Our experience with Parkinson’s Disease

From Ann Stradley and Rex Adamson

The Parkinson's red tulip started in 1980 when W.S. Van der Wereld, a Dutch horticulturalist who had Parkinson’s disease, developed a red and white tulip, and named his prized tulip the 'Dr. James Parkinson' in honor of the man who first described his medical condition and to honor the International Year of the Disabled.

Casino, NSW, Australia
Wednesday, January 15, 2025

Table of Contents

Part One –Introduction

This document combines the individual handout material we have prepared and updated regularly since 2020.

The original documents were written as education tools for family and friends and, while they are centered on Parkinson’s Disease, a lot of the material is also applicable to any situation where there is a caring role involved along with mobility issues.

This combined publication is designed to be printed in colour in booklet format for ease of distribution and handling.

It can be used freely as an educational and information document.

Introduction

Who we are.

We are retirees living in Casino, in rural New South Wales. Ann has Parkinson's Disease.

Photo taken August 2022

Having been born in 1941 and 1942 we are what are known as War Babies - not that you hear that term very often.

The first sign there was something amiss, was when Ann was suffering frozen fingers at her computer keyboard and the fingers had to be straightened by using the other hand.

This led to consultations with her GP and then the subsequent diagnosis of Parkinson's by the Neurologist in November 2012 on the day before she turned 70.

The gradual loss of mobility started not long after, beginning with the need to use a walking stick, or cane, especially on uneven ground. Subsequent mobility loss increased steadily, although slowly, over the years.

While loss of mobility is one of the motor functions that are affected by Parkinson’s Disease (PD), there are also non-motor functions that are adversely impacted by PD.

These can be just as life changing as the motor issues and require as much, if not more, attention.

There is a diagram of these at the end of this book.

Part Two - Carer or Manager

This section was written as a support document for people who are carers of someone with Parkinson’s Disease.

It was originally posted in a Facebook Group for Carers of people with Parkinson’s Disease

Ann and I have been on our PD journey for 12 years now, although in hindsight Ann clearly has had PD for closer to 20 years.

Only recently has it become clear that the issues she was having in the 2000’s were in fact part of PD.

In the 12 years since she was diagnosed by both a Neurologist and her then GP, we have certainly learned a lot and have worked our way through significant lifestyle changes.

I have written these notes in the hope they will assist you with managing your PD journey.

PD and the PD Journey.

We know that there is no cure and that any person with PD has two choices – throw in the towel and do nothing or work hard at slowing down the progression of the disease.

You cannot beat PD, but you can manage how quickly it affects your life.

This is manifested in how fast the symptoms, both motor and non-motor, develop and start to have an impact.

Parkinson’s Disease is a true designer disease – everyone gets a different version. No two are the same and everyone progresses at their own pace.

Involving the family

I believe it is critically important to have children - and other family members - fully across what you and your PWPD (Person With Parkinson’s Disease) are doing regarding the PD and the impact it is having on your lives, both current and perhaps in the future.

They need to be educated so they can be there for you both when they are needed – without there being any sudden surprises.

And you should certainly invoke their assistance as you need it. As a carer, it is essential that you manage your own health and get assistance rather than let your health suffer.

Education

You and your PWPD need to educate yourselves as much as you can about the PD symptoms, the medications prescribed, the side effects of the medications, how to take the medications etc. etc.

The National Parkinson's Disease organisations in the USA, the UK and Australia have a wealth of downloadable material, and the local organisations can offer advice and assistance in locating services.

There is so much information available, you can drown in information. But before you get overwhelmed, you need to figure out which sources give you the most helpful information for your particular situation.

In our own situation, I eventually compiled a lot of PD information into a PDF format compendium of over 550 pages, indexed and bookmarked. It is now my go-to reference book on any PD issue.

Pro-active actions to slow the PD progression.

Exercise is now seen as a major tool in the slowing of the progression of PD motor symptoms.

Our initial exercise program was designed by Vestibular Rehabilitation specialists in Brisbane 12 years ago to counter balance issues. Ann then joined a GYM and has remained a GYM member for the last 12 years. Ann had not set foot in a GYM before the age of 70.!

Over most of the last 12 years, Ann worked with various exercise regimes designed by her Physiotherapist and the then GYM owner and late last year we were finally able to see an Exercise Physiologist who designed a personal programme for Ann based on 8 GYM machines.

This programme is now the one we use two times a week at the GYM.

The complete set takes under 45 minutes to complete, with me assisting Ann into and out of machines as needed.

The other two days, Ann is in a local exercise group here in our village. They do chair based 45-minute workouts – then have coffee and cakes!

That is the social interaction bit – or so I am assured. ☺

And social activities, either associated with family or support groups, are also seen as being important for the Parkinson's Iceberg symptoms.

During the Covid -19 shutdowns we experienced with the GYMs shut down, Ann went backwards in terms of mobility.

She needed the portable scooter when we went for medical or allied health professional appointments etc. over shortish distances – like a couple of hundred yards from the car to medical office she needed the scooter as it was too far to walk.

With the re-starting of the GYMs and the application of the Exercise Physiologist designed exercise programme, Ann now covers the same trips with just a cane.

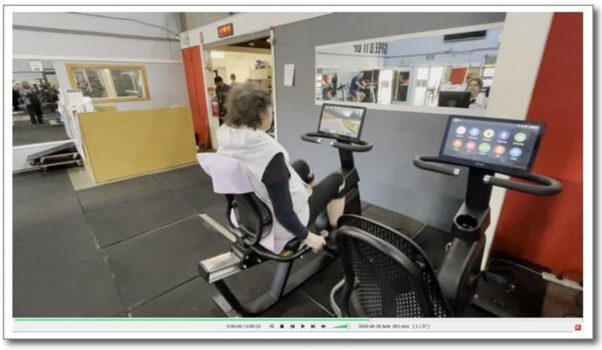
And Ann no longer uses either a cane or a walker in the house.

There is no doubt for us that regular, reasonably intensive exercise is hugely beneficial in managing PD.

Ann's Gym Routine as at June. 2024.

This workout has since been expanded with the addition of another routine and an increase in the number of sets per routine.

