

# Supported Decision-Making

A person with decision-making ability has the right to make decisions about their own life and if required, also the right to support, help and assistance in making decisions. We call this 'supported decision-making'.

This is different from 'substitute decision making', which is when someone else 'steps in' and makes decisions for a person.

There are a range of ways that people living with a dementia can be supported to make, or communicate decisions about their lives. A new free resource is available to better understand the issues relating to supported decision-making for people living with dementia.

Download this great new resource for people living with dementia and their care partners



The authors of this new booklet, the Cognitive Decline Partnership Centre (CDPC) aim to improve the lives of people with dementia by developing, communicating, and implementing research that improves care.

According to the CDPC, decisions may relate to healthcare, finances, lifestyle and personal matters. Supported decision-making is also to be found in everyday interactions, that enable people living with dementia to stay involved in decisions about their lives.

## A person has decision-making ability if they have:

- The ability to understand the information relevant to the decision
- The ability to use this information to weigh up options
- The ability to retain information long enough to make a decision
- The ability to communicate their wishes in some way (not necessarily verbally)

People are presumed to have decision-making ability, unless proven otherwise.

Decision-making can occur in different areas.

Some examples are:

 **HEALTHCARE** (e.g. agreeing to or refusing medical treatments or other healthcare)

 **LIFESTYLE** (e.g. living arrangements and relationships)

 **FINANCIAL** (e.g. use of money, gifts)

 **EVERYDAY** (e.g. weekly shopping, personal care, household jobs)



## The Byron carer

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[www.byronrespite.com.au](http://www.byronrespite.com.au)

Byron Shire Respite Service is located at the Brunswick Valley Community Centre, South Beach Rd, Brunswick Heads.

Our incorporated non-government community based organisation is managed by a local committee and covers the shires of Byron, Ballina and Lismore.

Respite care is delivered through our Changed Behaviour, Day Respite and Social Support projects, with a person centred enablement approach across the respite continuum.

Telephone Barbara Chambers on:  
02) 6685 1619  
or Colin Munro: 02) 6685 1921

Website: [www.byronrespite.com.au](http://www.byronrespite.com.au)  
Email: [service@byronrespite.com.au](mailto:service@byronrespite.com.au)



Byron Shire Respite Service acknowledge and pay respect to the Arakwal people of the Bundjalung nation, the traditional owners of the land on which we live and care – and pay respect to the Elders past, present and emerging.

continued overleaf ►

### How can supporters provide help in making decisions?

Things to consider:

- Know the person well.
- Identify other potential supporters.
- Learn about the person's wishes.
- Understand any special needs that the person has in decision-making.
- Identify the best time and place to assist the person in working through decisions.
- Collect relevant information in advance.
- Present options in a balanced way.
- Simplify options if needed.
- Explain things several times if needed.
- Put your own wishes aside.
- Help the person communicate their wishes to others.

The **Supported Decision-Making** project and accompanying booklet completed late last year was undertaken by a multidisciplinary group of investigators, including consumer representatives, clinicians and researchers with backgrounds in psychology, medicine, law and aged care. They worked closely with advisory groups across Australia to better understand the issues relating to supported decision-making for people living with dementia. The booklet also draws from over 100 interviews with people living with dementia, their family members and professionals over the three years of the project and includes practical tips and suggestions, provides a step-by-step approach to put supported decision-making into practice and a 'My decision Support Plan' to complete and keep for future reference.

To find out more and download your copy of the Supported Decision-making booklet and 2 page fact sheet, visit the Cognitive Decline Partnership Centre at: <http://sydney.edu.au/medicine/cdpc>

## What is motor neurone disease?

**Nerve cells (neurones) control the muscles that enable us to move, speak, breathe and swallow. Motor neurone disease (MND) is the name given to a group of diseases in which these neurones fail to work normally. Muscles then gradually weaken and waste.**

MND is known as amyotrophic lateral sclerosis (ALS) in many parts of the world, and also as Lou Gehrig's disease in the USA. According to *Motor neurone disease Australia*, the national voice representing all Australians who share the vision of a world without MND, the effects of MND, such as the initial symptoms, rate and pattern of progression, and survival time after diagnosis – vary significantly. The average life expectancy after diagnosis is two to three years.

#### Cognitive and behaviour change

About 50% of people with MND may experience some change in cognition, language, behaviour or personality.

Most people experience relatively mild changes. However, 5–15% will show more significant changes and will receive a diagnosis of 'motor neurone disease with frontotemporal dementia'

or MND/FTD. For more information about motor neurone disease, visit: [www.mndaust.asn.au](http://www.mndaust.asn.au)

#### What is frontotemporal dementia?

Frontotemporal dementia (FTD) is the name given to dementia when it is due to progressive damage to the frontal and/or temporal lobes of the brain.

According to Dementia Australia, the right and left frontal lobes at the front of the brain are involved in mood, social behaviour, attention, judgement, planning and self-control.

Damage can lead to reduced intellectual abilities and changes in personality, emotion and behaviour. The right and left temporal lobes at the two sides of the brain are involved in processing what we hear and understanding what we hear and see. Damage may lead to difficulty recognising objects or understanding

or expressing language. FTD is sometimes called frontotemporal lobar degeneration. It was first described 100 years ago by Arnold Pick and was previously referred to as Pick's disease.

The symptoms of FTD depend on which areas of the brain are damaged. In contrast to Alzheimer's disease, memory often remains unaffected in FTD, especially in the early stages. When the frontal lobes are affected first, the main changes are in personality and behaviour, and this is called behavioural-variant FTD.

