

STANDBYME

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My [Parkinson's] Life

Having Parkinson's is just one aspect of a person's life story - Sandra Elms

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From the CEO

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

The Parkinson's NSW 2019-20 financial accounts have been audited and I am delighted to tell you that our charity has declared a significant net profit of \$264,663. So, our organisation is in good financial health.

This positive result reflects the progress we are making on our 5-Year Strategic Plan. We are now more than two years through our Plan and have met every milestone set by the Board.

This edition of *Stand by Me* contains a full review of the 2019-20 financial year's activities.

The impact of COVID-19 continues to be felt by our community.

Support Groups are only now tentatively beginning to meet in small, socially distanced groups for outdoor coffee catchups. Education and Support Group Leader meetings via Zoom have become the new normal.

Please remember, if you are feeling isolated and need someone to talk to – or have questions about any aspect of Parkinson's – you can call our Parkinson's Registered Nurses on the InfoLine: 1800 644 189.

They can either help you directly, or connect you with other services including counselling, exercise, education, a local Support Group, Allied Health providers which have been vetted by Parkinson's NSW, or NDIS Advocacy and Support Coordination.

It's tough to feel positive sometimes – especially as COVID-19 drags on – but we are in this together so don't hesitate to pick up the phone when you need to.

Jo-Anne Reeves
Chief Executive Officer



Parkinson's NSW and Charles Sturt University collaborate on Nurse Specialist program for western NSW

Charles Sturt University is collaborating with Parkinson's NSW and the Western NSW Primary Health Network (WNSW PHN) on a four-year Movement Disorder Nurse Specialist Pilot Program to assist people living with neurological conditions in western NSW – including Parkinson's.

The community-focused initiative will recruit 12 registered nurses to participate in the program which will improve access to specialised nursing care for people living with neurological conditions including Parkinson's in the western NSW region.

Associate Professor of Nursing Rachel Rossiter of the Charles Sturt School of Nursing, Midwifery and Indigenous Health is the research and evaluation consultant for the program. It will extend to the South Australian border – including Bourke, Wentworth, Balranald, and Broken Hill in the west, and east to Bathurst, Mudgee, and other localities.

"The nursing model of care for this project has been strongly informed by the research funded by Parkinson's NSW that our research team has undertaken over the past three years," Professor Rossiter said.

Parkinson's NSW CEO, Ms Jo-Anne Reeves, said she is committed to this partnership.

"This program will be instrumental in helping to build knowledge around Parkinson's in rural and remote communities, and we're looking forward to supporting and working with the 12 successful Registered Nurse applicants," she said.

WNSW PHN CEO Mr Andrew Harvey said the pilot program will substantially improve health outcomes for patients in the region by providing more trained staff in more readily accessible locations for patients.

The steering committee for the Movement Disorder Nurse Specialist Pilot Program includes the President of Parkinson's NSW David Veness as well as key people from the Western NSW Local Health District, the Far West Local Health District, the Primary Health Network, the Outback Division of General Practice, Maari Ma Health Aboriginal Corporation, the Australasian Neuroscience Nurses Association – Movement Disorder chapter, a community member with lived experience of Parkinson's and a community carer.

Sources: Charles Sturt University School of Nursing, Midwifery and Indigenous Health

Western NSW Primary Health Network Disease

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Seeking counselling when you need it

When it rains look
for rainbows
When it's dark look
for stars

Many of us already have levels of anxiety and stress resulting from our everyday life or illness – and now we are living with the additional pressure of COVID-19 restrictions.

Sadly, there remains stigma around mental health issues and seeking support from counsellors and psychologists. Many people feel they require a cut and dried set of symptoms to warrant seeking support and disregard life's random disruptions.

Many of us living with Parkinsons are dealing with issues of health, self-confidence, anxiety, loss and anticipatory grief, carer burnout and carer fatigue, and uncertainty around the future. These feelings affect us every day – in our work performance, relationships and our sense of self and wellbeing.

Without actively and consciously facing these feelings, our thoughts and behaviour can escalate and immobilise our ability to function effectively manifest into something more serious. Here are some reasons for seeking support from a mental health professional.

