

# STANDBYME

IN THIS TOGETHER  
**parkinson's**  
NSW

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## IN THIS ISSUE

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# In this issue...

Welcome to the Spring edition of *Stand by Me*.

In this issue we feature a wide variety of articles on many different aspects of living with Parkinson's.

These include the experiences of Michael who has reinvented himself as a visual artist as his Parkinson's advances, and Mark who gives an insight into the career challenges which come from living with Young Onset Parkinson's.

## Magnesium, muscles, and Parkinson's

Do you often have night-time leg cramps, or restless legs syndrome? If so, you might be deficient in a very important mineral – magnesium.

Recent research has suggested that people living with Parkinson's are often deficient in magnesium, which may have a protective role to play in regard to neurological diseases in general.

Magnesium is a mineral involved in hundreds of processes throughout our bodies. It belongs to the electrolyte family, which affects functions such as muscle movement.

It can be difficult to pin down magnesium deficiency and – as blood tests aren't always reliable – it's important to be aware of symptoms, as they may be the best indicators of deficiency.

The symptoms of magnesium deficiency include insomnia, fatigue, and weakness; muscle cramps, spasms, and twitches; restless legs syndrome; confusion, irritability, anxiety, and depression; a loss of appetite; and difficulty breathing.

Confusingly, these symptoms can be caused by a range of other factors that are not to do with magnesium. However, since magnesium deficiency is widespread in Parkinson's, you should talk to your doctor if you experience some of these.

### What does magnesium do?

Magnesium is needed for energy production, to convert vitamin D to its active form, to control blood glucose, and to regulate blood pressure, among hundreds of other important tasks.

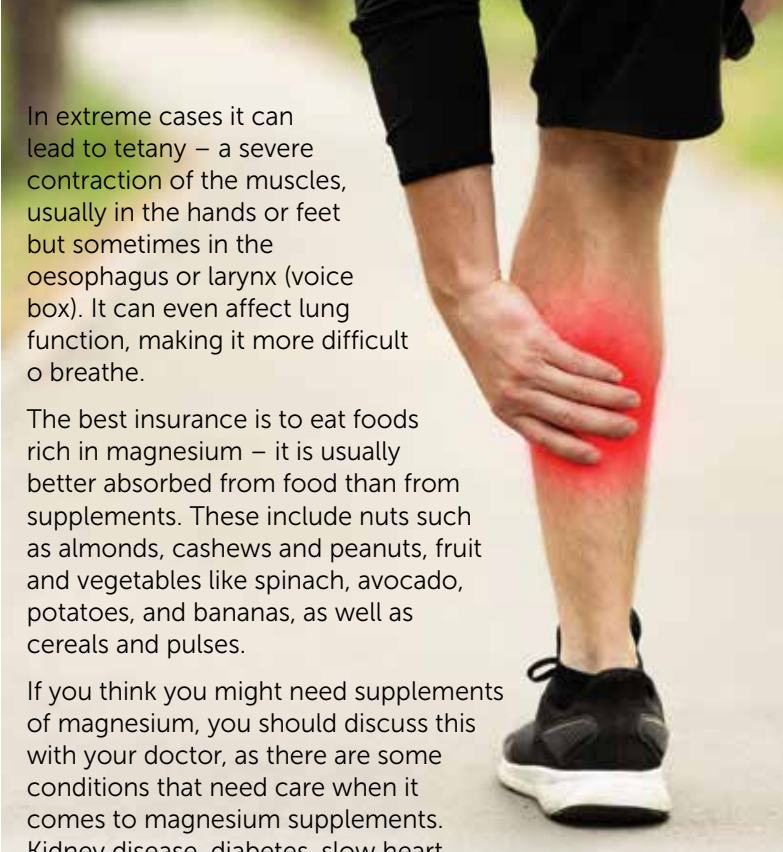
Perhaps most significantly for people living with Parkinson's, it plays an especially important role in muscle function. When there is a magnesium deficiency, the muscle isn't able to relax as easily, causing cramping or spasms.

There is a research article by prominent neurologists on what is fuelling the rapid increase of Parkinson's diagnoses across the world, and a wellbeing story on the importance of magnesium in your diet for treating sleep issues and improving muscle function.

And let's not forget exercise. In this edition there are even tips on exercises you can do in bed!

Enjoy your reading...

### The Team at Parkinson's NSW



In extreme cases it can lead to tetany – a severe contraction of the muscles, usually in the hands or feet but sometimes in the oesophagus or larynx (voice box). It can even affect lung function, making it more difficult to breathe.

