

## InTouch Newsletter

November 2022

### How singing helps with Parkinson's

Communication impairment in voice and speech changes affects most people living with Parkinson's eventually.

The most common communication disorder is hypokinetic dysarthria, which causes rigidity and slowness of communication systems, including breathing, swallowing, voice, and speech. It can lead to reduced voice volume, hoarseness, imprecise articulation, and tremors.

Studies have shown that singing offers an engaging way to enhance voice and communication for people living with mild to moderately severe Parkinson's. Intensive singing can increase vocal loudness, respiratory muscle strength, and voice-related quality of life.

Jenny Yoston is a neurological music therapist and founder of the Music Affect Centre in Canada. She uses music in her work with residents in a senior long-term care facility and in her private practice. She has found that music connects with people emotionally and socially, and she has seen its physical benefits.

"Singing is a great way to slow the progression of Parkinson's. It's particularly beneficial for speech and swallowing, and the sooner you start, the better."

She notes the rise in research using music and its elements for people with neurological disorders.

"Scientists and neurologists are collaborating with those in the music psychology and music therapy fields. I'm excited about these collaborations and their future findings. There is so much more to music. We just need to learn to share how to use its power!"

When the pandemic began, she saw that many of her Parkinson's patients were isolated and unable to come to appointments, so she developed a DVD people could use at home.

"*ParkinSing* is a music and fun scientific approach to vocal exercises and respiratory maintenance for people with Parkinson's. With the DVD, they can still maintain where they were during their in-person sessions in a fun way."

## Choral Singing

Paula Wolfson is an award-winning performer with a long career in professional theatre. She also works with vulnerable populations using music and is a certified artist-educator.

Paula became involved with a new choir through a study conducted by Dr. Frank Russo and Esztella Vezer of Ryerson University's Smart Lab in Toronto to see if "emotional" singing would impact the Parkinson's mask (the difficulty some people with Parkinson's have in producing facial expressions).

The results are still being finalised but showed that overall, the effects of ongoing group singing are beneficial on many levels, as Paula indicates.

"Voices, both speaking and singing, grow stronger; breath is better controlled as the expressive muscles of the face are exercised; there is a deep sense of belonging and communal support; there is pride and a feeling of accomplishment as the brain is engaged with learning new songs and vocal techniques."

Paula has continued to lead the Singing With Parkinson's choir. She emphasises that participants don't need any prior group singing experience.

"Partners and caregivers are welcome to join. Our choir participants tell us that the social hour after the singing session is equally as important as the singing because it provides a safe community where they can speak openly."

*DVDs or the streaming version of Jenny Yoston's vocal exercises can be purchased at [www.musicaffectcentre.com](http://www.musicaffectcentre.com)*

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## Tips on travelling with Parkinson's

The Christmas-New Year period is peak travel season for Australian families and singles – including those living with Parkinson's.

Here are some quick tips on travelling with Parkinson's to make your journeys easier and safer.

- Always carry your Parkinson's Passport. Don't have one yet? It can be downloaded from the Parkinson's NSW web site [here](#).
- Use a 'fanny' pack or backpack so that you have both hands free to balance as you walk, especially if walking any distance.
- Pack snacks and carry a water bottle to take medications.
- Wear comfortable, loose-fitting clothing and good walking shoes.
- When making hotel reservations, request a room on the ground floor or near the lifts. Ask if they have rooms that are handicapped-accessible because these usually include grab bars in the shower and bathroom and have wider spaces between furniture for wheelchair access.

## Traveling With Parkinson's Medications

- Always have at least a day's dosage of medication in your pocket or purse.
  - When flying, try to carry all of your medications in your cabin baggage, in the event that your check-through luggage gets misplaced.
  - Pack enough medications to last the entire trip – ideally more than you will actually need in case of delays in your itinerary.
  - Do not rely on out-of-town – or especially out-of-the-country – pharmacies for medication refills.
  - Find out if your medications are temperature sensitive and plan to carry them in cooled or insulated packs accordingly.
  - Use a watch with an alarm or an alarm pillbox. If you are traveling across time changes it may be difficult for you to remember on your own. It is best to stick to your routine according to the time zone you are in, not your home time zone.
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## Tips on managing grief

Grief is how humans respond when experiencing loss.