You need a new perspective

If you're living with physical or emotional pain, fear, doubt and uncertainty and don't feel you can share with family or friends, (or when family or friends may unintentionally hold you back) it may be time to consult a mental health practitioner.

A professional who offers an unbiased, confidential, independent view on things and specific tools which can help you manage the challenges in your life, find inner stability and reach your true potential.

You feel you need someone to listen to you

At times we find ourselves struggling with things that we don't feel comfortable talking to our partner, friend, or family about. Anything from a relationship, financial difficulties, health issues, the shame and loss of skill sets that can be experienced in having a degenerative disease like Parkinsons.

Keeping these types of stresses held internally can impact health. A mental health practitioner can be the person who can listen to you and in total confidence and can help alleviate your stress.

You are stuck, feeling frustrated and it's difficult to move forward.

A mental health professional can assist you to identify the cause of frustration and help prioritise the steps you need to take to get moving. They can also help you through setbacks and support you with tools that relieve your anxiety, build on your strengths and self-confidence.

When nobody understands you

Feeling misunderstood can make you feel frustrated, alienated, and lonely. This can lead to social isolation with lack of connections.

A professional has training in understanding your issues and specific strategies to help you overcome these. Loneliness is the biggest single factor decreasing health and quality of life for those living with Parkinson's.

Continually feeling overwhelmed

Living in a fast-paced world with a chronic illness is already overwhelming. Add COVID-19 and you've elevated your anxiety and stress even further. Learning some new strategies can assist in reducing that constantly overwhelmed feeling. Learning new time management or problem-solving skills assists in improving your mood and sense of empowerment.

Making peace with yourself

Being who you really are is a real challenge and is the key to how we can find real happiness. We need to take time to listen and acknowledge who we are.

We are all learning to live within our own limits and boundaries with Parkinson's. We each have our own skill sets and need to set realistic goals that are within the range of our abilities.

These may be different to other people living with Parkinson's and may also be very different to what they were prior to having Parkinson's. Finding real happiness rests in learning to make peace with our limitations and working within these to the best of our ability.

Being brave all the time

Being strong all the time is very tiring. Don't pretend things aren't important to you if they are. Each of us have our own particular vulnerabilities. What is important is to have the courage to reach out and accept the support and care of others

Seeking support isn't about feeling sorry for yourself but building courage and clarity in yourself around areas that you need help.

If you are seeking ways to look after your mental health, please refer to the evidence based resources available on the Mental Health Services and Support contact list.

The Government is providing additional mental health support during the pandemic – including 24x7 phone counselling service led by Beyond Blue and staffed by accredited mental health professionals to help people experiencing stress or anxiety associated with the impacts of the pandemic.

Think of utilising these resources to help lessen burnout, anxiety and stress.

Additional Resources:

Supporting the mental health of Australians through the Coronavirus pandemic
Coronavirus: Resources for Anxiety & Stress

2020: The year in review

The 2019-20 financial year was a pivotal point in the Parkinson's NSW 5-Year Strategic Plan.

Following a significant profit in fiscal 2017-18 we operated at a Board-approved loss in 2018-19.

This enabled us to invest in strengthening the infrastructure of our organisation, while simultaneously growing the range and reach of services to the NSW Parkinson's community.

This longer-term planning enabled our charity to deliver a significant net profit of \$264,663 in 2019-20 – despite the highly challenging and unusual operating conditions amid a pandemic.

The Parkinson's NSW Trust – which has a separate Board – is for the purposes of financial reporting considered a Related Entity. Due to the impact of COVID-19 on financial markets, investments by the Trust delivered lower returns than in previous years. So, although our charity delivered a profit, its consolidation with the Trust as a Related Entity resulted in a loss of \$309,249.

During the past fiscal year, service delivery reached historically high rates – particularly through the InfoLine, counselling services, community-based Parkinson's Specialist Nurses, National Disability Insurance Scheme (NDIS) advocacy and Support Coordination, and the community awareness building and audience engagement driven by our Marketing team.

