

InTouch Newsletter

October 2021

Anger management for caregivers

It is easy to understand why caregivers can become angry or frustrated at times.

It is often a sign that our inner resources for coping with the various stressors involved in caring for someone with Parkinson's are depleted.

The lockdown due to the coronavirus pandemic can be an added stressor because caregivers have been deprived of opportunities for small breaks from their partner or parent who is living with Parkinson's.

Exercise classes, physio visits, external carer support and Support Group visits are in many cases no longer available. Being at home all day with your partner – particularly if they are not communicative – can add more pressure and strain on the relationship.

These pressures can lead to feelings of loss of control of your outer circumstances. However, it is important to remember during these times that the one thing we can control, or change is our *inner* state.

Attention to our inner state is particularly important when we feel anger and frustration brewing over behaviours that we observe in our partners or parents that we think they should know how to manage better.

First steps

First and foremost, if you find your anger consistently rising around your spouse or parent then you may need some respite. Respite care is often a very helpful tool for caregivers who are struggling with stress levels and difficult emotions.

Whether you opt for adult day care, in-home care, or permanent placement, even the smallest break from repetitive issues that come up will help give you some perspective and provide a mental break.

Anger is not right or wrong, meaningful nor pointless, it simply is!

Anger is something we feel. It exists for a reason, and it deserves our respect and attention. It can often be a call for change – that we've tolerated something that has been difficult for too long, that we are exhausted, and something needs to change.

As a caregiver of someone living with Parkinson's there is much to do on a daily basis:

- You help to maintain the quality of life of your loved one.
- You educate yourself about symptoms, treatments, and the progression of the disease.
- You keep track of appointments with the doctor, allied health support, medication schedules, and exercise.
- You are often the mediator or go-between for a person living with Parkinson's who has impaired speech and other family members, friends, and the community.
- You offer the love and support required to meet the challenges of Parkinson's.

Warning signs of caregiver fatigue

To address caregiver fatigue, you and the people in your support network must be able to recognise the warning signs:

- An ongoing tendency to ignore or postpone taking care of your own health needs
- Growing feelings of isolation, often expressed by: "Nobody knows or understands what is really going on with me"
- Feelings of anxiety and uncertainty about the future.
- Outbursts of anger and frustration at the care recipient or situation, often followed by guilt.
- Feelings of profound tiredness and exhaustion not relieved by sleep.
- Emotional strain/stress, often manifesting as various physical symptoms.
- An inability to concentrate or make decisions.
- Bitterness toward friends or relatives who "...should help more".
- Tendency to use alcohol or drugs to try to lessen stress levels.
- Depression, despair, and feelings of hopelessness.

Notice when your anger flares

This is a signal worth listening to within yourself. Ask yourself what is really going on?

- Are you really hurt or grieving underneath?
- Are there specific needs or wants that you haven't been adequately addressing for yourself?
- Has there been a change in your partner's level of need, a decline in their cognition, or recent falls that have increased our level of stress?
- Does something feel not right? Where do you feel you need more support? Are you giving more or doing more than you are comfortably able to manage?
- Is there a part of you that tells yourself you need to take care of your partner on your own? You need to be strong enough to care for them?

How Does Your Anger Show Up?

- **Reactive Anger:** Are you on a short fuse? Does your anger come out in a flash so that you abruptly explode?

This type of anger can be caused by frustrating experiences around Parkinson's where you feel you've explained things over and over. Even though the person you're caring for seems to understand what you are asking they still don't get it. They quickly forget and keep doing the same things.

What's really going on for you? Is it hurt or fear? Worried that your partner isn't doing something that you see as important for their health? Fear that you are losing the person they were?

Or perhaps a painful reminder that Parkinson's is progressing? For example, the person for whom you are caring remembering to take their medications on time or to wear their vital call pendant when you go out.

- **Explosive Anger:** You feel you've kept a lid on things and haven't spoken up over several frustrating events, then suddenly you explode. It has all felt too much and you've been overwhelmed with all the little things piling up.

It may be the tiniest thing that then makes you snap. Managing and recognising your anger earlier is helpful. Address the smoke before it becomes a fire.

