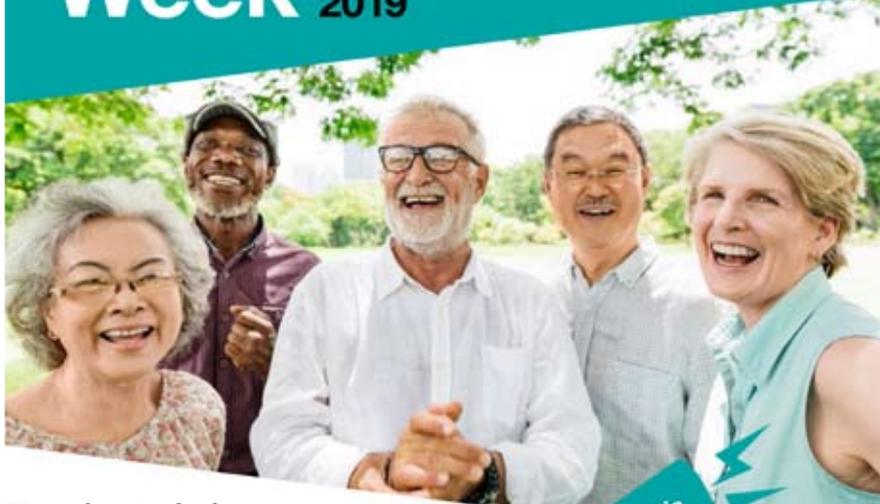




# Announcing Dementia Action Week 16-22 September 2019



Timed to include World Alzheimer's Day on the 21st of September, Dementia Action Week exists to raise awareness of dementia and the issues that surround dementia.



Activities during Dementia Action Week 2019 will include a survey, a large-scale national event to kick off the conversations, and DIY event kits for community organisations and community minded individuals.

## Dementia doesn't discriminate. Do you?

Dementia will impact most of us throughout our lives in one way or another, and Dementia Australia believe it is time to bring that conversation to the forefront, and acknowledge the impact dementia has on those living with the disease, their families, carers, friends and work colleagues. The right support, information and services can make a life-changing difference to people living with dementia and this begins in our own communities.

There are lots of ways we can support people in our communities living with dementia. For example, people living with dementia still experience all the usual adult emotions and want to continue their involvement in family and community activities, even though their ability to express themselves may have changed.

**1. Help the person maintain their independence.** Support friends with dementia so they can do as much as they can for as long as possible. Don't take over. Give the person the time and space they need.

**2. Listen and give time for responses.** Give your friend time to search their brain for the word they want to use. Try not to finish their sentences. Just listen and don't let them feel embarrassed if they lose the thread of what they are saying.



## 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 Janine Smith 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 ►

**3. Communicate clearly.** If you ask your friend questions, keep to closed ended questions (e.g. with yes/no answers) or ones with obvious answers (e.g. 'Would you like to sit here or sit there?'). Open ended questions (e.g. 'how are you feeling?' or 'what would you like to do today?') can be confusing to a person with dementia.

**4. Be realistic about memory loss.** Your friend will not remember everything, even recent events. Don't be offended if they don't remember something special.

## How to support a family member of someone living with dementia

Caring for a person with dementia can be emotionally and physically stressful. Some family members may be unsure of their own feelings and may believe others cannot understand how they feel.

It is important to remember that ALL members of the family are affected in different ways by their relative's dementia. As a friend, you can do a lot to support them.

**1. Keep in touch.** Maintain contact.

Think of ways in which you can help family members keep up their hobbies or interests.

Often family members or carers drop out of activities when a little assistance could help them stay active.

**2. Do little things – they mean a lot.**

You can help with day-to-day things. For example, if you are on

your way out to do an errand, check with a family member to see if there's anything they need.

**3. Give them a break.** Offer to spend time with the person with dementia so family members can do things like shopping, attend a support group, visit a friend or just have some personal time at home.

**4. Be specific when offering assistance.** Offer practical assistance. Ask the family specifically what they need help with and see if you can assist with jobs such as gardening, cooking, shopping, or find out what is available.

**5. Be a good listener.** Try to acknowledge the changes the person and their family are experiencing. You don't need to provide answers – just be a compassionate listener. Try not to question or judge but rather support and accept.

**6. Learn more and get involved.** Understanding dementia will help you be a supportive friend.

Visit [www.dementia.org.au](http://www.dementia.org.au) to read and download lots of great information and help sheets. Try to attend one of Dementia Australia's free community information sessions.

According to Alzheimers UK, people with dementia are more likely to be over 65 and can face both ageism and the stigma associated with dementia. There is also widespread assumption that dementia is merely 'getting old' rather than a serious disease. This has resulted in unequal treatment for people with dementia, including poor rates of diagnosis and a lack of appropriate services. However, Dementia is not just an older people's condition. Dementia Australia estimate 425,000 people in Australia are living with Younger Onset Dementia (onset before the age of 65 years), facing discrimination which includes being forced to give up work, excluded from some dementia services which may only support older people, forced to travel considerable distances to access age-appropriate services or left without support.