The best insurance is to eat foods rich in magnesium – it is usually better absorbed from food than from supplements. These include nuts such as almonds, cashews and peanuts, fruit and vegetables like spinach, avocado, potatoes, and bananas, as well as cereals and pulses.

If you think you might need supplements of magnesium, you should discuss this with your doctor, as there are some conditions that need care when it comes to magnesium supplements. Kidney disease, diabetes, slow heart rate, bowel obstruction, and myasthenia gravis are examples. Also, magnesium supplements can interact unfavourably with some medications.

If your doctor agrees that magnesium supplements are a good idea, they will indicate how much you should be taking.

Magnesium is among the minerals most vital to human health, but it's also one of the most neglected. Take a few moments to consider whether you're getting enough of this important nutrient, or whether it might be a good idea to talk with your doctor about supplements.

*Source: Kathrynne Holden, former National Parkinson Foundation dietician (UK)*

*Visit her website, [nutritioncanlivewith.com](http://nutritioncanlivewith.com), for more Parkinson's-related nutrition information*

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# Exercises you can do in bed

Parkinson's progresses at different stages for everyone. In the advanced stages some people may become bedbound.

Whether you are confined to bed due to Parkinson's, an injury, or surgery you risk losing muscle mass and strength. Your muscles will also shorten and tighten whilst in bed which will cause muscle cramps and pain.

However, there are several exercises you can do whilst in bed to help maintain your strength and flexibility.

**Palm Stretches** Palm stretches help maintain hand function, whether it's for reading books or engaging in your favourite hobbies while bedbound. This exercise can also prevent hand stiffness and pain. Stretch each hand out as far as possible and then make a fist and squeeze the fingers to the palms.

**Arm Lifts** When confined to bed for long periods your muscles become restless. Lift your arms off the mattress and hold them there for 10 seconds. This will strengthen the arms and shoulders and increase blood flow which helps circulation and prevents cramping. If possible, hold the position for 10 seconds.

**Shoulder Shrugs and Rolls** To exercise your shoulder, back and neck muscles try doing shoulder shrugs and rolls. Lift your shoulders as high as you can, hold a few seconds then pull down and hold a few seconds. Repeat around 10. These areas can get very stiff when your constantly in bed. This will make movement easier and less painful.

**Leg Lifts** Lifting your legs works your core muscles, including the abs, obliques, and lower back. These muscles can help you to sit up in bed or swing sideways to stand when necessary. Keep the knees bent to lessen the load on the abdominal muscles. If possible, hold the position for 10 seconds.

**Bridging** Lie on your back, bend both knees facing upwards. Lift the hips up and hold the position for 3 sec, slowly lower your hips back down. Repeat 6 to 8 times.

**Core** Bend both knees and tighten your lower stomach below the belly button. Hold this position and lift one leg upwards direction and slowly lower it down. Repeat

the same with the other side. This procedure can be done 7 or 8 times for each leg. Working on the core part of the body protects the back and keeps it stable while turning in bed or getting up from the bed.

**Flex and Point** Lying on your back, point the right foot while flexing the left foot at the same time.

Alternate this slowly around 10 times. Then flex your both feet to sense the stretch on your legs and calf muscles.

*Before starting any exercise regime, make sure you consult with your doctor first.*



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## David Veness recognised for service to people with Parkinson's disease

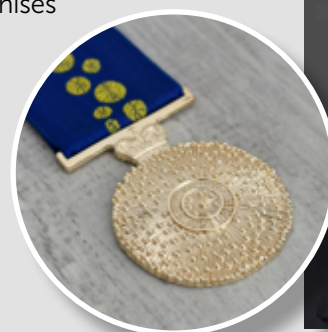
David Veness, long-time participant of the Bathurst Parkinson's Support Group and former Board Member, has been awarded the Medal of the Order of Australia (OAM) for service to people living with Parkinson's disease.

The Order of Australia is the pre-eminent means by which Australia recognises the outstanding and meritorious service of its citizens.

David has devoted himself to serving the Parkinson's NSW community.

He has been a Member, Vice Chair and Chair of our Board of Directors, and also concurrently served as a Board Member of the Parkinson's NSW Trust. Upon retiring from his Board positions, David became Parkinson's NSW Community Ambassador.

David is also well-regarded for his advocacy on behalf of people living with Parkinson's in rural and remote areas – and in particular the need for Parkinson's Specialist Nurses to support these communities.