When the temporal lobes are affected first, there is a loss of language skills. There are two types of FTD where language is impaired – progressive nonfluent aphasia and semantic dementia.

For more information about frontotemporal dementia, visit: [www.dementia.org.au](http://www.dementia.org.au)

### Byron Shire Respite Service Inc. Activity Timetable

monday	tuesday	wednesday	thursday	friday
10am – 2:30pm Changed Behaviours with Dementia	10am – 3pm Dementia Specific	10am – 3pm Changed Behaviours with Dementia	10am – 3pm Older people	10am – 3pm Dementia Specific

Lunch, morning and afternoon teas are provided and the cost for the day including transport is \$20.

Flushing wipes and cloth down the toilet can have serious negative impacts on our sewage treatment plants. Once in the system, these products cause blockages and increase energy costs of sewage treatment.

Everyone can do their 'bit' to help keep our infrastructure and environment, working and being renowned for its beauty around the world.



Like water utilities around the world, we are having an increasing issue with wet wipes in our wastewater system. London, New York and all Australian water utilities are facing the same problem.

Let your family, friends and carers know to never flush ANY wet wipes down the toilet, but instead dispose of them in the rubbish.

*A good reason to stop and think before you flush cloth wipes down the drain*



## Need support?

- **My Aged Care** 1800 200 422 for information about the Australian Government's aged care system and services. [www.myagedcare.gov.au](http://www.myagedcare.gov.au)

**If you require emergency respite, please call: 1800 052 222**  
(24hrs)

- **Call Colin or Barbara at Byron Shire Respite Service Inc. to discuss your role as a carer.** ph: 02) 6685 1921
- **National Dementia Helpline** ph: 1800 100 500
- **Carers Counselling Service** ph: 02) 6628 6416
- **Carers NSW** ph: 1800 242 636
- **Sandra Kimball Counselling** ph: 0458 175 962
- **Far North Coast Commonwealth Respite & Carelink Centre** ph: 1800 052 222
- **National Continence Helpline** ph: 1800 330 066
- **NSW Elder Abuse Helpline** ph: 1800 628 221

### Aids:

- **Byron Ballina Home Maintenance and Modification Service** 1/65 Centennial Circuit, Byron Bay ph: 02) 6685 7312
- **Bright Sky Cards for Continence Aids Payment Scheme (CAPS)** ph: 1300 886 601

### Need Transport?

- **Tweed Byron Ballina Community Transport** ph: 1300 875 895

Transport to medical appointments, weekly & fortnightly shopping outings & monthly social outings. The service is funded to support older people living at home independently or have a permanent disability or Indigenous Australians aged over 50 years. Phone Kathryn in the Byron office on: 1300 875 895 for transport to medical appointments or Amanda for any shopping bus or social bus enquiries.

Travel for medical appointments free with travel voucher or for Veteran and Widow Gold Card holders:

- **Byron Shire Limousines** ph: 02) 6685 5008
- **Brunswick Limousines** phone David on: 0412 855 747.

# DEMENTIA IN MY FAMILY

The *Dementia in My Family* website offers valuable resources and information for children and young adults who either know someone living with dementia or have dementia in the family.

If someone in your family has dementia, you might be impacted even if you don't live in the same house as the person with dementia. It can be very upsetting and stressful. You may experience confused and mixed feelings and feel overwhelmed at times. This is very normal. It is very hard to watch someone you love and who loves you go through personality change, lose their independence and not recognise the faces of the people who care the most.

It is important to remember that even if the person with dementia becomes angry, cries a lot or does really strange things, they have a brain disease and cannot help what they are doing. It is also important to remember that you have a life to live too, and have every right to feel like it's all quite unfair. Don't blame them or yourself for what is happening.

When visiting this website, you will be prompted to select the age-group (as shown here) that best describes you. This ensures that age-appropriate language will explain what dementia is and how it effects the brain. It will tell you how to deal with it and how to share your story.

Visit the Dementia In My Family website at:  
<https://dementiainmyfamily.org.au>



## Moving toward Dementia - friendly Community

A dementia-friendly community is a place where people living with dementia are supported to have a high quality of life with meaning, purpose and value.

### What can I do?

- Anyone who is interested in learning how they can help their community become more friendly to people living with dementia. As a dementia friend you can bring about change by raising awareness in our communities, schools, workplaces or social groups, getting involved and volunteering your time or expertise with a dementia-friendly group.

Become a dementia friend by signing into:  
<https://www.dementiafriendly.org.au>

By creating opportunities for people living with dementia and their carers to remain active and engaged members of our local communities, they will be better supported by the people around them, to remain living independently for as long as possible.



## CHILDREN LIVING WITH A PARENT WITH YOUNGER ONSET DEMENTIA

The term younger onset dementia is used to describe any form of dementia diagnosed in people under the age of 65. For the person with younger onset dementia and their family members there are a number of issues that may arise.

Dementia Australia report that younger onset dementia appears at an earlier stage in a person's life, when they are likely to still be physically and socially active, they may be in full-time employment, actively raising a young family, financially responsible for a family and physically strong and healthy.

'This is my family' is a kids' book that tells the story of Jack whose father lives with younger onset dementia. An engaging tale for any child who knows a younger adult with dementia, the locally printed version of this book has several bonus pages, including puzzles for kids and handy local contacts and links to local fact sheets.

To enquire about purchasing a copy, call Barbara on 02) 6685 1619 or email [dementiafriendly@byronrespite.com.au](mailto:dementiafriendly@byronrespite.com.au)