- **Passive-Aggressive Anger:** In this case it may look like you're okay on the outside, but your tone and sarcasm say something else – that really underneath anger is brewing. This can cause you to hang on to your anger for a very long time, which can create a feeling of helplessness and over time effects mental health.
- **Projecting Anger:** Something frustrating may have happened at work, or while you were at the doctor's office, and you come home and project the anger you felt but didn't express at work onto your partner or parent. This type of misdirected anger can hurt your relationship and can create a guilt spiral afterwards.

Anger Management Tips for Caregivers

These different aspects of anger often set off a shame cycle where we feel guilt and shame for having had the outburst. Things may quieten down for a while, but gradually and eventually lead to another outburst.

If you identify with one or more of the types of anger described above, then it may be beneficial for you to learn some techniques for breaking your anger/guilt cycle.

Many people find themselves lashing out uncharacteristically once they've invited the stresses of caregiving into their lives. Here are some tips on controlling your emotions and expressing anger in a healthier way.

With practice, the following techniques will enable you to better handle your emotions and feel more like your old self.

- **Count to Ten:** It may sound like a cliché, but there's a reason why counting to ten is a commonly recommended anger management strategy. Count slowly with a breath in between each number. It works.

When something upsets you, mentally taking a step back and counting to 10 helps prevent knee-jerk reactions and allows you extra time to decide how to handle the situation. If you haven't gathered your thoughts after counting to 10, feel free to continue counting as long as you need.

Remember to take slow, deep breaths to help calm your body as well. You can also take this method a step further by removing yourself from the room or building where your anger has been triggered. This tactic is particularly useful for people who are prone to explosive episodes of anger.

- **Be Direct:** It's okay to admit your anger or frustration to others as long as you do so in a relatively calm, direct manner. One of the best ways to express anger is to do so clearly and without too much drama.

This can be difficult for some individuals, especially in the beginning. However, with practice you can develop the mental skills necessary to recognise, control, interpret and communicate your anger in a productive manner.

- **Rewind:** To help you practice responding to frustrating situations, try an exercise called 'rewinding the tape'.

First, envision a time when you got angry in the past. Picture all the details in your mind's eye. Where did it take place? Who was there? What were people wearing? Treat the scene like a video and let it play out once without trying to change anything. Simply observe how the events unfolded.

Next, think about what you would like to have changed about how the event played out. How might you have responded differently to the situation to make it better? It is important to reflect on your own actions rather than those of others.

Remember that the only person you can ever really control is yourself.

Finally, replay the improved version of this encounter in your mind over and over until you feel as though you could do and say what you are envisioning in real life.

- **Move away and 'take 5':** The moment you recognise the anger building up in yourself, move away from looking at your partner. Looking at them can be a trigger point in escalating your anger. If possible, go into another room and take five deep breaths. This should take about a minute or two.

Deep breathing requires you to be very conscious about the movement of air into and out of your lungs. The period required to take the deep breaths will allow you to dissociate yourself from negative feelings. It also allows you to observe what these emotions and thoughts are all about.

Your Caregiving Action Plan

1. One small change I can make today that is just for me:

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.....

2. Two steps I will take in the next month to simplify my schedule or add joy to my life:

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3. It may be time to talk to a counsellor and practice some exercises that help calm and self-soothe your nervous system. If not a counsellor, speak to a friend you trust and let them know what you are struggling with.

Parkinson's may start before birth

People who develop Parkinson's disease before age 50 may have been born with disordered brain cells that went undetected for decades, according to new Cedars-Sinai Medical Centre research.

The research points to a drug that potentially might help correct these disease processes.

"Young-onset Parkinson's is especially heartbreaking because it strikes people at the prime of life," said Michele Tagliati, MD, Director of the Movement Disorders Program, Vice Chair and Professor in the Department of Neurology at Cedars-Sinai.

"This exciting new research provides hope that one day we may be able to detect and take early action to prevent this disease in at-risk individuals."

To perform the study, the research team generated special stem cells – known as induced pluripotent stem cells (iPSCs) – from cells of patients with young-onset Parkinson's disease.

This process involves taking adult blood cells "back in time" to a primitive embryonic state. These iPSCs can then produce any cell type of the human body, all genetically identical to the patient's own cells.

The team used the iPSCs to produce dopamine neurons from each patient and then cultured them in a dish and analysed the neurons' functions.

The researchers detected two key abnormalities in the dopamine neurons in the dish:

- Accumulation of a protein called alpha-synuclein, which occurs in most forms of Parkinson's disease.
- Malfunctioning lysosomes, cell structures that act as 'rubbish bins' for the cell to break down and dispose of proteins. This malfunction could cause alpha-synuclein to build up.

