

The Dementia Journey

This booklet is for family members, carers and supporters of people who are living with dementia



Dementia Tas - Training & Consultancy

This booklet has been created in collaboration with Dementia Tas and Glenview Community Services.

The information contained in this booklet has been designed to help carers, friends and supporters of people with dementia understand the dementia journey and assist them to walk alongside the person with dementia, providing a supportive and kind hearted relationship.

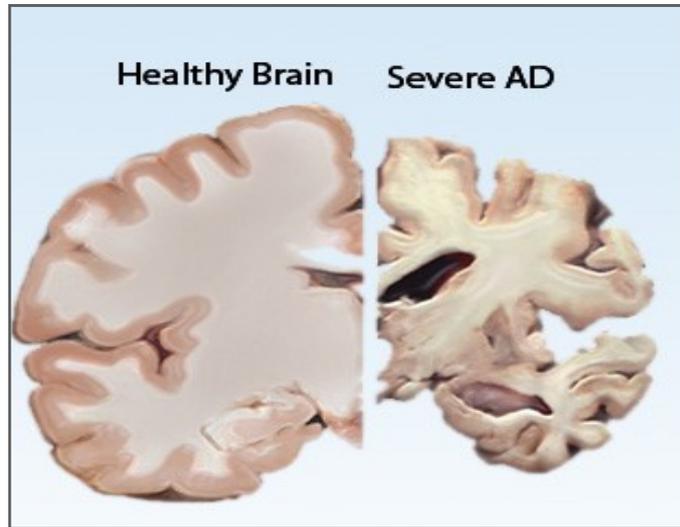


DEMENTIA TAS
GLENVIEW



What is Dementia?

Picture of a healthy brain compared to a brain with severe Alzheimer disease



Dementia is the overall term used to describe progressive changes to the brain.

There IS a difference between dementia and normal ageing.

Dementia is the progressive decline in thinking, memory, daily functioning, personality and social skills.

It's natural to forget things once in a while regardless of age. Some of us become more forgetful as we age and it may take longer to learn new things, remember certain words, or find our belongings.

These changes are often signs of mild forgetfulness, not serious memory problems or dementia.

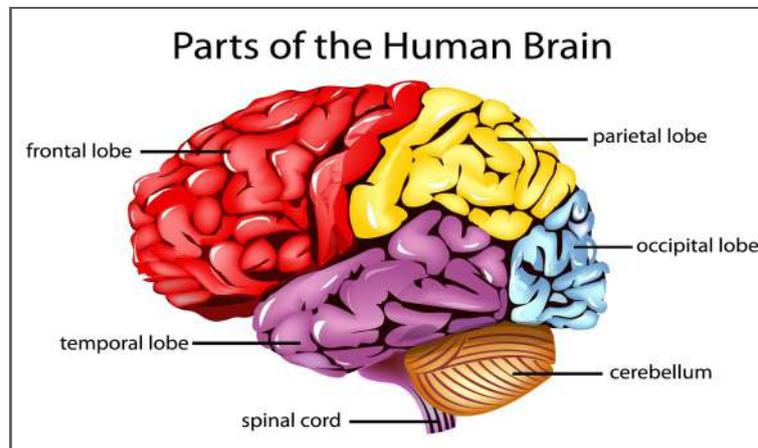
On the other hand, forgetting how to find your way home, the names of friends and family, or how to do everyday tasks may be signs of a more serious problem.

If you are concerned about any changes that may be happening to your brain or memory please contact your GP or alternatively phone or email Dementia Tas for further information.

0438 024 169

ros@dementiatas.com.au

How does dementia affect people?



If dementia is located in the *Frontal Lobe*:

the person may be unmotivated, they may have problems planning and organising activities. People may do things that we think are inappropriate. They may be unable to start or stop an action and be unable to control social skills. They may ask the same question repeatedly.

If the dementia is located in the *Temporal Lobe*:

the person may forget people and events, recent memories may be lost. They may be unable to remember words that are spoken, read, seen or heard.

If the dementia is located in the *Parietal Lobe*:

the person may have problems saying what they want to say, naming common objects and understanding what is said to them. People may have problems finding their way around, and they may be unable to recognise family members. They may have an inability to understand numbers and carry out planned or learned patterns of Movement.

If the dementia is located in the *Occipital Lobe*:

the person may see things that are not real (hallucinations) and their vision may be affected (not corrected by glasses).

