporting meaningful activities
- Communication and one to one interaction is an important part of activities.
- Interacting and participating in activities with patients can be very rewarding for volunteers
- People with dementia and delirium in hospital are unwell so their ability to concentrate and engage in activities is limited.



Talk to slide points

What is an activity?

- Anything a person does which can include:
 - Daily activities such as dressing, self care and eating
 - Hobbies
 - Conversation
 - Reading and listening to music



An activity is anything a person does and includes things such as dressing, eating and self-care activities but also includes activities of pleasure such as a hobby, engaging in a conversation, reading a paper, listening to music etc. In a hospital environment, many activities of purpose can also provide opportunities for pleasurable activities. For example, assisting a patient at meal time also provides the opportunity to engage in meaningful conversation.

In hospital activities also provide something for the patient to look forward to and can assist with building self-esteem and a person's self-identity.

Planning activities

- Important that it is meaningful
- Use or gain information from the personal profile
- Consider the way the activity is presented
- Consider the patients ability to participate



When planning activities it is always important to make it meaningful to the patient. This is where the Personal Profile becomes so important. Using the profile a volunteer is able to find out activities and routines that the patient currently or used to enjoy, as well as information about family, pets, past occupations and travel. This information can assist with engaging the patient in pleasant conversation and selecting activities that the patient may enjoy.

Often, the way an activity is presented to a patient is more important than the activity itself. It is important that the activity of choice has meaning to the patient and is not viewed as just a way to fill in time.

Remember patients in hospital are unwell and their ability to concentrate or participate in activities may be reduced.

Tips when undertaking activities

- Be flexible
- Be relaxed and enjoy your time with the patient
- Offer choices
- Support the persons independence
- Talking with someone one to one is an important activity



- Be flexible and able to change plans quickly if the person doesn't seem to be showing interest or if they get tired. Remember, the patient is experiencing an illness which has placed them in hospital and it is important they get plenty of rest time too.
- Use appropriate communication skills so you have the best opportunity for engaging the patient in a pleasurable activity
- Offer choices as appropriate because all people like to have some say in the things they do
- If possible set up activities that the patient can do independently while you visit other patients such as listening to a favourite CD, doing a crossword puzzle, or reading a paper
- Look for things the person can still do and encourage these skills in the activities you do.

Patients may not be able to do all the steps in an activity but may be able to complete and enjoy part of it. Encouraging their independence but ensuring the activity is not too hard for them is important.



Reminiscence



Ask participants what they understand by the term reminiscence?

Why could it be helpful for people with dementia?

Reminiscence



- Is memories from the past
- Very important for people with dementia
- Enhances self esteem and communication
- Allows the person to recall and share their experiences and feel valued
- Provides a sense of identity and recognition for the person

Kennard, C (2007) Reminiscence Therapy and Activities for People with Dementia



Reminiscence refers to recollections of memories from the past. It is familiar to us all and can be utilised for the benefit of others.

It is very important for people with dementia as their short term memory is often impaired but their longer term memories remain intact for much longer

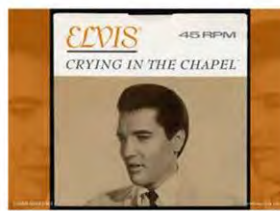
For people with dementia encouraging the act of reminiscence can be highly beneficial to their inner self and their interpersonal skills.

Reminiscence involves exchanging memories about the past and passing on information, wisdom and skills.

It is about giving the person with dementia a sense of value, importance, belonging, power and peace.

Activities that assist in reminiscence

- Photo's and pictures
- Music and film
- Touch and talking about the past
- Feeling different textures and objects



Some of the things which can assist volunteers with communication and reminiscence are:

Old photo's

Pictures and calendars

Music and film

Feeling different textures and objects

Touch and asking the person about their past

Distraction activities

- Can be very useful if the person is agitated
- Examples are:
 - Handbags filled with different textured materials
 - Fiddle boxes with locks and latches
 - Fiddle rugs, cushions and aprons
 - Small clothes basket full of washing to fold



In hospital when a person may be unsettled and agitated, distraction activities can be useful and help settle the patient for a period of time.

Examples of distraction activities are:

Handbags filled with scarf's and different textured materials. For infection control, the bags and contents need to be able to be wiped down or washed

Distraction or fiddle boxes with different locks and latches for men

Washable fiddle rugs, cushions and aprons

Clothes to fold

Other items that the person can fiddle with or feel.

There are a range of activity resources from distraction items such as fiddle rugs, rummage boxes and handbags to magazines, books, crosswords, domino's, music and DVD's.

Some hospitals will need to gradually build up their resources and this is where suggestions from volunteers can really help. If you have any suggestions for patient activities in the hospital you are volunteering in, let staff or your volunteer coordinator know. A list of possible activity resources are in your handbook.



Suggestions you may have for activity items is important



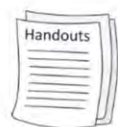
Ask participants if they can think of activity items that they think would be useful for patients with dementia and delirium and write answers on the board.

Discuss the range of activity resources from distraction items such as fiddle rugs, rummage boxes and handbags to magazines, books, crosswords, domino's, music and DVD's.

Explain that some hospitals will need to gradually build up their resources and this is where suggestions from volunteers can really help.

Advise participants that if they have any suggestions for patient activities in their volunteer role, to let staff or your volunteer coordinator know.

Some resources



Alzheimer's Australia Help Sheets
Therapies and Communication and Activities



A list of possible activity items to
consider



Handout 1: Therapies and communication Help Sheet:

Handout 2: Activities Help Sheet

Handout 3: List of possible activity resources: Talk through and discuss these resources.

If the program is just starting, this is an opportunity for discussing with the group some possible opportunities for gaining some resources either through fundraising or other service groups. You will find participants can be very resourceful in their suggestions



Personal Profile Activity

Handout completed person profiles

Ask participants to read through and discuss what possible activities or communication topics they would use with the patient

Allow 10 mins

Have each group feedback nominate the person to provide an overview of the persons profile and feedback to the group their suggestions for communication and possible activities.

Allow 10-15 minutes

Three sample profiles are included – more will need to be devised for the exercise depending on group numbers

Total exercise time 20-30 minutes

Optional Massage activity: Have group separate into pairs and massage each other hands. Allow 10mins and explore their experience of touch

Summary

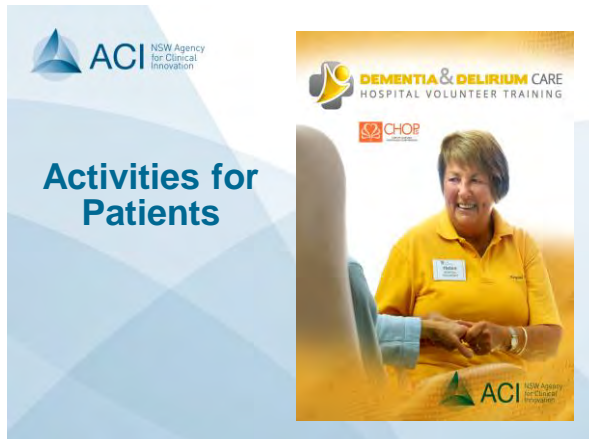
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- Interacting and participating in activities with patients can be very rewarding for volunteers
- Patients with dementia and delirium are unwell so their ability to concentrate and engage in activities is limited
- Your activity suggestions are important



Summarise points and ask if there are any questions

SESSION 4: POWERPOINT HANDOUTS

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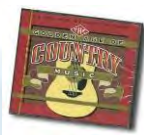
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Reminiscence



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Reminiscence

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- Very important for people with dementia
- Enhances self esteem and communication
- Allows the person to recall and share their experiences and feel valued
- Provides a sense of identity and recognition for the person



Kennard, C (2007) Reminiscence Therapy and Activities for People with Dementia



Activities that assist in reminiscence

- Photo's and pictures
- Music and film
- Touch and talking about the past
- Feeling different textures and objects



Distraction activities

- Can be very useful if the person is agitated
- Examples are:
 - Handbags filled with different textured materials
 - Fiddle boxes with locks and latches
 - Fiddle rugs, cushions and aprons
 - Small clothes basket full of washing to fold



Suggestions you may have for activity items is important



Some resources



Alzheimer's Australia Help Sheets
Therapies and Communication and Activities



A list of possible activity items to consider



Practical application of activities



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Summary

- The personal profile information greatly assists in identifying meaningful activities.
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- Patients with dementia and delirium are unwell so their ability to concentrate and engage in activities is limited
- Your activity suggestions are important



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
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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**



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

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.

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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

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Translating and Interpreting Service on
131 450

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
Other items	
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

SESSION 4: SAMPLE PERSONAL PROFILES

Personal Profile for Volunteer to complete with patient and/or carer

Patients Name: John Smith

Patients preferred name? John

Where do you live now?: Delegate

Where have you lived most of your life?: Delegate

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

Name	Relationship	Town they live in
Betty	wife	Deceased
John	Son	Canberra
Alison	Daughter	Cooma
David	Son	Delegate
5 grandchildren		

Other close friends/ neighbours /carers:

Name	Relationship	Town they live in

Do you have a pet? Y / N

If Yes Type of Pet? Y Name of pet Blue - farm dog

Favourite Food: steak & vegies

Special diets: -

Favorite drink: tea / coffee / Milo / milk / other : tea, black, 2 sugars

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

Life Experiences

War service: _____

Main occupation (past and/or present): farmer

Clubs and Associations: _____

Travel or holidays enjoyed: travelled Australia in a caravan
before wife died

Activities/interests: (please circle)

Sport:

Golf / bowls / bridge / (fishing) / swimming / lifesaving / football / hockey / tai chi / horse riding / (cricket) / horse racing / Other: please state: old cars & tractors

Other interests:

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

Farming, growing vegies, fixing engines

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:

newspaper, farmer's national times

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? wife passed away 11 months ago.
John lives on the same property as his son David.

Volunteer completing form: _____ Date / /

Personal Profile for Volunteer to complete with patient and/or carer

Patients Name: Elizabeth Taylor

Patients preferred name? Liz

Where do you live now?: Cooma

Where have you lived most of your life?: Melbourne

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

Name	Relationship	Town they live in
Jack	husband	Cooma
Veronica & Mitch	daughter & SIL	Melbourne
Evan	grandson	Melbourne
Susan & Peter	granddaughters & husband	Canberra

Other close friends/ neighbours /carers:

Name	Relationship	Town they live in
Flo Johnson	Neighbour & friend	Cooma

Do you have a pet? Y/(N)

If Yes Type of Pet? _____ Name of pet _____

Favourite Food: roast dinners

Special diets: -

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

Preferences on how drink is made: eg Milk and sugar: white

Life Experiences

War service: _____

Main occupation (past and/or present): home maker

Clubs and Associations: quilting group

Travel or holidays enjoyed: has previously travelled to Melbourne
alot to visit family but not since diagnosis

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: Neil Diamond, Glen Campbell

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: music station. She doesn't like the talking!

Reading

Enjoys reading? (Yes) / No Able to read independently? Yes / No Sometimes
Needs glasses to read? (Yes) / No Would like someone to read ^{with} 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 ____/____/____

Personal Profile for Volunteer to complete with patient and/or carer

Patients Name: Betty Davis ~~Betty Davis~~ Salvina Davis

Patients preferred name? Sally

Where do you live now?: Cooma

Where have you lived most of your life?: Canberra / Cooma

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

Name	Relationship	Town they live in
Steven	husband	Cooma
Michael	son	Cooma
Tanya	daughter	Cooma
Sally	grand daughter (7)	Cooma
Cooper	grand son (10)	Cooma

Other close friends/ neighbours /carers:

Name	Relationship	Town they live in

Do you have a pet? (Y) / N

If Yes Type of Pet? Cat Name of pet Soxie

Favourite Food: Mediterranean Diet preferred

Special diets: _____

Favorite drink: tea (coffee) / Milo / milk / other : _____

Preferences on how drink is made: eg Milk and sugar: Strong, black,
2 sugars

Life Experiences

War service: _____

Main occupation (past and/or present): shop assistant in a fruit shop.

Clubs and Associations: _____

Travel or holidays enjoyed: Travelled to Malta regularly & has travelled the world.

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: anything you can dance to!

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: Maltese news on SBS

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? Sally was born in Malta & used to cook a lot of Maltese foods but can no longer do this.

Volunteer completing form: _____ Date 1/1

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

Key Messages

- 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.

Resources

- Laptop and projector.
- Whiteboard.
- Post it notes.
- Butchers paper.
- Case scenario's.
- Vision Australia Macular degeneration and cataract cardboard glasses.
- Cotton wool balls.

Handouts

- PowerPoint slides.
- **Handout 1:** Alzheimer's Australia Help sheet : Changed Behaviours.
- **Handout 2:** Alzheimer's Society UK. Unusual Behaviour Fact Sheet.