The investigators also used their iPSC model to test a number of drugs that might reverse the abnormalities they had observed.

They found that that one drug called PEP005 – which is already approved by the Food and Drug Administration for treating precancers of the skin – reduced the elevated levels of alpha-synuclein in both the dopamine neurons in the dish and in laboratory mice.

Next, the team plans to investigate how PEP005 – currently available in gel form – might be delivered to the brain to potentially treat or prevent young-onset Parkinson's.

The team also plans more research to determine whether the abnormalities the study found in neurons of young-onset Parkinson's patients also exist in other forms of Parkinson's.

Sources

Cedars-Sinai Medical Center, Los Angeles, USA.

ScienceDaily Research News

What are you thinking?

In August we sent an email to all Support Group Leaders asking them what's on their minds? What concerns or needs do they have for their Groups?

Following is a consolidated summary of responses:

- We don't have the support of a Parkinson's Specialist Nurse.
- Caregivers are bearing the brunt of the lockdown – no visitors and little contact with other family members.
- Lack of exercise and social opportunities due to COVID-19 lockdown. We feel isolated.
- Increase in anxiety due to COVID-19 lockdown.
- Less access to neurologists due to travel restrictions.
- We're experiencing low numbers at meetings and our Group needs a reboot.
- Our Committee needs refreshing.
- Participants are unable to commit to a formal telephone tree to support one another.
- We miss the face time allowed by meeting in person.
- Formal meetings are just too hard at the moment, even though our area is not in lockdown. So we are limiting ourselves to coffee gatherings to maintain contact.

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- Our meetings are continuing OK via Zoom – including having guest speakers.

Do you have any feedback to add so Parkinson's NSW can gain a greater understanding of your challenges?

If so, please email: supportgroups@parkinsonsnsw.org.au

More resources:

- For a one-stop shop of information, support, and connection with support, call the Parkinson's NSW InfoLine: **1800 644 189**

The InfoLine can connect you with a Parkinson's Specialist, Counsellor, NDIS experts, a Parkinson's-specialised Personal Trainer, our Support Group Coordinator, and marketing specialists who can help your Group to grow.

It also maintains a database of Parkinsons-experienced Allied Health providers throughout NSW.

- Connect with one or many of our free, information-rich zoom sessions hosted by a variety of knowledgeable experts in their fields. Click [here](#) for a calendar of upcoming sessions.
- See also Parkinson's NSW videos and recordings of Zoom meetings on our YouTube channel: <https://www.youtube.com/user/ParkinsonsNSW>
- Keep an eye on the Parkinson's NSW COVID-19 web page [here](#) for the latest updates and advice.

Freezing of gait

Freezing of gait is a sudden, short, temporary, unpredictable inability to walk. This occurs despite the fact that the person wants to and is trying to walk.

It is described as "...feeling like my feet are stuck to the floor". The feet stay in place and the body continues the forward motion – increasing the risk of falling and injury.

It can be a common symptom of Parkinson's but not everyone living with Parkinson's experiences freezing. Many people experience issues with freezing of gait when they are in middle or advanced stages of their Parkinson's journey – it is dependent on the duration and severity of the Parkinson's.

Dopamine in the brain is very involved in the movement of the body. People with Parkinson's have reduced levels of dopamine in their brain which then affects movement including walking, falling, and freezing.

The brain circuitry that controls movement is very complex with different parts of the brain interacting to produce controlled movement. The frontal lobe of the brain plans and initiates movement. The basal ganglia controls and regulates voluntary movement so that it can be performed smoothly. The brainstem regulates balance and coordination.

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The cause of freezing is not fully understood, and it cannot be explained by slow movement or stiff muscles. It is thought to be linked to the medication cycle and occurs more commonly during 'off' periods.

Freezing can occur with other repetitive tasks including speaking, writing and teeth cleaning. It can also occur whilst attempting to multitask.

Start hesitation occurs when there is trouble starting a movement. It can happen when trying to step forward after standing up, starting to get out of bed or trying to swallow either food or fluid.