These are just some of the ways dementia can impact on people

How is Dementia diagnosed?

Due to the varying nature of the condition and the uniqueness of every person, diagnosis of the type of dementia can often be difficult. It may take quite a long time to diagnose dementia. It is not always possible for the person to be able to participate in blood tests, medical imaging and other medical checks that need to be carried out.

A General Practitioner (GP) is able to diagnose dementia by observing what is happening for the person and asking them questions that require more than 'polite conversational' answers and from listening to those who are supporting them.

Sometimes the person who has dementia can give the GP the impression that they are not experiencing changes in their life, and that everything is okay. However once the GP speaks to others who are close to the person, their diagnosis may change.

Often people who have dementia can be socially appropriate for periods of time, and may act very differently during the visit to the doctor than they do at home during everyday living.

There are many different types of dementia, but it is important to remember that every person will have their own journey with this progressive condition. It is important to understand the PERSON behind the dementia and to relate to them in a supportive and understanding manner.



Some types of Dementia explained.....

Alzheimer's disease

Alzheimer's disease is the most common form of dementia and accounts for between 50 and 70 per cent of all cases. It is a progressive degenerative condition that attacks the brain. As brain cells shrink or disappear, abnormal material builds up as 'tangles' in the centre of the cells and 'plaques' form outside the cells. These disrupt messages within the brain.

Vascular dementia

Vascular dementia is a broad term for dementia associated with problems of circulation of blood to the brain. Vascular dementia may appear similar to Alzheimer's disease. A mixture of Alzheimer's disease and vascular dementia can occur in some people.

Early Onset dementia

Early Onset dementia occurs in younger people (below the age of 65), often when people are in their 50's, but sometimes when people are in their 30's and 40's. Alzheimer's disease is the most common diagnosis for younger people, and it can often be hereditary or genetic.

Dementia with Lewy Bodies

Dementia with Lewy bodies is caused by the degeneration and death of nerve cells in the brain. People who have dementia with Lewy bodies tend to have visual hallucinations, and/or experience stiffness or shakiness as in Parkinson's disease. Their condition tends to fluctuate quite rapidly, often from hour to hour or day to day. These symptoms make it different from Alzheimer's disease. Many people with Lewy Body Dementia cannot tolerate psychotropic medication that is often prescribed for people with dementia.

Fronto temporal dementia

This is the name given to a group of dementias that involve degeneration in one or both of the frontal or temporal lobes of the brain. About 50 per cent of people with FTD have a family history of the disease.

Alcohol related dementia – Korsakoff's syndrome

Too much alcohol, particularly if associated with a diet deficient in thiamine (vitamin B1), can lead to irreversible brain damage. If drinking stops there may be some improvement. This type of dementia is preventable. The

National Health and Medical Research Council of Australia's

recommendations for the safe use of alcohol based on lifetime use is no more than two standard drinks daily for both men and women. Development of alcohol related dementia and Korsakoff's syndrome has not been reported in people drinking regularly at or below these levels. The most vulnerable parts of the brain are those used for memory and for planning, organising and judgement, social skills and balance. Taking thiamine appears to help prevent and improve the condition.

AIDS related dementia

AIDS related dementia, is a complication that affects some people with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). It is uncommon in people in the early stages of HIV/AIDS, but may increase as the disease advances. Not everyone who has HIV/AIDS will develop dementia.

Parkinson's disease

Parkinson's disease is a progressive disorder of the central nervous System characterised by tremors, stiffness in limbs and joints, speech impediments and difficulty in initiating physical movements. Late in the course of the disease some people may develop dementia. Drugs may improve the physical symptoms but can have side effects including hallucinations, delusions and a temporary worsening of confusion and abnormal movements.

Huntington's disease

Huntington's disease is an inherited degenerative brain disease that affects the mind and body. It usually appears between the ages of 30 and 50, and is characterised by intellectual decline and irregular involuntary movement of the limbs or facial muscles. Other symptoms include personality change, memory disturbance, slurred speech, impaired judgement and psychiatric problems. There is no treatment available to stop the progression of the disease, but medication can control movement disorders and psychiatric symptoms. Dementia occurs in the majority of people with Huntington's disease.

There are many other forms of dementia but the most important thing to remember is that every single person who has dementia is on their own individual journey and will experience the condition in their own way. This means that there is no "one size fits all" approach. We must ensure that we meet the required needs of the individual people.