Session overview


- Learning outcomes.
- Practical exercise of positive and negative experience.
- Person centred approaches to changed behaviours.
- Common terms used.
- Types of behaviours a volunteer may experience.
- Common causes and triggers.
- What volunteers are to do if they feel unsafe.
- Reporting concerns or changes with a patient.
- Ways volunteers can assist patients.
- The experience of existing volunteers.

SESSION 5: PRESENTATION OUTLINE



Show **Session 5 PowerPoint**.

Slide 2: Provide overview of learning outcomes.

Slide 3:  **Activity:** Positive and negative experience. Refer and talk to PowerPoint notes.

Material needed: Post it notes and butchers paper adhered to the wall.


Slide 4 - 5: Refer and talk to PowerPoint notes.

Slide 6: What are some behaviours which may present in patients with dementia and delirium?



Ask participants from what they have learnt to date what are some of the behaviours that patients with dementia and delirium may experience? Write answers on whiteboard and discuss

Slides 7-8: Refer and talk to PowerPoint notes.

Slide 9:  Ask participants what they think may be some causes or triggers for behaviours occurring. Write up responses and discuss.

Slide 10: Refer and talk to PowerPoint notes.


Slide 11:  **Vision and hearing impairment activity:**

Materials: "Macular Degeneration" cardboard glasses from Vision Australia. Bag of cotton wool balls.


Have participant's complete activity in groups of two and take turns. One participant wears the glasses and puts cotton wool in their ears. They then get up and walk around the room. The other participant tries to have a conversation with them and direct them back to their chair. Participants then swap. Allow 10 minutes for activity and then ask for group feedback on the experience.

See PowerPoint notes for prompts.

Slide 12: Refer and talk to PowerPoint notes.

Slide 13:  Refer and talk to prompts in PowerPoint notes.

Slides 14-17 Refer and talk to PowerPoint notes.

Slide 18:  Refer and talk to PowerPoint notes. Ask the group "What should you do if you feel unsafe or concerned about a patients behaviour? Write responses on the board and discuss.

Slides 19-21: Refer and talk to PowerPoint notes.

Slide 22: [Play video clip of volunteer interviews \(6 mins\)](#).

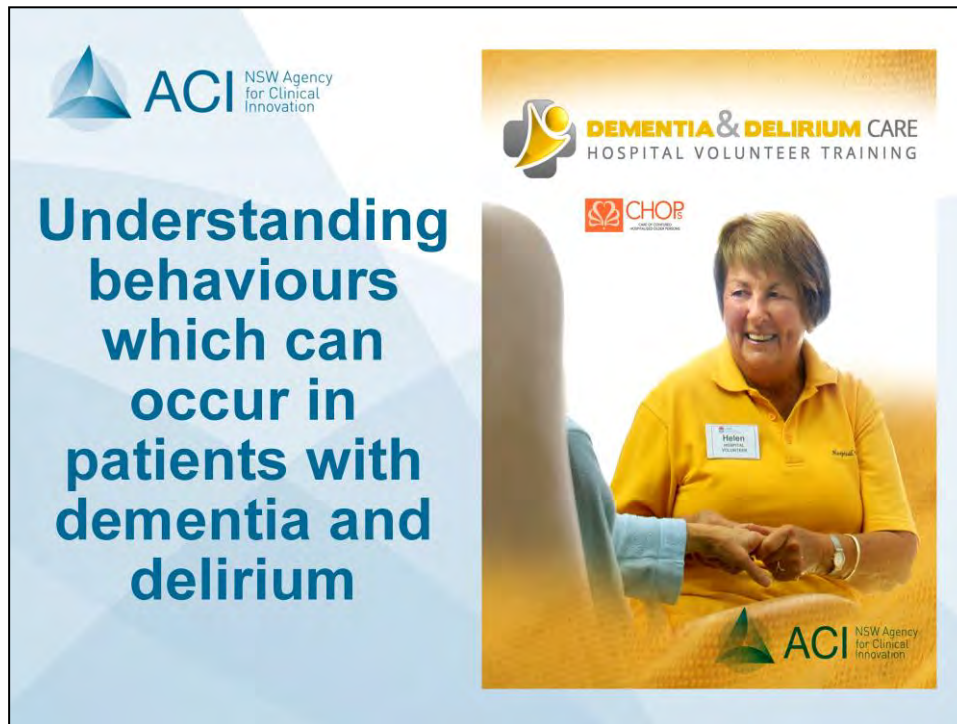
Slide 23: Talk to summary points. Refer to or provide **Handout 1 and 2**.

Slide 24: Option of a short break and stretch.

Slide 25:  **Case Scenarios.**

Depending on your group numbers divide participants into 3 – 6 groups of 3 or 4. Each group to nominate the person who is to feedback after the activity. Provide each group with paper and pen. Give each group one of the 6 case scenario's. Ask them to work on each scenario and decide what they would consider and do. Allow 10 minutes. The nominated person from each group reads out the scenario and the response that the group has decided upon. Encourage the rest of the group to participate after each response, adding anything else they may have considered. Facilitator to add any additional considerations 10 – 20 mins for feedback (total time 20 – 30 mins)

SESSION 5: POWERPOINT SLIDES WITH NOTES



Learning outcomes

- Gain an understanding of changed behaviours
- Understand how applying person centred care and using the personal profile can greatly assist you in supporting patients with changed behaviours
- Learn some common causes and triggers for changed behaviours.
- Learn some strategies to support patients with changed behaviours.
- Know what to do if you feel unsafe with a patient



Speak to dot points

Positive and Negative experience



- Think about a positive situation or experience you have had where you were told or shown you were appreciated or given praise. How did it make you feel?
- Think about a negative situation or experience where you were treated rudely or without respect. How did it make you feel?



Materials sticky note pads

Two sheets of butchers paper and blue tak to stick them on the wall. One sheet has a heading positive experience and the other negative experience

Give participants some sticky note pad pages

Ask each participant to think about and right down in 3 words how the positive experience made them feel

Then ask participants to think about and right down in three words how the negative experience made them feel

Participants are then asked to stick the positive experience feedback on the positive sheet and the negative on the negative sheet

Review each sheet with responses and pick out discuss common themes

Person centred care approaches to changed behaviours

- Involves gaining an understanding of the person and the possible triggers or causes for the behaviour
- Its about putting yourself in their shoes asking yourself how would I feel and act if this was happening to me
- Thinking about what the person may be perceiving is happening around them or to them



As we have covered person centred care is based on having an understanding of the person and using that knowledge to support meaningful interaction and activities. When a person is experiencing changed behaviours, having an understanding of the person can greatly assist in identifying possible causes for the behaviour.

It is about thinking about how you would feel if you were in the situation.

It is also about thinking what the person may be perceiving is happening to them particularly if they are seeing frightening things or believing that staff are trying to hurt them.

Common terms that are used

- Challenging Behaviours
- Behaviours of Concern
- Behavioural and Psychological Symptoms of Dementia (BPSD)



There are a number of terms used for describing behaviours that occur in people with dementia. These include Challenging Behaviours, Behaviours of Concern or Behavioural and Psychological Symptoms of Dementia. However in relation to this session and your volunteer role the term 'changed behaviours' is used as this relates to people with dementia and delirium



**What are some behaviours that
may present in patients with
dementia and delirium**



Ask participants from what they have learnt to date, what do they think may be some of the behaviours they may experience in supporting patients with dementia and delirium?

Write responses up on the board

Types of behaviours you may see

- **Lethargy or loss of interest in things**
- **Wandering**
- **Agitation or restlessness**
- Aggression
- Resisting attempts to help or resisting care
- **Trying to get out of bed**
- **Suspiciousness of others**
- **Calling out**
- **Repetitive speech or actions**
- **Teary and emotional**
- Seeing or hearing things that aren't there (hallucinations) or
- Falsely believing something is occurring that isn't (delusion)



The more common behaviours that a volunteer may experience in supporting patients are highlighted in bold. These are:

Lethargy or loss of interest in things

Wandering

Agitation or restlessness

Resisting attempts to help or resisting care

Trying to get out of bed

Suspiciousness

Calling out

Repetitive speech or actions

Teary and emotional

Volunteers will not be assigned patients who have been assessed as posing a risk to themselves or others

I suppose the most important thing to understand is that behaviours rarely just happen without a cause. They're often a reaction to triggers and working out what these triggers are can help to alleviate the person's distress and prevent the behaviour occurring or becoming worse.

Understanding behaviours

- Behaviours rarely just happen
- There can be one or many different causes or triggers
- Identifying the causes or triggers can assist in planning appropriate ways to prevent the behaviour either occurring or escalating.



Behaviours rarely just happen without a cause. There can be many different causes or triggers alone or in combination

Volunteers may often be in a position to see something that may be upsetting a patient and contributing to their particular behaviour. Identifying the possible cause and understanding the person and using a person centred care approach can often prevent or settle behaviours that can occur.



Ask participants to think about what they think might be some causes or triggers for changed behaviours in hospitals.

Write answers on white board and discuss.

Common causes or triggers

- Can be grouped into key areas:
 - Physical causes
 - Psychological causes
 - Emotional causes
 - Changes in the brain
 - Environment causes
 - Occupation or lack of occupation
 - Relationships with others



As you can see there are lots of common causes, some of which you have identified.

We will look in a bit more detail at each of these key areas and firstly we will talk about physical causes

Physical causes

Activity!

- Delirium
- Pain/discomfort
- Impaired vision or hearing
- Acute illness
- Effects of medications
- Chronic illness
- Constipation
- Dehydration
- Fatigue
- Incontinence
- Hunger or thirst



These are common causes in hospitals and are such things as pain or discomfort, poor vision or hearing which can increase disorientation and confusion, acute illness, vision and hearing impairment, the effects of medications, constipation, dehydration, sleeplessness, hunger and thirst and incontinence. These are also many of the causes for delirium which presents as a recent change in the persons mental state and function. Delirium can be a common cause of the onset of behaviours in people who already have dementia.

Ask the group how many of them wear glasses all the time?

What does it feel like for them when they have lost their glasses or don't have glasses on?

Vision and hearing impairment Activity

Materials: “Macular Degeneration” cardboard glasses from Vision Australia.

Bag of cotton wool balls

Have participants complete activity in groups of two and take turns

One participant wears the glasses and puts cotton wool in their ears. They then get up and walk around the room. The other participant talks to have a conversation with them and direct them back to their chair.

Participants then swap

Allow 10 minutes for activity and then ask for group feedback on the experience.

Question prompts:

How did the experience make you feel?

What were you thinking through the experience?

How do you think this experience would impact on someone who was not thinking clearly?

How would they appease their anxiety if they are unable to work out what was happening?

This consequences of this experience is interrelated with emotional causes for behaviour which we will talk about next.

Psychological and Emotional

Psychological causes

- Prior personality traits
- Anxiety
- Depression
- Existing mental health condition



Emotional causes

- Frustration
- Fear
- Loss of control
- Anxiety
- Grief
- Stress
- Loneliness



Psychological causes can include things such as an existing depression or anxiety or it could be the person's personality traits. The person may have been someone who had a position of authority and control and if this is taken away and there is someone else telling them what to do in a commanding tone they may react.

In hospitals the staff are very busy and sometimes patients can react when they feel they are being rushed or told to do something they don't want to do. This can cause an increase in agitation when in fact they just don't like being organised and told what to do.

This is why gathering information about the person from the carer as part of the personal profile is so important as knowing the person's past occupation and aspects of the personality can greatly assist in understanding the person.

Some people may also have co-existing mental health conditions such as Bipolar disorder. Patients with a mental health condition and dementia or delirium will only be referred to volunteers if it is appropriate and their mental health condition is stable.

Emotional causes are also common triggers: This can be things such as frustration in not being understood, or fear – particularly if the person is experiencing hallucinations (seeing frightening things) or delusions, such as falsely believing staff is out to hurt them. These triggers can often be the cause for someone becoming aggressive as they feel under threat or very fearful of what they are seeing. In these situations the person cannot process things logically to calm themselves down.

Grief and loss can also be triggers as can loneliness. Often patients who repeatedly call out can be lonely and wanting company.

Environmental causes



We have talked about the impact of the hospital environment on the person with memory and thinking problems.

In looking at this picture, what do you think might be some of the environmental causes or triggers for changed behaviours?

What sort of behaviours might this environment trigger for the person?

Write answers on white board?

Further discussion below can then occur.

Environmental Causes are common in hospital, because it's all so unfamiliar. This can be very disorientating and often made worse if the patient is moved into different rooms during their stay which can occur.

Common ones are:

- Loud and strange noises
- Rushed staff
- Poor lighting
- Unfamiliar environment
- Room changes in hospital
- Room temperature
- Clutter
- Unfamiliar medical equipment

As we have discussed in Chapter 2 the Hospital environment can greatly impact on the person with dementia and delirium resulting in increased confusion, anxiety and disorientation.

Occupational causes

- Change in daily routine
- Not enough social interaction
- Boredom
- Activities that are too easy or too hard
- Separation from usual social interactions/activities



Occupation causes refers to how people with dementia spend their time or how they are occupied. A change or disruption in the person's routine can be a trigger, so maintaining routine and familiar tasks are important in supporting people with dementia.

