

# DEMENTIA AND FAMILY CARERS CONFERENCE



# What is Dementia?

Belinda Nixon

Dementia Australia



# Dementia is...

The name given to the set of symptoms that are caused by brain disease. Dementia is a **disease process** that affects the way the brain is able to work.

There are many causes and forms of dementia, however, the most common cause is **Alzheimer's disease**.



# A Definition of Dementia

Dementia is a result of a progressive brain disease which significantly affects a person's thinking skills, social skills and the ability to manage day-to-day living.

Dementia is the umbrella term used to describe a collection of symptoms caused by disorders affecting the brain.

Dementia involves a degenerative decline in a person's cognitive and physical ability.

It is not a normal part of ageing

## What is Dementia?

No two people are affected in exactly the same way.

The main characteristic is a person cannot carry out their ordinary daily tasks

# Facts and figures

- "There are currently more than **447,115** Australians living with dementia
- Each day, **250** people are joining the dementia population.
- By 2058, if no medical breakthrough, almost **1,076,129** people will be living with dementia
- There are approximately **27,247** people living with Younger Onset Dementia



# TYPES OF DEMENTIA



**ALZHEIMER'S  
DISEASE**

**VASCULAR  
DEMENTIA**

**FRONTO-  
TEMPORAL  
DEMENTIA**

**LEWY BODY  
DISEASE**

**OTHER**



**dementia  
australia™**

# Signs & Symptoms of Dementia

- poor memory
- disorientation
- mood and personality changes
- less ability to initiate actions

Difficulties with:

- judgement and reasoning
- planning and decision-making
- language
- learning something new
- spatial orientation





# How The Brain Works

## **Frontal Lobes**

- 1) Planning, organising, decision making
- 2) Starting and stopping actions
- 3) Regulation of social behaviour
- 4) Working memory
- 5) Speech generation
- 6) Insight

## **Parietal Lobes**

- 1) Sensory processing
- 2) Attention
- 3) Reading and writing
- 4) Spatial orientation

## **Limbic Region**

- 1) Forming and processing emotions
- 2) Forming and organising memories

## **Temporal Lobes**

- 1) Auditory processing
- 2) Language comprehension

## **Occipital Lobes**

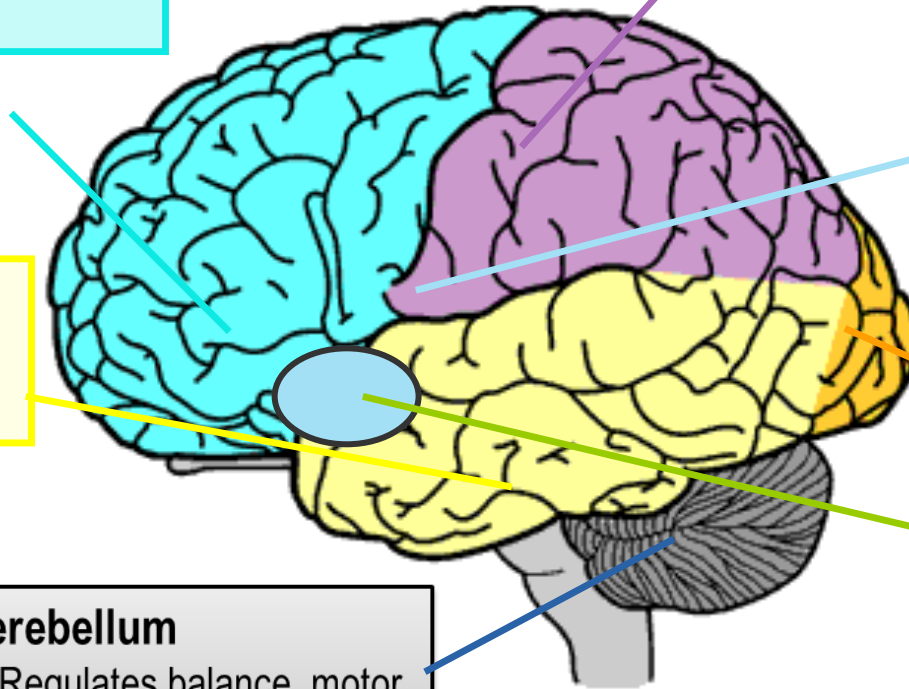
- 1) Visual processing

## **Cerebellum**

- 1) Regulates balance, motor movements, posture, coordination, speech

## **Hippocampus**

- (1) Memories are stored all over the brain, but the process is coordinated in the hippocampus



# Alzheimer's Disease

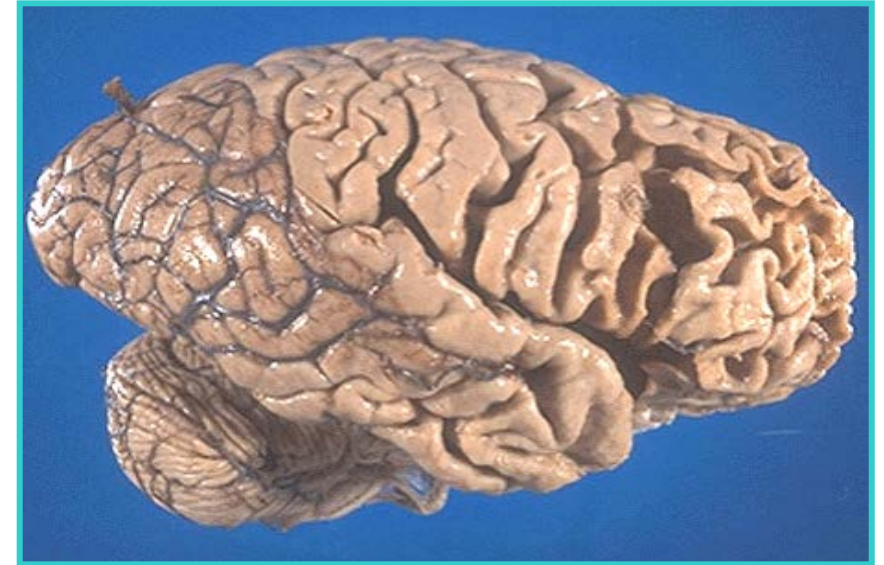
- Build up of protein (beta amyloid) in the brain, causes plaques and tangles
- Ability to learn and memorise new information
- Long term memory is often intact
- Difficulties with spoken and written language
- Ability to recognise people, objects, sounds, smells

# Vascular Dementia

- Caused by disease impairing blood flow to the brain
- Can affect planning, reasoning, judgement, memory, attention, spatial processing
- Behaviour changes depend on areas of brain affected
- Changes can be 'step-like'