Causes of freezing of gait

- It is not fully understood as to why a person freezes
- It happens when there is a disruption to the normal pattern of movement
- Anxiety and stress
- Losing concentration whilst walking
- Missed medication
- Constipation

Triggers for freezing

- Walking through doorways
- Turning around
- Turning a corner
- Multitasking
- Starting to walk
- Navigating obstacles or narrow or crowded spaces

Managing Freezing

- There is no magic treatment
- Medication review
- Physiotherapy to build core strength and reduce risk of injury
- Occupational Therapy review to minimize injury and advise on assistive devices
- Learn about triggers and strategies to manage a freezing episode
- Exercise regularly for fitness, strength, and balance
- Wear supportive footwear at all times
- Use prescribed walking aids
- Have regular vision checks
- Wear clean glasses
- Ensure that care is taken when wearing bi/multi focal glasses
- Maintain good posture by focusing and maintaining an exercise regime

Tips to Get Moving

- Take medication on time every time
- Focus, as attention is required for balance
- Wait and remain calm
- Do not rush
- Shift weight from side to side
- Sing, hum to a rhythm
- Use a metronome for the beat
- March on the spot
- Stand still and swing the arms
- Turn in a square or half circle instead of pivoting
- Avoid distractions
- Focus on taking long strides
- Pretend that there is an imaginary line to step over.

Useful resources

- Want to take part in Parkinson's research or studies? Visit this link on our website <https://www.parkinsonsnsw.org.au/services/take-part-in-research>
- *Clock Yourself* application – combines cognitive and physical challenges into a brain game that makes you think on your feet. Available for Apple and Android devices <https://www.clockyourself.com.au/>
- What is a metronome? Thanks to Viv, Nepean Blue Mountains Support Group leader for this explanation: It's a musical machine that gives the beat. Its adjustable for faster and slower beats, and available on your smart phone. *Metronome Beats* is a free application for Apple [App Store \(Apple\)](#) and Android phones: [Google Play](#).
- Dance for Parkinson's is offering online exercise classes three days per week. For more information <https://www.parkinsonsnsw.org.au/services/exercise/dance-for-parkinsons/>
- *Wellness Wednesday Video Series* offers information and guided exercise - https://www.youtube.com/playlist?list=PLNNFufiPBotL3pJw0XD3zgLEtkc_juZIG
- Speech and voice: The link to the free recorded lessons from the *Parkinson Voice Project* <https://www.parkinsonvoiceproject.org/ShowContent.aspx?i=2450>
- UTS runs a speech therapy clinic. For more information: <https://www.parkinsonsnsw.org.au/free-speech-pathology/>

Related research

- NeuRA and Sensoria Health are preparing to start a study to test smart sock prototypes that vibrate in order to stimulate the feet and encourage a smooth rhythm while walking. The project is called Walking Tall.
- Shake it Up is also doing research into brain exercises/training to increase reaction times but so far has only been a small group and needs to be undertaken in a larger study to gain real understanding and knowledge.

- Sydney University Brain & Mind Institute are doing some research in a stimulator to the spinal cord, but this is in the very earliest research stage

References

- Parkinson's UK
- American Parkinson's Disease Association
- Michael J Fox Foundation
- Parkinson's NSW
- Parkinson's Victoria
- Parkinson's Foundation
- Shake it Up
- NeuRA
- Professor Simon Lewis

Healthy and active for life

Healthy and Active for Life Online is a FREE 10 week program for adults aged 60 years* and over.

How does it work?

The program is delivered online, in the comfort of your own home. Simply log in to your online account to complete the weekly modules and exercises.

What do I get?

- Access to weekly online healthy lifestyle modules and two online exercise programs
- Weekly handouts and an exercise manual
- Telephone support to keep you motivated
- Ongoing access to the online modules and exercise programs for 12 months

What do I need?

- Access to a computer or tablet with internet
- Ability to understand and read English
- Space to exercise safely in your home

*Aboriginal people aged 45+ years can register.

To download the program flyer, please [click here](#)

For more information visit <http://www.activeandhealthy.nsw.gov.au>

Tamie Harvie appointed new Shoalhaven nurse

Tamie Harvie has joined Parkinson's NSW as the new Parkinson's Specialist Nurse for the Shoalhaven region.

She succeeds Nina Digiglio in this role. Nina has stayed with the organisation, stepping up to become a Nurse Educator with a state-wide remit.

Tamie brings to the Shoalhaven role 21 years of nursing experience, spanning complex care, acute care, emergency, pathology, and palliative care – and has a particularly strong background in mental health care.