Other triggers can be too much stimulation or too little which could lead to boredom. Or if a person is being asked to do too many things that are too hard for them. Being separated from their usual interactions and activities can be unsettling for some people. For example the person may be used to walking long distances every day or interacting with their pet. Being separated from this can result in wandering or agitation when the person is in hospital.

Relationship with others

- Being asked multiple questions
- Misunderstanding words
- Intimidation
- Multiple staff changes
- Feeling disrespected
- Reaction to others body language
- Not being at eye level when communicating



Finally but no less important are triggers in how others people relate and interact with the person.

We talked about the importance of communication and body language in session 3.

Many triggers relate to poor communication techniques such as being asked multiple questions or asking too many questions at once and not waiting for answers.

Poor use of body language such as standing over the person and not being at eye level, using a harsh or impatient tone can result in the person feeling intimidated or disrespected.

Remember the person may be misunderstanding your words, or you cant understand what they are trying to say or tell you. This can lead to the person feeling frustrated.

So these are just some of the common causes, there can be many others and sometimes it can take a bit of detective work involving carers and staff to find out what this might be.

Agitation and wandering in hospital can be common

- Difficulty being able to focus or stay still
- Trying to get out of bed or shifting constantly in bed
- Picking at bed clothes
- Rummaging through drawers
- Wandering and wanting to go home



Agitation and wandering in patients can be common in the hospital. As we have discussed in session two. Patients with delirium can fluctuate in their behaviour over the course of the day and often have disturbance in their sleep wake cycle. Patients with delirium can therefore sometimes be sleepy during the day and then as evening approaches start to become unsettled and agitated or start to wander.

Common presentations of agitation are:

- Difficulty in staying focused or staying still
- Trying to get out of bed or shifting constantly in the bed
- Picking at the bedclothes
- Rummaging through drawers
- Wandering and constantly wanting to go home

Aggressive behaviour

Common triggers for aggression in dementia and delirium can be:

- **Pain** - particularly on movement
- **Fear**
- **Frustration**



Pain can be a common trigger for people becoming resistive and angry. This is particularly the case if the anger or aggression occurs when the patient is being moved. Many older people can experience chronic pain. However people with dementia and delirium may be unable to tell people that they have pain and it is their behaviour which is the sign that they are in pain. They may call out or grimace or grip onto people or the bed rails when they are being moved. Or they may become angry and refuse to move as it causes them pain. If you think a person you are supporting is in pain, or they tell you they are hurting, inform the staff.

Think about when you have been in pain such as having a constant headache or pain somewhere. How did that change your mood or behaviour?

Discuss responses.

People may also be frightened of things they are seeing that are very real to them such as spiders on the wall or snakes in their bed. Imagine how you might feel if you were seeing things like this that were very real to you?

As we have previously talked about the person may perceive that staff are

going to hurt them and so feel threatened and respond defensively even when this is clearly not the case.

Frustration is another trigger for aggressive behaviour. Frustration is common in both dementing and delirious patients.



Volunteers will not be assigned patients who are known to be aggressive



Emphasis that Volunteer will not be assigned patients who are known to be aggressive.

However, there may be the rare circumstance where a patient who has been referred to the program who was not previously aggressive has a change in their behaviour due to medical or other causes. For this reason if you are even concerned or notice a change always talk to and check with staff first.

In any circumstance where a volunteer may feel unsafe it is important to know what to do.

We covered this a little in session 2 on dementia and delirium.

What should you do if you feel unsafe or concerned about a patients behaviour?

Write responses on the board and discuss.

If in any circumstance

You do feel unsafe or concerned about the patients behaviour

- Stay Calm
- Leave the room
- Report what has occurred to staff
- Do not approach the patient again until cleared by staff



Review responses from previous slide and reiterate points

If there is any circumstance where you do feel unsafe or threatened by a patients behaviour it is important that you.

1. Stay Calm
2. Leave the Room
3. Report what has occurred to staff
4. Do not approach the patient again until cleared by staff

Important things for volunteers to communicate

- Report to staff any changes you notice in the persons behaviour
- If the person is unsettled, upset or agitated, report to staff anything that you think may be causing or contributing to their behaviour.
- Document for other volunteers if you have found an activity or something that was helpful in settling a patient.



As a volunteer you and or the family carer may be the first person to notice a change in the patients behaviour. Through your use of the personal profile you also may identify possible triggers or causes for the behaviour which staff may not have observed or been aware of.

It is important that you inform staff if you notice any changes in the person behaviour you are supporting or anything that you notice that you think may be contributing to the behaviour.

If you have been successful in distracting a patient with a particular activity or that you have been able to engage them in a meaningful activity that they have enjoyed, it is important to document this information in your handover record to the next volunteer. This may then assist the next volunteer in their interaction with the patient.

Ways you can help patients

- Clear calm friendly communication and reassurance
- Explain who you are what you are going to do
- Remind the person of where they are and the time
- Avoid arguing or disagreeing
- Use distraction activities and redirection
- Refer to their personal profile
- Use encouragement, praise and touch if appropriate
- Support visual and hearing aides
- Play music they enjoy
- If they are wandering – walking with them
- Offer a warm or cool drink



ACI NSW Agency for Clinical Innovation

We have discussed some of the ways volunteers can assist patients with dementia and delirium in session 2.

For patients who may be experiencing changed behaviours in hospital, these are very similar

Volunteers can often greatly assist patients who may be agitated or unsettled. Referring to their personal profile may help in communication to redirect the person or identify suitable distraction activities.

Other important ways the volunteer can assist people experiencing behaviours associated with dementia and delirium are:

Be calm, speak clearly and slowly

Be friendly and caring

Remind the person of where they are and the time it is

Always prepare the person by explaining what you are and why you are there

Avoid arguing or disagreeing. It can be better to agree with what the person says or does, & then try distraction or humour.

Use encouragement, praise & affection and touch if appropriate

Ensure the person is wearing their visual and hearing aides

Often playing music they enjoy can be calming and reassuring as it is

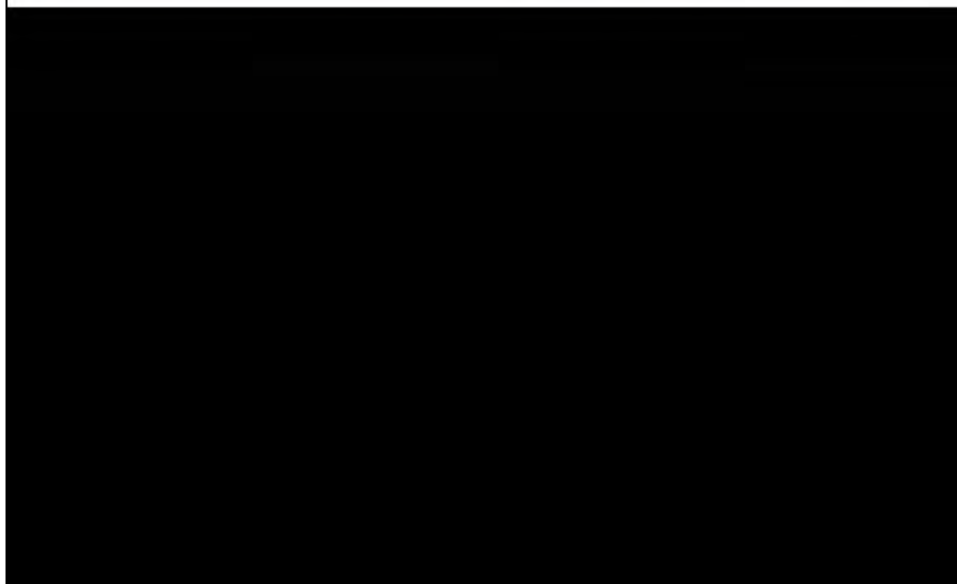
something familiar to the person.

If the person wants to walk or wander and it is safe for the volunteer walk with them and then redirect back to their room. This may help in settling them for a while.

Offering a warm or cool drink can be very reassuring to patients. This is a common social thing we all like to do and can assist with calming a person. Existing volunteers will often talk about how making a cup of tea for themselves and the patient and sitting and having it with them can greatly assist in calming and distracting a patient who is agitated.

In this next slide you will view a short video consisting of interviews with existing volunteers, who talk about their experiences of settling patients who have been fearful, agitated and wandering. Hopefully this will provide you with some additional tips to assist you in your future roles.

Some existing volunteer experiences



Summary

- There are many causes or triggers for why a person may exhibit a behaviour
- Identifying possible triggers or causes is the key to finding the solution
- Understanding the person and what they may be experiencing can assist with interventions



1. Alzheimer's Australia Changed Behaviours Help Sheet
2. Alzheimer's Society UK Unusual behaviour Fact Sheet



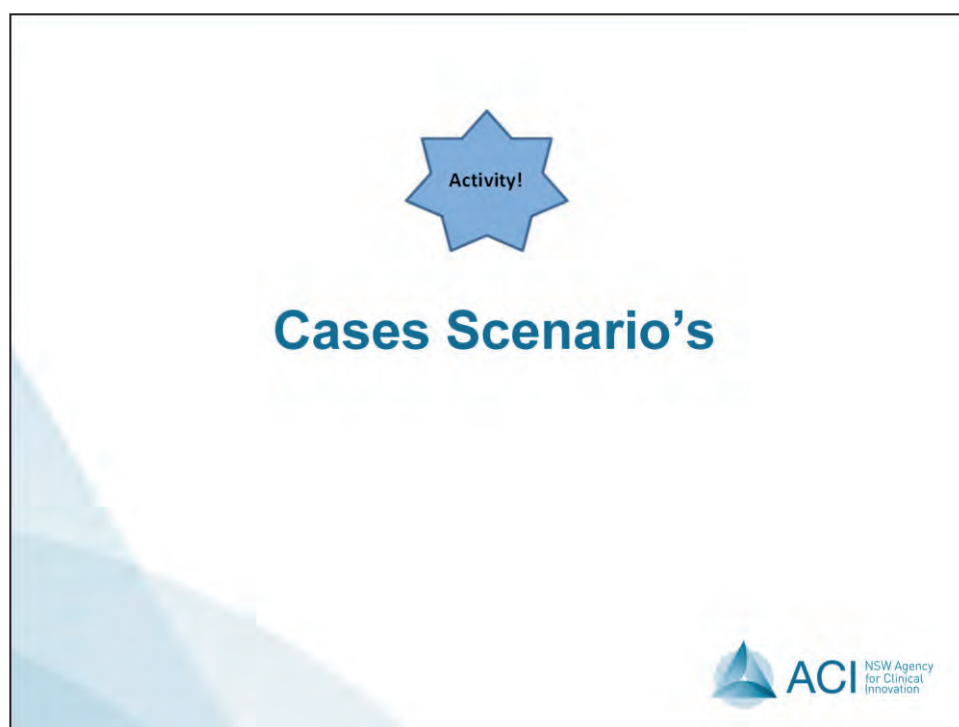
Talk to Summary points. Ask if any one has any questions or comments and group and discuss any issues raised

Refer to handouts for further information

1. Alzheimer's Australia Changed Behaviours Help Sheet
2. Alzheimer's Society UK Unusual behaviour Fact Sheet



Encourage the participants to get up, move around, stretch and get a cuppa before the practical activity of case scenario's



Depending on your group numbers divide participants into 3 – 6 groups of 3 or 4

Each group to nominate the person who will feedback after the activity

Provide each group with paper and pen.

Give each group one of the 6 case scenario's

1. Wandering
2. Calling out
3. Suspiciousness
4. Anger
5. Agitation
6. Repetition

Ask them to work on each scenario and decide what they would consider and do.

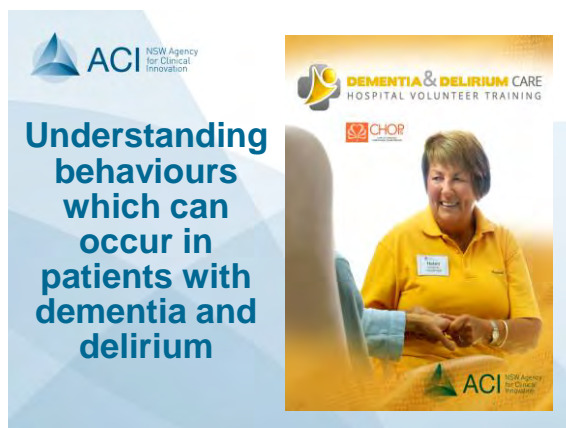
Allow 10 minutes

The nominated person from each group reads out the scenario and the response that the group has decided upon. Encourage the rest of the group to participate after each response, adding anything else they may have considered
10 – 20 mins for feedback (total time 20 – 30 mins)

Refer to case scenario's with suggested answers to support feedback

SESSION 5: POWERPOINT HANDOUTS

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Learning outcomes

- Gain an understanding of changed behaviours
- Understand how applying person centred care and using the personal profile can greatly assist you in supporting patients with changed behaviours
- Learn some common causes and triggers for changed behaviours.
- Learn some strategies to support patients with changed behaviours.
- Know what to do if you feel unsafe with a patient



Positive and Negative experience



- Think about a positive situation or experience you have had where you were told or shown you were appreciated or given praise. How did it make you feel?
- Think about a negative situation or experience where you were treated rudely or without respect. How did it make you feel?



