

STILL LEADING Living with Young Onset

Todd grew up in country South Australia, one of four boys in the twilight of an age before devices, screens and social media. Keeping themselves amused involved imagination, often ingenuity and almost always physical activity. Whatever needed to recreate an Australian sporting moment they would find a way to improvise. So it was not surprising that all four siblings share a deep confidence in physical abilities, co-ordination, balance and strength. What was surprising was the seemingly innocuous moments that contradicted this 'sporty' identity. A dropped catch in backyard cricket, a loss of balance walking slowly down a church aisle, and finally a strange tremor in Todd's left hand whilst typing a school newsletter.

A belated appointment with a GP - led to a neurologist referral, and by chance - after naively postponing the appointment Todd was seen by a movement disorder specialist. His specialist was onto the problem immediately and after a range of exercises from drawing shapes to standing on heels and toes - Professor Wilcox was very confident Todd was demonstrating symptoms of Young-Onset Parkinson's Disease. An MRI scan and a positive response to medication confirmed diagnosis - which would later be further strengthened by a rare mutated gene indicating a likely predisposition for PD, featuring in the results of genetic testing that took two years to complete.

Todd's world and the world of his family was flipped on its head. Tears of fear, confusion and grief flowed torrentially and were ridiculously contagious with relatively few people immune from the emotional effects of hearing the news. Each instance was beautifully balanced however, with support, love, and unabashed humour - which is definitely Todd's favourite coping mechanism.

Two years down the track from diagnosis, Todd's progression has been far more rapid than expected and has left him with little alternative, but to explore the path to 'Deep Brain Stimulation'. Although a potentially traumatic option, even a remote possibility of reducing the level of medication it takes to mask his symptoms; or the chance to live out his quiet, personal dream - of being able to enjoy even 5

“ even a remote possibility of reducing the level of medication it takes to mask his symptoms; or the chance to live out his quiet, personal dream - of being able to enjoy even 5 minutes of peaceful stillness - fills him with great excitement and more than enough courage to proceed. ”



PHOTO: Todd and his wife Mandy and his two girls.

minutes of peaceful stillness - fills him with great excitement and more than enough courage to proceed. Having reached this point in only two years - having initially only very briefly looked at DBS as a future possibility at least 5-10 years down the road - as a family, they are just not prepared; psychologically, emotionally or financially.

Thankfully, the enormous pride Todd takes in his work and with the support of his beautiful school community, wider education community, friendships and family; they are being carried forward by goodwill and God's grace.

A GoFundMe page has been setup by parents from the school where Todd is currently Principal - St John the Baptist Catholic School. It can be found at www.gofundme.com/shakey-leadership

The original goal has already been met, which is phenomenal. Todd now hoping that the generosity can continue so that we can help support Parkinson's SA by providing Parkinson's SA, the funds that go beyond the associated out of pocket expenses of Todd's surgery.

In order to raise awareness further Todd has decided to share his story wherever required and has created a blog with the hope that it may help someone battling their own diagnosis, or help to educate anyone looking to increase their understanding and compassion for those fighting Parkinson's. Visit Todd's blog at www.shakyleadership.digiwell.com.au and take a look, or like and share his facebook page: <https://www.facebook.com/Principaltoddmurfit/>



OUR VISION

Enhanced quality of life for people affected by Parkinson's or another movement disorder.

OUR MISSION

To maximise choice, independence and well-being for people affected by Parkinson's or another Movement Disorder through support, education and advocacy.

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Pat Mueller

from...

OLIVIA NASSARIS, CEO

Thank you to everyone that contributed to Parkinson's Walkathon being such a success – at the last count we have raised over \$25,000. However, you still have a month to get donations through Everyday Hero or manually so don't stop your great effort now. We also have received a very generous \$5,000 donation from the Carthew Foundation.



Big thanks to our major event partner Resthaven for their sponsorship and presence on the day and the Unley Council for their commitment and support of the event and SAPOL for keeping us safe on the roads.

Foodland Torrensville and Foodland Norwood, both of whom generously provide all of the catering supplies year after year. Joe Scuteri from CIBO for donating all the proceeds from the coffee stall and the Adelaide Lions Club, who for many years, has supplied the BBQ set up and run it like a well-oiled machine.