Referenced from papers & articles sourced from UTAS Library: utas.edu.au/library

COMMUNICATING WITH A PERSON WHO HAS DEMENTIA

People who have dementia are very good at picking up our body language and emotions. Here are a few strategies to assist with communication.

Make sure you are aware of your body language and try to remain calm.

Slow down and allow time to connect first before looking for a response. Always give the person time to sense you and feel comfortable.

Try not to rush the person, allow them plenty of time to respond.

Always maintain eye contact and use light touch if it helps the person to concentrate or focus on you.

Ask one thing at a time. Avoid flooding the person with information, suggestions or choices and allow them time to answer (this may take longer than you think).

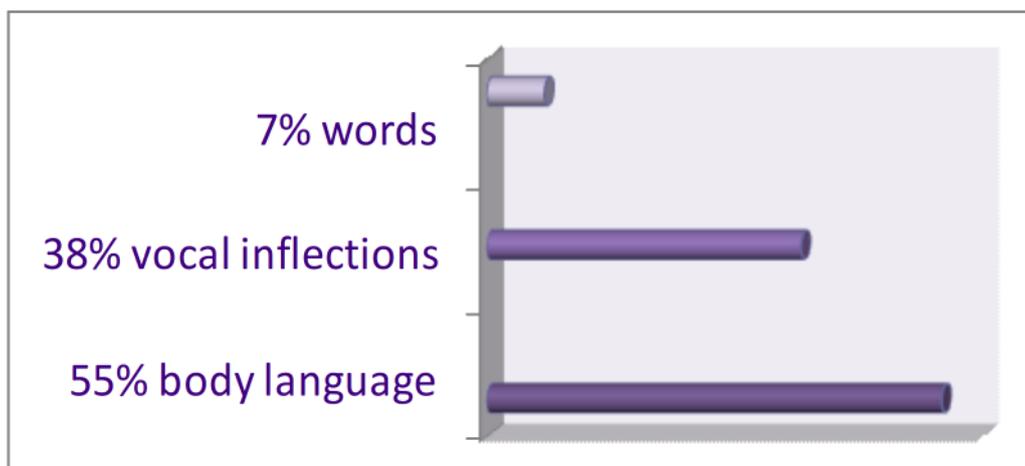
Yes and no questions are easiest for people with dementia to answer. Use visual clues to assist people to understand what you are saying.

Avoid arguing or raising your voice, this can increase confusion and cause people with dementia to feel fearful.

Listen with your ears (what do you hear), your eyes (what do you see) and your heart (what do you know about the person).

Try not to blame the person with dementia for something that may have happened.

COMMUNICATION



Not all of these suggestions will fit the person you visit or support but some may appeal to them.

Be creative with your thoughts.

Remember:

Try not to appear to be 'taking over' tasks or decisions - always include the person with dementia.

Never confront or argue.

Enter into the reality of the person and validate emotions.



Find their key to happiness, creativity and engagement.

Ideas of activities for a Person with Dementia

- Look at a photo album/ memory book
- Eat an ice cream
- Have a 'real' coffee/hot chocolate
- Poetry reading
- Story reading
- Walking/wheelchair tour of the garden/park
- Setting/cutting hair or shaving
- Hand/foot massage
- Manicure
- Flower arranging
- Dusting or cleaning with them
- Tidying cupboards/drawers
- Playing cards/board games
- Making a cup of tea
- Having lunch/tea
- Singing songs
- Watch a DVD
- Write letters/cards
- Read the newspaper
- Visiting with a pet
- Do mending/knitting
- Quiet time
- Reminiscing (talking about past times)
- Jigsaw puzzles
- Attend church services
- Going through a memory box
- Watch football
- Polish silver pieces
- Polish shoes
- Do some cooking together
- Visiting with a baby
- Picking and arranging flowers

Thinking about residential care?

Having to make the decision that a person may need to move into residential care is not an easy time for many people. There are many residential care homes, each offering a different experience for the resident. Some homes have secure units, specifically for people who have dementia, while others follow an integrated community model. Unless the person with dementia is a risk to themselves (or others) then they do not necessarily have to be in a secure unit.

If the time comes for people with dementia to move into a care facility, where possible families should include the person with dementia in the decision making. It will not be an easy process, but if the person with dementia is not included they may feel tricked or deceived by their family, which can create emotional stress for them.