Person centred care approaches to changed behaviours

- Involves gaining an understanding of the person and the possible triggers or causes for the behaviour
- Its about putting yourself in their shoes asking yourself how would I feel and act if this was happening to me
- Thinking about what the person may be perceiving is happening around them or to them



Common terms that are used

- Challenging Behaviours
- Behaviours of Concern
- Behavioural and Psychological Symptoms of Dementia (BPSD)



What are some behaviours that may present in patients with dementia and delirium



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Types of behaviours you may see

- Lethargy or loss of interest in things
- Wandering
- Agitation or restlessness
- Aggression
- Resisting attempts to help or resisting care
- Trying to get out of bed
- Suspiciousness of others
- Calling out
- Repetitive speech or actions
- Teary and emotional
- Seeing or hearing things that aren't there (hallucinations) or
- Falsely believing something is occurring that isn't (delusion)



Understanding behaviours

- Behaviours rarely just happen
- There can be one or many different causes or triggers
- Identifying the causes or triggers can assist in planning appropriate ways to prevent the behaviour either occurring or escalating.



Common causes or triggers for changed behaviours



Common causes or triggers

- Can be grouped into key areas:
 - Physical causes
 - Psychological causes
 - Emotional causes
 - Changes in the brain
 - Environment causes
 - Occupation or lack of occupation
 - Relationships with others



Physical causes

- Delirium
- Pain/discomfort
- Impaired vision or hearing
- Acute illness
- Effects of medications
- Chronic illness
- Constipation
- Dehydration
- Fatigue
- Incontinence
- Hunger or thirst



Psychological and Emotional

Psychological causes

- Prior personality traits
- Anxiety
- Depression
- Existing mental health condition

Emotional causes

- Frustration
- Fear
- Loss of control
- Anxiety
- Grief
- Stress
- Loneliness



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Environmental causes



Occupational causes

- Change in daily routine
- Not enough social interaction
- Boredom
- Activities that are too easy or too hard
- Separation from usual social interactions/activities



Relationship with others

- Being asked multiple questions
- Misunderstanding words
- Intimidation
- Multiple staff changes
- Feeling disrespected
- Reaction to others body language
- Not being at eye level when communicating



Agitation and wandering in hospital can be common

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Aggressive behaviour

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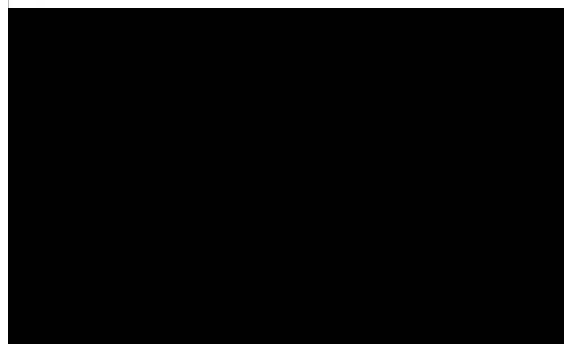


Ways you can help patients

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Some existing volunteer experiences



Summary

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1. Alzheimer's Australia Changed Behaviours Help Sheet
2. Alzheimer's Society UK Unusual behaviour Fact Sheet



Cases Scenario's



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



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

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

For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

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Factsheet 525LP

Last updated: November 2010

Last reviewed: November 2010

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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

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



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SESSION 5: CASE SCENARIOS

Wandering

You are assigned a patient who wants to wander out of their room and keeps entering other people's rooms.

As a volunteer, what would you do?

Some suggested answers:

- Approach the person from the front. Gently say "You are looking lost, can I help you? This may elicit what they are looking for or need
- Ask if they would like to walk with you for a little bit and after walking suggest going back to room for a cup of tea
- Check if they need to go to the toilet and help direct them there. Inform staff if they need assistance with this

Calling out

You are assigned a patient who keeps calling out “help” and names of people you do not know.

As a volunteer, what would you consider and do?

Some suggested answers:

- Go in and sit with them, tell them who you are and that they are in hospital. Ask if you can stay with them for a while. Use touch or hold their hand as appropriate. They may just be lonely
- Check their personal profile to support communication, distraction or other settling activities. Organising some music in their room may assist in settling the person.
- They may have pain or need to go to the toilet. Let staff know if you think this is the case
- Respond to the person’s emotions and feelings, even if you can’t find out who it is they are calling out for.

Suspicion and accusation

You arrive on the ward and go to see a patient who you were assigned the previous week. Last week the patient enjoyed your visit and the activities of reading and talking you did together.

This visit the patient does not seem to recognise you. They are asking who you are and what you want. They seem suspicious of why you are there. When you introduce your self they accuse you of stealing their purse that they had put in their drawer.

As a volunteer how would you deal with this?

Some suggested answers:

- Stay calm. Say you don't have their purse but if they would like you could help them look for it. Explain again who you are. The purse may be in their drawer and they have misplaced it. Inform the staff of the change in the patient since you last spent time with them.
- Stay calm. Tell the person you don't have it but the staff may know where it is and that you will go and ask them. Leave the room and inform the staff of the change in the patient since you last spent time with them. And ask if they know the whereabouts of the purse

Agitation

You are assigned a patient who when you visit is unsettled and agitated, they are fiddling with the bed clothes and pulling on the bed rails as if trying to get out of bed.

As a volunteer what would you consider and do?

Some suggested answers:

- Explain who you are and why you are there. Ask if they are uncomfortable or wanting something. If you think the person may be in pain or discomfort or if they tell you are in pain, tell the person you are going to get a staff member to help them and inform the staff.
- Explain who you are and why you are there and tell them they are in the hospital. Try to distract them by talking to them about the day outside. Ask if they would like a drink or cup of tea. Refer to information on their personal profile to support communication and distraction activities

Repetition

You are assisting a patient with his dinner. He keeps asking you where his wife is but you know from his personal profile that his wife died 2 years ago.

As a volunteer how would you respond?

Suggested answer:

- Ask the person to tell you about his wife, encourage them talking about her - when they were married. Talk about his children (if any) and things he and his wife used to do. This will help distract him from asking where she is and support reminiscence. You may then be able to change to talking about other things in his life.
- Refer to the personal profile to support communication
- Acknowledge his feelings of wanting someone familiar around him and advise him that although his wife isn't there, you are happy to stay with him for a while and have a chat.

Anger

You are on an evening shift and go in to visit a patient who was admitted to the program two days ago. The previous volunteer documents that he had a good morning and enjoyed sitting and having a chat.

When you enter the room the patient seems angry. He demands to know who you are. When you tell him you a volunteer at the hospital he tells he doesn't want to see any one and yells at you to get out of his room.

As a volunteer, how would deal with this?

Suggested answer:

- Stay calm, tell the person you are going, leave the room and report to staff. Inform staff of the noticeable change from when you saw the patient 2 days ago. Do not return until cleared by staff. Inform other volunteers that patient is not to be visited until cleared by staff.

SESSION 6: ASSISTING PATIENTS WITH EATING AND DRINKING

Key Messages

- 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.

Resources

- Laptop and projector.
- Whiteboard.
- Marshmallows.
- Water or orange juice.
- Packaged thickened fluids: a range of mildly, moderately and extremely.
- Packaged oral supplements (have a range of flavours)
- Small plastic cups for tasting.
- Plastic spoons.
- Aids and utensils: non slip placemats; 2 handled cups; built up handles on eating utensils; plate guards.
- Menu examples.

Handouts

- PowerPoint handouts.
- **Handout 1:** Australian Food Standards.
- **Handout 2-3:** Is this a Problem Food?
- **Handout 4:** Alzheimer's Australia Nutrition Help Sheet.
- **Handout 5:** Tips for Caring for a Patient with Swallowing Difficulties.
- **Handout 6:** Standard Fluid Amounts.

Session overview

- Learning outcomes.
- Normal and abnormal swallowing.
- Safety at mealtimes.
- Texture modified food and fluids.
- Undernourishment and dehydration.
- Aids and utensils.
- Oral care and dentures.

SESSION 6: PRESENTATION OUTLINE



Show **Session 6 PowerPoint**.

Slide 2:  **Introduction to practical activity.**

Identify your favourite food or what did you have for breakfast.

Swallowing activity: Eat a marshmallow without using your tongue. **Purpose:** to demonstrate how difficult it is if you have limited or no tongue control.

Slide 3: Objectives of session: Refer to and talk to PowerPoint notes.

Slide 4: Swallowing phases - DVD/pictures (The Process of swallowing Deglutition – Dr Prodigious)
http://www.youtube.com/watch?v=0naM78LJZ_A

Slide 5: Refer and talk to PowerPoint notes.

Slide 6: Refer and talk to PowerPoint notes. Identify patients at risk.

Slide 7: Refer and talk to PowerPoint notes. Discuss signs of swallowing difficulty.


Slide 8: Textured Food and Fluids


Slides 9-10: Refer and talk to PowerPoint notes. Refer to or provide **Handout 1 : Australian Food Standards**

Slide 11: Difficult Foods Group Activity.

Provide **Handout 2 and 3: Food chart exercises**. Participants work in pairs to sort food items into: Sticky; Chewy; Fibrous; Floppy – large pieces that are difficult to handle; Hard and consequently a choking risk. Refer to PowerPoint notes.


Slide 12: Refer and talk to PowerPoint notes

Slide 13:  Ask the group if they think ice cream, ice, ice blocks and jelly are thick or thin fluids?
Correct answer : thin.

Slide 14:  **Activity: Thickened fluids.** Refer to PowerPoint notes for activity instruction (20mins)

Slide 15: Refer and talk to PowerPoint notes.

Slide 16: Maximising safety at mealtime.

Slides 17-20:  Show slide and ask group for correct versus incorrect answers re-positioning at mealtimes. Refer to PowerPoint notes.

Slide 21: Undernourishment and dehydration.

Slides 22-25: Refer and talk to PowerPoint notes.

Slide 26:  **Activity: Trial and experience of different oral supplements.** Refer to PowerPoint notes.

Slide 27: Refer and talk to PowerPoint notes.

Slide 28:  Fluid amounts activity. Refer to instructions in PowerPoint notes.

Slides 29-31: Refer and talk to PowerPoint notes.

Slide 32:  Activity of using the different aids and utensils. Refer to PowerPoint notes.

Slides 33-36: Refer to PowerPoint notes. **Handout 4: Alzheimer's Australia Nutrition Help Sheet.**

Slide 37: Refer to PowerPoint notes. **Handout 5: Tips when caring for patients with swallowing difficulties.**

Slide 38: Option of a short break.

Slides 39-40:



Case study activity on PowerPoint slides 38 and 39. Refer to slide notes.

Slide 41: [Play video of volunteer assisting with meals and menu completion \(13mins\)](#). Discuss.

Slide 42: Refer to **Handout 6: Standard Fluid amounts**.

SESSION 6: POWERPOINT SLIDES WITH NOTES





Ice breakers.

a) Each participant asked to identify their favourite food or tell us what you had for breakfast

b) Swallowing activity – Eat a marshmallow without using your tongue.

Purpose: to demonstrate how difficult it is if you have limited or no tongue control.

Gain feedback from the group

Objectives of session

- Understand the risk and safety issues for patients with and without swallowing difficulties
- Know the correct positioning for patients when assisting them with eating and drinking
- Understand different food and fluid textures
- Understand the effects of undernourishment and poor fluid intake.
- Understand the volunteer role in assisting patients with eating and drinking



Patients will often require assistance and encouragement with their eating and drinking while in hospital.

In many cases this may involve assisting with the setting up for their meal, such as undoing packages, buttering bread and cutting up their meat or chicken so that the patient can eat by themselves. In other cases, patients may need a volunteer to fully assist with their eating and drinking.