It is a normal, natural, and inevitable response to loss and can affect every part of a person's life. It can seem like a roller coaster with good days and then bad days.

Grief allows you to gradually adjust to the loss – and the changes that the loss brings. It helps you to seek a way forward without the person who has passed away.

Everyone's experience of grief is different. There is no right or wrong way to experience grief. It is a very individual experience.

Its feelings may be intensely felt and can be described as anxiety, anger, disbelief, sadness, panic, numbness and even relief.

Some people are fearful that they may lose their personal connection or memory of the person who has passed away. Some may feel disloyal if they start to enjoy activities.

Also people can feel confused and unable to concentrate, or they may feel that they are never going to be able to get over the loss or move on with their lives.

There may also be some physical reactions to grief such as lethargy, loss of appetite, nausea, and pain. These symptoms need to be checked to ensure that they are not related to illness.

Self-care can be neglected and dependency on alcohol or drugs can be potentially harmful. Grieving people can also lose contact with their spiritual beliefs.

Just as there is no 'correct' way to grieve, there is no 'right' period of time for grieving. Eventually though, life will again have meaning.

Some prefer to express their grief privately while others may express publicly how they are feeling. Some people prefer to talk to and want to express their feelings

while others are reluctant to talk. Even individual members of the same family or group can react differently, and their reactions need to be respected.

Grief is an unknown journey which cannot be planned or controlled. Some tips on managing grief include:

- Don't make big decisions too soon
- Create a memorial to honour the person you have lost
- Continue the relationship with the person who has passed away
- Allow space to have private thoughts and special time with the person
- Develop your own way to honour or spend time with the person
- Exercise
- Continue with your religious or spiritual beliefs
- Read about how others manage their grief
- Try meditation, massage, or aromatherapy
- Share your feelings with others
- Allow others to help you
- Share memories and feelings with family and friends
- Try to enjoy things as well as grieving
- Join a support group
- Talk with a counsellor

If you know someone who is grieving, it is difficult to watch, and you may not know what to do. A few things you can try are:

- Keeping in touch
- Being prepared to just listen
- Show your care and concern
- Talk about the person who has passed away
- Remember there are many who may be grieving, including children, grandparents, and friends
- Make contact again and again
- Share memories and stories
- Acknowledge all significant dates
- Always ask the person if they are OK.
- Be there for them by reaching out and being a great listener.

Things which may be *unhelpful* to the person grieving are:

- Avoiding the grieving
- Taking anger personally
- Saying "I know how you feel"
- Instructing them how to grieve
- Changing the subject
- Not using the name of the person who has passed away

- Making suggestions of replacing the person

If the person grieving is feeling overwhelmed, they may require more assistance than you can provide. Signs of this include:

- High levels of insomnia
- A strong sense of hopelessness
- Inability to continue relationships
- Deep depression or anxiety
- Thoughts of or threats of self-harm or harm to others

If this has raised any issues or concerns for you, please contact the Parkinson's NSW HealthLine on 1800 644 189. If the issue or concern is really serious, please contact Lifeline on 131114

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## Improving medication safety for Parkinson's patients

Michael Ortiz has Parkinson's. Like many with this disease, he's been hospitalised on many occasions for conditions other than Parkinson's.

On too many of those occasions, according to Michael, the medication [levodopa](#) – vital to help him with his Parkinson's symptoms – wasn't administered on time and his stay in hospital and levels of comfort were impacted.

As a trained pharmacist Michael was keen to improve outcomes for himself and others. He reached out to the Clinical Excellence Commission's Medication Safety team. He also sought out the best clinical practice in caring for patients with Parkinson's.

The clinician doing a wonderful job according to Michael Ortiz, is Vince Carroll, Parkinson's Clinical Nurse Consultant at Coffs Harbour Hospital. Vince's position is co-funded by Parkinson's NSW and the Mid North Coast Local Health District.

