

I am a 69 year old woman married to a 71 year old man who has Parkinson's Disease. He has a level 3 Homecare Package. We have no other support.

Having experienced a range of problems\* when working with a traditional Homecare Provider we moved to a self-managed Homecare Provider, and continue to be delighted by the people in our team - handpicked by my husband.

**\*Some of the problems we experienced with a traditional Homecare Provider were:**

- The care plan was financially focussed and we did not feel our input was welcome.
- People arrived on our doorstep unannounced and we often didn't know what their roles were – nurse, physio, OT or cleaner.
- We had no say in who the carers were who came to support my husband
- We had no ability to choose carers with experience of my husband's Parkinson's condition. I then had to 'train' them in safe practices related to the condition.
- There was a different carer each week (pre Covid!), requiring my time to train them each week, in our home setup and my husband's needs.
- There was no way of directly contacting carers who didn't show up. Even the Provider contact couldn't! We had regular no shows when they were booked and needed to take my husband to specialist appointments, or keep him safe while I went to specialist appointments.
- Some carers were impatient and shouted at my husband as if he were deaf, because people with Parkinson's can be slow to respond verbally, and show little facial expression. I had to ask them to speak quietly and wait for his reply. I couldn't leave my husband in their care, so even though **in home respite** was listed in the care plan it actually wasn't possible.

**The benefits we have found from Self-managing**

- We were active participants in preparing my husband's Care Plan. His medical team were welcomed as part of his overall care team.
- We have regular, useful, check ins with our care manager. When my husband had a dreadful year last year and needed minor home modifications, they responded rapidly to the OT and medical recommendations. This meant he was able to return home rather than going into a rehab facility – a dreadful situation for people living with Parkinson's, and in particular for my husband who suffers from very dangerous Delirium in a hospital or unfamiliar overnight situation.
- I am able to keep a close eye on the agreed budget and care plan, and it is spent totally (minus 14 percent to the Homecare Provider) on making my husband's life as comfortable, stimulating and healthy as possible. Which, incidentally, helps my mental health a little, in my 24/7 unpaid carer role.
- We have the freedom to build our wonderful support team, while maximising our Home Care Package funding.
- My husband and I have developed wonderful relationships with our carers who are all from our local community that are much more than a job and a client.
- We have much better continuity of carers for my husband. Because we can contact each other if there is a need to make a change it can be easily and quickly done.
- Our team is adaptable and work together with us to continue to cover care needs with Covid interruptions. This was discussed with each one when we interviewed them.

We use Mable for most of our carers and so appreciate the fabulous ideas and updates from Mable. I would not have thought of using Facetime to keep contact with carers and important routines going for my husband with Parkinson's, during lockdowns and times of his poor health.

Due to health vulnerability going out with carers for social support is difficult, so suggestions by Mable, for example, to use carers to help with Hobbies, Christmas present wrapping and setting up decorations, is making life for my husband more interesting and empowering during these very challenging times.

We have been able to introduce other small local business providers to Mable, such as our local Occupational Therapist. A profession that is called on frequently by every user of a Homecare Package. We now have someone local, who knows us and our house, that we can call on for reports, in Mable, when recommended by my husband's medical team.

### **Setting up contracts with our usual service providers who are not in Mable**

Our Homecare Provider has very good processes in place for us to continue to use my husband's specialised exercise physiologists/ physiotherapists etc through doing appropriate checks of them and setting up contracts with them – at no extra cost.

Other traditional providers have insisted on my husband using their own staff - who my husband doesn't know, and they may not be qualified to work with Parkinson's clients. Or they charge an exorbitant extra fee for us to continue with our own specialised exercise physiologists/ physiotherapists etc.

### **In my role as a mentor for the frail, elderly**

I am the secretary for our very large Parkinson's support Group (over 90 members) and one of my roles is to mentor members in accessing Homecare packages, or helping them check that their provider is providing appropriate care.

Below are some concerns arising from my experiences with members.

### **Concerns about Information Privacy and unscrupulous Providers**

As soon as our members have been approved for a Homecare package they are bombarded with phone calls from "My Aged Care" but in fact the caller is a providers trying to sign them up. I spoke to one last week who introduced herself as from MyAgedCare – and definitely wasn't.

It would seem providers can see our private MyAgedCare records/status and are unscrupulously using this information to bamboozle and pressure elderly, confused and anxious people into signing up with them, without understanding the fees they will have to pay for very little service. And then these poor people are extremely stressed with trying to change to a new provider.

### **Care plan ignored**

Many of these providers refuse to provide items that are clearly listed in the agreed care plan, and have supporting documentation from specialists – eg to repair/replace/service a CPAP machine. Important supports have been finally offered after some members have died.

Not so with the 2 self-managed providers my husband and I have used.