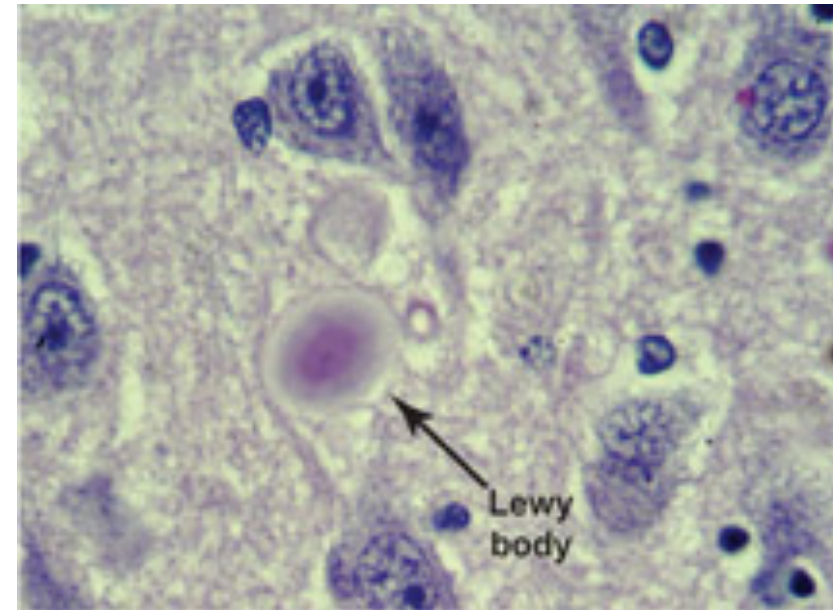
# Frontotemporal Dementia

- Can have language, behavioural or motor symptoms
- Often occurs in younger people (50s-60s)
- Caused by build up of 2 types of protein (Tau & TDP-43) which damage brain cells
- Progressive changes in behaviour, personality, emotions, intellectual abilities, and speech
- Memory often remains intact



# Lewy Body Disease

- Lewy body disease, an abnormal build up of a protein (alphasynuclein) in brain cells
- Spectrum Disease – Parkinson's Disease
- Problems with motor skills and movement, cognitive and behavioural issues
- Hallucinations and delusions



# Mixed Dementia

- People may be affected by more than one disease.
- Most common is Alzheimer's disease and Vascular dementia.
- Alzheimer's disease and Lewy body disease is also common.



# Assessment - complex

- No definitive test
- Personal & family medical history
- Physical, neurological & psychiatric examination to rule out other conditions
- Lab tests, ECG, CT scan, MRI, PET, SPECT, Lumbar Puncture
- Memory, language & cognitive tests eg. MMSE, GPCOG
- Can often involve an initial assessment, followed by re-assessment 6-12 months later for new or changed symptoms

# These Can Make Dementia Symptoms Worse

- Depression
- Sensory loss (*e.g. hearing, vision*)
- Malnutrition (*incl. vitamin deficiency*)
- Dehydration
- Constipation
- Infection (*e.g. urinary tract infection*)
- Medications
- Metabolic disorders (*e.g. diabetes, hypothyroidism*)
- Pain (*e.g. arthritis, tooth ache*)

# Dementia Australia is here to help you



**Call us on 1800 100 500  
to access our services**





**dementia.org.au**

National Dementia Helpline

**1800 100 500**



For language assistance  
call 131 450

# THE IMPACT OF CARING



# This presentation



- **Role of a carer**
- **What caring offers**
- **What carers say – the reality**
- **Possible impacts on ourselves and others**
- **What might help**
- **Questions**

## What's involved



**Partner    child    parent    nurse    doctor**  
**companion    advocate    counsellor**  
**D.I.Y    driver    accountant**

\*\*\*\*\*

**interpreter    protector    peacekeeper**  
**interior decorator    organiser    friend**  
**life coach    nurturer    referee**

\*\*\*\*\*

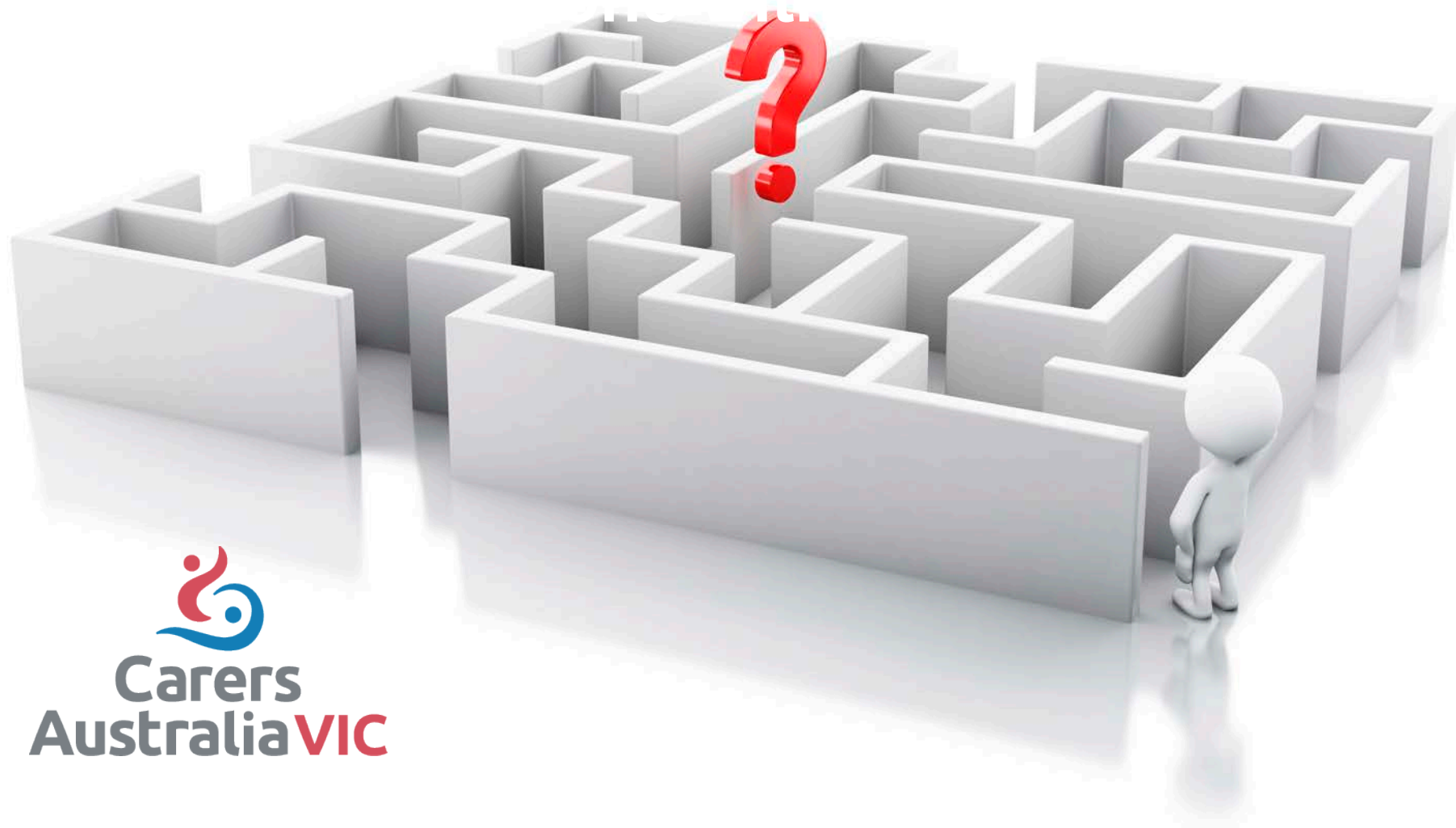
**cook    dietician    secretary    entertainer**  
**decision - maker    EXPERT!**