Olivia Bryant and Simon Tilley and crew for their luscious cupcake stand – which sold out faster than usual (before I could even purchase one!) and the many volunteers that assist them. Each year this group astounds us with their creativity, gorgeous presentation and, best of all, delicious flavours.

The many Parkinson's SA volunteers that come out early on the day to help run stalls and registration. Also remembering that staff are also volunteering their time in the lead up to the event and on the day. What people may not know is that their partners and families also come out in force to ensure that many hands make light work even though it's so early on a Sunday morning – we couldn't do it without you all.

Congratulations to Simone, Communications and Fundraising Coordinator, for organising this event for the first time. With her at the helm of Parkinson's Walkathon I am sure we will see this event grow significantly each year.

In other Parkinson's SA news, the Photobiomodulation (light therapy) trial is at the half-way point with Group A finishing treaming and Group B just beginning. The outcomes of the trial will be presented at the Parkinson's SA conference on September 10 at the National Wine Centre.

Apologies for those waiting for news on 25 King William Road and Brain x Body Fitness Studio, building works are slow due to the fact that the current structure is very old and has to be brought up to code for fire and safety standards which requires a lot more planning. Thanks to everyone for your patience.

Olivia

WHAT A WEEKEND

Mindfulness, NDIS, young onset clients meeting together

The last weekend of February saw a group meet for an information-rich weekend, aimed specifically towards the younger onset Parkinson's clients supported by Parkinson's SA.

It is clear that with a younger group, experiences and concerns can differ from the traditional aged sector of Parkinson's clients, so traditional seminars and support groups have not always been the most effective awareness and support mechanism.

The aim of the weekend was to bring together the 20s to 50s group, provide age specific information to them, and gain an idea of how best younger onset clients would like to interact with Parkinson's SA.

The weekend itself was held at the local sporting car club, and was attended by approximately 25 clients; both carers and those living with Young Onset Parkinson's. Whilst everyone at the sessions came from different backgrounds and stages of diagnosis, it proved a great opportunity to connect with a group and share experiences.

The opportunity for clients to attend the invaluable young onset sessions would not have been possible without the support of QBE which allowed Parkinson's SA to fund accommodation and travel costs for regional clients from Tumby Bay, Whyalla, Port Lincoln and Kangaroo Island.

The weekend-long schedule included mindfulness sessions, Q & A panels, NDIS sessions, and employment sessions, as well as a social event allowing an opportunity for attendees to make connections and share experiences.

Feedback from the event was undertaken via an online survey; results coming back from the group have been overwhelmingly positive.

“ Definitely glad I attended! Thanks so much for a well run, informative weekend. It was great connecting with other people and sharing experiences.”

We asked participants which session they found most useful and informative, and received a strong response identifying the most valuable as the panel with Neurologist, Neuro-physiotherapist and Pharmacist.

Survey results also identified that clients wish to have sessions on current research updates, DBS and Mental Health.

All responses from the weekend will be taken into account for future planning for young onset events and seminars.

For those diagnosed with young onset, you can join and connect with others on the young onset Facebook group by searching “Young Onset Parkinson's South Australia”.



PHOTO: Young Onset Group Weekend

WHEN OILS AREN'T OILS

A discussion on alternative medicines with pharmacist and Parkinson's SA Board Member, Michael Bakker

Navigating the market of supplementary, alternative, traditional or complementary medicines, or one of the many names they fall under, is a difficult task even for the highly trained. Where the line exists for saying that a treatment has "evidence for its use" is a topic that is polluted by interpretation and esoteric issues such as study design.

There is no hard and fast recipe that I can provide you with that will help you know bingo from bogus in the alternative medicines market. In Australia, areas such as naturopathy, homeopathy and complementary medicines are largely unregulated and consumers rely on the good will of the person we are seeking help from to have all of our interests at their front of mind.

I instead hope to provide you with an encouragement of healthy scepticism in approaching new therapies, and an understanding of how the products end up on the shelves. From the get-go, I would like to acknowledge that this is not an attack on any particular regulated or unregulated areas of health care, or calling out unscrupulous characters. This is, however, also not an attempt to excuse bad science.