“I joined Parkinson's NSW because it this role offers me a unique opportunity to help people along their Parkinson's journey,” said Tamie.

“It allows me to bring just about all of my nursing experience to bear, offering personalised care – and the opportunity to be part of something really positive.

“Having worked for NSW Health so long in the area, I also bring with me a network of relationships with hospitals, consultant physicians and diagnosticians,” she said.

Tamie is a Shoalhaven local who loves the beach, the bush and live music. She balances the challenges of her nursing role with being the mum of two kids aged 6 and 12 – and is an important human in the lives of two dogs who are also much-loved members of the family.

Tamie likes to relax by bike riding with her family, painting with a group of friends and tending to her garden.

Benefits of warm water exercise for Parkinson's

People living with Parkinson's who exercise regularly reduce the impact and progression of the disease better than those who do not.

Exercising in heated water has some unique properties that enable both therapy and fitness – especially for people who can't exercise comfortably on land.

Poor balance, gait and gravity cause fear and injury for many people with Parkinson's. Exercising in water removes the risk of falls and therefore the fear. Water also offers buoyancy which allows for practice of bigger movements to progressively improve the large range of motion.

Simultaneously the turbulence of the water acts to challenge balance and coordination, leading to improved walking and overall stability for daily tasks.

The water's multi-directional resistance helps the individual to maintain or enhance muscular strength and endurance even with gentle movements – enabling better focus on movement.

The heat of the water helps sooth and relax the muscles, lessening tremors, reducing rigidity and pain, and giving a feeling of freedom that's not available on

land. People living with Parkinson's can stand tall in water with increased back extension, improving their posture.

Hydrostatic pressure is another benefit of exercising in water. Hydrostatic pressure is the force exerted by the water on the body.

Hydrostatic pressure can:

- Reduce swelling
- Reduce pain
- Help the heart and boost circulation
- Reduce sensory input to the brain
- Reduce the pooling of blood in the extremities

These are a lot of benefits for just getting into a pool.

Water makes low impact exercise possible, whilst doing the same exercise on land may stress joints and muscles. Many people who have difficulty moving on land find movement easier and can continue longer in the water – thereby improving the effectiveness of the exercise and improving their quality of life.

The reluctance to exercise on land will cause muscles to weaken and joints to stiffen, leading to even smaller weaker ranges of movement. People living with Parkinson's who don't attempt to exercise find themselves moving less, losing confidence – and eventually their independence.

Those who exercise in water generally have a successful exercise experience, giving feelings of productivity, enjoyment, and the desire to continue exercise.

So, to sum up the benefits of water exercise:

- No fear of falling.
- Posture support and improvement.
- Ability to perform exercise that you couldn't do on land.
- Improving the effectiveness of exercise.
- Bigger stronger freedom of movements.
- Water resistance building strength.
- Water turbulence challenges and improves balance, gait, and coordination.
- Warm water reduces tremors, stiffness, and pain.
- Reduces swelling.
- Help the heart and boosts circulation.
- Reduces the pooling of blood in the extremities.
- Reduces sensory input to the brain, calming it.
- Improved bowel function.
- Potentially gives social interaction and enjoyment, decreasing feelings of isolation and depression and encouraging an overall sense of well-being.

Patients who have tried warm water exercise report:

- A wider range of movement
- Better stability
- Greater independence
- Increased confidence
- Better quality of life

However, be mindful of some considerations prior to commencing water exercise.

- Obtain a medical release form from your doctor
- Speak to your primary caregiver before starting a new exercise program.
- Wear aquatic footwear to protect the feet from scrapes or cuts.
- Never swim alone.

As the goal of exercise is to improve symptoms, slow the progression of Parkinson's, improve overall function, and enhance quality of life to maintain independence, it makes warm water exercise a great choice.

References:

<https://pubmed.ncbi.nlm.nih.gov/30904467/>

<https://www.goodshepherdrehab.org/press-releases/aquatic-therapy-benefits-people-with-parkinsons-disease/>

<https://waterresist.com.au/pages/parkinsons-and-aquatic-therapy>

<https://www.hydroworx.com/blog/aquatic-exercise-benefits-people-with-parkinsons-disease/>

https://www.apdaparkinson.org/uploads/files/Aquatic-Book_8-08---edited-2015-oUM.pdf