## Despite the demands....caring can



- **Purpose & meaning**
- **A sense of self**
- **A good feeling**
- **A sense of giving back**
- **A strong identity**

# Same issues – different experience



## Carers have mentioned that they...



- **Feel guilty**
- **Fear I made them unhappy /unwell**
- **Can't be happy when.....**
- **I can't let my guard down**

# If I could just.....



- **Protect them**
- **'Fix' them**
- **Do more**
- **Do it better**
- **Get it right**
- **Cope**
- **Not feel like I've failed**



# What exactly are you trying to manage?



- **Ongoing unwanted change**
- **Cognitive deterioration**
- **Changed behaviour**
- **Losses for the person with dementia**
- **Losses for the carers**

**Resulting in.....**

# Resulting in the.....



# Associated Losses



- **Personality change**
- **Expectations (ours & others)**
- **Relationships**
- **Sharing / companionship**
- **Communication**

# Losses within the caring role



- **Dreams / plans**
- **Friends / hobbies**
- **Choice / control**
- **My needs / role / sense of self**
- **Understanding**
- **Peace**



# How grief can look



## Not always expressed by tears

- Anger
- Frustration
- Confusion
- Apathy
- Resentment
- Withdrawal
- Fear

## What carers say helps.....



- **Learn to trust self**
- **Realistic expectations of self and others**
- **Look after myself**
- **Speak to someone who understands**



# How do I find this help?



**Find the support where it is – rather than where we think it should be:**

- **Support groups**
- **Someone neutral to speak to**
- **Counselling**

# Summary



- **Strong identity**
- **Can be fulfilling / contentious**
- **Considerable impacts**
- **Constantly adapting to change**
- **Help is available**



Mary O'Mara | Counsellor  
Carers Victoria  
Carer Advisory Line 1800 242 636

[www.carersvictoria.org.au](http://www.carersvictoria.org.au)

# DEMENTIA AND FAMILY CARERS CONFERENCE



# Advance Care Planning

Dr Barbara Hayes  
Clinical Lead – NH Advance Care Planning  
[acp@nh.org.au](mailto:acp@nh.org.au)

# *Victorian Medical Treatment Planning & Decisions Act*

- ❑ Came into effect March 2018
- ❑ Is about medical decision-making and consent:
  - Advance Care Planning
  - Consent for those lacking capacity
  - Medical treatment decisions with / without an Advance Care Directive

# Advance Care Planning

Process of planning for future health care

- Where a person's values, beliefs and preferences are made known
- So they can guide or direct medical decision-making in the future
- When that person lacks the ability to make or communicate their decisions



# Advance Care Planning

- Thinking about, talking about and maybe writing down what you would want others to know for future medical decision-making

# Advance Care Planning

- Undertaken by a person with capacity for themselves
- Can involve:
  1. Identification / appointment of **Medical Treatment Decision Maker**
  2. Conversations about **preferences and values** for future healthcare
  3. Writing an **Advance Care Directive**

# The medical treatment decision maker

1. Person's appointed medical treatment decision maker.
  - Includes MEPOA appointed < 12<sup>th</sup> March 2018
2. Guardian appointed by VCAT with power under that appointment to make medical treatment decisions.
3. The first of the following in a **close & continuing relationship**:
  - a. spouse or domestic partner of the person
  - b. primary carer of the person
  - c. adult child of the person
  - d. parent of the person
  - e. adult sibling of the person

**\*\*** If more than one person in the same position, the eldest is the MTDM

**Northern Health**

## Chat & Communicate

Speak with MTDM, families / friends to talk about:

- Things I value are....
- Future situations that I would find too burdensome/distressing in relation to my health are....
- Specific treatments that I would NOT want considered for me are.... ( **and WHY?** )
- This is who I would like to be involved in decisions....

## Put it on Paper

If there is something a person feels strongly about they can write it down and give a copy of their documents to the relevant people. (MTDM, Family, GP, hospital, community nursing etc)

- Advance Care Directive (one form; two parts)
  - Instructional Directive
  - Values Directive

# Advance Care Planning

...is preparing the substitute medical decision-maker for 'in the moment decision making'

*(Sudore & Fried. 2010)*



# Autonomy





# Dementia or Cognitive Deterioration

- Dementia / progressive cognitive deterioration
  - Foreseeable loss of cognitive capacity
  - Prolonged period of impaired capacity ahead
- Cognitive loss might be sudden eg stroke
- Dementia/cognitive loss may be one of many illnesses



# No Advance Care Directive

- ❑ Many people will not have written an ACD
- ❑ They may have done oral ACP
- ❑ There may much that can be known about their preferences and values if we facilitate the discussion



# Learning about the person

The story... of the person and the illness experience

- Establish the illness trajectory
- How did they respond at significant points?
- How have they been coping with the illness?
- What is the worst part of the illness?
- What matters most?
- Have they said anything about this sort of situation?
- What do they fear most?
- What do they hope for?

**Northern Health**

## What I understand to be the person's preferences and values:

Information to help guide future medical decisions for a person who is unable to express their own preferences

*Before you begin, please take a moment to read these instructions*

### Who is this form for?

This form records information about a person who cannot express their preferences about medical treatment. What you write in this form will help the Medical Treatment Decision Maker and health professionals to make medical decisions that the person would want.

This form is only for people who cannot make medical decisions or express what they want. If a person can clearly express their preferences regarding medical treatment, even if they need assistance to write them down, they should complete an Advance Care Directive. Advance Care Directive forms are available on the Office of the Public Advocate website [www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au) or by phoning the Office of the Public Advocate 1300 309 337.

If the person has already completed their own Advance Care Directive, the information in that document would be given priority in medical decision-making over any information in this form.

### Who can complete this form?

This form can be completed by one or more people who know the person well. This can include:

- the person's Medical Treatment Decision Maker (see page iii of these instructions for more information)
- a family member, carer or close friend
- a professional care worker who the person has known for some time and who has knowledge of what is important to the person.