The world of marketing and advertising medicines is a nightmare. Without knowing what the trial looked at, how many people were involved and what they did; the claims of "clinically proven" or "clinically tested" mean little more than the self-adhesive label they are printed on. The only fact we can hold true is that marketing and advertising turns over faster than academic studies and the regulatory bodies can keep up with. Claims of "effectiveness" can often be found to be studies of groups of 5-10 people over a very short time, with little meaningful change or with huge leaps in assumption from animal studies to humans.

The reality of the "natural medicines" market in Australia is that no one has to prove any of it in order for their product to appear on the shelves of your local naturopath or pharmacy; they just have to say that proof exists. Proof in the legal system, if required to do so, still stands. But this very rarely happens because companies withdraw medicines and settle cases when pursued by the Therapeutic Goods Administration, who don't have the resources to chase down every new complimentary medicine introduced or ordered online. The TGA has bigger fish to fry and, by comparison, these treatments are lower risk to the public.

When discussing the harm that these agents may cause, it usually means one of two things: could this treatment directly cause you harm through side effects or interactions? OR could delaying seeking further investigation and treatment by taking this treatment be detrimental to your outcomes? Your pharmacist can advise you on both of these.

A third and all too common, seldomly considered risk to consumers is "What harm could diving in, taking a number of treatments without tangible measure of effect cause me and my family financially?"

People seek alternative treatments for themselves or their loved ones for a variety of reasons, so it is difficult to lump together the experiences and the risks that go with them. With compelling evidence for the importance of exercise and lifestyle in the management of



Parkinson's disease, my emphasis will always be on trying to engage people in making these meaningful changes first. It can be hard and difficult to maintain, but it is the only area we can say, with confidence, that will have ongoing impacts. If you asked me to choose between recommending \$50 a month on a new headline grabbing complementary medicine or an exercise class, I will always side with lifestyle, as it offers a legacy, experience and value of empowering you to participate in outcomes that cannot be understated.



PHOTO: Dance for PD class in progress.

The last piece I have to say on this, is that it is important to get the value and expectation alignment right with your health care providers, regardless of their role. In cases where this is not, can lead to consumers feeling exploited or not understanding how the financial value translates into outcomes for them. We, as health care providers, need to understand this too, so that we are mirroring your concerns and not sending you down a path of misguided treatments by failing to hear your requests for help and support.

In any case, when you plan to start or cease a complimentary medicine, please discuss it with your Pharmacist, GP or movement disorder specialist.



Should you wish to discuss any issues concerns or query anything brought up this article

please contact Client Support on 1800 644 189



MICHAEL BAKKER
Pharmacist - Aged Care,
Rehabilitation and General
Medicine, SA Health

Michael has had a long term affiliation and passion for volunteering his pharmacy services to Parkinson's SA, it's clients and staff.

He has has a passion for innovation in health care and practical driven solutions to patient health. Michael has recently been involved in the establishment of the pharmacy services within the tele rehab section of SA Pharmacy.

The multi disciplinary model delivers rehabilitation services such as speech pathology, physio therapy and occupational therapy in their places of residences and out of hospital to the patient through video calls and app driven programs.

Michael is actively working towards research in pharmacy practice and Parkinson's disease and hopes that his passions for tele-health and Parkinson's Disease will lead to changes in the way we deliver information to patients of all locations. He was appointed to the Board of Parkinson's SA in 2017.

DEMENTIA RATES DECLINING

research evaluation undertaken by SAHMRI based Registry of Older South Australians (ROSA)



Dementia rates among older Australians accessing home or long-term care services are declining according to a large-scale evaluation undertaken by the SAHMRI-based Registry of Older South Australians (ROSA).

The project's lead author, SAHMRI Research Fellow Dr Stephanie Harrison, says the positive findings could be the result of national public health measures to improve overall health of the population.

"Research consistently shows that there are measures which can be taken to reduce risk of dementia," Dr Harrison said.

"By improving our physical health, we might also be improving our cognitive health.

"Initiatives to improve factors such as smoking rates might be helping but we also have to consider that some risk factors for dementia, such as mid-life obesity rates, are increasing in Australia.

"It's likely there are a combination of factors impacting dementia prevalence so there is probably still room for improvement."