Gym Images



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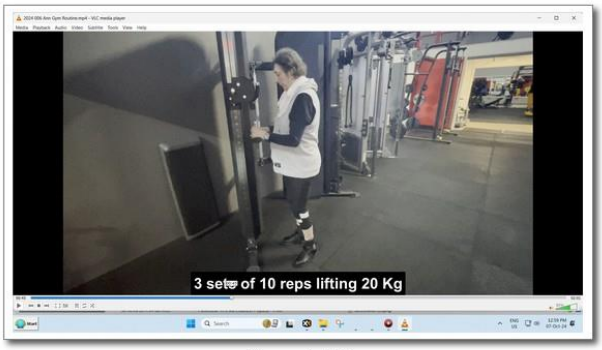

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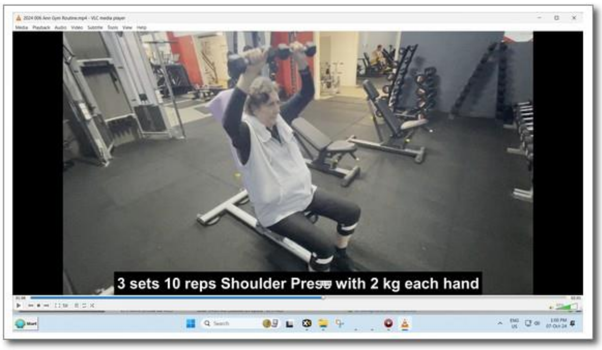

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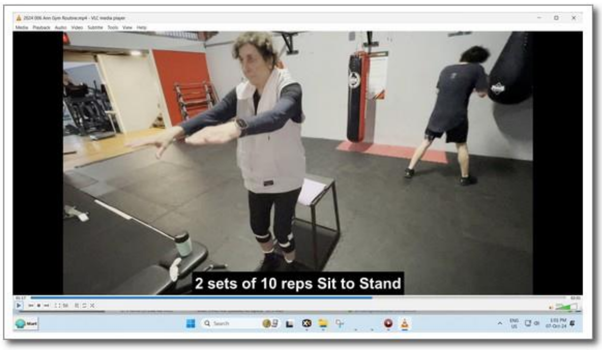

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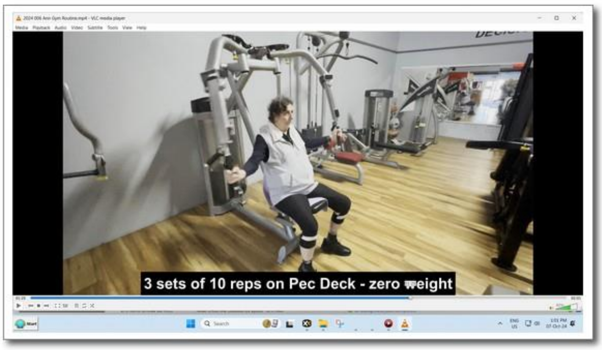

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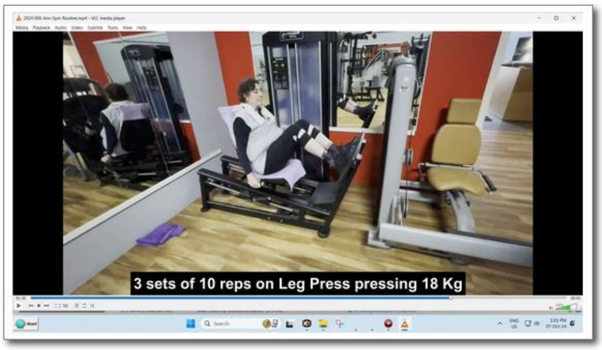

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Page: 1 / 1

Driving and Mobility

The loss of mobility creeps up on people with PD and it is probably one of the hardest to look at objectively. Making the appropriate decisions about mobility loss are really hard ones, as they impact on ego and self-esteem.

Where we live, New South Wales, PD is a notifiable disease for the purposes of being licensed to drive.

People with PD are generally required to undergo an on-road driving test each year as Neurologists are rightly reluctant to sign off on the relevant State Government paperwork without documented proof of driving ability.

Ann felt she was unable to pass a test in 2021 and surrendered her license.

As a result, we first purchased a large mobility scooter for Ann to use within our village and then a portable scooter to use in shopping malls and clubs where we are members. Then followed a Parkinson’s Disease specific walker, the U-Step II.

The rest of the equipment, including two outdoor specific walkers and an electric golf cart for use in our village rounded out our collection of major mobility aids.

So, we now have two scooters, three walkers and a golf cart as well as numerous mobility aids installed throughout the house.

Lack of driving license means that Ann is now totally dependent on others for accessing anything outside the village.

Role changes

Depending on your prior arrangements, role changes can be very significant. There is also a mindset associated with the changes.

Are you managing or caring? And what is the difference between the two?

One has an emotional aspect, and the other doesn’t. Caring evokes all sorts of emotions while managing less so – at least for us and specifically me as the carer.

Carer or Manager

In an attempt to sort out what we are actually doing, I listed the current managing and caring roles in our household. And it seems like I do very little caring.!

I do almost all the household management and I help a little with dressing as needed.

For example, Ann used to do all the shopping and cooking and now does no shopping and only does around half the cooking.

But see the table below for a detailed analysis of our current roles.

Carer or Manager

MANAGING		
Household	**Self**	**Spouse**
All cleaning – floors, bathrooms, and toilets	Yes	
Laundry and clothes drying and subsequent putting away of clothes	Yes	
Manage all Finances	Yes	
Managing technology	Yes	
Groceries		
All Grocery shopping and storage	Yes	
Maintenance of pantry stocks	Yes	
Manage Refrigerators and freezers	Yes	
Prepare Shopping List	75%	25%
Meals		
All table setting and clearing away	Yes	
Preparing and cooking meals	50%	50%
Washing dishes and storage	Yes	
Medications		
All medication ordering	Yes	
Filling dosage boxes	Yes	
Managing scrips	Yes	
Monitoring taking of medications	Yes	
Other		
All car Driving	Yes	
Appointments and calendar	80%	20%
Packing Vehicle	Yes	
CARING		
Personal Hygiene		
Showering		Yes
Toileting		Yes
Oral Hygiene		Yes
Dressing		
Bras	50%	50%
Overhead tops	50%	50%
Panties		Yes
Slacks		Yes
Socks and shoes	25%	75%
Indoor Mobility		
Is mobile		Yes
Outdoor Mobility		
Assistance required	75%	
Medication Taking on time		
Manages		Yes

Medication Management

Medication needs to be taken on time every time if it is to be effective. And for some, this seems to be very difficult to manage.

The so-called Gold Standard medication delivers Levodopa to the brain to replace the dopamine that is being lost in the brain cells. And it needs to be replenished, or motor symptoms return.

We use Google Home devices in each room of the house, and they broadcast when it is time to take medications. As they are in every room, you cannot escape the reminder.

I fill the weekly pill cases every month. This of course can be done by a pharmacy, but I prefer to do it myself.

As Ann is now using a Duodopa Pump for Levodopa delivery, the timing issue is less important for us.

Gut Management and Constipation

Around 90% of people with PD suffer from constipation caused by the PD medications. Constipation is now seen as a significant factor in managing PD symptoms.

It adversely affects how well PD medications are absorbed into the blood stream and then make their way to the brain.

Current thinking is that there is a need to get ahead of the constipation curve. Treating constipation after the event is not the smartest course to take.

We use our GP to assist with constipation management as it is not really part of the Neurologist purview – even though they know it causes issues with medication efficacy.

Our Neurologist even told us to get our GP involved in managing the constipation.

Support Groups

There is benefit in being a member of both real support groups and internet-based ones.

The man benefit is educational through the exchange of experiences and ideas.

I belong to internet groups for people with PD and their carers and groups for just carers only.

Your Support Team

I know it seems obvious, but a key to successfully managing the PD journey is to assemble a team of medical and allied health professionals to manage both the PD issues and general health.
It is hard to manage living with PD if there are other health issues that get out of control.

And it is important to keep them all informed of what is happening with the PD and to get the Neurologist to keep in touch with the GP – if you can.