### How can information in this form be helpful?

A Medical Treatment Decision Maker makes medical decisions for a person when that person can't make their own decisions. The decisions should reflect what the Medical Treatment Decision Maker knows about the person's preferences for medical treatment and about what the person values most. The decision should be what the person would want; not what others want.

<https://www.nh.org.au/resources-for-people-who-lack-capacity-to-undertake-advance-care-planning/>

**Northern Health**

# What I understand to be the person's preferences and values form

Can be completed by:

- Medical Treatment Decision Maker
  - Other family, carers, close friends
  - Professional care worker
- ❖ A living document that can be updated



THIS IS NOT AN ACD / ACP DOCUMENT

**Northern Health**

# Consent

*(i) A medical assessment & a medical decision about treatment and what is clinically feasible*

*...then within those constraints*

*(ii) A decision-making discussion between clinician and patient and/or Medical Treatment Decision Maker*

*...leading to*

- Shared understanding of the medical treatment plan including:*
  - Overall medical treatment goals &*
  - Specific emergency medical treatments / limitations*

# Consent

*(i) A medical assessment & a medical decision about treatment and what is clinically feasible*

**‘Everything’**

*...then within those constraints*

*(ii) A decision-making discussion between clinician and patient and/or Medical Treatment Decision Maker*

*...leading to*

- *Shared understanding of the medical treatment plan including:*
  - *Overall medical treatment goals &*
  - *Specific emergency medical treatments / limitations*



# Consent

(i) *A medical assessment & a medical decision about treatment and what is clinically feasible*

**Apply Instructional Directive & RTC**

then within those constraints

(ii) *A decision-making discussion between clinician and patient and/or **Medical Treatment Decision Maker***

...leading to

**Apply Values Directive, other ACP documents, known preferences & values**

- *Shared understanding of the medical treatment plan including:*
  - *Overall medical treatment goals &*
  - *Specific emergency medical treatments / limitations*

## Advance care planning and planning for those who lack capacity for advance care planning

### Resources update

In 2018, the *Victorian Medical Treatment Planning and Decisions Act (2016)* came into effect. This legislation has changed aspects of consent and advance care planning in Victoria. The following information relates to adults.

#### Consent

The Victorian Office of the Public Advocate has an updated **Can your Adult Patient Consent Flowchart**, which provides a very useful summary of medical consent.

<https://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/flowchart-1/341-can-your-adult-patient-consent-flowchart> This is also available as an App.

#### Advance care planning (ACP)

This is planning ahead for future healthcare, for a time when the person may lose capacity to make their own medical treatment decisions. It should be a conversation and it may result in completion of one or more written documents:

- Appointment of a medical treatment decision maker
- Appointment of a support person
- Completion of an advance care directive, which has two parts:
  - i. An Instructional Directive giving future consent or refusal to specific treatments; and/or
  - ii. A Values Directive describing a person's preferences and values that must be given effect to by the medical treatment decision maker when making medical decisions for the person. People who lack medical treatment decision making capacity may still be able to complete a Values Directive.

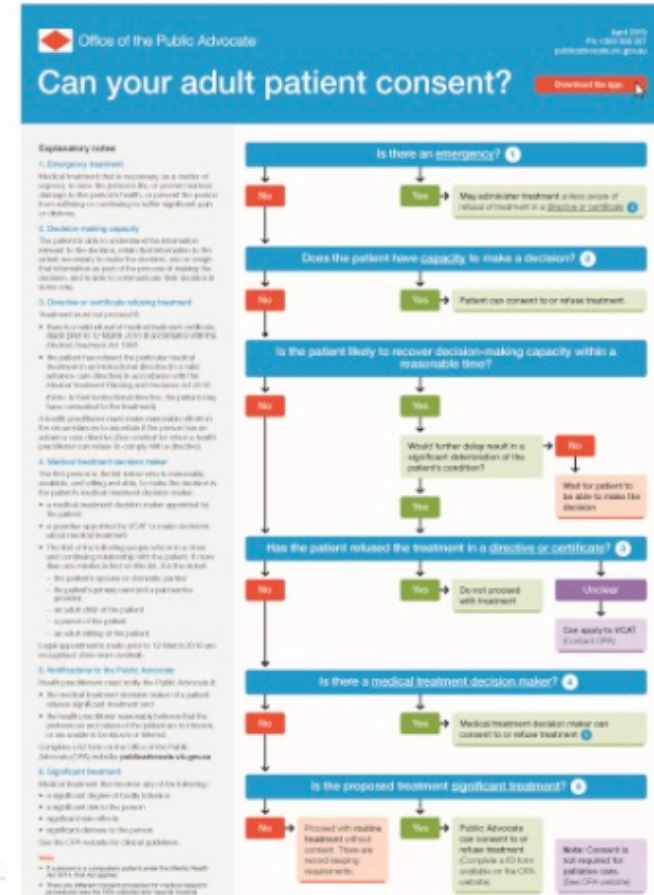
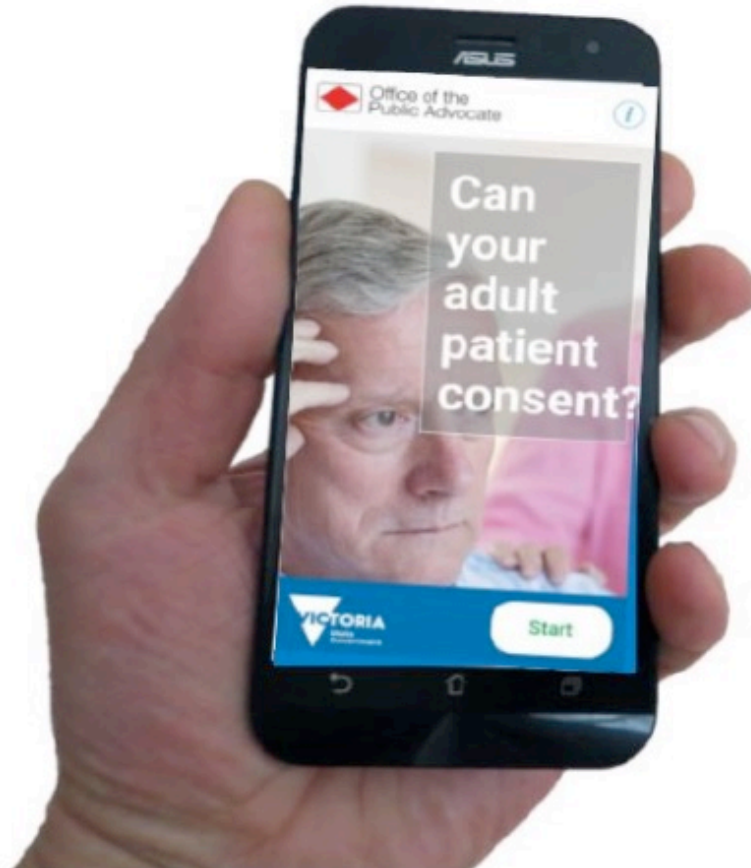
<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/medical-treatment-planning-and-decisions-act>

Completion of an advance care directive is voluntary and based in human rights. If a person lacks capacity to complete an advance care directive, no-one else is permitted to complete it on their behalf. (*See the following section*).