In this session on assisting patient with eating and drinking, we will cover:

- Normal swallowing and swallowing difficulties
- The types of patients who are at risk of swallowing difficulties
- Signs of swallowing difficulties
- Important safety and positioning considerations
- What texture modified food and fluids are and why they are used
- Undernourishment and dehydration and why they can occur
- Aids and utensils used to assist patients
- Oral care and
- Your role in assisting patients with eating and drinking

Swallowing

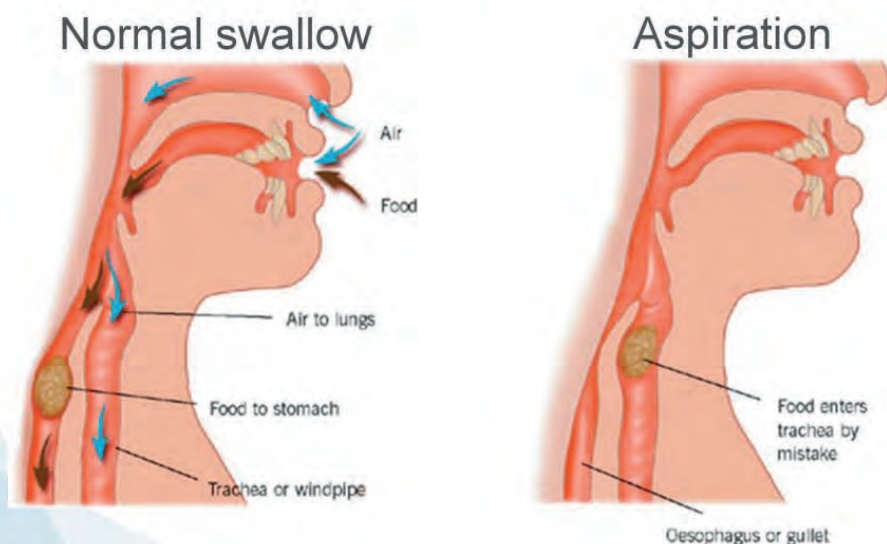
- What is a normal swallow?

http://www.youtube.com/watch?v=0naM78LJZ_A



This You tube link can be used to assist a volunteer's understanding of the process of swallowing.

When swallowing goes wrong...



During aspiration food or fluid can enter the trachea and the lungs. When this occurs it can lead to inflammation or infection of the lungs which can cause aspiration pneumonia.

Patients at risk:

- **Stroke**
- **Breathing difficulties**
- **Dementia**
- **Parkinson's disease**
- **Frail or acutely unwell older people with multiple health issues**
- Head injury
- Head and neck surgery
- Fractured neck of femur or spinal surgery
- Chemotherapy or radiation treatment to the head and neck
- Recurrent chest infections
- Severe disability

Reference: Dysphagia Screening Tool – Queensland Health



Patients at risk of swallowing difficulties in hospitals is common . These are some of the types of patients who are at risk of swallowing difficulties.

Patients highlighted in bold lettering are the most likely patients that volunteers will be assisting.

Signs of swallowing difficulty

- Coughing or throat clearing
- Change in voice quality
- Change in breathing or shortness of breath
- Food residue in the mouth

Reference: ASSIST – Acute Screening of Swallow in Stroke/TIA. Stroke Dysphagia Framework (2004)



SAFETY ALERT: If you are feeding a patient and notice any of the above signs of swallowing difficulty, it is important that you cease feeding the patient and let staff know immediately.



Textured Food and Fluids

Texture modified food and fluids

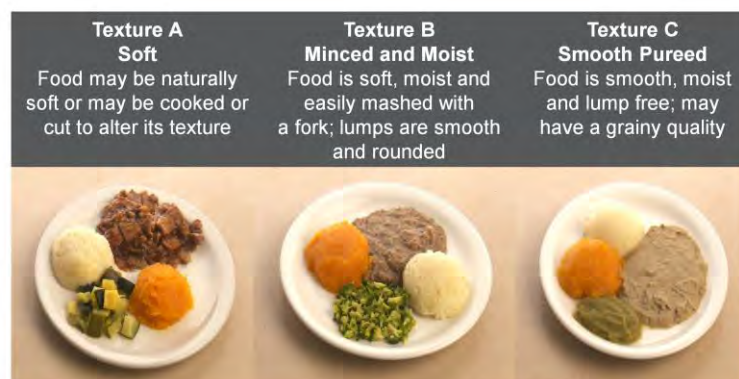
- Many patients require texture modified foods or fluids
- The consistency of food or fluid is altered to make it easier and safer for patients to swallow
- Patients on texture modified diets and fluids are at greater risk of becoming undernourished and dehydrated



When patients have chewing or swallowing difficulties, a texture modified diet or texture modified fluids will be prescribed by a Speech Pathologist. The consistency of the food or fluid is altered to make it easier and safer for patients to swallow. Thickened drinks may be better tolerated, as they move around the mouth more slowly and allow better control when swallowed. The food and fluid texture modifications for patients are not a choice but a necessity for patients who have difficulty chewing and swallowing regular food. A Speech Pathologist will assess patients and then prescribe a diet based on the patient's needs.

A modified diet may be easier for patients to swallow, because of the underlying problems with swallowing and chewing, however, patients on textured modified diets and fluids are at greater risk of becoming undernourished and dehydrated.

Texture modified foods



Source: Australian Food Standards for Modified Foods –Novartis (Nestle)



Although a modified diet is easier for patients to swallow, because of the underlying problems with swallowing and chewing, patients on textured modified diets and fluids are at greater risk of developing malnutrition and dehydration. In addition, the food does look different and consequently patients may find their food unappetising. A volunteer can assist by using a positive approach when assisting patients with their modified food and fluids.

The range of textured modified food diets on this slide which may be ordered by a speech pathologist for patients include:

- Soft diet – naturally soft and moist with minimal cut up required
- Minced and moist diet
- Smooth puree – smooth and lump free
- **Refer to or provide Handout 1:** Australian Standards for Texture Modified Food and Fluids.

Difficult foods

Food chart handout

Some foods (but not all) may cause difficulty with swallowing. Look at the variety of food textures in your handout. Consider how these foods may be difficult to manage because they are:

- Sticky
- Hard (and consequently a choking risk)
- Chewy
- Fibrous
- Floppy



Food Chart exercise



Provide food chart **Handout 2 and 3**

Group activity – Group to work in pairs to sort food items. Given alternating handout 2 and 3 to each pair so that each has one page of food items to work through. Ask participants to identify which foods are:

- Sticky
- Chewy
- Fibrous
- Floppy – large pieces that are difficult to handle
- Hard and consequently a choking risk

Mention that these foods are not often not provided by the hospital but are just used as examples of what may be difficult foods for patients with swallowing difficulties to eat.

Allow 5 minutes for group to work through and 10 minutes for discussion.

Texture modified fluids



Mildly Thick Level 150

Fluid runs freely off the spoon but leaves a mild coating on the spoon



Moderately Thick Level 400

Fluid slowly drips in dollops off the end of the spoon



Extremely Thick Level 900

Fluid sits on the spoon and does not flow off it



Refer to handout 1

The fluid types which can be ordered for patients with swallowing difficulties are:

- Mildly thickened – similar to a fruit nectar consistency.
- Moderately thick – similar to a honey consistency at room temperature
- Extremely thick – similar to a pudding consistency, holds its shape on a spoon and has no flow.

The companies who commercially produce thickened fluids colour code the lids to assist in identifying the different fluid thicknesses. However there can be some variation between the different companies. In general:

Mildly thickened fluids come in varying shades of green.

Moderately thickened fluids come in earthy colours of orange or mauve.

Extremely thickened fluids come in varying shades of blue.

As a volunteer it is important to check that the correct fluid one is being used according to the patients diet menu. If you are unsure always ask the nurse.

Are these thin or thick fluids?



- Ice cream
- Ice
- Ice blocks
- Jelly



Ask the group if they think ice cream, ice, ice blocks and jelly are thin or thick fluids?

Correct answer thin.

These fluids as well as thin watery soups are not suitable for patients who have been prescribed thickened fluids.

Activity: Thickened fluids

- Trial of different fluid thicknesses
- Why do you think patients on thickened fluids are more at risk of dehydration?
- What are some ways you could positively encourage patients who are on thickened fluids to drink?



Resources for practical exercise:

- Different varieties and thicknesses of fluids
- Use plastic spoons and small plastic or paper (medication) cups, to spoon in amounts for volunteers to try
- Have volunteers open the containers to experience the level of difficulty with this task.
- Gain feedback from volunteers about what they think about the taste and consistency of the fluids.

Brainstorm the following questions as a group:

- Why do you think patients on thickened fluids are more at risk of dehydration?
- What are some ways you could positively encourage patients who are on thickened fluids to drink

Assisting patients on texture modified diets and fluids

- On referral, staff will identify if the patient is on modified food or fluids and if they can be safely assisted by a volunteer
- Changes can occur after admission
- Time is needed – don't rush assistance
- Always ask if you are unsure
- Let staff know if you are not confident
- Report any concerns



- When a patient is referred to the volunteer program, the staff will document if the patient has been prescribed modified diet or fluids. They will also decide if it is safe for the volunteer to assist the patient with eating and drinking. Patients on modified diets and fluids may require extra time to eat and drink as well as plenty of positive encouragement. At these times volunteers can be very valuable as they have the time to provide patients with positive encouragement when eating and drinking while assisting them.
- Patients who have severe swallowing difficulties will be assisted by staff and not volunteers.
- In some circumstances a patient may be placed on a modified diet after their admission to the volunteer program because of a change in their condition. In this circumstance a speech pathologist and nursing staff will inform the volunteer whether they are to assist with feeding the patient. If you are unsure ALWAYS ASK the nurse looking after the patient or the speech pathologist if he/she is available. If you are unsure or lack confidence with feeding a patient, please inform the staff.



Maximising safety at mealtimes

It is important that patients are sitting upright and not in a slumped position when they are eating and drinking. Otherwise, they are at risk of swallowing food incorrectly. If a patient is able to sit up and move themselves up in the bed, it may only require a volunteer to use the electric bed control to raise the head of the bed. Alternatively, if the patient is in a chair they may only need a prompt to sit upright. However, frequently after sleeping, patients will have moved or slipped down in the bed or chair and are unable to move themselves up again to be upright, on their own. In this circumstance they will require assistance. Volunteers are not to attempt to move patients on their own. ALWAYS ASK the nurse to assist with correct positioning of the patient in a 90 degree upright position for eating and drinking.

Alertness when eating?

Drowsy?



Alert?



The correct positioning of a patient for feeding is very important.

Group activity where participants indicate if it is safe or not to feed a patient when drowsy or alert.

Correct answers:

Picture 1 – NO

Picture 2 – YES

Patients who are drowsy or sleeping are at risk of swallowing their food incorrectly, or potentially aspirating their food or fluid.

If a patient is drowsy or sleepy at meal time and does not wake up easily the volunteer should not feed the patient but report the situation to nursing staff.

Best position for eating?

Slouched or upright?

Chin tuck or chin extended ?



Group to feedback

Correct answer:

Sitting upright at a 90 degree angle is the safest position for feeding.

The person in picture 1 is at risk for aspirating their food or fluid as the chin and neck are extended. The person should be sitting upright with their chin tucked towards their chest.

Best mealtime environment?

Social or quiet?



Mouth full or mouth clear ?



The best mealtime environment is one without excessive distraction. However, if you are assisting a patient, some social interaction with positive encouragement to eat and drink is important.

Correct answer

Mouth clear – Picture 2

It is important to ensure the person has fully finished and swallowed their mouthful before further intake of food or fluid .

Some patients with dementia can be compulsive with their eating and will try to continue eating while their mouth contains food.

In this circumstance a volunteer can assist by encouraging the patient to slow down and finish one mouthful before having another.

Best option after feeding?



- Sit upright for 5 minutes?
- Lie down in bed?
- Sit upright for 2 hours?
- Sit upright for at least 20 minutes?



To assist with digestion, it is safer that patients remain upright in their bed or chair for at least 20 minutes after a meal (Brockett, 2006). Some patients have delayed gastric emptying so may require a longer period of elevation.

Reference: Brockett, R. (2006). Medical management of patients at risk of aspiration. In J. Cichero, & B. Murdoch (Eds.), *Dysphagia: Foundation, theory and practice* (pp. 112-125). Chichester: Wiley.



Undernourishment and Dehydration

Causes of undernourishment

- Loss of appetite
- Unable to feed themselves
- Social isolation
- Reduction in taste and smell
- Slow eating
- Increased support needs
- Swallowing problems



Poor appetite, weight loss and undernourishment or 'malnutrition' are common in older people in hospitals and in particular those with dementia and delirium. There are a number of contributing reasons. In hospital these patients are unwell, so a poor appetite or interest in food can be common. Additionally, these patients may often be sleepy or drowsy and miss eating their meals. They may eat small portions or may be slow with eating their meals. Patients may be unable to open the different packages that their food arrives in. They may have difficulty with cutting their food or in some cases feeding themselves at all.

Due to the changes in the brain in a dementing illness, patients with dementia may lose the ability to recognise familiar daily items, such as a cup or cutlery and will require guidance or prompting to assist them with eating and drinking. The impact of illness as well as the effects of dementia and other conditions can cause swallowing difficulties which can also lead to undernourishment

Undernourishment

Consequences of undernourishment:

- Longer hospital stay
- Poorer outcomes
- Increased susceptibility to infection
- Difficulty with memory and thinking
- Weakness and reduction in mobility



Some of the consequences of undernourishment in hospital patients are:

- Longer hospital stay
- Poorer outcomes
- Increased susceptibility to infection
- Difficulty with memory and thinking
- Weakness and reduction in mobility

Use of oral nutrition supplements

- These supplements are high in energy and protein and may help a patient meet their nutritional requirements in a quick, convenient form.
- Available in a range of milk and fruit based supplements
- They are usually served between meals.
- Serve chilled and shake before serving.