The study of 188,846 older people receiving home care services found the prevalence of dementia fell from 26 per cent in 2005 to 21 per cent in 2014. For 348,311 older people starting long-term care the dementia rate fell from 50 per cent in 2008 to 47 per cent in 2014.

"The findings are consistent with other studies reporting a decline in the prevalence of dementia in countries such as the US and the UK," Dr Harrison said.

There are currently estimated to be more than 436,000 Australians living with dementia. Those figures are predicted to rise above 589,000 people by 2028 and above 1 million people by 2058.

"The overall number of older Australians with dementia and people accessing aged care will increase because of the ageing population," Dr Harrison said.

"But there could be a need to reassess current estimates as we should consider that the prevalence of dementia in Australia might be changing."

<https://www.sahmri.org/research-theme/news-242/?fbclid=IwAR0>

The research, the first in Australia to investigate dementia prevalence, was published today in *The Journal of Gerontology: Medical Sciences*.

You can view this publication by visiting <https://doi.org/10.1093/gerona/glz032>

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THERAPY ON TWO WHEELS

When I need to rest my head - I use my legs.
That's why I have just push biked from Adelaide to Sydney...

When I left Adelaide January 29th, I was mentally exhausted, but my legs were fine. 4½ weeks and some 2000 kilometres later I rolled my push bike up in front of Sydney Opera House and something certainly had changed.

Now I was physically exhausted, but mentally I felt just fine as my head had the rest it so badly needed. The change was no surprise to me, as the same thing happened five years ago, when I took leave from my job back in Denmark and push biked 10,000 kilometres through New Zealand and Australia.

My head needed a rest as 2018 was a very busy, mainly happy but at the same time very stressful year for me. I had my diagnosis, married Kate (an Aussie whom I met on my tour five years ago), submitted a partner visa application to immigrate to Australia, wrote a 400 page book about my tour and published it myself. At the same time I continued to work as journalist in Denmark, did presentations about my original tour and thought a million thoughts about the impact of resigning from the job I love, leaving family and friends behind and moving to Australia to live with my lovely Kate.

I arrived in Adelaide early December 2018. Not long after, I told Kate that I wanted to -and needed to - do another bike tour as my head needed a rest, and I just love the simplicity of push biking. Get on the bike and your legs will do the rest - and you don't need to think a lot, so your head can relax.

At first Kate did not like the idea at all as she was worried both for my safety and why getting a job wasn't my priority, but after thinking about it for a while she agreed, and she was my number one supporter throughout my tour, but far from the only one. Several times I stayed for free (or at a reduced price) in hotels and caravan parks, as the owners wanted to show their support for my project.



PHOTO: Frank celebrating riding over 2000kms by posing for a photo in front of the Sydney Opera House



PHOTO: Frank checking out the views of the Great Ocean Rd

Their support and support from people I randomly met were some of the highlights of my tour. Another one being revisiting people I met on my first tour five years ago. I hadn't been in touch with them since, but I wrote them a mail saying I was doing another tour, and I was welcomed with open arms.

Something I did not like seeing again though was head wind. Except for 45 kilometres from Wellington to Meningie I had to struggle with head winds for 700 kilometres from Adelaide to somewhere on the Great Ocean Road. The head winds were very strong and it meant extremely hard work for me, but the good thing is that your will power is tested - and I am happy to say that I passed with flying colours.

“ The head winds were very strong and it meant extremely hard work for me, but the good thing is that your will power is tested - and I am happy to say that I passed with flying colours. ”

Kate flew to Sydney to welcome me and seeing her in front of Sydney Opera House was a fantastic way to end my tour. The love of my life in front of an iconic building designed by a fellow Dane. Perfect.

Having recovered from the tour I am now ready to boost the hunt for a new job, preferably as a journalist/communications consultant, but being new to the Aussie labour market, I am open to other opportunities, including temp and/or part time positions.

I was certain that I would benefit from the tour and very happy that I did, but why should I be the only one benefitting? That is why I decided to raise funds for Parkinson's SA and so far, we have raised more than \$4,500 dollars and you can still donate: <https://frankdownunder.everydayhero.com/au/frank-down-under> or you can raise funds yourself by living out a dream. The thing about Parkinson's is that it only gets worse, so if you have a dream that you want to realise, perhaps you should just do it - and rather today than tomorrow.