# 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:

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

U Try to enjoy things as well as grieving

U Join a support group U 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:

U Keeping in touch U Being prepared to just listen

U Show your care and concern

U Talk about the person who has passed away

U Remember there are many who may be grieving, including children, grandparents, and friends

U Make contact again and again

U Share memories and stories

U Acknowledge all significant dates

U Always ask the person if they are OK.

U Be there for them by reaching out and being a great listener.

Things which may be unhelpful to the person grieving are:

U Avoiding the grieving

U Taking anger personally

U Saying "I know how you feel"

U Instructing them how to grieve

U Changing the subject

U Not using the name of the person who has passed away

U 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:

U High levels of insomnia

U A strong sense of hopelessness

U Inability to continue relationships

U Deep depression or anxiety

U 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**



# The Challenges of Young Onset Parkinson's Disease

What are the main differences between Young Onset Parkinson's Disease and someone who has typical, Late Onset Parkinson's disease? Why does this subclass of disease exist in younger people, relative to typical Parkinson's in more elderly people?

**Author and healthcare writer Mark Chlad – who is himself living with Young Onset Parkinson's – takes us through some of the everyday issues and choices that people in his situation may have to face.**

## How many people with Parkinson's have the Young Onset form?

The estimates vary widely because organisations use different age brackets when discussing how many Young Onset patients with Parkinson's exist at a given point in time. However, most organisations appear to be moving towards the age of 50 years as the point at which patients with typical Parkinson's develop symptoms.

In 2018 the number of people living with Parkinson's in Australia was around 82,000, making it the most common major movement disorder<sup>1</sup>. By 2022 estimates had risen to somewhere between 84,000 and 212,000<sup>2</sup> in Australia. In the USA, Young Onset Parkinson's occurs in 4 to 20 percent of all patients with Parkinson's.

While symptoms are similar to typical Late Onset Parkinson's, people with the Young Onset form have different challenges to face. Because they are at a different life-stage, challenges in employment and finance may occur.

## What were the main challenges with employment and creating regular income?

The biggest challenge I faced when I came to Australia in 2010 was finding work relevant to my experience along with an employer who could see the potential in me (plus the experience and knowledge I could bring to a company).

I deduced that getting a new job was all down to the interview process, which for me usually presented the following scenarios:

- I could begin the interview with a 'cards on the table' approach: "Now, some of you are looking at me, thinking 'what's wrong with this fella?' Well, it's called Parkinson's." Notebooks all closed in unison and the interviewing panel studied my responses to questions fired at me over the course of the interview, as if I were a new specimen they were viewing under a microscope...NO second interview!

## Or...

- I could begin the interview with a 'cards close to the chest' approach: I would say nothing about my Parkinson's and just hoped that the doubled-up dose of medication I took beforehand would continue to work through the interview – without dyskinesias! Usually this would end up with a frustrated interviewer who could see something was 'not quite right' about this candidate... NO second interview!

Both approaches are poles apart in strategy and were both as ineffective as the other. It is very frustrating with respect to the 400 jobs I applied for and the handful of interviews that I was offered in the first few years of living in Australia.

## Differences between Young Onset and Late Onset Parkinson's?

One of the main differences is the rate of disease progression, which is slow in people with Young Onset Parkinson's, maintaining functionality and remaining cognitively unimpaired for a longer period of time. This may explain why people with Young Onset Parkinson's tend to live longer than people with Late Onset Parkinson's.

People with Young Onset Parkinson's may demonstrate an increase in side-effects, particularly more frequent dyskinesias or involuntary body movements from dopaminergic medications. Earlier and more frequent dystonias (cramping, unusual posture, arching of the foot) are common in Young Onset Parkinson's.

Lastly, people with Young Onset Parkinson's are less likely to develop dementia.

*Mark Chlad is a healthcare writer. He has written and had published two books about his adventures with Parkinson's Disease, 'Drivin' Daughters and Parkinson's' and 'The Time Thief' (both under the pen name: Marco Preshevski). These are available online via retail book shops' websites or can be ordered through any bookshop. Marco's third book is due out in 2024.*

## References:

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# Are we facing a Parkinson's pandemic?

Historically, Parkinson's was rare. In 1855, for instance, just 22 people living in the United Kingdom died with Parkinson's disease.

Today, in the United States, the National Institutes of Health (NIH) estimate that about half a million people are living with the disease.

Recently, a group of experts from the field of movement disorders published an article in the *Journal of Parkinson's Disease*. Titled 'The emerging evidence of the Parkinson's pandemic,' the authors outline their growing concerns and what might be done.