Our team consists of:

Medical

Neurologist, for PD Symptom Management
GP, General Health and Constipation Management
Ophthalmologist for Eye Maintenance
Urologist for PD caused Urinary Issues and Over Active Bladder

Allied Health Professionals.

Dentist for teeth and gum maintenance and PD related cheek chewing.
Physiotherapist, for attention to PD caused issues to back, neck and shoulders Podiatrist, for PD caused dystonia in the toes and feet.
Podiatric Surgeon for Arthroplasty on the toes to correct PD caused toe curling.

Other

Exercise Physiologist, for GYM based exercise programme.
Gym Owner / Manager for practical GYM equipment advice.

Legal Aspects

Legal aspects – we are just starting on this trip, and you are talking about legal aspects.!

Yes, because it is such a variable disease it can suddenly surprise a carer and catch them unaware. And it is never too early to put in place some very important legal documents.

Whether we are caring for someone with PD or not, we generally need at least the following:

A Will, a POA, an EG and certainly an ACD - Power of Attorney, Enduring Guardianship, and an Advanced Care Directive.

The key difference between POA and EG is that a Power of Attorney makes decisions over financial and legal affairs. Whereas an Enduring Guardian has the power to decide on matters regarding lifestyle, health, and welfare.

An advanced Health Care Directive is also sometimes known as a Living Will. Also, Enduring Guardianships and Advanced Health Care Directives are slightly different in nature.

Each State is a little different, so this is an area where you unfortunately do need to spend some money and get the documents prepared professionally. You can either use a Solicitor or a State based Public Trustee.

And if you already have them, you need to make sure they are valid where you live and that they are current. For example, in NSW a POA needs to be established in NSW to be valid.

The preparation of these documents can also be a good time to get children, or other family members, across what you are doing, especially regarding the POA and EG and ACD.

Depending on individual family circumstances, you may choose to leave Wills out of that discussion.

Conclusion

Parkinson’s Disease is not easy, but living with it can be a whole lot easier if you are very pro- active in your approach.

It is what we have tried to do over the last 10 years, and I hope these brief notes will be of some assistance to you as a carer starting out on this PD journey with your PWPD.

And of course, do seek medical and allied health professional advice with managing the PD.

Make sensible use of the Internet, look at the respected PD Organisations like Michael J Fox and Davis Phinney as well as the Parkinson’s Disease sites, both here and overseas.

And remember, Dr Google is NOT a replacement for the Neurologist, GP, or any other Health Professional in the support team of the person you are caring for.

Part Three – Aids we have Installed.

Mobility Aids Installed

For

Ann Stradley

Diagnosed with Parkinson’s Disease

In 2012 at the age of 70.

We started purchasing aids in earnest in 2019 and have continued adding items as we saw a need.

They have been grouped by function, rather than by date obtained.

Mobility – outdoors

We purchased a Drive Scooter in July 2019 for use in the Village where we live. This is a large three-wheel full mobility scooter suitable for use in all outdoor conditions.

It can be used on the footpaths in NSW and is suitable for travel to the local shopping centre. It is too large for use inside shopping centres and shops.

As Ann's mobility decreased, we found visits to shops and clubs a fairly tiring experience and a portable scooter was seen as an option.

So, in January 2020, 6 months after buying the large Drive mobility scooter, we purchased a Solax Genie and Hoist combination.

While some mobility scooters, especially the three-wheel variety, are very light, Ann wanted one with 4 wheels. The most suitable unit was the Solax Scooter.

The hoist avoids me having to lift the scooter in and out and risk injuring myself.

The increasing amount of mobility gear we were carrying meant we needed to upgrade our vehicle to a larger van style unit.

The choice then was a basic delivery van or a more expensive vehicle with more comfort.

We went for the latter and purchased a 2020 model Kia Carnival which has the same room as a small delivery van, but rides like a car. It also easily takes all the current mobility gear with room to spare.

We then upgraded this unit to a current model in 2023.

Here is the Solax Scooter and Hoist combination. This combination is sold at a number of outlets – a Google search will provide details of current stockists.

Mobility Aids - Outdoors

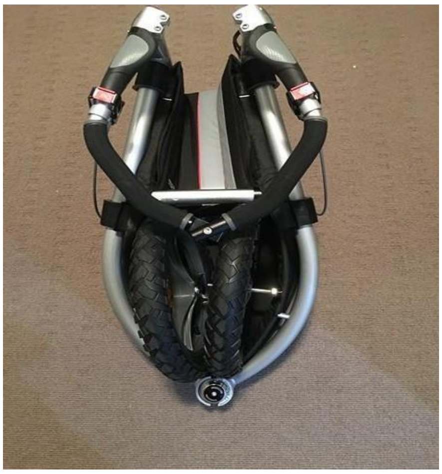
While both mobility scooters are great at fulfilling their intended function, neither of them is of use in an outdoor situation away from home.

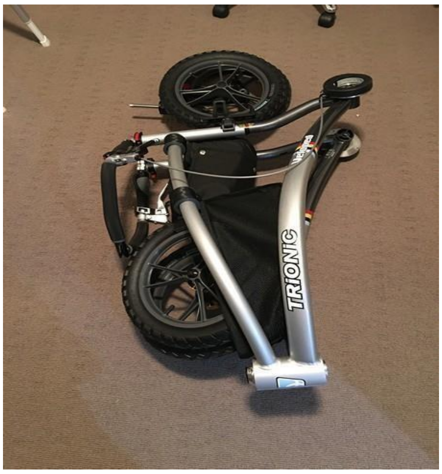
You can’t take the big 3-wheeler unit without using a specialised trailer like a golf cart trailer, and the Solax is intended for indoor flat floor use only – very small solid wheels.

This led to the purchase of a dedicated all-terrain outdoor walker – a Trionic Veloped Tour from Sweden.

This walker folds up and the wheels detach (no tools needed) for easy storage in a car. It weighs 12 Kg or 7.5 Kg with the wheels removed – so a fairly easy lift into and out of a car.

It is exceptionally easy to use and with the 14-inch pneumatic tyres handles almost any terrain. Ann is delighted with this unit.





In early 2023, Ann determined she was no longer able to safely manage the large three-wheel mobility scooter.

With Ann no longer able to drive herself around the Village and both of us reluctant to use the car for such short distances (400 meters and less) on a regular basis, we searched for an alternative.

A golf cart was the obvious choice as we live in a gated Lifestyle Community where golf carts are a common means of transport.

In NSW we are able to get conditional registration – complete with registration plates – that enable legal use of a golf cart within our village. For a minimal cost of under $50 a year.

Our search for a suitable golf cart led us to an E-Car that we purchased in July 2023.

This is a 4 seat, 4 door enclosed weather proof, heated, and air-conditioned unit that can carry Ann's walker in the back seat area for use at our destinations within the Village.

It is battery driven using standard Golf Cart battery packs and plugs into household power for charging.

It has been a really positive addition to our mobility equipment.

However, it is clearly an indulgence on our part and is by no means a necessity. But we do love it!

Mobility Indoors

Indoor mobility has its own set of challenges. If using a walker, it needs to be agile enough to turn in small areas and narrow enough to get through doorways.

There are a huge number of walkers – or rollators – on the market. We settled on the U-Step II for several reasons.

