

Today in Australia, **37 people** will hear the words **'you have Parkinson's'** for the very first time. That's more than one person every hour, of every day.

Parkinson's impacts more than a person's movement and speech. There are more than 50 symptoms – many invisible. These are called non-motor symptoms because they are not related to movement. According to Parkinson's NSW, because these symptoms are unseen, they are often misunderstood and hard to talk about. Yet they can have a greater effect on relationships, social life and overall quality of life than the more obvious symptoms of Parkinson's.

CARING FOR SOMEONE WITH PARKINSON'S DISEASE

Parkinson's disease, like any chronic disease, affects families as well as individuals.

Close family members and friends often take on the role of caregiver as the disease progresses and, in many ways, are as constrained as the person with Parkinson's disease. Carers can find themselves in a role that may increasingly isolate them from work, family and social activities as they dedicate themselves to care giving. While they may take on the role willingly, the fact is they also experience significant loss in terms of opportunities and the future they may have planned.

Carers need factual, credible information and support and may need someone to talk to about their feelings as much as they might need practical advice. Caring doesn't always come naturally and carers may need to learn new skills. Communication and negotiation skills are particularly important in order to balance the needs of both carer and their loved-one. Carers also need to look after their own health by getting enough sleep and exercise and prioritising some time for themselves.

If you or your family members need to talk about Parkinson's, you may like to arrange to speak to a specialist counsellor. You can contact the Parkinson's NSW InfoLine on 1800 644 189. Parkinson's NSW can help with all this by providing information about the disease, counselling and access to support groups. Visit: <https://www.parkinsonsnsw.org.au>

LOCAL SUPPORT GROUPS

There are more than 90 Parkinson's support groups throughout NSW and in our area, there are support groups in Tweed Heads, Ballina, Lismore and Casino run by local volunteers who have been touched by Parkinson's and supported by Parkinson's NSW staff. Support groups offer support, advice, information, resources and shared experiences. They also provide motivation and inspiration to help you deal positively with the changes to your lifestyle. If you are impacted by Parkinson's disease, groups also give you a chance to meet new people, which helps to break down any feelings of isolation. Support group meetings range from group discussions, to educational sessions by guest speakers, social outings or just sharing a cuppa.

If you would like to be connected with your local Parkinson's support group, telephone the Parkinson's NSW InfoLine on: 1800 644 189. You can also email Parkinson's NSW at pnsww@parkinsonsnsw.org.au

IN THIS TOGETHER
parkinson's



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 Janine on: 02) 6685 1629
or Karen and Emma on 02) 6685 1619

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.

Exercise is a vital part of the daily routine for anyone living with Parkinson's

Exercise doesn't have to be repetitive or boring. It can be as fun and as imaginative as you allow it to be. The keys are consistency, force and complexity. Exercise can build strength, flexibility, gross and fine motor skills and reduce stress and anxiety.

How the symptoms of Parkinson's can be improved with specific exercises:

If You Have Difficulty in These Areas	Focus on These Exercises
Strength	Weight training, body weight training, swimming, household lifting
Flexibility	Stretching, yoga, body balance, Tai Chi classes
Gross Motor Skills	Jumping, balancing, obstacle runs
Fine Motor Skills	Drawing, puzzles, writing, juggling
Stress and Anxiety	Meditation, yoga, hypnotherapy

If your loved-one is living with Parkinson's, every day you might like to encourage them to:

Learn something new

That could be reading newspapers or journals, listening to radio shows, listening to audio books, or joining a book club. Also investigate puzzle memory training puzzles on websites or apps.

Challenge themselves

Try volunteering, perhaps with a Parkinson's NSW Support Group or community service organisation, or even in a knitting or sewing group.

Make sure your loved-one goes out each day, even if they feel a little unsteady on their feet.

Use a cane or walker for greater confidence.

Practice writing by making big sweeping movements

A pen grip may help with control and make it easier to grasp your pen lightly and decrease the force required to move it across the page.

Exercise the voice

Practice speaking slowly, loudly and clearly. Read aloud daily and enjoy a good sing together (and even a dance!) to a favourite song or entire album.

Exercise the body

Choose the exercises to suit the person's needs and interests to maintain physical and emotional health.

Parkinson's NSW
believe that every day, people with Parkinson's should aim to learn something new, to challenge themselves, practice writing by making big sweeping movements, and exercise the voice and body.

Communication is key to caring for anyone

According to Parkinson's Australia, you may come across communication barriers because of your loved-one's Parkinson's.

Tips for carers and friends:

1. Have patience
2. Speak to a person with clear tone and timing. You do not need to speak louder (unless you are aware that they have a known hearing impairment)
3. Speak slowly enough for that person. Repeat their turn of phrase to also help them slow their speech down
4. Provide time for them to respond to any questions
5. Encourage the person to use single words or short word phrasing so their message is clearly conveyed
6. Provide empathy as often communicating for a person living with Parkinson's may leave them with a loss of confidence in addition to being frustrating and exhausting
7. Where appropriate, try asking closed-ended questions where people can answer simple 'yes and no' answers
8. Always acknowledge when you have understood their questions and communication (e.g. nodding your head and saying 'thank you')
9. Provide time for the person to finish their conversation and/or question.

