



Fernanda one of our volunteers communicating happiness and delight in working with clients through her beautiful smile.



The Byron carer

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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.

NDIS Registered Provider

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

Telephone Karen on: 02) 6685 1619
or Emma on 02) 6685 1629

Website: www.byronrespite.com.au
Email: caremanager@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.

Byron Shire Respite Service Inc. is supported by the Australian Government Department of Health. Visit www.health.gov.au

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

If you require emergency respite care, please call the Carer Gateway on:

1800 422 737

Communication

Communication is a very important part of our every day lives. For everyone, but especially carers, good communication is vital. Generally, we express ourselves through words, spoken and written, however, at times we or the person for whom we are caring may find this difficult or lose the capacity to do so. Sometimes it is the topic of conversation which we find difficult. This can be particularly the case when we look ahead and think about the needs of our loved one into the future. Often we find it too hard and put it off for another day. Yet, it is easier to have the difficult conversations and plan before it becomes essential. One area which is important to consider earlier rather than later is **advance care planning**.

Advance Care Planning

What is advance care planning?

If you cannot communicate your preferences for care, who would speak for you? What would you want them to say? Advance care planning helps make sure your loved ones and your doctors know what your health and personal preferences are.

Advance care planning gives you/ your loved one, the opportunity to think about, discuss and record your preferences for the type of care you would like to receive and the outcomes you would consider acceptable. It helps to ensure your loved ones and doctors know what your health and personal preferences are and that these preferences are respected.

As a carer, advance care planning may well involve planning for future health and end-of-life care for both yourself and the one for whom you are caring.

Are you caring for someone living with dementia?

Ideally, conversations around advance care planning would have started before the diagnosis of dementia, but these things can come unexpectedly. So, if these conversations haven't happened, try to engage your loved one in advance care planning as early as possible so that they can be involved in a meaningful way. As dementia progresses a person's capacity to be involved in making and communicating important choices will deteriorate. As this occurs, you, as carer, will often be required to be involved in this planning process and decision making. You may feel uncertain as to your loved one's preferences for ongoing care and end-of-life.

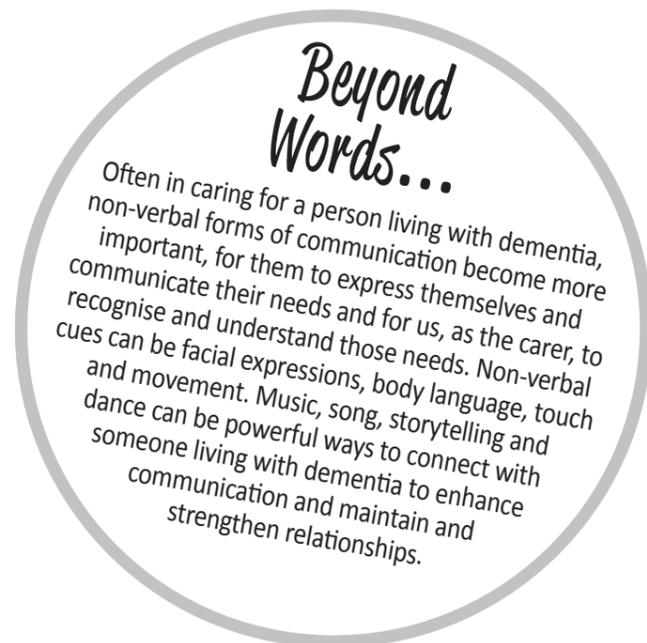
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According to *Advance Care Planning Australia*, advance care planning is a key means to help ensure quality of care for people living with dementia. Having an advance care directive, has been associated with significant reductions in rates of hospitalisations, and increased use of hospice services, allowing the person to stay at home if that is their wish. It can reduce anxiety, stress and depression for you, the carer, and other family members.

It is important to note that advance care planning is a voluntary process, and some people may well prefer to leave the decision making to others.

<https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-settings/advance-care-planning-and-dementia>.



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Need support?