InfoLine

During the past fiscal year, the InfoLine team actioned 4,433 calls. This does not include routine enquiries or duplicated calls or emails.

In previous years, the length of calls used to range up to 40 minutes. This past year, with the pressures of COVID-19, the length of calls blew out to 65 minutes each.

As an indicator of the trust placed in the skills and knowledge of our InfoLine Team, Parkinson's South Australia diverted its calls to Parkinson's NSW for several months while its organisation restructured.

That meant the team was fielding enquiries from people living with Parkinson's in South Australia as well as the Northern Territory – which is usually serviced by Parkinson's South Australia. They also occasionally receive out-of-area calls from people in Queensland and Victoria.

Information the InfoLine can provide

- Parkinson's Information Packs
 - Parkinson's Medication Information
 - Parkinson's Symptom Management
 - Allied Health Services
 - Parkinson's Clinics
 - Referral to community-based Parkinson's Specialist Nurses
 - National Disability Insurance Scheme (NDIS) information
 - Information on Advanced Therapies
 - Information on Assistive Devices
- and much more ...**

Community-based Parkinson's Specialist Nurses

The part-time role in Coffs Harbour was increased to a full-time position. Existing full-time Parkinson's Specialist Nurses in Port Macquarie and Shoalhaven remained in place.

The Northern NSW Local Health District signed an agreement with Parkinson's NSW to co-fund a new position in the Tweed region. A highly qualified nurse was recruited and began work in October.

We also signed a Memorandum of Understanding with Hornsby Hospital for a Nurse placement to support Parkinson's patients living on the northern fringes of the Sydney metropolitan area.

Due to the impact of COVID-19 restrictions, the number of face-to-face consultations and home visits by nurses declined by more than 50 percent while the number of telephone consultations increased by the same amount.

However, nursing support for people receiving advanced therapies such as Apomorphine and Duodopa continued without interruption – 68 patients were supported over the year.

Our Parkinson's Specialist Nurses also maintained their close links with Support Groups, attending 127 meetings over the year – initially in person, and then via video-chats when COVID-19 restrictions were imposed.



The number of community-based Parkinson's Specialist Nurses in regional and rural areas grew in the 2019-20 fiscal year.



Education

Sixteen education seminars were developed and delivered across NSW in the 2019-20 fiscal year.

This number is lower than previous years due to the impact of the catastrophic bushfire season, closely followed by the COVID-19 pandemic which resulted in wide-spread restrictions.

When it became obvious that the COVID-19 issue would not be quickly resolved, the Education team began development on a self-guided, Internet-accessible version of the course for Aged Care Nurses and Support Workers.

This new digital course is in its final stages of testing and once completed, elements of this online course will be adapted and expanded to meet the needs of other audiences willing to participate in this new form of learning.

Support Groups

Support Groups are legally part of Parkinson's NSW and supported by employees of the organisation – including a Support Group Coordinator, and the Senior Leadership, Marketing and Fundraising teams.

This support from the Parkinson's NSW team became even more important during the second half of fiscal 2019-20. That was when toughening COVID-19 restrictions deprived Support Group participants of valuable face-to-face meetings with like-minded people in their communities.

To maintain contact between different Support Groups and individual Support Group participants, Parkinson's NSW staff quickly researched, developed, and disseminated guides for setting up online video-chat meetings.

Most Groups also moved quickly to establish their own telephone and email check-in protocols to ensure that no individual was left unsupported in the absence of face-to-face contact.

Despite the pandemic, the Support Group network managed significant growth over the 2019-20 fiscal year – nine new general Groups and the same number of specialised Carer Groups were established.

There is now a total of 91 Support Groups across NSW with more than 1,850 participants. This represents a growth of 30 percent in the network.

In addition, online Support Groups were launched. There are now three Facebook Groups: the Parkinson's Support Groups Online Community with 122 members, a Support Group Leaders Community with 13 members, and a Young Onset Parkinsons community with 59 members.

NDIS services

Parkinson's NSW gained Registered Service Provider status with the National Disability Insurance Scheme (NDIS) in the 2018-19 financial year. We expanded our support for both potential and successful applicants for NDIS funding over the past fiscal year.