## Savings and Rebates for NSW residents

### THE COST OF LIVING SERVICE

Bringing together more than 40 rebates and savings in one handy location

Older people and Carers often struggle to make ends meet, but may be unaware of their eligibility for rebates and savings. The Cost of Living Service is a NSW Government initiative that can help.

NSW customers can view, access and apply for over 40 rebates and savings online at: [www.service.nsw.gov.au](http://www.service.nsw.gov.au)

The Cost of living service website has a **Savings Finder tool** on the website which allows customers to answer six simple questions to quickly identify which rebates and savings they are eligible to apply for.



The NSW Service Centre also offers a service to assist customers that need more help to access and apply for rebates and savings. Telephone **13 77 88** for more information or visit one of our local **NSW Service Centre** such as the:

- Lismore Service Centre at 58 Ballina Road, Lismore
- Ballina Service Centre in the Ballina Homemaker Centre, 26 Boeing Avenue, Ballina
- Murwillumbah Service Centre at 289-291 Tweed Valley Way, Murwillumbah.

Byron Shire Respite Service Inc. is supported by the Australian Government Department of Health. Visit [www.health.gov.au](http://www.health.gov.au) for more information.

Although funding for the Commonwealth Home Support Programme has been provided by the Australian Government, the material contained herein does not necessarily represent the views or policies of the Australian Government.

## FREE DEMENTIA CARE EDUCATION FOR FAMILY CARERS AND FRIENDS

### UNDERSTANDING DEMENTIA, EFFECTIVE COMMUNICATION AND FUTURE PLANNING

In conjunction with Dementia Australia, Social Futures (the social justice organisation based in Northern NSW) is holding a **FREE information session in Mullumbimby this month.** The morning will cover an introduction to dementia and explain the causes of dementia, the importance of diagnosis and early planning.

Ideal for family carers and friends of people with dementia, this session will also explore changes in communication that occur for a person with dementia and helpful suggestions.

WHEN: Thursday 19th of September 9am-1pm  
WHERE: Mullumbimby Ex-Services Club, Dalley Street, Mullumbimby.  
Complimentary lunch provided  
RSVP: For more information or to register, call or text 0406 409 747 or email [linda.wirf@socialfutures.org.au](mailto:linda.wirf@socialfutures.org.au)



**Our Vision Statement:**  
With a focus on caring, wellness and reablement, provide person centred support to people with diverse needs to enhance their quality of life and maintain a familiar lifestyle in the community and in their own homes.



### 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.

# 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 Janine 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.

Early planning can reduce stress and anxiety for individuals and their families.

## Planning ahead with your loved one

By introducing the topic of planning ahead you are helping to ensure your family member or friend's wishes regarding lifestyle, financial and healthcare decisions will be known and they have the opportunity to put in place arrangements to potentially improve their quality of life at a later time when they may not be able to make these decisions independently.

**Early planning conversations are often welcomed and can reduce worry.**

**To make the conversation easier:**

- Start discussing what is important for them in the future - how the person wants to live, not how they want to die
- Explain that planning ahead is about maintaining control, not giving up control
- Explain that planning ahead can assist family members who may be asked to make decisions in the future.

## When to discuss planning ahead

Planning ahead is thinking about your future, and putting things in place so that your choices will be known and acted on if you cannot express these choices yourself later in life.

This may happen if you have a sudden accident, become very ill or develop a condition such as dementia that affects your memory and your

planning ability. Planning ahead can include issues related to your finances, lifestyle or health care. We usually raise the



To view and download the original transcript of this article and access more informative help sheets to assist you to support a person with dementia, visit Dementia Australia at [www.dementia.org.au](http://www.dementia.org.au)  
You can also join Australia's over 20,000 Dementia Friends by becoming a dementia friend at [www.dementiafriendly.org.au](http://www.dementiafriendly.org.au)

## Supported Decision-Making

If a person is living with a dementia, there is a range of ways they can be supported to make, or communicate decisions about their lives. 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.

The free downloadable booklet 'Supported Decision-making' from the Cognitive Decline Partnership Centre (CDPC) is available to better understand the issues relating to supported decision-making for people living with dementia. 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.

- The booklet below 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>

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



issue of planning ahead when we've had changing life circumstances such as retirement, divorce or death of a spouse. We might also be interested if we've had negative experiences with loved ones who had not done any early planning.

### Other times might include:

- memory problems or signs of early dementia,
- progression or worsening of a chronic disease,
- diagnosis of a life limiting illness, increasing dependence on others for support and care,
- as part of a 75+ health check or chronic disease management plan,
- admission to a different form of care arrangement.

Planning includes completing a will and financial enduring power of attorney documents. **It is also important to ensure that we learn the benefits of health and personal planning including:**

- discussion about what is most important to our loved ones and what guides how they make decisions
- discussion about a their future wishes including lifestyle choices such as where they will live, who will support them and who will care for any pets.
- how their money may be spent in caring for them as they get older eg: consumer directed care
- the benefits of appointing a substitute decision maker for personal and health care
- the role of advance care planning.