It has a smaller turning circle than the majority of walkers, it has a Parkinson’s Disease specific laser light attachment for unfreezing available as an option, **and it has always on brakes – which we regarded as an important safety feature.**

And it easily folds up for carrying in the car.

Ann can turn around in this hallway without hitting the walls with the U-Step II.

While the U-Step is an ideal indoor walker, it is really not suited for any use outdoors even on footpaths and paved roads. It will do the job, but it will be a rough ride.

There are many situations where we need to park and walk and where the portable scooter is not a viable option, and the terrain is too rough for the U-Step.

Carrying the Veloped in the car is easy enough, but it then leaves us with a rather large walker not suited for indoor use at our destination. So, the solution was a smaller walker, still portable and one with large pneumatic wheels to cope with parking lots etc.

Choice was another Trionic product, the Trionic *Rollator Walker 14*

This walker folds for easy carrying and weighs under 7Kg.

In April 2024 we decided to add another walker that would stay in the car permanently to avoid the constant shuffling of the Trionic Walker 14 from the car to the E-car with the consequent adverse effect on my back!

We considered another Trionic Walker 14, but the price had escalated substantially so an alternative was sought.

Looking ahead, it seemed a walker that could also convert to a light weight wheelchair would be an ideal option.

We located one less expensive than the Trionic that met those requirements with the added advantage of being electric as well.

It is a STELLAR Motorised Rollator described as a 5in1 device that replaces your walker, manual rollator, mobility scooter, electric wheelchair, and walking stick.

The Stellar motorized rollator in walker configuration.

Given the relatively small wheel size, this is essentially an indoor, smooth surface unit. Ideal for around the house or in shopping centers etc.

This is definitely not an outdoor unit.

The Stellar Motorised Rollator in wheelchair configuration.

The bag under the seat contains the Lithium battery which is good for around 12 – 20 klms travel.

Speed range is 1.2 to 6 km/H going forward and 1 to 2.2 km/H going backwards.

Weight capacity is 100 Kg.

This means we now have four walkers, each fulfilling a specified role, and while it may seem over-kill, we are about making life as easy as we can while we live with PD.

U-Step II PD Specific Walker

TRIONIC Veloped Outdoor

TRIONIC Walker 14

Stellar Motorised Walker

Fall prevention.

Ann has had only one fall and was unhurt. She attributes this to the fall prevention steps we have taken throughout the house.

We have installed over 40 grab rails, most of them screw into the studs variety but also a number of suction style grab bars.

Screw into the stud knurled grab rail will hold full body weight up to 250kg. The knurling gives an improved grip. Evekare Brand

Suction Grab Rail – a disability product – designed as a balance aid only. Bunnings web site say they support up to 20kg but not body weight. Evekare Brand.

Trojan Glass Lifter – a tradesman's tool – has a static load rating of 60kg – according to Bunnings Web Site - and costs around a third of the price of the disability product – but looks ugly.

Stander Security Poles

While grab rails and bars are fine in small spaces like bathrooms, toilets, or hallways, they do not cover open spaces. Negotiating open spaces when balance is an issue, normally needs a walking aid, like a cane or a walker.

There is another option, a Security Pole of some kind. We chose Stander brand products. They come with or without a handle in black or white.

Promotional photos from the Stander USA web site.

They are suitable for ceilings up to 9 ft and can be installed without permanent fixing.in case they need to be moved.

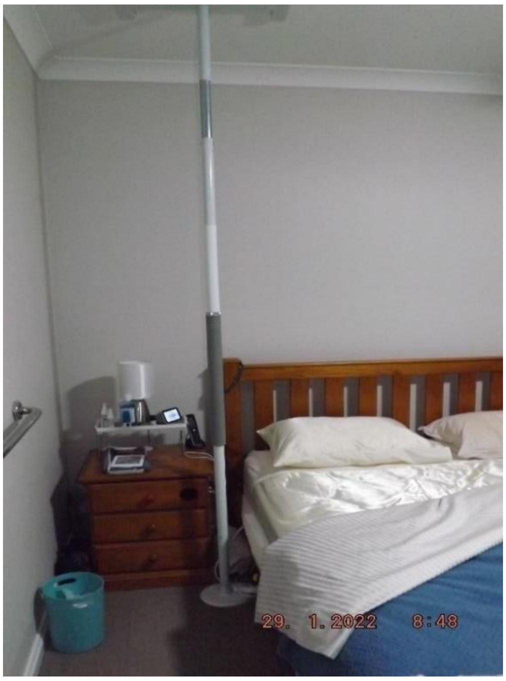
The price varies considerably and the supply of them is patchy at best. We have purchased from three different suppliers due to limited stock availability.

We now have 14 of these poles installed – 6 with a handle and 8 without. Here is how we have used them.

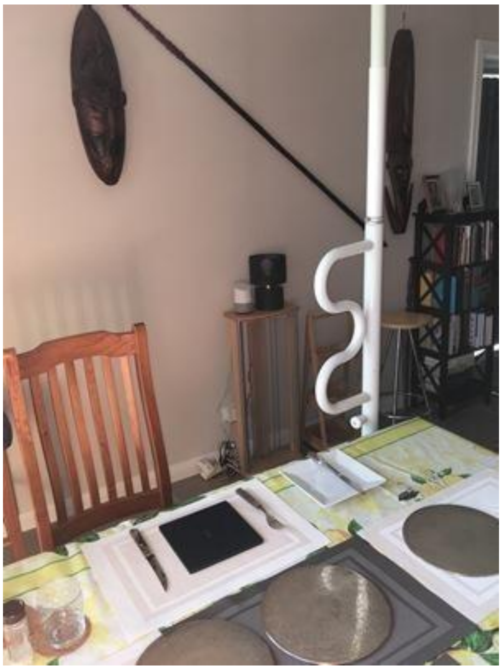
Mobility Aids – Falls Prevention

At the toilet

Beside the bed



Beside the dining room chair



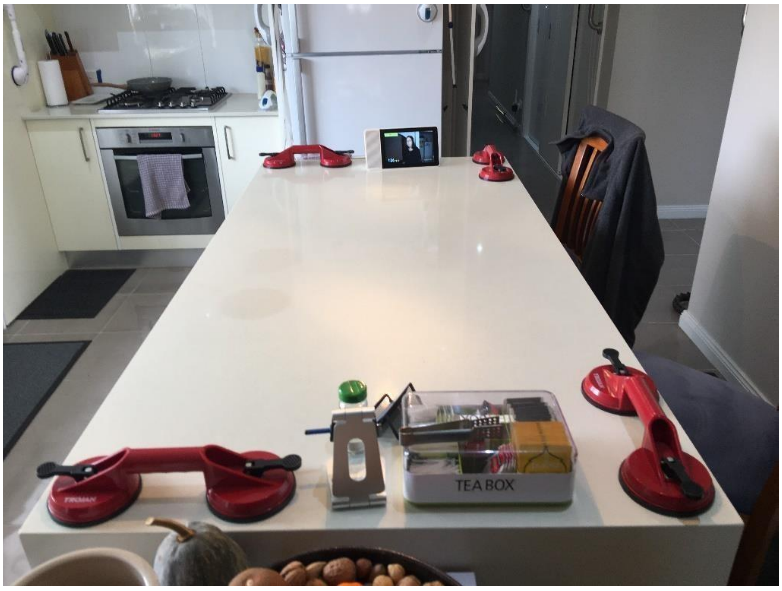
In the shower itself

Beside the lift chair and behind and 2 poles in an open area

While all these poles make the house look something like a pole dancer’s paradise, they serve a very useful purpose; and while not used every time Ann goes past, they are there just in case.

