

Case Study

Maintaining our independence- being on a part pension and understanding what is value.

Erica had symptoms of Parkinson's disease as early as 1988 and was diagnosed in 1990. Progressively her illness has meant that she has some days where being mobile now can be very difficult. The past few years has been a journey with her husband James that can be described as full of care, attention to each others needs and a desire to have the best life possible within the limitations that this chronic disease presents. Prior to getting the package some HACC services had been provided and had been very useful. They included house cleaning, and assisting with shopping. However, it became clear that they needed more support if Erica was to stay at home.

An assessment by ACAT was done in October 2014 and a level 4 package was recommended, but not taken up at that time. As Erica's care needs increased, a provider was approached late in 2015. After an initial interview with the manager of the service, and then the care coordinator, the package began on the 11th of December 2015. They started on a level 2 package but a level 3 package was soon found thanks to the Care Coordinator. The paper work to get to this point seemed to take ages to get through. Erica knows about Centrelink as she use to work there as a social worker and even with a good knowledge of the system (albeit a while ago) it was still a bit baffling. They knew they had to pay the daily care fee but because Erica gets a ComSuper pension and James has some super it wasn't clear how much the income-tested contribution was going to be. It came out to be \$10.40 a day which meant they were paying \$20.10 a day (included with the universal daily care fee of \$9.70/day), so around \$140 a week. Initially this seemed high for the amount of direct care they would access, but after consideration of the potential benefits it seemed reasonable. They both receive around \$350 a fortnight as a part-pension.

The care package began a little shakily. The support worker firstly was unable to work in school holidays. The next worker was very good but then left the area - at this point they really began to wonder about the value of the package. Consistent direct care workers were one of the keys to the Home Care package being of value. Once school holidays finished the original direct care worker began support work, and Erica reported "This direct care worker can multi task and provide care, exercise assistance in the pool, transport and cleaning. She is like a friend." Then Erica and James approached a worker who had been involved with a neighbour. The provider was able to sub contract and to make it work, to be an extra resource for say, care in evenings if James needs to go out. This has been wonderful for both Erica and James. The provider has also been able to be really flexible - supplying cab-charge vouchers and paying for other bills that have to do with the care of Erica.

The package has much more funding than Erica and James normally use, so a surplus is building up. This is making it possible to purchase a customised (made to measure) wheel chair that will make mobility within the home much easier for Erica. They have ordered it and are waiting for it to arrive. Watching the monthly statements has also been very helpful as the funds seem to accrue quite quickly, helping Erica and James to decide on purchasing the special wheel chair.

James highlighted that, "we are working on a 'shared management' option that this particular provider offers. This means that the administration fees are lower and the hourly rate charged to us for the direct care worker is lower. (They also offer 'agency managed', with closer direction of tasks and hours but a greater guarantee of always supplying a worker – and higher fees and rates.) The care coordinator has been great. She was the one that found the level 3 package and she checked the compatibility of the direct care workers. She has been very helpful but are not always easy to

catch on the phone, however has been very responsive by email. We are able to manage the times for the workers to come and we send in the other bills that need to be paid – sometimes quite significant bills. We always know when the workers are coming. Sometimes the accounts take some time to appear on the statements, and it would be good if they were quicker, we would then know exactly how much we are able to spend.”

Erica and James are very conscious about how the chronic disease may play out over time and have considered a variety of different scenarios. Erica certainly wants to spend more of the money but James is keen to have some there for a rainy day. James is particularly thinking about needing to provide assistance if or when someone is required to sleep overnight. Erica was particularly concerned about what would happen to the package money if she went into residential aged care. They also worried about the impact of the new pension scales for part pensioners and if this will have a big impact on the pension they currently receive and the amount they pay with the means testing for the package. Finally they commented. “Explaining how the package works to the family is not easy. However overall we are now very happy with the package and we would be prepared to pay another \$10 per day to receive this significant subsidy from the Government, because for us the value really is there and the flexibility is great and the direct care workers are now very good, just like friends.”