Oral nutrition supplements can greatly assist patients who are undernourished.

These supplements are high in energy and protein and can assist a patient meet their nutritional requirements in a quick and convenient form.

There are a range of fruit and milk based supplements

They are usually served in between meals.

It is important that they are served chilled and that they are shaken before serving.

If the supplement has been poured into a cup the remaining supplement can be sealed, labelled and put in the fridge for a later period.

It is important that any non - eaten portions of refrigerated foods are labelled with the patients name and placed in the designated fridge for them as soon as possible. Only ever refrigerate or store unopened or non-eaten food portions. Do not refrigerate or store any food that has been partially eaten as this may be contaminated with saliva.

Some oral supplements



Supplements

- Trial of different supplement drinks
- What do you think?



Have a variety of the different supplement for volunteers to trial

Resource

Supplements

Small paper or plastic medicine cups

Ask the group to feedback on the taste/experience

These supplements have been proven to assist patients with their recovery – they are quick to consume and they empty quickly from the stomach making it easier for the patient to manage the next meal.

If a patient is having difficulty drinking the volume offered – consider offering small frequent serves of the supplement.

Also consider the patients preference for flavour.

Dehydration

- Most people need more than 1600ml per day
- Some patients fail to recognise they are thirsty
- Reduced fluid intake often occurs with thickened fluids



Patients who do not drink enough while in hospital is also common. Poor fluid intake can then lead to dehydration. Most people require an intake greater than 1600mls of fluid in a day. That is about 6 – 8 cups of fluid a day or two 600ml bottles of water, or two large cups of tea. In hot weather people may need even more fluid.

If the person does not like water, cordial can be used instead

An adequate fluid intake is even more difficult for people on thickened fluids. As you have seen and experienced there are a variety of pre packaged modified fluids available. The use of pre-packaged modified fluids is the preferred option. However, if the patient does have a fluid they enjoy that does not come pre packaged, thickening powder can be used as per prescribed thickness levels instead.

Dehydration



Activity!

Think about the fluid you drank yesterday

Add up the amounts

Did you drink more than 1600mls?

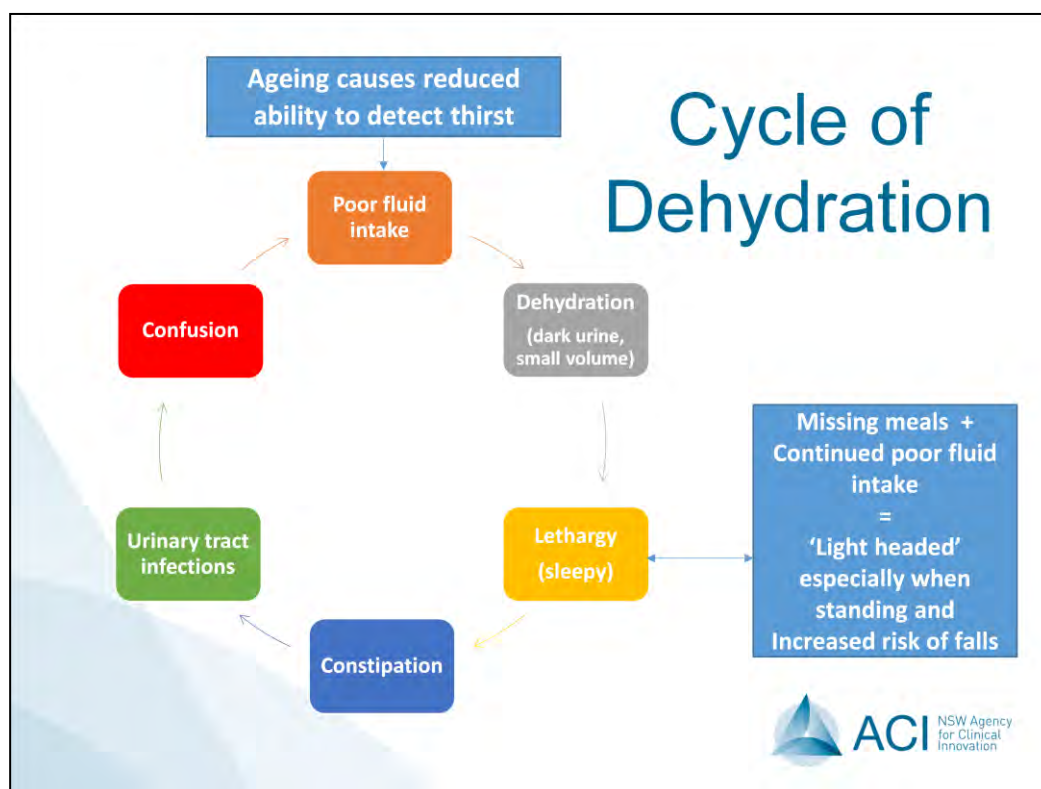


Group activity

Ask each member to jot down and add up the amount of fluid they consumed the previous day.

Ask who in the group drank 1600mls or more?

Discuss answers



The cycle of poor fluid intake can lead to dehydration, concentrated urine which can lead to lethargy, constipation, urinary tract infections and confusion. The patients you will be assisting in your volunteer role will most likely be more at risk of becoming dehydrated. Therefore it is important to ensure these patients are drinking enough fluids.

Dehydration

Tips to improve fluid intake:

- Provide small amounts of fluid regularly
- Have recommended fluids available at all times
- Use suitable cups
- Cordial may make water more acceptable, especially with thickened fluids



For patients with poor fluid intake, offering small amounts of fluids regularly and having it readily available at all times is advisable. Finding out about favourite drinks and using suitable cups for them to drink from, can assist in improving their fluid intake.

Some tips to improve fluid intake are:

- Provide small amounts of fluid regularly
- Have recommended fluids available at all times
- Use suitable cups
- Cordial may make water more acceptable especially with thickened fluids.

Signs or alerts you may see

NIL BY
MOUTH

RESTRICTED
FLUIDS

ENCOURAGE
FLUIDS

THICKENED
FLUIDS

DIETARY
RESTRICTIONS

FLUID
BALANCE



These are some of the signs or alerts you may see. These may be written on a patient's whiteboard near their bed or perhaps be a sign that is placed on or near their bed.

If a patient tells you they have been told they cannot eat or drink anything and there is no sign indicating they are Nil By Mouth, always check with staff.

If you are unsure about any aspect of assisting patients with eating and drinking, always check or ask staff.

Note: It will be useful if the facilitator can provide some examples of the types of signs that may be used in your facility to show to the volunteers.

Oral Care

Bacteria can develop quickly in the mouth when it is not cleaned.

Oral care such as rinsing the mouth after meals can help:

- Prevent infections
- Keep the mouth moist
- Promote patient comfort



Emphasise that poor oral health is associated with an increased risk of oral and chest infections. Oral infection may make it difficult to chew and food intake may be affected.

Dentures

- Check if the patient has dentures
- Ensure these are in place and correctly fitting
- Use gloves when handing dentures to the patient
- If unsure check with staff



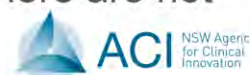
Many older patients will have dentures that they may take out overnight and place in a container of water. Before meals always check that the patient has their dentures in. If not, most patients will be able to fit their dentures in their mouths themselves when they are handed to them.

NOTE: Use gloves if you are handling the patient's dentures

If you think the dentures are too loose or not fitting properly in the patient's mouth, report this to the nurse. If you are unsure or have no experience with assisting people to put their dentures in then ASK the nurse.

In summary

- Ensure a patient is alert and sitting upright at 90°
- Check the tray ticket at mealtimes
- Ensure dentures are in place
- Ensure glasses are being worn
- Check the need for aids/utensils
- Encourage independence
- Avoid distractions during meal times; e.g. TV
- Social mealtimes are fine provided there are not too many distractions



To date in this session we have talked about some of the important ways volunteers can assist patients with their eating and drinking. However there are many other ways volunteers can assist patients in their role. In summary, these include:

- Ensuring the patient is alert – not drowsy and is sitting upright at 90 degrees for their meal. Ask staff to sit the patient up if they are slumped and unable to sit up themselves
- Checking that there is the correct patient's name on the tray ticket with the correct meal. If you think the meal is not the right one for the patient remove the tray or let staff know before the patient starts eating.
- If the patient has dentures check that they are in and fitted properly
- Check if the patient needs any aids or utensils to assist them. These are commonly kept on the meal trolley but this may be different depending on the hospital, so check with staff.
- Encourage the person's independence
- Avoid distractions during meal times such as the TV, but maintain social interaction to support their enjoyment. For many patients texture modified food may not look appetising but often smells and tastes good. Use positive encouragement such as saying "it smells really good, have a taste"

In summary (cont.)

- Use a positive approach to food and fluids
- Assist with undoing packaging and with meal set up as needed
- Recognise individual needs and preferences
- Encourage small, frequent, nutritious meals
- When requested – encourage fluids



Alzheimer's Australia
Nutrition Help Sheet



Assist with undoing packaging and with meal set up as needed. As you have experienced some of the packaging can be very difficult for older people to open or undo.

Refer to the personal profile to find out what is important to them at mealtime and their particular preferences for fluids, or ask the patient or their family carer.

Often patients when they are unwell, cannot eat a full meal at once. When assisting with or filling out menus, think about ordering food that can be stored in the fridge and eaten later. For example yoghurt, jelly or fruit. Or order sandwiches in addition to other food.

If the patient cannot eat all their breakfast, the yogurt can then be labelled and stored in the fridge for later. In this way patients can be encouraged with smaller, more frequent meals.

Although there will be some patients in hospital on restricted fluids, many patients need encouragement to drink more, particularly those on thickened fluids.

While you may be able to help two or three patients with undoing packages and meal set up, you can only assist one patient at a time with their eating

and drinking. It is important that you take your time as this is what the patient needs. Sometime it is helpful to talk with staff about the patients you are seeing and gain advice on prioritising patients who may require your assistance.

Refer to **Handout 4** Nutrition help sheet for further reading

In summary (cont.)

- Take your time
- Oral care – encourage the patient to rinse their mouth or move their tongue around after meals
- Record & report fluid & meal amounts to staff
- Report concerns & ask questions



Tips when caring for patients with swallowing difficulties



Oral care be assisted by asking the patient to move their tongue around their mouth to remove any lodged food and encouraging mouth rinsing.

It is essential that you note down the amount of food and fluids the patient has had each time and report this to staff as per the procedures for your hospital. This is particularly important where patients are on what is called fluid balance charts where their fluid intake and output is recorded by staff.

Finally as we have talked about previously never hesitate to ask if you are not sure about anything, and report any concerns about the patient or your ability to assist them.

Refer to and go through Handout 5

Tips when caring for patients with swallowing difficulties

Time for a short break and stretch!



Encourage the participants to get up, move around, stretch and get a cuppa before the case study and video



A case study to solve!



Activity: Case Study

A 72 year old male is in hospital with mid-stage dementia. He can have a simple conversation. He is underweight and has recently lost 5 kgs in 3 weeks. He requires feeding assistance. He has difficulty swallowing fluids. The speech pathologist has placed him on a minced moist diet with mildly thick fluids.

What will you need to consider when assisting this patient with eating and drinking?



Brainstorm answers as a group and write answers on the board

Answers Case Study 1

- Ensure correct positioning
- Check the patient is awake and alert
- Check he has his dentures in place
- Check the menu and diet order to ensure correct name and meal
- Talk in a positive way about the food – particularly smell
- Ensure the patients finishes each mouthful before attempting another
- Label and store any unopened food in fridge so that it can be eaten later
- Encourage frequent drinking of fluids - Find out preferences
- Encourage moving tongue around mouth to clear food or rinsing if the patient is able to do safely this himself
- Record and report food and fluid amounts to staff
- Suggest trialling an oral nutrition supplement in between meals that is thickened to the prescribed thickness

Practical mealtime support



This Mealtime component of the DVD to highlight the importance of carer and patient interaction with respect to mealtimes. Observe interactions surrounding the intake of food and fluids, checking menus and general safety considerations with posture, mouth care and use of utensils.