And so are a huge confidence boost.

Some days they are used more than others, but that is the perverse nature of PD.



Note the Trojan Glass lifter suctioned on the end of the bench top. There is one at each corner of the kitchen bench top. Ugly looking, but very effective.

Fall Detection

Apple Watch

After reviewing the market for fall detection devices, we decided on the Apple Watch as the device that best suited our needs.

We started with a Series 7 watch and then moved on to the 2022 Ultra series as it also has an audible alarm. We purchased both watches with the E-Sim but have so far not used that facility.

The watches work fine without the E-sim enabled as long as they are within range of our iPhones.

We know the fall detection works as it has been tested by a simple fall that Ann had in November 2022.

Ann was unhurt, and the Apple Watch emergency alert function worked perfectly.

The Ultra version of the Apple Watch is expensive, but we believe it is worthwhile.

Indoor Security Cameras

We installed a number of indoor security cameras so I can see the situation if Ann has a fall while I am out either doing my own exercise, shopping or any of the other activities that take me away from the house.

Ann's Apple Watch would call me in the event of a fall, and I could see the actual situation as well as talk with her either via the camera or my own Apple watch.

We used Eufy brand Indoor Pan and Tilt cameras and all but two are wall mounted.

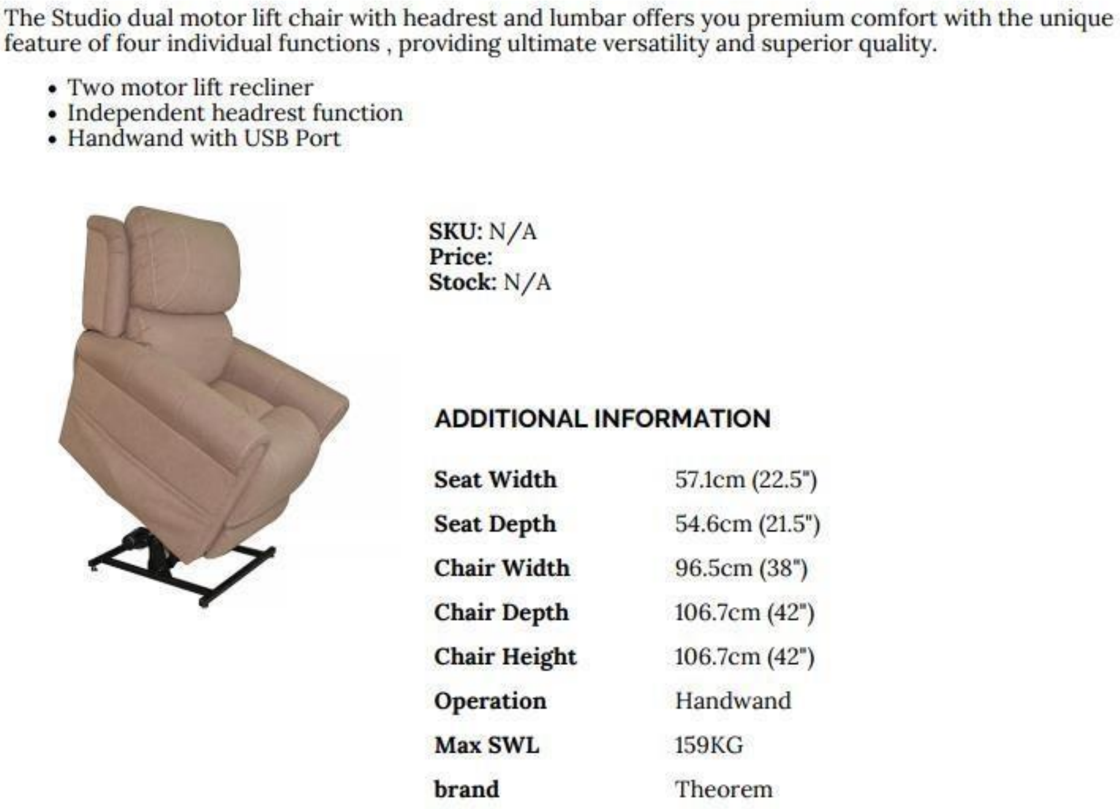
General Assistance

Lift Chairs

One of our early purchases was two lift chairs, one for each of us.

There is a wide variety of chairs to choose from, and the ones with two motors, while more expensive, provide more options for back and neck support.

This has made a significant difference to Ann’s ability to sit and enjoy whatever she is doing without the worry of getting in and out of a lounge chair.



The Studio dual motor lift chair with headrest and lumbar offers you premium comfort with the unique feature of four individual functions , providing ultimate versatility and superior quality.

- Two motor lift recliner
- Independent headrest function
- Handwand with USB Port

SKU: N/A
Price:
Stock: N/A

ADDITIONAL INFORMATION

Seat Width	57.1cm (22.5")
Seat Depth	54.6cm (21.5")
Chair Width	96.5cm (38")
Chair Depth	106.7cm (42")
Chair Height	106.7cm (42")
Operation	Handwand
Max SWL	159KG
brand	Theorem

Dining Chair swivel seat.

Probably the least expensive item we have bought but it works a treat. Readily available from E- Bay or other online suppliers.

Wonder Sheet

These are from a Queensland-based supplier and work really well in terms of in-bed mobility. Ann is able to turn over with relative ease – comparatively speaking.

Stander Assist – A - Tray

Stander promotional text.

The Assist-A-Tray is a couch-side handle that makes it easy to stand from your favourite couch or chair. It comes with a convenient multi-use swivel tray so you can eat, surf the web, or simply keep handy items close by. And like all of our products, it blends in with your living room (like another piece of furniture) so you can maintain the comforting feeling of your home.

While our chairs are a little too large for the optimal use of this unit, it still functions really well and is now in constant use by Ann when she is seated in her lift chair.

Ann does not use the handle to assist with standing as there are two Stander Security poles beside her chair that she uses for standing assistance – as well as the lift chair itself.

Toileting and Showering

Toilet seat frames or Toilet safety Rails

These are a fairly standard item, readily obtained. Ours came from Bunnings.

Raised Toilet seat with arms.

A standard item available from most mobility aids shops. This one actually sits on the inside of one of the toilet safety rails shown above and replaces the standard toilet seat and lid. This is in the Guest bathroom, used mainly by me, but on occasion by Ann. Hence the raised seat and there is also a Stander Security pole with handle next to that toilet. Note the Trojan Glass lifter on the wall.

Bidet

As constipation management started to become a semi-major task, we decided that a bidet would be useful for personal hygiene issues arising from the on-again off-again normal bowel movements.

We discovered there is a wide range of products available, some of which do not meet current plumbing standards.