There is no guarantee that you'll succeed just like there was no guarantee that I would, but I will rather try and fail, instead of not failing - because I didn't try. So go for it - and good luck

Read more about my tour: <https://www.facebook.com/FrankDownUnderinAus/> or feel free to contact me on fan1803@hotmail.com.

A SPRING IN ALICES STEPS

New Support Group connecting Alice Springs clients...

Alice Springs has a new support group headed by Annie Ernst. The group is a valuable opportunity for Alice Springs clients to find and share peer support with others, and a great chance to socialise and connect with the Parkinson's Community.

Annie Ernst, Disability Advocate encourages anyone who would like to be involved in planning meetings and activities for the group in the second half of 2019 to get in touch with her. Planning is underway for coming months and it's already looking to be an exciting schedule.

Parkinson's SA will be making a visit to Alice Springs in May 2019 – after taking over support of the Northern Territory in early 2019. Parkinson's SA is also videoing its 'living well' seminar series taking place in 2019, making them available for Alice Springs clients to view.



PHOTO: Annie Ernst, Alice Springs Support Group Leader

To get in touch and find out more about the Alice Springs Support Group contact Annie on 8953 1422 or advocated@das.org.au



NBN AND MEDICAL ALARMS

Many medical alarms rely on the existing landline phone network. As the nbn gets rolled out, the old landline technology is being replaced. This may affect how medical alarms connect and provide services. It is therefore important that all medical alarm users check the compatibility of their existing alarms with the new network. This can be done by contacting the medical alarm provider and/or the nbn.

We recommend that all medical alarm users register their medical alarm with the nbn. This will mean that the nbn can provide medical alarm users with additional information and support when they move across to the nbn network. This will also help to minimise any break in service. Registration is free, and can be done online or by calling 1800 687 626.

Further information about medical alarms and the nbn is available at nbn.com.au/medicalalarms or by calling 1800 003 095.

Helping a charity doesn't need to be time-consuming or difficult. Hold a Party for Parkinson's during International Parkinson's Awareness month this April, and help support Parkinson's SA to continue supporting those living with Parkinson's. Speak to Simone at simone@parkinsonssa.org.au or 8357 8909 to discuss your fundraising ideas



WORLD
PARKINSON'S
DAY
THURSDAY
11 APRIL 2019

MARK YOUR CALENDARS

Upcoming Events



parkinson's in the touch™
SOUTH AUSTRALIA
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QUIZ NIGHT

29 June 2019

Goodwood Community Centre 32-34 Rosa St, GOODWOOD

BYO drinks & supper (tea & coffee provided)
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Ring 8357 8909 to book your table

TICKETS: \$15 members (\$20 non members)

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- SILENT AUCTION
- DOOR PRIZES
- GAMES
- RAFFLES



10 SEPTEMBER 2019 PARKINSON'S SA CONFERENCE

Featuring national speakers from the research and support community, the 2019 Parkinson's SA Conference will enable South Australians living with Parkinson's, or caring for people living with Parkinson's; academics, researchers and health professionals the opportunity to come together to share the latest information on the condition.

Stay tuned for more information to come in the next edition of InTouch...



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CARER NETWORKING

Coping together...words of wisdom from two grateful carers

Carers undertake a specialist job for which there is little support or training, making the ongoing support provided by Parkinson's SA invaluable: numerous seminars which are as vital for carers as for people with Parkinson's; courses such as "Coping for Carers"; support groups; staff who provide a professional and important service with personal help and advice when needed; and more.

The caring role is a partnership between the carer and the Parkinson's sufferer, and it affects many aspects of their lives. The carer simply cannot fall down on the job.

Life takes on different rhythms: simple things such as standing up or preparing to go out may now take longer; meal-times may become inflexible; timetables must centre around that of one person, so more pre-planning is required.

Meanwhile, the carer's own normal daily responsibilities continue. Even though life may be constrained, the value of caring is beyond description.

In many ways, carers operate on their own and sometimes feel tired, helpless, isolated, even frustrated; often it is only other carers who have experienced the same challenges who are able to understand.