**A pandemic?** Globally, neurological disorders are the leading cause of disability. Of these, Parkinson's disease is the fastest growing. From 1990 to 2015, the number of people living with Parkinson's doubled to more than 6.2 million. By 2040, experts predict that number will reach 12 million.

The term 'pandemic' is normally associated with diseases that can spread from person to person. Of course, this does not apply to Parkinson's. However, according to the study authors, the condition's spread does share some of the characteristics of a pandemic.

For instance, it is a global concern that is present in every region of the planet. It is also becoming more prevalent in all regions that scientists have assessed.

Additionally, pandemics tend to move geographically. In the case of Parkinson's disease, it seems to be moving from West to East as demographics slowly change.

**Increasing risk** Because Parkinson's primarily affects people as they grow older, the steady increase in humanity's average age means an inevitable increase in the prevalence of Parkinson's. This slow lift in our average age is not the only factor playing into the hands of a potential epidemic.

Some studies show that, even when analysis accounts for increasing age, Parkinson's disease still seems to be becoming more prevalent.

This means that the average older adult today has an increased risk of developing Parkinson's disease.

The study authors outline some of the factors that appear to be increasing the risk of Parkinson's disease today.

**Tobacco's surprising influence** Globally, the number of people who smoke tobacco has dropped significantly over recent decades. People rightly consider this to be a huge benefit to public health.

However, smoking tobacco appears to reduce the risk of Parkinson's disease. Some studies have shown that smoking can reduce risk by more than 40 percent.

Reducing tobacco consumption may therefore be raising the overall prevalence of Parkinson's disease.

**The growth of industry** Also, industrialisation might be playing a part in the steady rise in Parkinson's risk. As the authors write: "Numerous by-products of the Industrial Revolution, including specific pesticides, solvents, and heavy metals, have been linked to Parkinson disease."

For instance, China – a country that has witnessed rapid industrial growth – has had the swiftest increase in Parkinson's disease.

Scientists are still debating the role that pesticides play in Parkinson's. However, one in particular, paraquat, is



strongly linked to the condition and is now banned in 32 countries.

Despite this, the study authors say that in the U.S., people are using it "...in ever greater quantities." The U.K. is one of 32 countries to have banned paraquat usage. Regardless, they continue to manufacture it and sell it to countries including the U.S., Taiwan, and South Africa.

*"Parkinson's disease is increasing and may be a creation of our times," write the authors. "As opposed to most diseases whose burden decreases with improving socioeconomic level, the burden of Parkinson's disease does the opposite."*

Increasing rates of Parkinson's disease are concerning for obvious reasons, but what can we do? Can we turn the tide?

The study authors believe that the key to transforming this seemingly inevitable rise in Parkinson's disease is activism.

Conditions such as HIV and breast cancer have benefited widely from this approach. For example, many focus on raising awareness, amassing funds, improving treatments, and changing policy.

Stopping the production and use of certain chemicals that may increase the risk of Parkinson's is essential.

Also crucial, as ever, is financial backing. More research is needed to understand why the condition appears and how it progresses, and this type of scientific investigation is never cheap.

In particular, scientists need to develop better medications. Currently, the most effective therapy is levodopa, which is 50 years old and not without its issues, including both psychological and physical side effects.

While this recent analysis is worrying, the authors leave the reader with some positivity, concluding that "...the Parkinson pandemic is preventable, not inevitable."

Sources:

*The Times They Are a-Changin': Parkinson's Disease 20 Years from Now*

Authors: Dorsey, E. Raya; \* | Sherer, Todd | Okun, Michael S.c | Bloem, Bastiaan R.d

Editors: Patrik Brundin, J. William Langston, and Bastiaan R. Bloem

*Medical News Today*

# My [Parkinson's] Life

## Michael Costello

Michael Costello was raised in Clemton Park, a south-western Sydney suburb. He was the youngest of three children under five of a divorced mother, a situation which meant the family really struggled.

But Michael's mother backed her children as much as she could, and Michael's creative interests and positive outlook began in childhood.

*"I was always an artistic person," recalls Michael, now 70. "I guess I disappeared into make-believe. I always liked writing, but I never saw it as something I could do as a profession."*

*"When I was in primary school, I entered an open writing competition for Anzac Day and won. My teachers didn't believe I had written it myself and sent home a message that whoever was doing my writing, please stop. My mum went up to the school and set them straight."*

When Michael finished high school, he became a public servant for 38 years until he retired in 1997. But he wasn't just focussed on his day job; after an early marriage ended, he took on evening work to pay off the settlement.