#### Resources for people who lack capacity for advance care planning

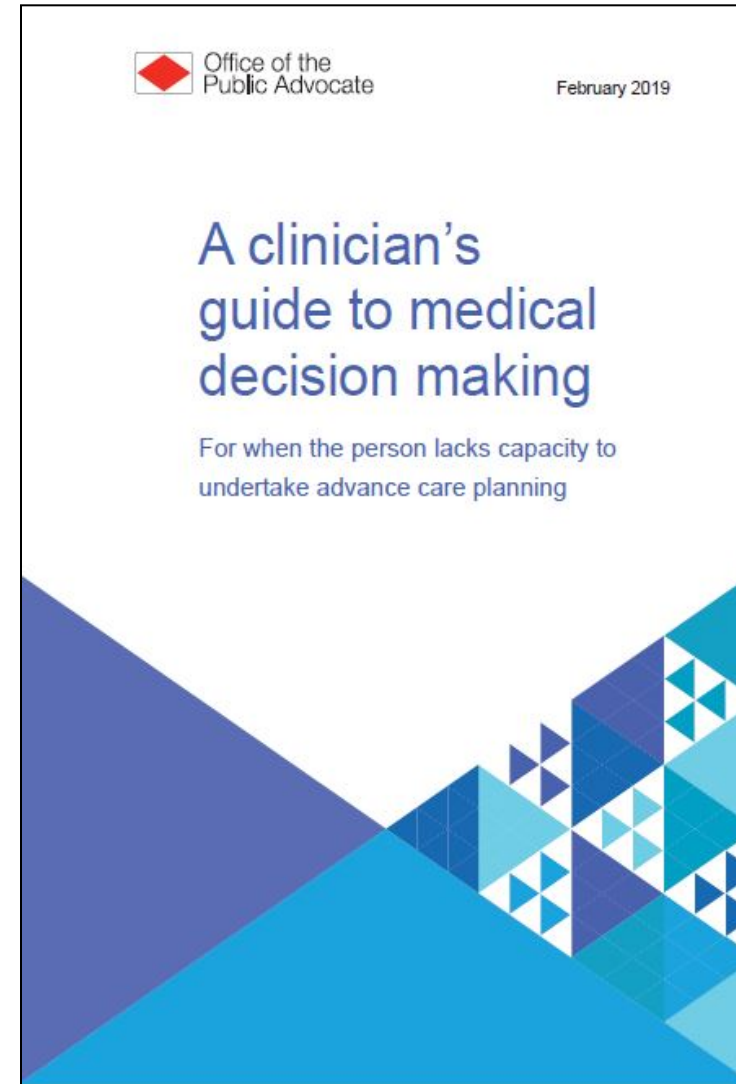
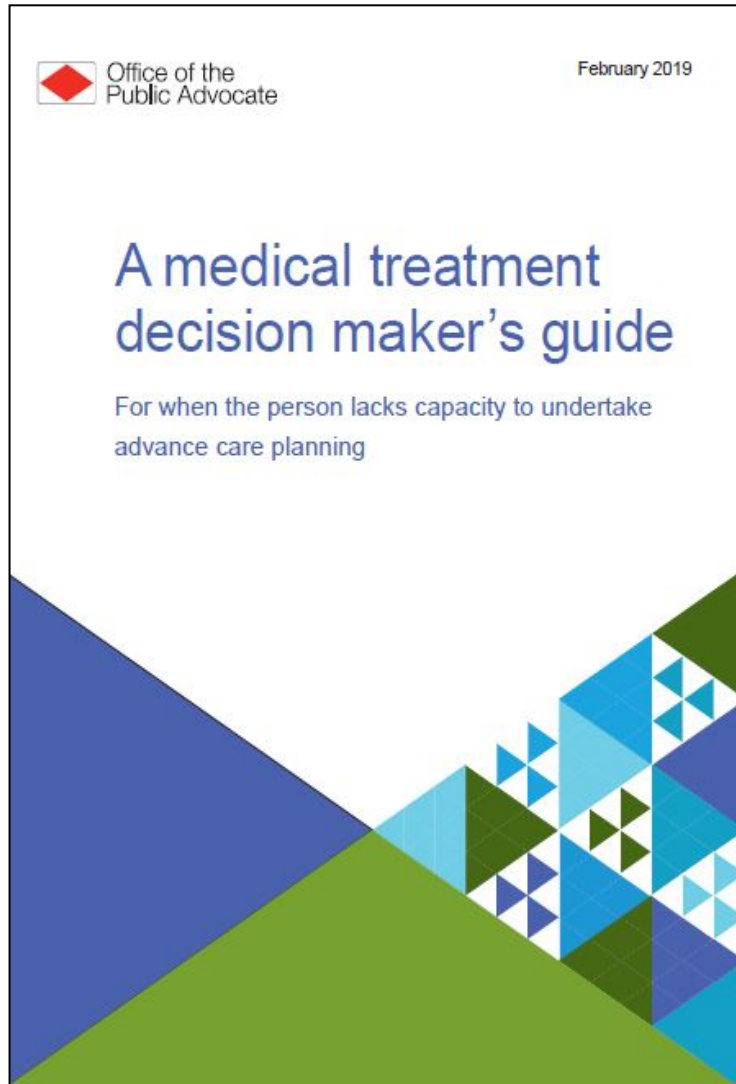
The following resources have been developed by a Working Group of the Department of Health and Human Services Victoria.

# Updated: 'Can your adult patient consent?' flowchart and app



Northern Health

# Resources – Office of the Public Advocate



# Resources

**Department of Health and Human Services - Advance Care Planning:**

<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning>

**Office of Public Advocate Victoria:**

<https://www.publicadvocate.vic.gov.au/>

**Northern Health:**

Advance Care Planning:

<https://www.nh.org.au/service/advance-care-planning/> or [acp@nh.org.au](mailto:acp@nh.org.au)

Resources for people who lack capacity for Advance Care Planning:

<https://www.nh.org.au/resources-for-people-who-lack-capacity-to-undertake-advance-care-planning/>

**Advance Care Planning Australia:**

<https://www.advancecareplanning.org.au/>

**Northern Health**



# DEMENTIA AND FAMILY CARERS CONFERENCE



# JAPARA

## UNDERSTANDING AND RESPONDING TO BEHAVIOUR CHANGES ASSOCIATED WITH DEMENTIA

Ben Gatehouse  
Dementia Strategist



# What is dementia ?

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning.

There are many [types of dementia](#) including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia can happen to anybody, but it is more common after the age of 65.