PHOTO: Carer's Pamper Day 2018

This is where Parkinson's SA activities provide many valuable, but often over-looked connections. Undertaking the joint connections, and communicating with a variety of fellow carers,



PHOTO: Dru Yoga Session

provides invaluable learning opportunities.

A multitude of Parkinson's SA activities - such as exercise programs, dance classes, art groups, etc. - occur regularly, on a monthly, fortnightly or even weekly basis, offering their own special experiences.

Carers may choose to take time-out from the activity, as respite-time, or even just to chat.

Carers can get to know each other on a more informal level, particularly where there are opportunities for social interaction. Informal times where one can talk, listen and share experiences form an important component of caring and, over time build opportunities to discuss caring issues in the absence of the people who are being cared for.

This type of contact works both ways. Just as it is important that people with Parkinson's have time alone to talk with each other, so it is beneficial for carers to have similar opportunities to share their stories. The empathy, ideas and encouragement resulting from friendships and sharing enable carers to maintain and improve the quality of care: carer-to-carer contacts benefit those for whom we care. It must never be forgotten, however, that successful caring relationships are founded on genuine partnerships between carers and those who are being cared for.

Thank you, Parkinson's SA for all that you provide to Parkinson's carers.

Caring with Calm

- Do you struggle with difficult thoughts or feelings as a family carer?
- Do your responsibilities feel overwhelming sometimes?
- Are you stuck in habits of mind which drag you down or wind up anxiety?
- Would you like more peace in your daily life?

Caring with Calm is a Parkinson's SA small group counselling course based on Acceptance and Commitment (ACT) therapy. Alongside other carers, you will learn ways to let go of struggle through mindfulness techniques and acceptance.

The upcoming workshop runs at our Unley Parkinson's office (23a King William Road Unley) over 4 consecutive Wednesdays: May 22, May 29, June 5 and June 12 from 1:30pm to 3:30pm.

Sessions are progressive, so participants need to be available for all four dates.

The course is free for PSA members, non-members pay \$30.

Please ring 8357 8909 and speak with PJ to book – numbers are strictly limited.

Respite services may be available to look after the person you care for if necessary to allow you to attend.

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If you are a carer looking for support, or interested in any of the recreational activities mentioned in this article,

you can contact Client Support on 1800 644 189 and find out what supports are available for those caring for family with Parkinson's.



IN MEMORIAM



Parkinson's SA acknowledges the donations which have been given by families and friends in memory of the following people. The thoughtfulness of these families in arranging for donations to be given to Parkinson's SA is greatly appreciated.

Gareth Lorraine Bevan

Ronald (Ron) Delmore Hight

Luigi Sabbadin

Kevin Wilfred Bailey

Ron Hirre

Domenic Salzone

Coral Jean Coleman

Ross Lambert

Barbara Pauline Sandon

William (Bill) Deer

Dr Terence (Terry) Peter O'Reilly

Brian Smith

Libero DeLuca

Warren Keith Pearson

Heather May Turnbull

Philip Dennis Henthorn

Pietro Pedicini

"Parkinson's SA has offered us so much support throughout our journey.

We believe it's only fitting that we give back to the organisation in our Will."

Ros and Phil Cassidy



Have you thought about your legacy?

Legacy gifts offer the perfect opportunity to reflect on what/who has been important in your life, or mirror what you'd like to actively see supported in the future.

Leaving a legacy gift to Parkinson's SA is a simple way to continue caring, and ensures your passion for Parkinson's SA will continue to support those with Parkinson's far in to the future.

Would you like to leave a legacy gift to Parkinson's SA?
Contact Olivia Nassaris
on 08 8357 8909