To read the original transcript of these articles and learn more about Parkinson's, please visit: <https://www.parkinsons.org.au>

Dementia and Parkinson's Disease

Not everyone with Parkinson's will develop dementia, however it is estimated to occur in 30-60% of people affected by Parkinson's.

There are many types of dementia, but the two types primarily associated with Parkinson's are Parkinson's disease Dementia (PD-D) and Lewy Body Dementia (LBD). The Movement Disorder Society has laid down guidelines regarding the differences between the two types in order to clarify the potential

diagnosis. Risk factors for developing Parkinson's disease Dementia (PD-D) are:

- Longer duration of Parkinson's
- Older age
- Diagnosis of Parkinson's at an older age
- Non-tremor dominant presentation of Parkinson's.

Lewy Body disease

Lewy body disease is an umbrella term referring to a common neurodegenerative

process and includes Parkinson's and Lewy Body Dementia. The name refers to the pathological signs of Lewy Bodies which are seen at post mortem and are not identifiable in life. According to Parkinson's Australia and Dementia Australia, Lewy body disease is a common neurodegenerative disease of ageing which affects over 100,000 Australians.

Lewy body disease causes gradual brain damage. For reasons not fully understood, it occurs when there is an abnormal build up of a protein called alphasynuclein in brain cells.

These abnormalities occur in specific areas of the brain, causing changes in movement, thinking and behaviour.

Lewy body disease is one of the most prevalent causes of dementia, but unlike Alzheimer's disease, it is not well known.

Lewy body disease includes three overlapping disorders:

- dementia with Lewy bodies
 - Parkinson's disease
 - Parkinson's disease dementia
- This overlap results in the disease being called a spectrum disease.

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

If you require emergency respite care, please call the Carer Gateway: 1800 422 737

- **Telephone Janine at Byron Shire Respite Service** to discuss your role as a carer. telephone: (02) 6685 1629
- **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
- **National Continence Helpline** telephone: 1800 330 066
- **NSW Elder Abuse Helpline** telephone: 1800 628 221

Aids:

- **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: (02) 6685 1619
- **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 Amanda for any shopping bus or social bus enquiries.

Northern Rivers Carers Coffee Club

Are you caring for someone with dementia? If so, we'd love to see you at our monthly Carers Coffee Club on the 4th Wednesday of every month in Brunswick Heads. The next meeting is the 28th April. If you are interested in joining us, please email Emma on: emmawhite@byronrespite.com.au or telephone 02) 6685 1619 for more information.



Friendship

Changes will occur as a result of dementia, but important elements of the friendship still remain and the essentials of the interests you shared can survive.

What makes a good friend?

A good friend accepts you as you are (non-judgemental)

A good friend listens

A good friend is there for you

You can share things with a good friend that you might not share with others

Good friends respect each other as equals.

To help maintain a good friendship with your friend living with dementia, visit: https://www.dementia.org.au/sites/default/files/Friends_Matter_24pp_booklet_with_checklist.pdf

Joyce and Carol enjoy each other's company at the centre-based program



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 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 including transport is \$22.00 (Fees subject to change). Telephone: 02) 6685 1916 or email: caremanager@byronrespite.com.au				

Carers + Employers

The Carers + Employers network brings together employers who are interested in learning and sharing best practice approaches to support carers in their workplace.

Caring is having a large and growing impact on Australian workplaces and the Carers + Employers program supports workplaces across NSW to become more carer-friendly and inclusive, and is powered by a network of employers to champion improved outcomes for carers. This program defines best-practice standards for supporting staff with caring responsibilities, and is the first initiative in Australia to formally accredit carer-friendly employers.

The program includes an accreditation framework to recognise employers that are actively supporting paid work for people with caring responsibilities.

There are three levels of accreditation:

Level 1: Activate, Level 2: Commit, Level 3: Excel

Employers that join the program will become part of a network that has access to a dedicated website and member resources, such as a closed LinkedIn Group to share information and best practice, ongoing support, toolkits and access to training. Becoming an Accredited Carer Employer contributes to staff wellbeing, workforce management and wider corporate social responsibility.

If you would like more information for your workplace, or would like to register to become a carer-friendly workplace, visit the Carer + Employees website <http://www.carersandemployers.org.au/> or email the team directly at info@carersemployers.org.au

The Dementia Australia Dementia Forum

This forum provides a place where people with dementia, their families, carers and friends can gather and share information. It provides a place to share your stories, connect with others in a similar situation, ask questions and share information. To join the forum, visit: <https://www.helpwithdementia.org.au/forums>

Friends + Dementia

Spending quality time is not about what you do, but how you are doing it together.

You can help the person you care for stay involved in everyday activities, so they feel productive and able to contribute.

There are 3 P's when spending time together:

- 1. Pleasure** – you both enjoy the time
- 2. Participation** – you both get involved as much as possible
- 3. Presence** – you show you want to be with the person.

Remember:

- Any simple activity can be a positive experience.
- Past hobbies and skills from working lives can be good starting points when thinking about something to do together.
- You might be surprised which activities work well.

Try not to rule anything out prematurely.

To find out more, visit: https://www.dementia.org.au/sites/default/files/resources/FamilyAndFriendsMatter_english.pdf