# What are the early signs of dementia?

The early signs of dementia are very subtle and vague and may not be immediately obvious.

Some common symptoms may include:

Progressive and frequent memory loss

Memory loss

Confusion

Personality change

Apathy and withdrawal

Loss of ability to perform everyday tasks

Language changes

**JAPARA**





**All behaviours = unmet need**

**minimise control , maximise choice**

**Communicate with effectively**

**focus on the person strengths**

**Go with flow of their reality**

**support meaningful occupations**

**stimulate the senses**

**Promote a supportive environment**

**Have a Wellness Approach vs 100% safety**

**JAPARA**

Questions?

Thank  
you!

JAPARA



# DEMENTIA AND FAMILY CARERS CONFERENCE



# **Anita Brown-Major**

***Occupational Therapist***

***BSc Occupational Therapy Hons.***

***Grad Dip Health Science***

***Phone: 0424034096***

***[www.thriverehab.com.au](http://www.thriverehab.com.au)***

***[thriverehab16@gmail.com](mailto:thriverehab16@gmail.com)***





***What is sexuality?***

***Consent***

***Taboo Topics***

***Resources***



# Important

**CASA (center against sexual assault)**  
(Victoria) 1800806292



**Lifeline : 13 11 44**



**Relationship Australia**

**1800RESPECT (Australia) : 1800 737**

*Relationships Australia*



# WHO Definition

*“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.”*

*Influenced by many factors:*

*Psychological*  
*Biological* *Social* *Economic* *Legal*  
*Spiritual* *Political* *Historical* *Ethical*  
*Religious* *Cultural*

WHO (2006) Defining sexual health: report of a technical consultation on sexual health. 28-31 January 2002. Available: <http://tinyurl.com/387umt5>



## Sexuality and Dementia

***‘Sexual sensations are among the last of the pleasure-giving biological processes to deteriorate, and are an enduring source of gratification at a time when pleasures are becoming fewer and fewer.’***

*Roach SM. Sexual behaviour of nursing home residents: staff perceptions and responses. J Adv Nurs 2004;48:371e9.*

# *Sexuality is integral to our personalit y*



## *MOTIVATES US*

*To find love, contact,  
warmth, intimacy*



## *EXPRESSED IN*

*Way we feel, move, touch  
and are touched*



## *INFLUENCES*

*Thoughts, feelings,  
actions, interactions,  
mental & physical health*

**Edward & Coleman  
(2004)**

# Anne & Matt



*Hiding  
under the  
couch to get  
sleep*



*WHO's role is it?*





# *Myths and Misconceptions*



Beware of assumptions!



# *Aging and sexuality - the reality*

- ***Interest in sex***
  - ***70% Men >65yrs***
  - ***50% women >65yrs***
- ***Sexual activity in last month***
  - ***53% 65-74yrs***
  - ***26% 75-85yrs***



*Those who were sexually active - more likely to rate health status positively*

## Residential Aged Care

Oh yes, yes,  
yes, I do miss  
intimacy . . .  
companionship  
and love.

87 year old man with dementia

I don't see anything  
wrong with it (sex).  
It's happened since  
time began. These  
people (staff) can't  
alter it.

80 year old man with dementia

We've tried to  
lie on the one  
(single) bed and  
there just isn't  
room.

90 year old married woman

Michael Bauer, Deirdre Fetherstonhaugh, Laura Tarzia, Rhonda Nay, David Wellman & Elizabeth Beattie (2012): 'I always look under the bed for a man'. Needs and barriers to the expression of sexuality in residential aged care: the views of residents with and without dementia, *Psychology & Sexuality*, DOI:10.1080/19419899.2012.713869



“Residents, including those with dementia, **saw themselves as sexual beings and with a continuing need and desire to express their sexuality.....**

**Many barriers to sexual expression were noted,** including negative attitudes of staff, lack of privacy and limited opportunities for the establishment of new relationships or the continuation of old ones.”

- ▶ Michael Bauer, Deirdre Fetherstonhaugh, Laura Tarzia, Rhonda Nay, David Wellman & Elizabeth Beattie (2012): 'I always look under the bed for a man'. Needs and barriers to the expression of sexuality in residential aged care: the views of residents with and without dementia, Psychology & Sexuality, DOI:10.1080/19419899.2012.713869

# Heteronormativity

“The concept of heteronormativity refers to a general perspective which sees heterosexual experience as the only, or central, view of the world.”

Harrison, J. (2001). 'It's none of my business': Gay and lesbian invisibility in aged care. *Australian Occupational Therapy Journal*, 48(3), 142-145. doi: 10.1046/j.0045-0766.2001.00262.x



# *Capacity & Consent*

## *Decision Making Capacity*

*Capacity is specific,  
not global.*

*A person is presumed  
to have decision  
making capacity  
unless there is  
evidence to the  
contrary.*

*Section 4 Power of Attorney Act 2014*



***Capacity relates to a person's decision making ability - not the particular decision that they make.***

***Is engagement in sexual behavior closer to decision about to have ice-cream or not, or is it closer to consenting to surgery?***

***Richardson JP, Lazur A. Sexuality in the nursing home patient. Am Fam Physician 1995;51:121e4.***



*How do  
we assess  
Consent?*

Signals of Sensor**Sensory-Emotional-physical**  
*consenting to sexual interaction in people living  
with dementia* ∴

Overt (visible) signs of pleasure, relaxation, contentment, happiness, and/or engagement with the other person.