SUPPORT & EDUCATION

Adelaide Hills

Contact: Lyn Marshall
0447 793 150

Brighton

Contact: Julie O'Brien
0413 618 084

Brighton Carers Group

Contact: Lorraine Flanagan
0414 424 838

Elizabeth

Contact: Northern Carers Network
8284 0388

Gawler

Contact: Helen Hoppmann
0403 295 348

Kingscote

Contact: Kerri Welden
0409 696 069

Kingston and Robe

Contact: Liz Wingard
0466 723 263

Lower North Country Carers SA

Contact: Lynn Stewart
8842 1118

Mount Gambier - Boandik Lodge

Contact: Wendy Merrett
8724 1251

Murray Bridge Resthaven

Contact: Caroline Tenny
8531 2989

North Eastern

Contact: Parkinson's SA
8357 8909

Onkaparinga

Contact: Lyn Paunovic
8384 8357

Paradise Resthaven Carers' Group

Contact: Sharyn Atkins
8337 4371

Riverland

Contact: Glenys Badger
8588 2883

Salisbury

Contact: Marlene Fenwick
0418 804 124

Southern Fleurieu Resthaven

Contact: Caroline Tenny
8554 1801

Tumby Bay

Contact: Natasha Clark
0438 269 502

Upper Sth East Comm. Health Service

Contact: Karen or Raelene
8762 8160

Western

Contact: Tracy Leaney
0413 596 080

Whyalla

Contact: Peter & Yvonne Atkinson
0488 915 740

Yorke Peninsula / Southern YP / Northern YP

Contact: Kerri Choules
8821 2444

SPECIALISED GROUPS

Deep Brain Stimulation Group

Contact: Dianne Biddle
0428 828 089

Dystonia Lunch Group

Contact: Jacqueline Jeremy
sadystonia@gmail.com

Focus on Family Carers' Group

Contact: Parkinson's SA
8357 8909

Parkinson's Plus Lunch Group (PSP, MSA, CBD)

Contact: Parkinson's SA
8357 8909 (RSVP essential)

20's - 50's Group

Contact: Parkinson's SA
8357 8909

Women with Parkinson's

Contact: Alice Langsford
8357 8909

EXERCISE GROUPS

Adelaide Hills Health Service

Contact: Simone Krohn
8393 1833

Aldinga & Reynella Lifecare

Contact: Melissa Fielke
8168 7600

Blackwood Recreation Centre

Contact: Karyn Powell
8296 4500 or 0419 840 484

Christie Downs

Contact: Robert Lloyd
8386 2761

Eastern Region - Boxing

Contact: Jo Blaess
8366 4227

Elizabeth Northern Resthaven

Contact: Rosalind Wren
8252 6811

Glynde LHI Retirement Services

Contact: Ruth Brunt
0434 477 724

Goolwa Fleurieu Physiotherapy

Contact: Stuart Thompson
8528 7650

Elizabeth Northern Resthaven

Contact: Rosalind Wren
8252 6811

Glynde LHI Retirement Services

Contact: Ruth Brunt
0434 477 724

Goolwa Fleurieu Physiotherapy

Contact: Stuart Thompson
8528 7650

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Contact: Stuart Thompson
8528 7650

Greenacres North Eastern ECH

Contact: Alex Vorrasi
1300 275 324

Henley Beach Seaside ECH

Contact: Emma Hodge
1300 275 324

Hope Valley LHI Retirement Service

Contact: Ruth Brunt
0434 477 724

Largs Bay Southern Cross Care

Contact: Courtney Brook
8242 2985

Marion Resthaven Southern

Contact: Michelle Eeles
8296 4042

Murray Bridge Resthaven

Contact: Caroline Tenny
8531 2989

Northfield Hampstead Rehab. Centre

Contact: Bob Barnard
8222 1811

North Plympton Southern Cross Care

Contact: Sally Goetz
8179 6825

Paradise Resthaven Eastern

Contact: Grant White
8337 4371

Payneham & Reynella Life Care Active

Contact: Melissa Fielke
8168 7600

Rostrevor & Salisbury ACH Group

Contact: Sarah McMullen-Roach
1300 224 477

Unley Physiotherapy

Contact: Abbey Bailey
8373 2132

Victor Harbor Seaside ECH

Contact: Caroline Crawford
or Chelsea Hastings 1300 275 324

Westbourne Park Anglicare

Contact: Lydia DeCaux
8229 6723

RECREATIONAL GROUPS

Brushlines Art Group

Contact: Parkinson's SA
8357 8909

Dance Programs (based on the Dance for Parkinson's model)

Alexandrina - Burnside - Clarence Park
Norwood - Onkaparinga - Mt Gambier
Contact: Parkinson's SA
8357 8909

Parkinson's Pedallers' Cycling Group

Contact: Mike Hannan
8278 6069

Photography Group

Contact: Beth Manoel
0438 387 532

Sing for Joy Group

Contact: ACH Group
1300 224 477

IN THE LIBRARY

A review...by Paul Gresham

This is the most remarkable book I have been asked to review. It is "written by people with Parkinson disease, for people with Parkinson disease, their families, their friends, and all who love and care for them", and published by Parkinson's Creative Collective, a not-for-profit organisation. The editors including a neurologist are people with Parkinson's. Each section has an introduction written by editors and accompanied by inputs from a variety of people, most of whom have Parkinson's, bringing the section to life.