During 2019-20, our Parkinson's Nurse Advocate guided 292 people aged under 65 and living with Parkinson's through the complexities of applying for NDIS funding – an increase of 56 percent over the previous year.

Of these applicants 115 were successful while others are being assisted through the re-application and appeal processes.

The second component of the NDIS support services provided by Parkinson's NSW is Support Coordination.

Once an NDIS participant has Support Coordination approved in their plan, we can assist with services that are billable to the NDIS, including linking people with their community, as well as mainstream and Government services.

Our part-time Support Coordinator is currently assisting 20 participants – a growth of 63 percent within the past year. A second Support Coordinator was recruited in October to cope with the growing NDIS workload.

Counselling Services



Demand for specialist Parkinson's Counselling increased during fiscal 2019-2020. We therefore added another Counsellor to the team in the second half of the year.

One of our Parkinson's Counsellors works from two locations in Sydney – War Memorial Hospital and Wolper Jewish Hospital. The other is based in the Parkinson's NSW headquarters in North Ryde.

As with our Parkinson's Specialist Nursing services, the Counselling team had to adapt quickly to manage the challenges of COVID-19 restrictions.

The number of face-to-face counselling sessions dropped by 30 percent while the number of telephone consultations increased by 55 percent. Video-chat sessions also became more popular with 174 conducted during the fiscal year.



Positive responses to first Client Satisfaction Survey

Parkinson's NSW recently engaged an independent organisation to conduct the first of a series of regular surveys of the satisfaction levels of people receiving Parkinson's NSW services and support.

The independent provider managed the survey process, undertook a comprehensive analysis of the data provided and produced a report for the Board and Leadership Team of Parkinson's NSW.

Clients had access to the online survey via an email link. There was no paper survey available, but clients had the option to call a staff member to complete a survey over the phone if they preferred. No clients availed themselves of this option.

1,445 Parkinson's NSW clients were sent an email inviting them to complete this survey. Twenty surveys 'bounced', therefore 1,425 clients received the survey.

When the survey closed in, 282 responses had been received.

The accompanying graphics summarise the top-line findings of the survey. Overall results were positive, particularly considering the survey was undertaken amid the COVID-19 pandemic.

Action is already being taken on areas where a need for improvement was indicated – for example effective communication of the organisation's Strategic Plan.

Read the full report on the Parkinson's NSW website: parkinsonsnsw.org.au/what-clients-think-about-parkinsons-nsw