● **Carer Gateway** telephone: 1800 422 737 for information about planned & emergency respite & other carer supports. www.carergateway.gov.au

● **Australian Government Department of Health** For more information about COVID-19 call the Coronavirus Health Information Line on 1800 020 080 or www.health.gov.au

● **My Aged Care** telephone: 1800 200 422 for information about the Australian Government's aged care system and services. www.myagedcare.gov.au

● **Telephone Karen or Emma at Byron Shire Respite Service to discuss your role as a carer.** telephone: 02) 6685 1619

● **National Dementia Helpline** telephone: 1800 100 500

● **Carers Counselling Service** telephone: 02) 6628 6416

● **Carers NSW** telephone: 1800 242 636

● **Sandra Kimball Counselling** telephone: 0458 175 962

● **NSW Elder Abuse Helpline** telephone: 1800 628 221

Aids:

● **National Continence Helpline** telephone: 1800 330 066

● **Byron Ballina Home Maintenance and Modification Service 1/65 Centennial Circuit, Byron Bay** telephone: 02) 6685 7312

● **Lismore Home Maintenance and Modification Service 43 Habib Dr, South Lismore** telephone: 02) 6622 2323

● **Bright Sky Cards for Continence Aids Payment Scheme (CAPS)** telephone: 1300 886 601

Need Transport?

● **Byron Shire Respite Service** can assist with transport to medical appointments. Telephone Emma or Karen on: 02) 6685 1629

● **Byron Shire Limousines** telephone: 02) 6685 5008 Travel for medical appointments free with travel voucher or for Veteran and Widow Gold Card holders

● **Brunswick Limousines** telephone David on: 0412 855 747

● **Tweed Byron Ballina Community Transport** telephone: 1300 875 895

Tweed Byron Ballina Community Transport provide 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 any shopping bus or social bus enquiries.

You may be feeling a little overwhelmed by even the thought of doing this, but there is help available. *Advance Care Planning Australia*, has the following printable guides:

- Advance care planning and dementia
- Choosing a substitute decision-maker
- Making a decision for someone with dementia

Dementia Australia also has resources on their website - <https://www.dementia.org.au/about-dementia/i-have-dementia/advance-care-planning>

If you are feeling overwhelmed there are a few simple steps to begin the process if you haven't already.

1. Begin thinking about what you/ your loved one might want. It doesn't have to be complicated, but it is important to be open about what you would like.
2. Talk with your loved ones. This can be one of those difficult conversations as most of us don't want talk about end of life, but it is important. Talking about these things helps relieve the decision-making burden on those closest to you. Sometimes, the hardest part about difficult conversations can be knowing where to start. Below are some ideas to help get you started.

"I know it might be hard to talk about, but it's really important for us."

"We've talked a bit about what happens after you pass away, but we haven't spoken about your end-of-life care."

"I've been speaking to our doctor, and they have asked me to think about a few things..."

If you need more help to initiate this conversation, click on the link below for a "What Matters To Me" conversation guide.

<https://www.health.gov.au/sites/default/files/what-matters-to-me-conversation-guide.pdf>

3. Once you've thought about what you/ your loved one want and perhaps spoken with your family, talk with your GP. They can guide you through some questions and document your wishes for you. They will then have a record for future reference.

To know more, look at the following websites:

<https://www.health.gov.au/health-topics/palliative-care/planning-your-palliative-care>

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

Palliative Care NSW has a fact sheet about Advance Care Planning which you might find useful as well.

<https://palliativecarensww.org.au/wp-content/uploads/2021/11/Brochure-Advance-Care-Planning-PCNSW-1.pdf>

Part of the difficult conversations with your loved ones may include:

1. Considering Residential Care

Byron Shire Respite Service aims to assist people to continue to live in their own homes for as long as possible, however, as care needs increase, sometimes, a carer may need to consider residential care for their loved one. Everyone involved in person-centred care sees this as a last resort. Thinking about this option can bring up a range of emotions. This online session may be helpful for carers and other family members in considering Residential Care should it become necessary.

Considering Residential Care, an online session. Thursday, 16 June 2022 10:00am-12:00pm AEST

Dementia Australia is offering this online session about the process of considering and preparing for residential care. It includes strategies to help family carers to decide when residential care may be needed, information on the process for application, and understanding the emotional impact of the change.

This session is specifically for carers and family members of people living with dementia. It will be delivered interactively by facilitators who have specialist knowledge, skills and experience in this area. You will be encouraged to share your experiences with other participants, providing an opportunity for you to build new support networks.