In the end we went with a bricks and mortar store specialising in Bidets rather than buying on-line. And we even travelled 2 hours to the Gold Coast from our home in Casino to examine and buy a unit.

We purchased a Coway Bidet and associated seat riser that sits on top of the existing toilet bowl and attaches through the normal fixing holes at the rear of the toilet bowl.

It has adjustable twin nozzles (front and rear), remote control, heated seat, warm water wash and warm air blow dry.

Ann absolutely loves it.

Shower Chair

This was purchased so Ann could shower with her leg outside the shower stall after she had Arthroplasty surgery on her toes.

Another Evekare product from our local Bunnings store.

Used along with this item - a shower stool to put her leg on while it was outside the shower stall. This all needed assistance from me to set up the chair and then, after she was seated, the stool.

So, not a do-it-yourself arrangement by any means, but it did work and allowed Ann to shower un- assisted and in comfort while keeping her recently operated on foot outside and dry.

Additional Shower Head.

Because Ann would be seated having a shower in the shower chair, she would not be able to reach the shower head in order to manage the shower herself.

The solution was to install a second, accessible, shower head with an also accessible switching tap, so she could manage to shower herself.

Fairly important for self-esteem.

The second shower head is hanging from the black Stander Security pole, and the switching tap is located on the wall just at the bottom of the small suction grab rail.

It is within easy reach when seated in the shower chair, as is the main water tap.

Black pole in shower. Second shower head.
Grab rails on wall. Note white pole just outside shower

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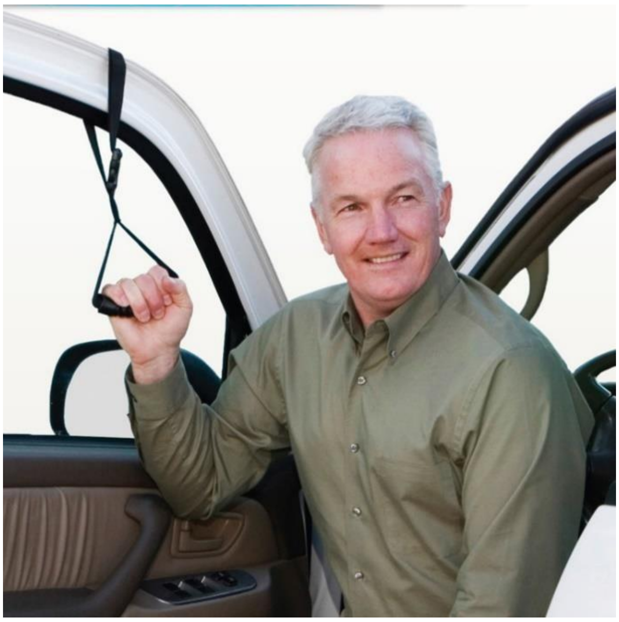
Car Aids

Getting out of the car, despite the bum height seat, was getting difficult so we installed two simple devices to assist.

A Stander Handybar

A Stander Car Caddie



Both of these simple devices make a huge difference to Ann exiting our car. They are readily available either as a genuine Stander product or any number of similar copies from either Amazon or E-Bay.

We also purchased one of these items, which I use to get Ann out of various items of Gym Equipment at our local gym.

Called a Stander Handy Handle.

Again, a simple device from Stander that actually works.

12-volt car blanket for legs while travel

Ann was suffering from leg pains after more than 30 minutes of car travel, probably from the car air conditioner – despite having individual controls and Ann running her side of the car a few degrees warmer than my side.

So, we purchased one of these. We had used them in the past on long car trips.

In any case, it is now used on any trip longer than 30 minutes and keeps Ann's legs warm and free from pain as well.

Readily available from on-line stores. Search for 12-volt car blanket. We bought ours from Amazon.

The heated leg cover, along with the heated passenger seat in the car (a standard feature in the Kia), means Ann now has relatively pain free car trips – a definite improvement over our older 2011 model Hyundai Santa Fe.

Outdoor Modifications

Acorn Stair Lift

Even though there are only 4 steps on our front stairs, they have become an almost impassable barrier.

The lift was installed in 2020 and has been a great success.

Poles at the top and bottom were added subsequent to installation.

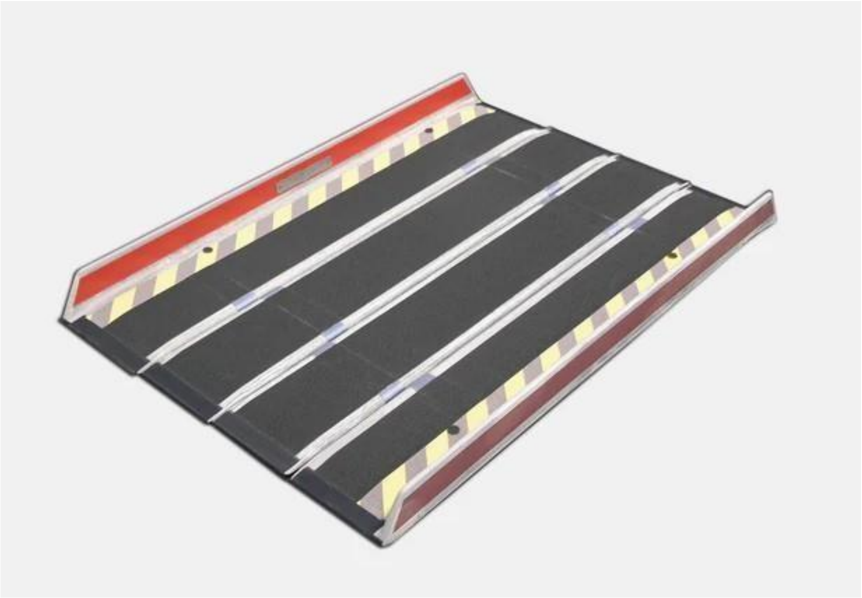
Provides something for Ann to hold onto as she gets up from the seat. Means she can use the lift without me being at either end to help her exit the seat.

The pole in the middle is there to aid other users of the steps in ascending or descending.

Threshold Ramp

To allow easier access to our outdoor deck and Bar-B–Q dining areas, we needed to install a ramp suitable for use with the U-Step II indoor walker.

We chose a portable folding ramp with side rails from Invacare. This is sufficiently light to be truly portable yet has a loading capacity of 300 Kg.



Part Four – Cost of Aids Installed

Financial Aspects

We are self-funded retirees. The only recurring Government funding we receive is the Carers Allowance paid to me as Ann's carer. This is not means-tested and comes in at $153 every two weeks with a $600 annual lump sum payment – so just under $4,600 a year.

In addition to the Australian Government Stimulus payments in 2020 we both also received the much more generous USA Economic Stimulus payments from both President Trump and President Biden.

Those combined payments and the recurring Carers Allowance have contributed to the costs of our purchases to date.

<u>We do realise that many of the items we have purchased over the last five years are expensive and we hope that this document may provide ideas that can be tried for less than the costs we have incurred.</u>

With that in mind, below is a listing of our expenditure on mobility aids over the last three years. This list is approximately in the order of purchase.