The person with dementia should take personal items that have significance to them, for example a couple of pieces of small furniture (favourite chair, small table, cushions etc) with them. Family should have a conversation with the someone from the care facility to establish what is allowed. Perhaps a favourite bedspread or rug, family photos, a clock or ornaments may be important.

If people with dementia have favourite clothing that they are comfortable in then family members should ensure there are a few items that are exactly the same. Sometimes people with dementia are reluctant to change their clothing, and if items are the same it makes it easier for staff to exchange soiled clothing for clean without the person with dementia thinking their clothes are being stolen when they are taken to the laundry.

Communication books can often work well for family members to communicate with each other or staff about things that are important for the person with dementia.

Create a positive relationship with the care facility staff - tell them as much information as possible to assist the person with dementia settle into their new life.

The following pages may help...

cut along the dotted line

My full name is: _____

I prefer to be called: _____

I have moved from: _____

These are my family members: _____

These are friends who are important to me:

Family Pets: _____



How best to support a person who has dementia

Build a working relationship with the care staff of the care facility.

Provide as much information about the person with dementia as you can to the care workers, so they can get to know the person and understand their needs.

Enquire as to how you can be part of the team in providing the best possible care and support so the person with dementia can live with dignity and quality of life.

Communicate openly and honestly with other family members and always put the wishes of the person with dementia above all others.

Be kind to yourself - take time out for you - remember you are grieving for the person who has dementia - allow time for that process to happen.

If you are not happy with any aspect of the delivery of care provided to the person with dementia, find the right person to talk to (usually a Clinical Care Manager rather than a care worker).

Have realistic expectations and always remember whatever happens should be in the best interest of the person who has dementia.

Give the person with dementia time to settle into the new way of life in care. We are all different, and it takes some people longer to feel settled than others.

If you need further information about dementia or how to provide positive support contact Dementia Tas.

Phone: 0438 024 169

Email: ros@dementiatas.com.au

Website: www.dementiatas.com.au



THOUGHTS FOR FAMILY & FRIENDS

Forgetting & laughing is better than remembering and being sad



Life must be lived with love and humour -
love to understand and humour to endure



A person with dementia may forget what you said
They may forget what you did
But they will never forget how you made them feel



Don't live in the past
Don't dream of the future
But concentrate on the present



There comes a point in our life when you realise who matters
Who never did
Who won't anymore
And who always will
So don't worry about people from your past
There is a reason why they didn't make it to your future
Be kinder than necessary because everyone you meet is fighting some
kind of battle



We cannot change the destiny of people
But we can make the journey easier
We all walk to a different drum
Take the time to learn the beat of your people and walk with them
Sit a while
Listen with your heart and hear the message your people have for you
Teach others so they too may understand the message and learn the
rhythm of life



Dementia Tas - training & consultancy

Since 2010 Dementia Tas has delivered numerous training sessions on dementia and related topics to Age Care & Disability workers as well as family members. Feedback from participants suggests that the training is informative, relevant and easy to understand.

In House Training: Cost effective training tailored to your organisational requirements and supporting positive person focused dementia care practices.

Lifestyle Assessment: An affordable fee-for-service consultation provides staff and/or families with strategies to assist with the changed responses and unexpected actions from a person with dementia.

Family Information Sessions: Assists families adjust to the progressive nature of dementia and empower them to provide positive support for people who have dementia both in residential care and the community.

Dementia Care Mapping (DCM): DCM is an excellent way to determine training gaps or to evaluate programs and/or care for continuous quality improvement. Full comprehensive reports are provided from fully qualified and sensitive professionals.

Structured training: Dementia Tas organises training sessions throughout the year including a quarterly Lifestyle & Leisure Networking session. Registrations can be completed online via the website. (www.dementiatas.com.au)

Contract training: Offering RTO's the opportunity to deliver quality training for the dementia units within aged care & disability training packages.

Experiencing Dementia: Walk in the shoes of a person with dementia. This interactive session will give workers greater understanding of what it might be like to have dementia. Suitable for all levels of staff.

FOR FURTHER INFORMATION ON TRAINING
OPTIONS

PLEASE PHONE 0438 024 169
OR EMAIL ros@dementiatas.com.au





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This booklet has been produced by Dementia Tas
and is proudly supported by
Glenview Community Services



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Created in memory of all the people who have taught me so much
during their dementia journey
Ros Calvert - Dementia Tas