*"I was working as a waiter when I met my partner Graeme Haigh through friends at a Balmain pub," he explains. "We were just good friends for a while at first, and now we've been together for 40 years."*

*"I had always still wanted to write," says Michael. "I didn't want to get to 70 and then wonder what I could have done."*

*"I started writing while I was still in the public service. I joined an amateur theatre group, and I would write plays in longhand and Graeme would type it up for me. Then I'd edit it and he'd type it out again."*

*Michael would submit his plays to various theatre companies for consideration. To his amazement, a play he submitted to the Ensemble Theatre, in harbourside Kirribilli, was accepted and performed.*

*"To my knowledge it is still the first unsolicited play they ever put on!" he says. "But from that I got TV work, including a commission from Sue Smith, then the head of ABC drama."*

He was one of six writers chosen from a field of 200 whose original work went into production.

A second play, *Royal Affair*, earned Michael an AWGIE award, given for outstanding achievements of Australian performance writers and their contribution to the cultural landscape.

*"We had booked a holiday in Thailand the day after the awards presentation and I thought that there was no way I was going to win," says Michael. "The awards night was in Melbourne. We had friends meet us at Sydney airport and threw the prize into their car while we got on the plane to start our holiday."*

Michael's last writing challenge was a novel, *Season of Hate* – a novel about relationships in a country town – was completed and published in 2015. It received positive reviews and strong sales.

It was around that time, while going for walks, that Michael noticed that one arm wasn't moving as he walked along.

*"I knew I hadn't had a stroke," he says. "I wondered if a tumour was affecting me."*

*"One neurologist said it wasn't a tumour but sent me to a Parkinson's specialist. He asked me whether I could smell bananas or strawberries, which I'd never thought of, but of course when I tried it at home I couldn't."*

*"The Parkinson's diagnosis followed, and I started to develop a tremor and a tingling in a finger, and I have a dropped shoulder as well. But I'm regarded by my neurologist as fully functional in that I can still do things for myself."*

Michael's functionality is more surprising because he's also had 11 operations in 14 years to deal with knee, toes, hip, and spinal issues from years of playing tennis and squash, doing aerobics, and running on hard surfaces.

*"In some ways, the way I'm getting around is good," says Michael, who moved to The Residences with Graeme in 2018.*

*"We realised that we weren't going to be able to cope with our house and garden. We saw this place when it was opening and decided it was time to move. We enjoy the community here."*

*"I can't do running or tennis anymore, but I do mahjong, bridge, Scrabble, carpet bowls, table tennis, line dancing and art. I also put on movies here every third Sunday – Michael's Movies – and I like to encourage people to join in and try activities."*

*"I have my down moments, but they are fleeting. I can't turn back the clock, that's the cards you are dealt. We do what we can do."*



# Be part of a future

where no-one has to  
face Parkinson's alone.

By leaving a gift in your Will, you can give people living with Parkinson's a better future.

Without access to specialist information and supports, the Parkinson's journey can be a lonely one. It can be filled with fear, grief – and misinformation.

But through your legacy, people with Parkinson's – and their carers and loved ones – don't have to feel they're going it alone. You can empower them every step of the way.

You'll be making sure people can always access expert, specialist supports and information that helps them be part of life in their community and make the most of every moment.



**Your legacy** Your kindness will impact the lives of countless people into the future, giving them expert, specialist support so they don't have to face Parkinson's alone.

**Our shared vision** You'll be part of the greater mission to empower people through knowledge, information, education and advocacy.

**Their future** Your gift gives people living with Parkinson's a better future – a future where they have more chance to make the most of every precious moment and a future where they will have access to expert and quality services whenever needed, and wherever they live.

## A legacy that lives on: John's story

John decided to leave a gift in his Will to Parkinson's NSW to honour his late mother Patricia, who had Parkinson's for 20 years.

*"She was only 59 when she was diagnosed, just when she was looking forward to retirement. I saw what she went through.*

*I also donate to Parkinson's NSW every year, and I know exactly what they do with my money because they tell me about the difference I'm making. They have such a personal approach. They make me feel like my gift is really valuable.*

*I know I'm helping employ nurses in regional areas to help people with Parkinson's. Their services are really hands-on. This is stuff that really, really helps people."*



We welcome the opportunity to discuss how you can be part of a future where no-one has to face Parkinson's alone. We are happy to help with any questions you may have about leaving a gift in your Will. Please call our Donor Development team on **1800 644 189**.

*"Thank you for thinking of people living with Parkinson's now and into the future."*