Vince and two other clinicians – Jess Andrews, a pharmacist and Kirsten Deutschmann, an occupational therapist – led a multidisciplinary team in an award-winning clinical practice improvement project to improve safety for this vulnerable patient group by addressing medication management.

**In their project, conducted at Coffs Harbour Hospital, the team found in patients with Parkinson's who were admitted to hospital each year only 44 percent were receiving medications on time.**

Delaying medications for greater than 15 minutes can worsen tremors, rigidity, confusion, agitation, and anxiety.

The Coffs Harbour team's interventions focused on bridging departmental and professional barriers with exact medication routines, identifying and avoiding certain medications harmful to patients with Parkinson's and identifying alternatives for when a person cannot take medication orally.

**Results showed improvements in patients having medications on time, a reduction in average length of hospital stay for Parkinson's as a secondary diagnosis from 9 to 6.2 days, more rapid access to correct medications, and both improved teamwork and consumer satisfaction.**

In addition to the contribution to the project of the CEC's safety notice, it also was influential in development of the Parkinson's education module on *My Health Learning* – the NSW Government Health Education and Training (HETI) online training platform.

It was also foundational to a research collaboration between Parkinson's NSW, the Mid North Coast Local Health District and Charles Sturt University on the benefits of a Parkinson's specialist nurse.

Changes to clinical practice made by the team included simply moving medications to make them easier to access.

The very simple thing was the Emergency Department (ED) staff saying 'well let's put the first line medications in the ED and trial and see how it works'. That was a simple fix but it took cultural change to make it happen.

Michael Ortiz and Vince Carroll have both published articles on improvements to Parkinson's medication management in hospitals.

#### **Sources**

Michael's paper is ['On time – every time'](#) and Vince Carroll has documented results of the project in Coffs Harbour in ['Purposeful collaboration: Enriching lives for people with Parkinson's disease'](#).

*Article courtesy of the NSW Government Clinical Excellence Commission (CEC) and the Mid North Coast Local Health District.*

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## **Leading neuroscientist Glenda Halliday names NSW Scientist of the Year**

Internationally acclaimed neuroscientist Professor Glenda Halliday FAA FAHMS from the University of Sydney is the 2022 NSW Scientist of the Year.

Professor Halliday, who received a prize of \$60,000, is one of 10 exceptional researchers, innovators and educators honoured in the 2022 Premier's Prizes for Science & Engineering.

Premier Dominic Perrottet said Professor Halliday received the award for her ground-breaking work on neurodegenerative diseases, which has changed the way we diagnose and treat these conditions globally.

Professor Halliday's research looks at how the human brain is affected structurally and biochemically by neurodegenerative diseases.

Her current focus is on the underlying causes of the non-Alzheimer's neurodegenerative diseases – particularly Parkinson's disease and frontotemporal dementia.

"It is incredibly satisfying to know our work is recognised by our peers in this way, even though we feel there is always more work to do," Professor Halliday said.

"I hope this award will inspire those I am working with and others to find the cures needed in this area of research."

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## **Support Parkinson's NSW with your Christmas gift shopping**

Generous Parkinson's NSW donors often ask what their donated funds will be spent on.

Well this Christmas, the choice will be yours – and you can donate as a Christmas gift on behalf of one of your friends or family members.

The new Parkinson's NSW Virtual Christmas Gift Store allows you to choose exactly what you would like your donation to be spent on – and for whom.

Perhaps something as basic (but important) as an information kit to be sent out by our 1800 HealthLine? Or you could choose to underwrite an education seminar, a nurse's visit, or some other Parkinson's support activity.

There is a wide range of choices at an equally wide range of prices – the choice will be yours.

And when you give, a Christmas card will automatically be generated and emailed to the person for whom you donated.

It's Christmas giving with practical and social value. Christmas shopping solved!

Visit: <https://www.pitchinforparkinsons.org.au/christmas>