Refer Handout 6: Standard Fluid amounts



Ask the group if they have any questions or comments regarding the film clip and discuss

References

- Dietitians Association of Australia (2007), The Authors Journal Compilation. Nutrition & Dietetics 2007, 64 , Supplement 2. 553-576.
- NSW Agency for Clinical Innovation (2011). Nutrition Standards for Adult Inpatients in NSW Hospitals.
- Cichero J., Heaton S., Bassett, L. (2009) Triaging dysphagia: nurse screening for dysphagia in an acute hospital. Journal of Clinical Nursing, 18, 1649–1659
- Stroke Dysphagia Framework April (2004) - ASSIST © Managers of Greater Metropolitan Speech Pathology Services in NSW Health –

Used in Quality in Acute Stroke Care Services (QASC) Trial www.acu.edu.au/qasc



SESSION 6: POWERPOINT HANDOUTS

Agency for Clinical Innovation



Objectives of session

- Understand the risk and safety issues for patients with and without swallowing difficulties
- Know the correct positioning for patients when assisting them with eating and drinking
- Understand different food and fluid textures
- Understand the effects of undernourishment and poor fluid intake.
- Understand the volunteer role in assisting patients with eating and drinking



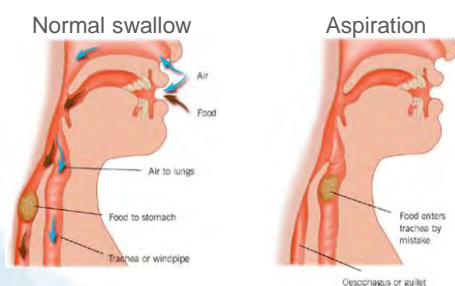
Swallowing

- What is a normal swallow?

http://www.youtube.com/watch?v=0naM78LJZ_A



When swallowing goes wrong...



Patients at risk:

- Stroke
- Breathing difficulties
- Dementia
- Parkinson's disease
- Frail or acutely unwell older people with multiple health issues
- Head injury
- Head and neck surgery
- Fractured neck of femur or spinal surgery
- Chemotherapy or radiation treatment to the head and neck
- Recurrent chest infections
- Severe disability

Reference: Dysphagia Screening Tool – Queensland Health



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Signs of swallowing difficulty

- Coughing or throat clearing
- Change in voice quality
- Change in breathing or shortness of breath
- Food residue in the mouth

Reference: ASSIST – Acute Screening of Swallow in Stroke/TIA. Stroke Dysphagia Framework (2004)



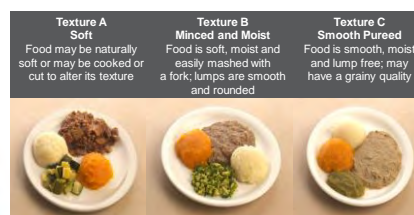
Textured Food and Fluids

Texture modified food and fluids

- Many patients require texture modified foods or fluids
- The consistency of food or fluid is altered to make it easier and safer for patients to swallow
- Patients on texture modified diets and fluids are at greater risk of becoming undernourished and dehydrated



Texture modified foods



Source: Australian Food Standards for Modified Foods – Novartis (Nestle)



Difficult foods

Food chart handout

Some foods (but not all) may cause difficulty with swallowing. Look at the variety of food textures in your handout. Consider how these foods may be difficult to manage because they are:

- Sticky
- Hard (and consequently a choking risk)
- Chewy
- Fibrous
- Floppy



Food Chart exercise



Texture modified fluids



Mildly Thick
Level 150
Fluid runs freely off the spoon but leaves a mild coating on the spoon



Moderately Thick
Level 400
Fluid slowly drips in dollops off the end of the spoon



Extremely Thick
Level 900
Fluid sits on the spoon and does not flow off it



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Are these thin or thick fluids?



- Ice cream
- Ice
- Ice blocks
- Jelly



Activity: Thickened fluids

- Trial of different fluid thicknesses
- Why do you think patients on thickened fluids are more at risk of dehydration?
- What are some ways you could positively encourage patients who are on thickened fluids to drink?



Assisting patients on texture modified diets and fluids

- On referral, staff will identify if the patient is on modified food or fluids and if they can be safely assisted by a volunteer
- Changes can occur after admission
- Time is needed – don't rush assistance
- Always ask if you are unsure
- Let staff know if you are not confident
- Report any concerns



Maximising safety at mealtimes

Alertness when eating?

Drowsy?



Alert?



Best position for eating?

Slouched or upright?



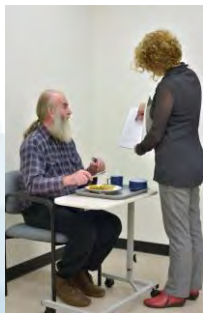
Chin tuck or chin extended ?



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Best mealtime environment?

Social or quiet?



Mouth full or mouth clear ?



Best option after feeding?



- Sit upright for 5 minutes?
- Lie down in bed?
- Sit upright for 2 hours?
- Sit upright for at least 20 minutes?



Undernourishment and Dehydration

Causes of undernourishment

- Loss of appetite
- Unable to feed themselves
- Social isolation
- Reduction in taste and smell
- Slow eating
- Increased support needs
- Swallowing problems



Undernourishment

Consequences of undernourishment:

- Longer hospital stay
- Poorer outcomes
- Increased susceptibility to infection
- Difficulty with memory and thinking
- Weakness and reduction in mobility



Use of oral nutrition supplements

- These supplements are high in energy and protein and may help a patient meet their nutritional requirements in a quick, convenient form.
- Available in a range of milk and fruit based supplements
- They are usually served between meals.
- Serve chilled and shake before serving.



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Some oral supplements



Supplements

- Trial of different supplement drinks
- What do you think?



Dehydration

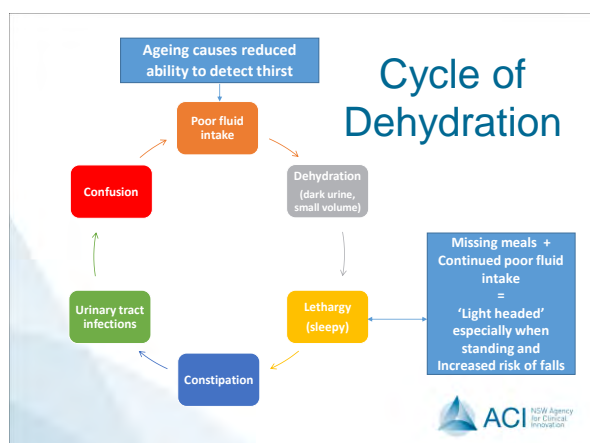
- Most people need more than 1600ml per day
- Some patients fail to recognise they are thirsty
- Reduced fluid intake often occurs with thickened fluids



Dehydration



Think about the fluid you drank yesterday
Add up the amounts
Did you drink more than 1600mls?



Dehydration

Tips to improve fluid intake:

- Provide small amounts of fluid regularly
- Have recommended fluids available at all times
- Use suitable cups
- Cordial may make water more acceptable, especially with thickened fluids



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Signs or alerts you may see

NIL BY MOUTH

RESTRICTED FLUIDS

ENCOURAGE FLUIDS

THICKENED FLUIDS

DIETARY RESTRICTIONS

FLUID BALANCE



Aids & utensils

Activity!



Oral Care

Bacteria can develop quickly in the mouth when it is not cleaned.

Oral care such as rinsing the mouth after meals can help:

- Prevent infections
- Keep the mouth moist
- Promote patient comfort



Dentures

- Check if the patient has dentures
- Ensure these are in place and correctly fitting
- Use gloves when handing dentures to the patient
- If unsure check with staff



In summary

- Ensure a patient is alert and sitting upright at 90°
- Check the tray ticket at mealtimes
- Ensure dentures are in place
- Ensure glasses are being worn
- Check the need for aids/utensils
- Encourage independence
- Avoid distractions during meal times; e.g. TV
- Social mealtimes are fine provided there are not too many distractions



In summary (cont.)

- Use a positive approach to food and fluids
- Assist with undoing packaging and with meal set up as needed
- Recognise individual needs and preferences
- Encourage small, frequent, nutritious meals
- When requested – encourage fluids



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In summary (cont.)

- Take your time
- Oral care – encourage the patient to rinse their mouth or move their tongue around after meals
- Record & report fluid & meal amounts to staff
- Report concerns & ask questions



Tips when caring for patients with swallowing difficulties



A case study to solve!



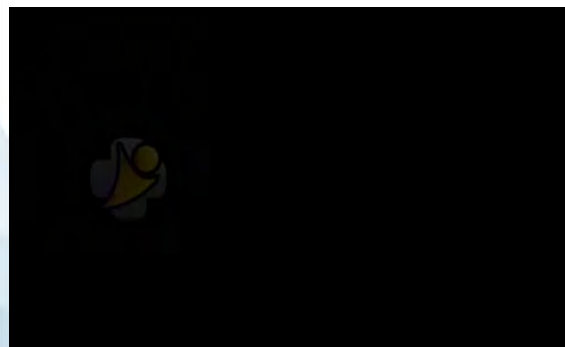
Activity: Case Study

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What will you need to consider when assisting this patient with eating and drinking?



Practical mealtime support



References

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- Stroke Dysphagia Framework April (2004) - ASSIST © Managers of Greater Metropolitan Speech Pathology Services in NSW Health –

Used in Quality in Acute Stroke Care Services (QASC) Trial www.acu.edu.au/qasc



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.

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.









Please contact Novartis on 1 800 671 628 or visit 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 Australia Pty Ltd ABN 46 004 521 513
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For further information, please call 1 800 671 628 (Australia)
or 0800 657 622 (New Zealand) <http://www.novartisnutrition.com>

Fluid		
Mildly Thick Level 150 Fluid runs freely off the spoon but leaves a mild coating on the spoon	Moderately Thick Level 400 Fluid slowly drips in dollops off the end of the spoon	Extremely Thick Level 900 Fluid sits on the spoon and does not flow off it
		
Food		
Texture A Soft Food may be naturally soft or may be cooked or cut to alter its texture	Texture B Minced and Moist Food is soft, moist and easily mashed with a fork; lumps are smooth and rounded	Texture C Smooth Pureed Food is smooth, moist and lump free; may have a grainy quality
		

<p>Is this a problem food?</p> <p>Suggested descriptors- stringy; sticky; floppy; fibrous; chewy; choking risk</p>	
 <p>Bagel crisps Yes/No..... Why?.....</p>	 <p>Fruche Yes/No..... Why?.....</p>
 <p>Cheese crisps Yes/No..... Why?.....</p>	 <p>Frankfurts Yes/No..... Why?.....</p>
 <p>Jelly chews Yes/No..... Why?.....</p>	 <p>Grapes Yes/No..... Why?.....</p>
 <p>Cheese sticks Yes/No..... Why?.....</p>	 <p>Ripe Avocado Yes/No..... Why?.....</p>
 <p>Peanut butter Yes/No..... Why?.....</p>	 <p>Apple Yes/No..... Why?.....</p>

Is this a problem food?

Suggested descriptors- stringy; sticky; floppy; fibrous; chewy; choking risk



Soft Muesli bar

Yes/No.....

Why?.....



Green salad

Yes/No.....

Why?.....



Cooked green beans

Yes/No.....

Why?.....



Jelly

Yes/No.....

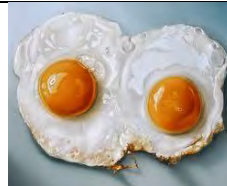
Why?.....



Mixed sandwich

Yes/No.....

Why?.....



Fried eggs

Yes/No.....

Why?.....



Ice cream

Yes/No.....

Why?.....



Nuts

Yes/No.....

Why?.....



Pikelets

Yes/No.....

Why?.....



Chocolate

Yes/No.....

Why?.....

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 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

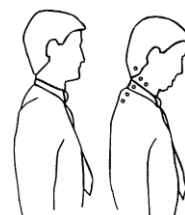
Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at fightdementia.org.au










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

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 for Volunteer/staff Fluid Balance Chart Documentation

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

Source: Bega Valley Dietitians. May 2014

SESSION 7: SAFE WALKING WITH PATIENTS

Key Messages

- Encouraging regular walking is beneficial for many patients.
- Our body language and how we communicate is very important in positively encouraging patients with walking and gentle exercise.
- There are a number of different walking aids that a volunteer may see patients using.
- Volunteers will only walk with patients who are independent or require supervision only either with or without a walking aid.
- Ensuring the safety of volunteers as well as the patients is essential.

Resources

- Laptop and projector.
- Whiteboard.
- Range of walking frames.
- 4 Wheel Frame (4WF)
- Pick Up Frame (PUF)
- 2 Wheel Frame (2WF)
- Fore Arm Support Frame (FASF)
- Walking Stick.
- Chair.

Handouts

- Powerpoint handouts.

Session overview

- Walking aids.
- Mobility terms.
- Encouraging walking.
- Prompting 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.

SESSION 7: PRESENTATION OUTLINE



Show **Session 7 PowerPoint**.

Slide 2: Provide overview of learning outcomes.

Slide 3: Walking Aids and Terms. Refer and talk to PowerPoint notes.



Overview for slide 3

Have available a range of different walking aids. Talk through and demonstrate aids.

Write up abbreviations for walking aids mobility and assistance terms used on whiteboard.

Explain where terms are documented in your hospital for volunteers to be aware of. Eg. Do patients have whiteboards where their mobility status is documented or is it in their care plans?

Consider and inform volunteers how they can check on the patient's mobility status.

Emphasise that will only be walking with patients who are independent or require supervision. This can be with or without a walking aide. Write terms on whiteboard.

