parkinson's australia

CASE STUDY

REX ADAMSON

CARE PARTNER TO ANN

Care partners are an integral part of the care team. Rex has been Ann's care partner for 12 years, though they both agree her PD was evident in hindsight to over 20 years ago. He has been an active care advocate and runs a facebook group for care partners in ANZ.

Diagnosis journey

We are retirees living in Casino, in rural New South Wales. Ann has Parkinson's. Having been born in 1941 and 1942 we are what are known as War Babies - not that you hear that term very often anymore.

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.

In the 12 years since she was diagnosed we have certainly learned a lot and have worked our way through significant lifestyle changes. This includes an EP's exercise regime for Ann.

In terms of the non-motor symptoms, we have so far been relatively lucky with constipation, sleep difficulties, saliva control, speech issues, bladder dysfunction, pain and temperature regulation/ sweating the main ones.

Education - involving friends & family

I believe it is critically important to have your loved ones fully across what is happening regarding the symptoms, treatments and the impact Parkinson's 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.

You and your PWP also need to educate yourselves as much as you can about the symptoms, the medications, the side effects, how to optimise the medications and that you can ask to review this at anytime should symptoms change or side effects become worrisome.

Take care, as there is so much information available, you can drown in it. But before you get overwhelmed, you need to figure out which reputable sources give you the most helpful information for your particular situation. There is also benefit in being a member of both real support groups and internet-based ones.

Carer or manager?

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.

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 only does around half the cooking. She currently moves around the house without using a walker but does rely on the extensive network of 14 Stander Security Poles and the various grab handles installed.

Managing:

- cleaning
- finances
- laundry
- technology
- groceries
- meals
- dishes
- meal prep & cooking
- medication management (getting and filling scripts, filling pill boxes, reminding her to take meds)
- driving
- appointments (medical and social)
- logistics and planning

Caring:

- personal hygiene (e.g. showering, toileting, oral care)
- dressing
- indoor & outdoor mobility
- emotional support.

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.

Your support team

I know it seems obvious, but a key to successfully managing the Parkinson's journey is to assemble a team of medical and allied health professionals to manage both the Parkinson's issues and general health. It is very important to keep them all informed of what is happening with the Parkinson's and to get the neurologist to keep in touch with the GP – share reports if you can.
In addition to the GP and neurologist, our team consists of:

- Ophthalmologist
- Urologist
- Dentist for teeth and gum maintenance and PD related cheek chewing.
- Physiotherapist
- Podiatrist
- Podiatric Surgeon for Arthroplasty on the toes to correct PD caused toe curling.
- Exercise Physiologist.

This case study was kindly provided by Rex Adamson, care partner & Australia & New Zealand Parkinson's Group for the Carers Facebook Group admin.