Chapter 1: "Parkinson's Basics" contains lists of common symptoms, medications with possible side effects, explanation of deep brain stimulation, advice about handling initial reactions to the diagnosis and other people's responses.

Chapter 2: "More Than a Movement Disorder" covers other problems that can come with the disease or the medications.

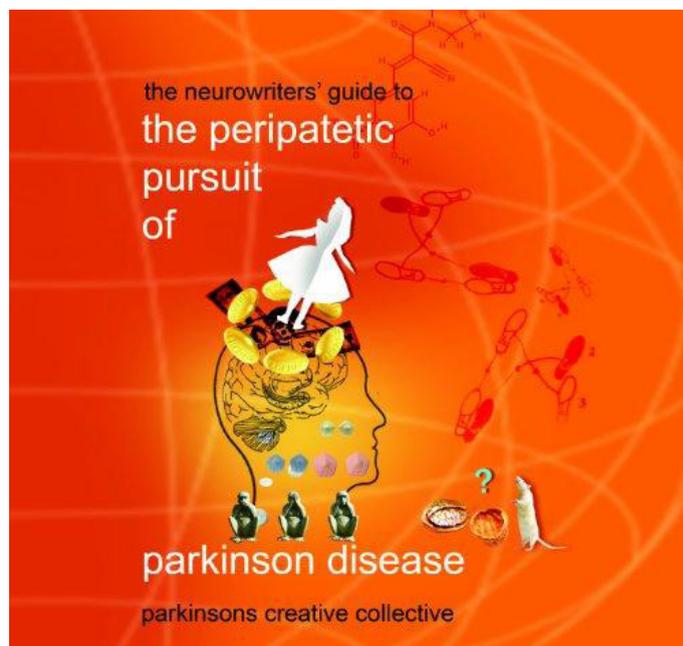
Chapter 3: "Helping Ourselves" covers topics such as exercise, nutrition, meditation, staying socially active, and so on.

Chapter 4: "Quality of Life" deals with coping and appreciating life - accepting life in the slow lane, enjoying our children etc.

Chapter 5: "The Difficult Bits" deals with late-disease issues such as home care and hospitals.

The book, being a compilation of items from people who are dealing effectively with their Parkinson's, contains a wealth of information. Its strength lies in their refreshing honesty as they write about their experiences, reflecting the many different ways in which people are affected. This is important because Parkinson's is what is known as a snowflake disease - every presentation is different, in the same way that every snowflake is unique.

It is an interesting and informative educational resource which some people read a chapter at a



time, while others prefer to dip into it. However, as often heard on broadcast programs 'it is not to be taken as professional and personal advice'.

The aims are clearly stated: "For those with Parkinson's disease, it's a support group between two covers; and for everyone else, it's a window into the world of life with Parkinson's disease".

For me this aim is achieved, giving me a deeper understanding of Parkinson's and its effects on people's lives. It is readable and interesting, with plenty of humour and clear vivid descriptions showing how a wide variety of people have faced their challenges and learned to cope with them.

But how could one reviewer - a carer - provide a useful general opinion for the many readers of *In Touch* about a large and unusual book with so many different contributors? I read over 50 reviews written by people with Parkinson's, family members, nurses, etc. The almost unanimous consensus was that the book is remarkably readable, highly informative and amazingly helpful for those who need to understand and live with Parkinson's disease.

The book is out-of-print but available from Parkinson's SA library. An improved updated ebook version is now available and is very readable on a tablet or computer.

A copy of The Peripatetic Pursuit of Parkinson Disease is available to loan from our Parkinson's SA library, or you can download a pdf version by visiting www.parkinsonscreativecollective.org/pdf.html