Large 3-wheel scooter	$ 5,915	Used within the Village
Lift Chair	$ 2,480	In constant use
Portable Scooter and hoist	$ 5,461	Used when outside Village
Swivel seat for dining chair	$ 30	Used always when seated
Acorn Stair Lift	$ 6,858	Used each time stairs are negotiated
U-Step 2 Parkinson's Walker	$ 1,744	Used indoors constantly
Toilet Safety Rail x 2	$ 130	Used each time toilet is used
Grab Rails x 40 and 3 posts	$ 1,455	Used as needed
Bidet for en-suite bathroom	$ 2,140	Used each time toilet is used
Stander Car Aids	$ 110	Used to exit car
Stander Security Poles x 14	$ 4,600	Some always, others as needed.
Wonder sheet sets x 2	$ 260	Bed sheets
Trionic Tour Veloped	$ 2,313	Used outdoors for walking
Trionic Rollator Walker 14	$ 2,308	Used outdoors and indoors
Portable ramp for deck access	$ 820	Used to access outdoor dining area
Apple Watch –Ultra	$ 1,299	Worn all the time
Apple Watch Series 7	$ 749	Worn all the time
Indoor Security Cameras	$ 935	Full time recording
Stander Assist A Tray	$ 500	Used while in lift chair.
E-Car for use in Village	$17,639	Used constantly in the Village.
Stellar Motorised Walker	$ 2,589	Used indoors and at shops.
Total	**$60,335**	

Other Expenditure

The list does not include expenditure on:

Arthroplasty Surgery for her toes, $1,500, Once off
Symbyx PDCare device for gut biome treatment, $1950, Once off
Orthotics and Podiatry footwear, $1,000 +, Recurring probably every 2-3 years.
On-going Physiotherapy and Podiatry treatment $250 - Annual
Gym fees, $350 - Annual
Bladder Botox to treat Bladder Dysfunction $350 annually.

The above list plus other items have come to over $7,000 over the last five years.

There has also been expenditure associated with the move to the Duodopa Pump therapy.

We have added a Pharmacy grade vaccine refrigerator for the storage of the Duodopa Gel. In addition, we purchased an electric start generator to run the Pharmacy Fridge when we have our not infrequent power outages in Summer.

If we lost our Duodopa Gel due to a power outage, the replacement cost of a month supply of the gel – outside the PBS time frame – is $6,000. We see the fridge and generator as a security blanket and these two items added another $5,200 to our total capital outlays.

So, our out-of-pocket costs from 2019 to early 2025 in PD related expenditures – without the luxury item of the E-car - have been just under $55,000. This is made up of $42,700 approx. for mobility aids, $7,000 for PD related procedures and activities and $5,200 for the Vaccine Refrigerator and generator.

Our grand total outlays, including the E-car, are just over $72,500 since 2019.

Given the nature of PD, we expect both recurring and non-recurring expenses will increase over the coming years.

We acknowledge there are items in our list that are not essential and can be classed as luxury in nature – the E-car being the main offender. Nevertheless, they are included to provide a complete picture and to perhaps trigger ideas for others.

Part Five - Parkinson’s Disease Symptoms

Parkinson’s Disease Motor Symptoms

The illustration below shows the visible or Motor Symptoms of Parkinson’s Disease – in other words the things that people see.

Not all people with Parkinson’s have all these visible symptoms.

While medications control some of these, like the tremors, others have to be managed via exercises.

Ann has some of these, including tremors, but these are well managed by her medications.

Parkinson’s Disease - The Unseen Symptoms

There are a whole range of Non-Motor symptoms of Parkinson’s Disease that are unseen. The most common ones are shown in the diagram below.

In terms of the Non-Motor symptoms, we have so far been relatively lucky. The ones we have had to concentrate on are:

Constipation.

This is an area that has a significant impact on the efficacy of the PD medications that Ann takes to control the motor symptoms of her PD.

We eventually got our GP involved in managing Ann’s Constipation and we are now largely ahead of the curve – which is where you need to be with Constipation.

Neurologists recognise that constipation is an issue and both of the last two neurologists have referred us to our GP to manage the issue.

Ann takes Coloxyl – 2 tablets one night, and Movicol is used to supplement as required.

This regime now has Ann ahead of the curve.

Sleep Difficulties

We have tried various medication to aid with sleep, and in Ann's case none worked well enough to continue their use. Currently Ann uses a bed wedge, and this has improved her sleep a fair bit, but sleep is still broken and is compensated for by late morning sleeping – not an ideal solution by any means, but it does prevent fatigue setting in.

Saliva Control

While not listed in the Iceberg, it is a problem that can cause difficulties with swallowing and speech.

Ann had excessive saliva to the extent that we consulted an ear Nose and Throat specialist to confirm there were no other problems causing the excess saliva.

After confirming the absence of other issues causing the excess saliva, the specialist recommended a nasal spray to counter the problem and to prevent the tickling cough at the back of the throat.

Ann currently uses Nasonex Allergy metered spray which contains 50 micrograms of Mometasone per spray. This spray works well and was one of a half dozen recommended by the ENT Specialist.

Ann also chews Chewing Gum to assist in reducing the amount of saliva.

In addition, Ann uses Atrovent, an Asthma Inhaler, to spray into her mouth for saliva control. And this spray works surprisingly well. An example of a medication designed and used for another condition, being useful in the control of Parkinson's symptoms.

Bladder Dysfunction.

Ann has been having Botox injections into her bladder for around 9 years now, so Bladder Dysfunction is no longer an issue. Ann has had 10 Bladder Botox treatments.

Ann also suffered from Latch Key Incontinence – that very unwelcome event where you pee yourself as soon as you put the key in your front door to enter the house. Hence the name of Latch Key Incontinence.

She no longer has that problem.

Speech

This is starting to become an issue for Ann, and we have got as far as investigating on-line speech therapy and exercises.

There are no local speech therapists who have experience in any of the recognised Speech Therapy programmes aimed at people with PD-related speech difficulties.

Pain

Leg pain often wakes Ann during the night and so far, apart from Sifrol for RLS (Restless Leg Syndrome), she uses Magnesium spray equivalent to Magnesium 18mg/ml to counter the pain.

Magnesium Spray works well and provides almost instant relief.

Ann also takes 1 x Magnesium Chelate 1000mg equivalent to 200mg per tablet at night.

Sweating

This is a minor problem which we counter via the house air-conditioning system, which allows us to turn rooms on or off as needed and so provide a comfortable environment for Ann while still accommodating me. – i.e. Not too cold or too hot.

Other Iceberg Items.

So far none of the other Iceberg items have become apparent.

We are conscious that the Sifrol that Ann is taking has a very undesirable side effect of compulsive behavior and we are closely monitoring this – even though the Sifrol at .75 mg is still considered a low dose.

Part Six – The Duodopa Pump

Stock photos of the Duodopa Pump

Pump and tubing entering the body via a stoma for Levodopa delivery.

How the pump is worn via specialised clothing

Why have a Duodopa Pump?

Parkinson's disease is caused by a loss of nerve cells in the part of the brain called the substantia nigra. Nerve cells in this part of the brain are responsible for producing a chemical called Dopamine.

Dopamine is a neurotransmitter, and it plays a role as a “reward center” and in many body functions, including memory, movement, motivation, mood, attention and more.