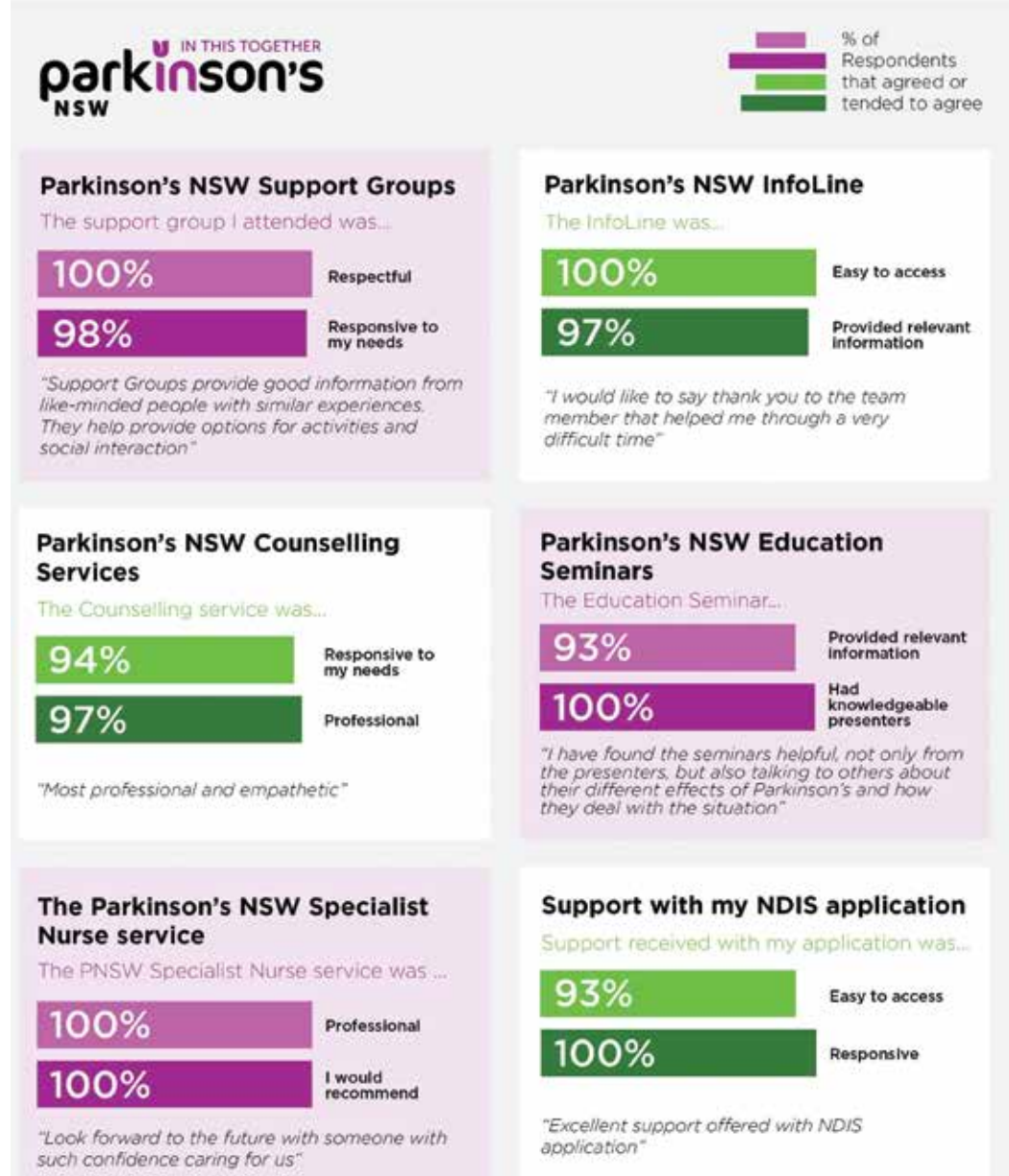
Do you have questions about the Client Satisfaction Survey results?

Phone the **Parkinson's NSW InfoLine** on **1800 644 189** to arrange a chat with a member of the Marketing Team who will be able to assist you.

Alternatively, email pnswn@parkinsonsnsw.org.au or use the response form on the Parkinson's NSW web page here.

More information on the Survey is also available here.

Here is what our clients said about the services we provide



My [Parkinson's] Life

Sandra Elms was born in England but has spent several periods of her life in Australia – firstly as a child growing up in Perth with her parents and sister, then as an 18-year-old travelling with a friend for three years.

Travelling to other countries was always something that interested her and when she married, she moved with her husband to the Sudan.

“We had three years working at the University of Khartoum, which was amazing,” Sandra explained. “It was a bit of a time warp, with colonial things like lawn tennis courts and tiffin – although it was never a British colony; it was governed jointly by Egypt and Britain.”

The couple then travelled overland back to England, travelling through Pakistan, across the Khyber Pass into Afghanistan and through what was still thought of as Persia (Iran) and into Europe and then home.

Back in England Sandra decided it was time to have children and they had two girls and twin boys, but unfortunately the marriage broke up.

“I decided to bring my four children to Australia to start a new life,” she explained.

“Being a single parent was very, very hard, but we were a very cohesive group. The girls and boys always helped each other and somehow we managed and they all went to university.

“We kept in contact with the children’s father and the children have done incredibly well and they have interesting and excellent careers.


“I was a teacher in London after a career in medical research and I continued to teach in Sydney. I loved teaching and eventually became the Year Coordinator at an independent girls’ school. I also ran the social justice group and have always focused on helping other people. We have so much compared to others in the world.

“I stopped teaching in 2008 and went to Southern India for four months’ voluntary work at a small school and women’s centre in Kerala. I always intended to go back for a longer time.”