To find out more and register, click on the link below. <https://www.dementia.org.au/events/considering-residential-care-16>

Carers - My to Do List for Today

Count my blessings • Practice kindness (to myself as well) • Let go of what I can't control
Listen to my heart • Be productive yet calm
Just breathe

2. Palliative Care

Who is palliative care for?

Palliative care is for every person who has a life limiting illness. A progressive or life-limiting illness means an illness that is going to get worse, and which will eventually shorten the person's life.

What is Palliative Care?

Palliative care recognises the unique needs of a person who is approaching and reaching the end of their life, as well as the needs of their family and carers.

Palliative care aims to improve the quality of life for patients, their families and carers by helping the person live as well and as comfortably as possible during their illness through to their death.

<https://palliativecarensww.org.au>

High quality palliative care for all Australians

Prior to the last Federal Election and beyond, Palliative Care Australia (PCA) asked and continues to ask that political parties commit to adequate investment in palliative care to meet the rapidly rising demand.

With the population growing and ageing, the need for palliative care services in Australia is expected to increase by 50 per cent between now and 2035, and double by 2050.

Additionally, the pandemic has seen the demand for palliative care spike, with no additional funding. https://palliativecare.org.au/campaign/its-everyones-right/?mc_cid=ab3901924a&mc_eid=e016840fa4

Palliative Care NSW recognizes the joys and demands of your role. They provide resources and useful links to networks to help you do your best in your carer's role. Just go to their website to learn more and access their resources. <https://palliativecarensww.org.au>

You can also speak with your GP about palliative care. They can refer you to the local Palliative Care Service, Lismore Community Health – Richmond Specialist Community Palliative Care Service, when it may be required.

Apart from government funded services, there are also private services such as:

- **Tweed Palliative Support Inc. & Wedgetail Retreat**
24/7 Hospice and Palliative Care Outreach Services
<https://www.tweedpalliativesupportandwedgetailretreat.com>
- **Lotus Palliative Care**
<http://lotuspalliativecare.com.au/?msckid=4819df37cf5411ec835545775435939c>

As a carer you are already well aware that caring for someone with a life-limiting illness can be both rewarding and challenging. You may also have other family or work commitments. It is important to find ways to balance your caring role and other responsibilities so that you maintain a sense of wellbeing.

If you feel you would like to share with other carers, you might like to join the Carers' Coffee Club.



Carers Coffee Club

If you are caring for someone with dementia and would like an opportunity to meet with other carers - we'd love to see you at our monthly Carers Coffee Club on the 3rd Wednesday of every month in Brunswick Heads.

The next meeting is
Wednesday 15th of June.

If you are interested in joining us, please email Emma on: emmawhite@byronrespite.com.au or telephone **02 6685 1629** for more information.

Are you interested in being involved in a study looking at the effects of music and reading?

HOMESIDE is an international study investigating the effects of music and reading activities for people living with dementia and their family caregivers. Previous research indicates that such activities may help to increase wellbeing, strengthen relationships, and improve care.

HOMESIDE is currently looking for people across Australia to be part of this study.

Who is the study for?

This study is for people living with dementia and their family (or informal) caregivers. You can participate in the study if:

- You or your loved one has a diagnosis of dementia OR significant memory problems
- You are or you have a family caregiver
- You live together at home.

As Homeside, in partnership with Dementia Care, say, "Your voice can, and does, matter: but we need your help to create change."



In response to COVID-19 and community needs relating to social isolation, HOMESIDE is now being offered via an online delivery model. We hope that participating in HOMESIDE during this time will support your wellbeing at home and provide a chance to connect with their team and contribute to valuable research.

If you want to register your interest, go to the link below <https://www.homesidestudy.eu/australia>

2022 Byron Shire Respite Service – Day Program Timetable

Monday	Tuesday	Wednesday	Thursday	Friday
10am – 3pm centre-based day respite <i>dementia friendly</i>	10am – 3pm centre-based day respite <i>dementia friendly</i>	10am – 3pm centre-based day respite <i>dementia friendly</i> 10am – 3pm Fortnightly Bus Outings & shopping days	10am – 3pm centre-based activities for older people	10am – 3pm centre-based day respite <i>dementia friendly</i>



Lunch, morning and afternoon tea is provided.

The cost for the day for CHSP clients, including transport is \$30.00 (Fees subject to change).

For more information, please telephone: 02) 6685 1629 or email: caremanager@byronrespite.com.au