High or low dopamine levels are also associated with restless legs syndrome, attention deficit hyperactivity disorder as well as Parkinson’s Disease.

In Parkinson’s Disease, the cells producing the Dopamine are degenerating and dying. There is no cure for this degeneration and the Dopamine levels can only be supplemented on a temporary basis by medications.

The so-called Gold Standard medication used to do this is Levodopa. Levodopa crosses into the brain itself where it is converted to Dopamine. This temporarily adds Dopamine, which is no longer being produced naturally in sufficient quantities, because of the lost nerve cells.

At first the medication is taken a few times during the day at scheduled times, but as Parkinson’s Disease progresses, patients begin to take more medication more frequently, including rescue doses if they have an

Unfortunately, the progression of Parkinson’s disease also affects how the body functions. One effect is the slowing of the digestive tract and erratic emptying of the stomach contents. This affects the absorption of the medication causing fluctuations of Dopamine in the blood. This can result in unpredictable motor function.

By early 2023 Ann had reached a stage where the standard medication regime was not providing a desired quality of life for Ann.

Our then Neurologist referred Ann to Neurologist specialising in Advanced Parkinson’s treatments.

At that time, we were not sure if it was for advanced treatments or treatments for Advanced Parkinson’s – two entirely different things. We had our first consultation with the new Neurologist in Queensland on June 1st, 2023. The consultation was 45 minutes and very detailed.

Ann was looking for two outcomes from the consultation:

Obtaining an improved medication therapy centering on medication delivery

and

Arranging the Botox for Saliva Control injections.

None of the standard mobility tests were done, as we were there on referral from our usual Neurologist, so Ann's overall situation was well documented.

Ann remained seated on her scooter during the consultation.

The Neurologist concentrated on Ann's current medication schedule and her reactions to the Levodopa dosage of 950 mg / day. She commented on the Dyskinesia Ann was displaying as she sat there and naturally noted that Ann did not walk into the surgery but rather rode in on her scooter – an obvious indicator of the mobility issues that Ann has.

The Neurologist concluded that Ann was indeed a suitable candidate for the Duodopa Gel therapy and spent time discussing the option with us, outlining the benefits and the risks – minimal as they are.

Once Ann agreed it was an approach she was willing to try, the Neurologist set about organising the procedure to be done on July 7th through 14th, 2023 just 6 weeks from the consultation.

And as an added bonus, the Neurologist said they could do the Saliva Botox injections at the same time if needed.

So, we left the Specialist Center with confirmed bookings for both the outcomes Ann was seeking.

And we now knew that the Neurologist was a specialist in the treatment of Advanced Parkinson's.!

And 6 weeks later Ann was in a private hospital starting the process for the Duodopa Pump installation.

What is the Duodopa Gel

Duodopa is designed as a continuous infusion of the standard Parkinson's medication of Levodopa and Carbidopa into the intestine where it can be absorbed without the delay of erratic stomach emptying.

This therapy is an advanced treatment for Parkinson's Disease and provides a superior mechanism for the delivery of the key Parkinson's medication – Levodopa.

It means the level of Dopamine in the brain is more constant and some of the movement side effects are lower.

The pump is worn for around 16 hours a day, is taken off for showering and at night for sleeping. Medication kick in time in the mornings is usually around 10 – 15 minutes.

Pump dosages are measured in mL (Milliliters) of the gel in three tranches across the day. Morning Dose, Continuous Dose, and a Bolus Dose.

So, pump dosage notations look like this: 10/3.1/1 which translates as 10 mL of Gel as morning dose, 3.1 mL per hour as a continuous dose during the day and a 1 mL Bolus dose available on demand, but with a one-hour time-out.

Each mL of Duodopa Gel contains 20 mg of Levodopa and 5 mg of Carbidopa – the standard 4:1 ratio used in Sinemet pills or capsules. Madopar uses Levodopa and Benserazide in lieu of Carbidopa.

As is normal with Parkinson's, each person has a different response to medication.

Some common side effects of Duodopa include involuntary movements and muscle cramps (dyskinesias and dystonias), slow movement, dizziness on standing, depression, hallucinations, fatigue, confusion, sleepiness, nightmares, euphoria, loss of memory and other mental problems such as psychotic episodes or elevated mood.

But apart from all that, life with a Duodopa Gel Pump does provide for a much-improved quality of life for people with Parkinson's Disease.

Current Pump Situation – January 2025

The current Pump dosage for Ann is set at 8/2.6/2 having been titrated down from 10/3.1/1 in September 2023. This setting provides 914 mg of Levodopa over the day.

In addition, Ann has a Madopar Rapid at 6:30 am for 50 mg of Levodopa, uses a boost dose of 40 mg of Levodopa every day at 3:00 pm and a Madopar HBS at 10:30 pm for another 100 mg of Levodopa.

So her total Levodopa intake over a day is 1104 mg of Levodopa.

This is considered a moderate to high daily dosage of Levodopa. However, dosages of 2,000 mg a day of Levodopa are not unheard of -especially among Duodopa Pump users.

This dosage is slightly up from the old amount of 1050 mg a day in June 2023. So, an overall Levodopa increase of only around 5 % over the last 18 months since pre-pump times.

Ann also takes Sifrol .75 mg each night to aid with the RLS (Restless Leg Syndrome).

However, Sifrol (Pramipexole) can cause unwanted compulsion behaviors such as excessive gambling, shopping, anti-social activities, sexual urges to name just a few. Ann also uses a Magnesium spray for nightly leg pains.

Results after 15 months

<u>These are the key results to date leading to a much-improved Quality of Life:</u>

No more “Offs”
No more dystonia in the toes in the morning
Significantly reduced night time leg cramps
Improved handwriting
Improved walking gait
Improved feeling of wellbeing - SWPD says she feels even all day.

Ann is adamant that she will not go back to oral Levodopa unless absolutely necessary.

Further improvements will no doubt occur but may be fairly minor.

Part Seven – Summary

Summary

Age

Ann is 82 years old, was diagnosed at age 70 but has probably had PD for closer to 20 years rather than the 10 years DX.

Mobility and Caring

Ann currently moves around the house without using a walker but does rely on the extensive network of aids we have installed, particularly the 14 Stander Security Poles and the various grab handles.

While I am the official carer in the household, Ann still tends to her own showering and toileting needs. Ann mostly dresses herself with occasional assistance from me.

Exercise

Ann has two GYM workouts a week – of 45 minute duration following a programme designed by an Exercise Physiologist.

As an adjunct to the GYM work, Ann attends two 50-minute workouts in an exercise class here in our Village.

Conclusion

Feel free to use this document any way you wish. Use it as a resource or as something to give to family and friends who are seeking to understand PD.

Or contact us if you want a PDF copy sent to you for your own use.

Email: adamson@adamsonstradley.com

Part Eight - The Toys

The Toys

Outdoor Mobility Scooter

Village Street July 2019

Indoor/Outdoor Mobility Scooter

Woolworths - December 2022

At the GYM January 2023


2023 - January at the gym

Our driveway - July 2023

On the Beach - May 2024

Using her Stellar as a wheelchair – May 2024


April is
Parkinson’s
Awareness
Month