**Leaning toward the person**

**Eye contact or looking at the person**

**Smiling at the person or with them**

**Relaxed posture**

**Touching the person (may be mutual – hand holding)**

**Transient – Moment to Moment**



# Indicators of no consent



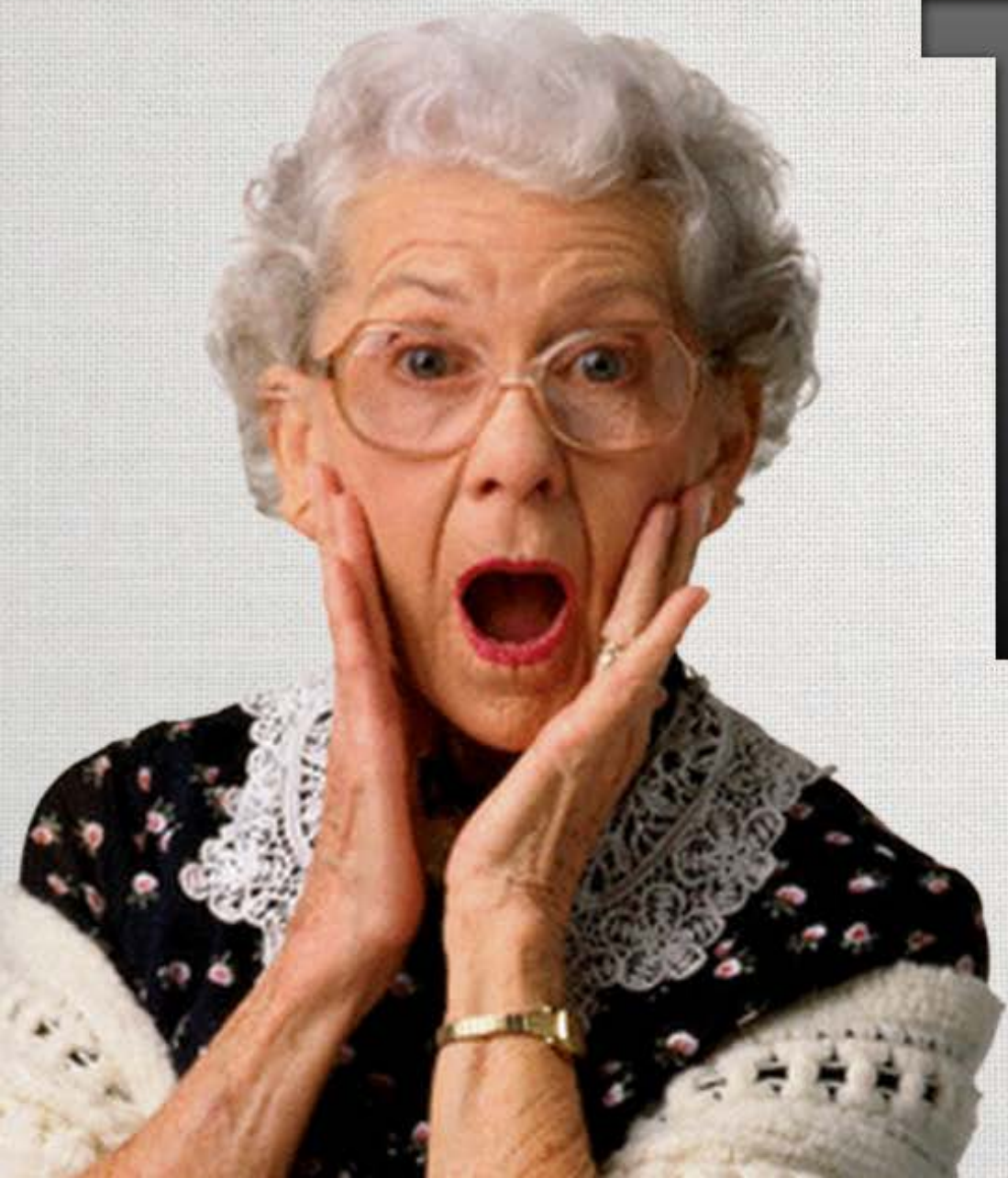
**Negative mood and/or disengagement**

**No signals = No consent**

**Passive acceptance of the other person is not consent. Freezing.**

Bernie McCarthy (2011) *Hearing the Person with Dementia*  
*Person-centred Approaches to Communication for Families and caregivers.*






# Taboo

Discussing the difficult.



A photograph of a man with grey hair, wearing a blue jacket and an orange backpack, reaching out with his right arm to assist another person. The person being assisted is wearing a blue jacket and is partially visible on the left side of the frame. They are in a forest setting with trees and greenery in the background. A semi-transparent white circle is overlaid on the image, containing text.

“Caretaking is a powerful  
anti-aphrodesiac”

“Responsibility and desire  
butt heads”

- Ester Perel



*Inappropriate  
behaviour*



# Behavioural Assessment and Specialist Intervention Consultation Service (BASICS)

## What we do

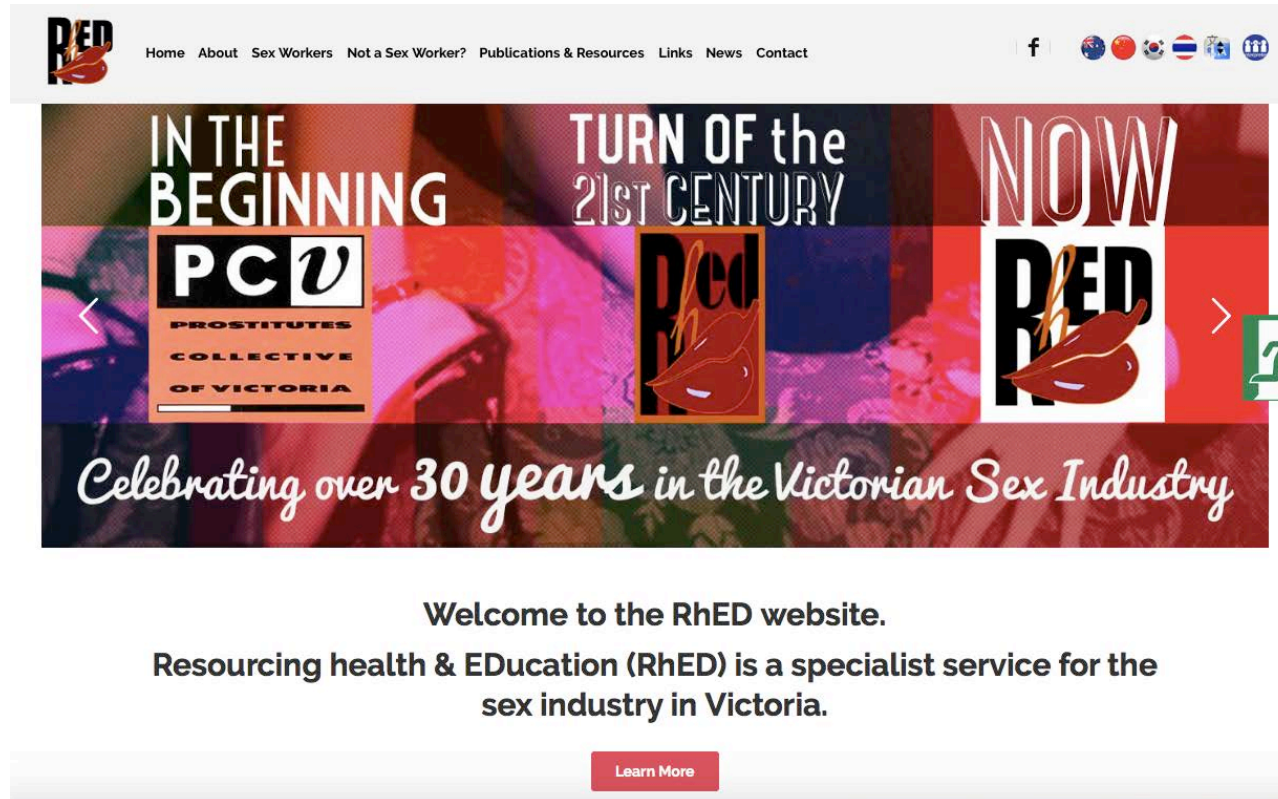
The Behavioural Assessment and Specialist Intervention Consultation Service (BASICS) provides support to consumers with a mental health concern or a dementia living in a residential care facility, their family and those providing their care.