Independent - (I) which is no need for any assistance.

Supervision - (SV) needs to have someone watching and directing them.

Demonstrate prompting a patient with standing from chair to walking aid. Emphasis safety aspects for the volunteer.

Slide 4 : Practical and safety considerations.

Show video with practical example of Volunteer walking with patient; what to do if a patient becomes unsteady and what to do if you find a patient who has fallen (7mins).

Slide 6: Summary points.

Slide 6: Discussion and questions.

SESSION 7: POWERPOINT SLIDES



Learning outcomes

- Learn about the common walking aids used
- Learn the common terms used to describe patients walking ability
- How to prompt and encourage patients with standing and walking
- How to position yourself when walking with patients
- What to do if a patient becomes unsteady
- What to do if you find a patient who has fallen



Walking aids and walking terms



Materials for session

The range of different walking aids

Whiteboard and marker

Walking aids

The use of walking aids is common in the hospital. The most common ones a volunteer will be involved with are walking frames and walking sticks.

There are many different types of frames. Some people call the same frame different names.

For example a 4 wheel frame (4WF) is also commonly called a rollator, walker, wheelie walker, pusher or handbrake frame.

Other types of walking aids are:

Pick up Frame (PUF)

2 Wheel Frame (2WF)

Fore Arm Support Frame (FASF)

Walking Stick

Walking assistance terms

There are different terms used for the level of assistance patients require with walking.

These terms can range from no assistance (Independent) to full assistance (FA).- Right terms on board

Explain where terms are documented in your hospital for volunteers to be aware of. Eg. Do patients have whiteboards where their mobility status is documented or is it in their care plans

Consider and inform volunteers how they can check on the patients mobility status

Volunteers will only be walking with patients who are independent or require supervision. This can be with or without a walking aide.

Because of safety issues for patients and volunteers, Volunteers WILL NOT be walking with patients who are unsteady on their feet.

Volunteers will therefore only be walking with patients who have the following terms and abbreviations. These terms are often written on whiteboards near the patient's bed or in the care plan

Independent – (I) which is no need for any assistance

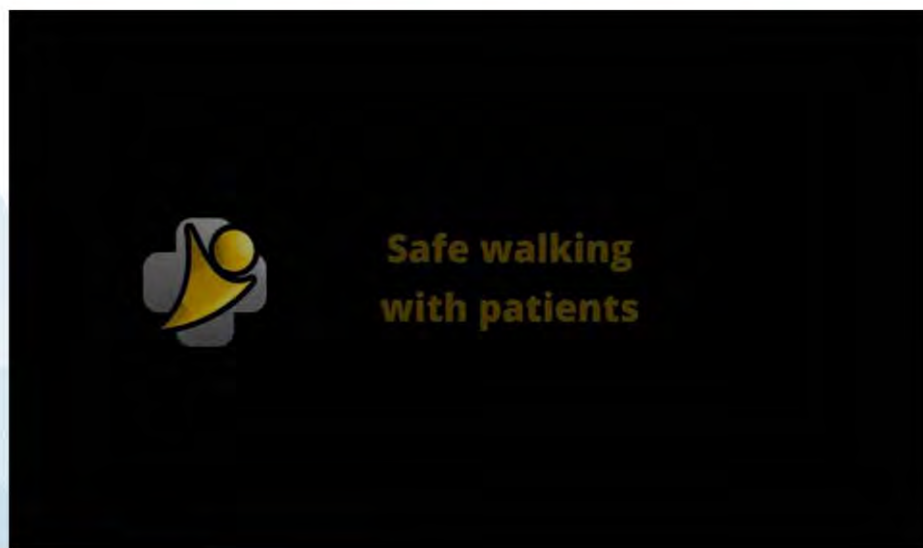
Supervision – (SV) needs to have someone watching and directing them.

Write terms on whiteboard

Even if these terms are used and you are unsure or the patient does not seem safe or steady when they stand up. Do not walk with the patient.

ALWAYS CHECK WITH STAFF.

Practical and safety considerations



Play film scenario covering practical and safety considerations when walking with patients:

Encouraging mobility and safe walking with patients

What to do if a patient becomes unsteady

What to do if you find a patient who has fallen

Discuss any other relevant safety considerations for your service

Summary

- There are a number of different walking aids that a volunteer may see patients using
- Regular walking is beneficial for many patients
- Volunteers will only walk with patients who are independent or require supervision only either with or without a walking aid
- Ensuring the safety of volunteers as well as the patients is essential



Talk to dot points

Any Questions?



SESSION 8: COMMENCING AS A VOLUNTEER

Key Messages

- That volunteers understand their role and the program procedures.
- Volunteers understand reporting lines.
- Volunteers will receive appropriate orientation and support when they commence in their roles.
- Volunteers are aware of the support and governance structure.
- Feedback on the training program is provided.
- Volunteers are acknowledged for their commitment to training.

Resources

- Laptop with speakers and projector.
- Whiteboard and whiteboard markers.
- Post education questionnaire.
- Evaluation form.
- Certificates.
- Camera for taking photos.

Handouts

- Powerpoint handouts.
- Staff and volunteer procedure and resource manual.
- Sample position description –included in manual.
- Orientation checklist.
- Roster template.

Session overview

- The volunteer program procedures for the facility.
- Location of referral folders and process of referral.
- Volunteer sign on and sign off.
- Location of volunteer filing cabinet and desk.
- Volunteer documentation.
- Volunteer reporting.
- Support for volunteers when they commence.
- Volunteer network meetings.
- Continuing volunteer feedback.
- Orientation to the ward.

SESSION 8: NOTES FOR FACILITATORS

1. Practical Session: In this session the procedures for your facility will be covered and discussed. This should include:

- The procedures for the volunteers each shift.
- Signing on and signing off.
- Location of space for volunteers.
- How patients will be referred.
- The location of the referral folder/forms.
- Volunteer documentation forms.
- Reporting lines.
- Identification badges and uniforms.
- Incident reporting.
- Grievances.
- When volunteer meetings are to be held including setting the date for the first meeting.
- The process for continuing volunteer feedback following commencement.

2. Defining volunteer shifts and the roster for the first month. Provide the roster template to participants and ask them to identify which shift they are available for. The template provided has two shifts. 8am-12.30pm and 3pm-7pm. If your service has decided on different shifts this will need to be adjusted. Ongoing roster coordination can also be discussed.

3. Volunteer support on their first shifts. If the program is starting, explain to volunteers how they will be supported in the initial shifts. For subsequent training programs, explain the buddy system and how this will be coordinated.

4. Orientation to the ward: Depending on the size and nature of your facility and the number of volunteers, consideration needs to be given to whether group orientation to the ward/site will be given as part of this session or provided individually when the volunteer commences. The orientation checklist should be used to guide the orientation process. Signed records of the volunteer's orientation to the ward will need to be kept.

5. Evaluation and post education questionnaire: Allow time for participants to complete the training evaluation form and the post program questionnaire

6. Certificate of training completion:

This is an opportunity to recognise the importance and value of the volunteers and their commitment to undergoing the training program. Consider providing a morning or afternoon tea and having a person of authority such as the Manager of the facility or service handout the certificates to volunteers.

Take photos of volunteers receiving their certificates and as a group.

Smaller services may like to invite the local media to promote or showcase the commencement of the program or send a photo and media release following the training.

TRAINING EVALUATION FORM

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.

POST EDUCATION QUESTIONNAIRE

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

ROSTER (TEMPLATE)

Regular Volunteer Shift Times

Time	Monday	Tuesday	Wednesday	Thursday	Friday
8 am – 12:30 pm					
3:30 pm – 8 pm					

Other Availability

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Weekends
Morning						
Afternoon						



Certificate Of Completion

Has Completed The

DEMENTIA & DELIRIUM Care
HOSPITAL VOLUNTER TRAINING PROGRAM

Dates: _____

Coordinated by

DEMENTIAL DELIRIUM CARE WITH VOLUNTEERS EXAMPLE WORKSHOP SESSION PLAN: DAY 1

Session Title	Time	What the session covers	Responsibility	Resources
Session 1: Volunteer Role	8.45am-9.30am	<ul style="list-style-type: none"> Welcome and introductions Facilitators introduce selves Ask volunteers to talk in pairs about each other and then take turns to introduce each other. Program overview Person centered care 		<ul style="list-style-type: none"> Attendance record Pre education questionnaire Note books and pens Volunteer training handbook with Session 1 handouts PP Session 1 Projector Laptop
	9.30am-10.15am	<ul style="list-style-type: none"> Overview of types of patients; patient allocation criteria; prioritization, shifts. Roles and responsibilities/confidentiality Duty description Do's and don'ts for volunteers Overview of roles and responsibilities Volunteer hand book Meetings/support Rostering 		<ul style="list-style-type: none"> Code of conduct Health service volunteer handbook Whiteboard Roster
	10.15am-10.30am	<ul style="list-style-type: none"> Video resource is played in slide 16 		<ul style="list-style-type: none"> Projector Laptop Speakers
10.30am - 11am MORNING TEA				
Session 2: Understanding Dementia and Delirium	11am-11.30am	<ul style="list-style-type: none"> Dementia 		<ul style="list-style-type: none"> PP Session 2 and notes Projector Laptop Speaker
	11.30am - 12.30pm	<ul style="list-style-type: none"> Delirium The Patient Experience The Volunteer Role The Carer Experience 		
12.30pm - 1pm LUNCH				

Session Title	Time	What the session covers	Responsibility	Resources
Session 3: Communication and PCC	1pm-1.45pm	<ul style="list-style-type: none">• Communication• Communication exercises		<ul style="list-style-type: none">• PP Session 3• Projector• Laptop• Speakers• Handouts• Communication exercises
	1.45pm-2.30pm	<ul style="list-style-type: none">• Person centered care• Video of completing the personal profile		
2.30pm -2.45pm				
Session 4: Activities with patients	2.45pm-3.45pm	<ul style="list-style-type: none">• Overview and purpose and range of activities and use of Reminiscence• Using the personal profile to select Activities• Chapter 4 of DVD		<ul style="list-style-type: none">• PP Session 4 and notes• Projector• Laptop• Speakers• Sample completed personal profiles
	3.45pm-4pm	<ul style="list-style-type: none">• Questions discussion of day• Preparation for next day		

DEMENTIAL DELIRIUM CARE WITH VOLUNTEERS EXAMPLE WORKSHOP SESSION PLAN: DAY 2

Session Title	Time	What the session covers	Responsibility	Resources
Review Day 1	8.45am	<ul style="list-style-type: none"> • Welcome and reflections from Day 1 		
Session 5: Understanding behaviours that can occur in Dementia and Delirium	9am-10am	<ul style="list-style-type: none"> • Practical exercise of positive and negative experience • Common Behaviors • Triggers and causes • Practical exercise for visual and hearing impairment • The volunteer role • Safety considerations • Volunteer strategies 		<ul style="list-style-type: none"> • Whiteboard • PP Session 5 • Laptop/Projector/SpeakersHandouts • Vision Australia glasses • Cotton wool
	10am-10.30am	<ul style="list-style-type: none"> • Case studies 		<ul style="list-style-type: none"> • Case Studies and answers
	10.30am - 11am MORNING TEA			
Session 6: Assisting patients with eating and drinking	11am-12.30pm	<ul style="list-style-type: none"> • Normal and abnormal swallowing • Safety at mealtimes • Texture modified food and fluids • Undernourishment and dehydration • Aids and utensils • Oral care and dentures 		<ul style="list-style-type: none"> • Laptop/Projector/SpeakersHandouts • Whiteboard • Marshmallows • Water or orange juice • Packaged thickened Fluids: A range of Mildly, moderately and extremely • Packaged oral supplements • Small plastic cups for tasting • Plastic spoons • Aids and utensils: • Menu examples
	12.30pm-1pm	<ul style="list-style-type: none"> • Stretch • Case Study • Video in slide 41 		<ul style="list-style-type: none"> • Walking aids • Laptop/Projector/Speakers
1pm - 1.30pm LUNCH				

Session Title	Time	What the session covers	Responsibility	Resources
Session 7: Safe walking with patients	1.30pm-2.15pm	<ul style="list-style-type: none"> • The volunteer program procedures for the facility • Location of referral folders and process of referral • Volunteer sign on and sign off • Location of volunteer filing cabinet and desk • Volunteer documentation • Volunteer reporting • Support for volunteers when they commence • Volunteer network meetings • Continuing volunteer feedback 		<ul style="list-style-type: none"> • Laptop/Projector/Speakers • Whiteboard and markers
2.15pm -3pm SHORT AFTERNOON BREAK				
Session 8: Commencing as a volunteer	3pm-4.15pm	<ul style="list-style-type: none"> • Certificates and evaluation 		<ul style="list-style-type: none"> • Post education questionnaire • Certificates • Evaluation form • Camera for taking photos
	4.15pm-4.45pm	<ul style="list-style-type: none"> • Questions discussion of day • Preparation for next day 		

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