On Sandra’s return, she moved to Newcastle to be closer to one of her daughters and it was in Newcastle in 2012 that she was diagnosed with Parkinson’s.

“I had a tremor, but I thought it was going to be a thyroid problem as my mother and my sister had thyroid issues,” she recalled.

“I knew Parkinson’s was the other possibility, but I didn’t really think it was going to be that, so it was a bit of a shock. The thing with Parkinson’s is that there is no single test, it’s a slow process of elimination.



“I saw one rather unpleasant neurologist who bluntly told me that in ten years I’d be in a wheelchair when I asked what my prognosis was. I didn’t go back to him! It’s so important you find someone you’re comfortable with that you trust, and a good GP,” said Sandra.

“Because I taught science, and was a medical researcher, I’ve researched a lot and read a lot and I more or less decide on what medications I will take, with my neurologist.

“I also know the importance of exercise in slowing the progress and managing my mood. And I am grateful that it’s something which can be treated, it’s not something worse.”

Sadly, Sandra has personal experience of a more shocking diagnosis. Just a year after discovering she had Parkinson’s, her daughter’s husband was diagnosed with a brain tumour.

“It was dreadful, so awful,” Sandra recalled. “That one thing has moulded my life. I had to help her with her children for a few years, that was my life. Fortunately, now her children are older and she has met someone else.”

While Sandra was kept busy helping out with her grandchildren, she was also becoming very involved with expanding activities for the Newcastle Parkinson’s support group.

“I’m not a singer but I love music so I thought we needed a choir,” she explained.

“While right now we are going through a difficult stage with not being able to gather to sing, the choir has been fantastic. For six years we’ve done concerts and fundraising and visiting nursing homes to perform. We’ve even been on the ABC, on the 7.30 Report!

“We’ve also added dance and exercise programs to what is available for people through the Newcastle support group, as that’s so important. Art therapy is the latest venture. We are trying to give as much support to people living with Parkinson’s as we possibly can.”

In a busy life which has always involved caring for, helping, and teaching other people while fighting her own battles, Sandra understands that life isn’t always easy. But her advice is not to be a quitter, even if you are having difficult times.

“So many people are having a hard time and it can be easy to feel depressed,” she said. “But I think if you give up, that’s when life becomes unpleasant.”

"We never dreamed of a year like this..."

This year, as COVID-19 was devastating the globe, Will and Lisa's world was falling apart.

High-school teacher Will had always been a keen reader with a lively mind, but he was "slowing down". His thoughts were wandering. He was losing his way in conversations and words were hard to find. Physically, every movement was stiff and slow.

Desperate to know the cause of these terrifying and mysterious changes, Will and Lisa headed in to see a neurologist in February. As they were told, "it's Parkinson's" Will felt convinced he was hearing his death sentence. Lisa remembers being "a blithering mess".

None of us ever dreamed we'd see a year as difficult as this. But for the 13,000 Australians like Will who were also adjusting to a new Parkinson's diagnosis in 2020, the shock and uncertainty have been unbearable.

IN THIS TOGETHER
parkinson's
NSW



The good news is that you can help:

This Christmas, please make sure people like Will and Lisa don't have to face a Parkinson's diagnosis on their own. Give generously to the Parkinson's NSW Christmas appeal.

YES, I would like to help improve the lives of people living with Parkinson's and their families...

Title: _____ First Name: _____ Last Name: _____

Address: _____

Email: _____ Phone: _____

Please accept my donation of the following amount:

\$15 \$30 \$50 Other \$ _____

I would like to make a monthly donation of \$ _____ (\$15 minimum)
Please debit my credit card monthly, until further notice.

I would like to pay by:

Cheque/Money order (payable to Parkinson's NSW)

Credit Card (details below) Visa Mastercard American Express

Card number _____

Name on card _____

Signature _____

Exp date _____

Please send me at no obligation, information on how I can leave a bequest to Parkinson's NSW

I have already included Parkinson's NSW in my will

**THANK YOU
FOR YOUR SUPPORT**
Donations of \$2
and over are tax
deductible