Our services include:

- providing information and advice
- education and tailored information workshops
- assessments
- assistance with case management and care planning
- mentoring and modelling of behaviour management techniques

We endeavour to better understand and respond to each person as a unique individual and to work collaboratively to enhance well-being and quality of life.

# Rhed - Victoria



# Carers re-partnering





# Carers re-partnering

## **RADIO NATIONAL**

Earshot program : The three of us.

[www.abc.net.au/radionational/programs/earshot/the-three-of-us/7556598](http://www.abc.net.au/radionational/programs/earshot/the-three-of-us/7556598)

*We all know about the plight of the thousands of unrecognised, unpaid, exhausted carers in this country. But their sex life? Their romantic life? The intimacy they are wordlessly expected to give up remains an unspoken taboo.*



# Lubricants

## ***Lubricants***

### ***Water***

*( won't harm rubber toys, flush out easily but they do dry up)*

### ***Silicone***

## ***Ingredients (parabens, allergies and Consistency***

*(refer to [www.comeasyouare.com](http://www.comeasyouare.com)) ( Luke warm sex, episode 2)*



# Conclusion

*THANKYOU*

*Anita Brown-Major*

*Occupational Therapist*

*Thrive Rehab*

*Email: [thriverehab16@gmail.com](mailto:thriverehab16@gmail.com)*

*[www.thriverehab.com.au](http://www.thriverehab.com.au)*

*Phone: 0424034096*





# *Sexuality Shops*

- ▶ *What's in your area?*
- ▶ *What shops are on line?*
- ▶ [www.comeasyouare.com](http://www.comeasyouare.com)
- ▶ [Lovehoney.com.au](http://Lovehoney.com.au)

# *Decision Making Capacity*

*Capacity is specific, not global.*

*A person is presumed to have decision making capacity unless there is evidence to the contrary.*

*Capacity if :*

- Understand the information relevant to the decision and effect of the decision and*
- Retain that information to the extent necessary to make the decision; and*
- Use or weigh that information as part of the process of making the decision; and*
- Communicate the decision and the person's views and needs as to the decision in some way, including by speech, gesture or other means.*



# Consent

*Not black and white.*

<https://youtu.be/h3nhM9ULJjc> - *Consent for kids*

<https://youtu.be/fGoWLWS4-kU> *Consent is like a cup of tea*

<https://youtu.be/-JwIKjRaUaw> *Consent and bike riding*

<https://youtu.be/TD2EooMhqRI> - *video on consent by Laci Green*

<https://youtu.be/EvGyo1NrzTY> *TED talk on consent ... great*

# *Aged care homes with policies*



**Uniting**



Melbourne man Brian\*, a carer for his wife with frontotemporal dementia, says medical professionals should be talking to patients and their partners about the impact of illnesses on sex and relationships. (ABC News: Margaret Burin )

# SEXUALITY ASSESSMENT TOOL (SexAT) for residential aged care facilities



**Australian Centre for Evidence Based Aged Care (ACEBAC)**  
A centre of the  
**Australian Institute for Primary Care & Ageing (AIPCA)**  
**La Trobe University**

# Videos Clips

<https://youtu.be/eMAJHmoj9zs> *Insight 2016, Ep10: Sex and Disability (full episode)*

<https://youtu.be/qA020ShNQr8>  
*(Sex)abled: Disability Uncensored*

<https://youtu.be/TD2EooMhqRI> *Consent LacciGreen*



# DEMENTIA AND FAMILY CARERS CONFERENCE





# Eastern Palliative Care

Lee-Anne Henley Palliative Support Nurse

“Why people living with dementia should have access to palliative care”



Eastern Palliative Care Association Incorporated acknowledges  
the support of the Victorian Government



# What is a Palliative Approach?

Optimal care & comfort

Relieves distressing symptoms

Aims to improve quality of life

Anticipates future problems

Holistic approach & family support



# Why does it apply to people with dementia?

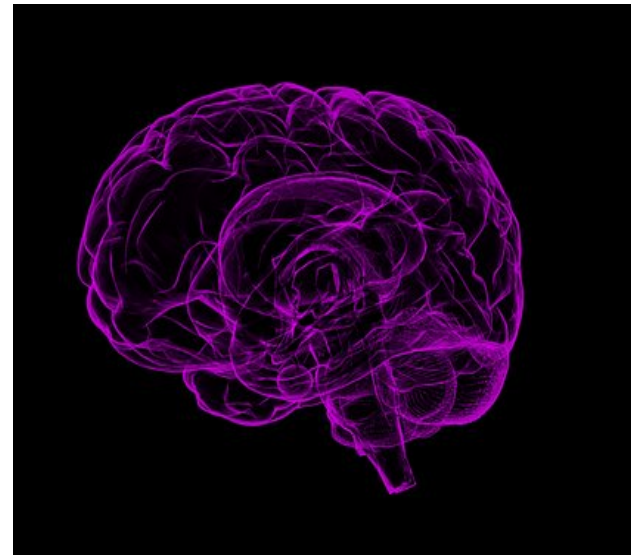
Dementia is a life limiting illness

Behavioural, physical & cognitive difficulties

Potential for later issues with communication

Other co morbidities

Support need for families is high



# Communication

Person with dementia has difficulty recognising and communicating their needs

Nursing or medical staff may not detect symptoms i.e. pain



# Falls

Muscle weakness, lack of balance and vision disturbance leads to falls.



# Susceptibility to infections

Increased vulnerability to infection.





# Hospitalisation

Ambulance transfer,  
Emergency Department  
and lengthy stay can be traumatic.



# Weight Loss

Nutrition & Hydration  
Swallowing difficulty



# Pain

- Recognition of pain
- Treatment may reduce behavioral symptoms



# Services available

- Specialist Palliative Care for complex needs
- Palliative approach to care in Aged Care Facilities
- Information online
- [www.caresearch.com.au](http://www.caresearch.com.au)



# References

Chang, E. (2011). *Dementia, information for carers, families and friends of people with severe and end stage dementia*. University of Western Sydney

Chang, Esther & Johnson, Amanda. (2012). Challenges in Advanced Dementia. 10.5772/31294.

Hudson, R., & Allan, R. (2012). *Affirming life: What is a palliative approach? A guide for family and friends with loved ones in aged care*. Tasmania: Dept of Health and Ageing.

World Health Organization. WHO definition of palliative care. [cited 2018 February 19]. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>



every day.



Eastern Palliative Care is a partnership between the Order of Malta, Outer East Palliative Care Service Inc. and St Vincent's Hospital (Melbourne) Ltd



Eastern Palliative Care acknowledges the support of the Victorian Government



# DEMENTIA AND FAMILY CARERS CONFERENCE

