

## Case Study:

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I'm really pleased to be here to share some of my family's and dad's experiences being the recipient of a level 4 Home Care Package. My dad, Alec, was 70 years old, only semi-retired and living a very busy life at home with my mum when he had a sudden, catastrophic haemorrhagic stroke on June 8<sup>th</sup>, 2013.

At the time, his doctors at the Royal Melbourne told us these types of bleeds generally kill 9 out of 10 people they occur in. When dad finally made it out of ICU after several weeks, the rehabilitation consultant was clear that she envisaged dad would not be going home. Rather, she believed he would be discharged to high support aged care accommodation.

We valued and respected their frank and expert advice, but also appreciated that not only is there so much that's still not known about the brain and its capacity to rewire itself; we as family knew something that no health or human services professional we encountered could possibly know; and that's who our dad is as an *individual* - his personality, his life history, what motivates him; his unique spirit. We knew that these must be as important an influencer as anything on how he would respond to treatment and support. So until he was able to speak for himself, we used our expert knowledge of what we know about dad to ensure that he was given every opportunity to improve because we knew it was his wish to stay living at *home*, if at all possible.

As soon as dad was able to be dressed and sit up, we made sure he attended all the team meetings that family were invited to. Sometimes, admittedly, it felt like we were enacting a scene from "*Weekend at Bernie's*", because at that time he really couldn't remain awake for more than a couple of minutes without his chin falling to his chest and him beginning to snooze. We persisted though, because we wanted them to see dad as we did, regardless of this thing that had happened to him. We didn't want his condition to define him, or for it to mean they regarded him as anything less than the most central, active and important person *still*, when it came to making decisions about his life.

Working in community disability accommodation services for the Department of Human and Health Services (Victoria), my experience told me that if we could access the right services, it is absolutely possible for people with even the most profound disabilities to remain out of institutionalised care; to make empowered choices about their own lives. But finding the right support services is not always easy and they need to be staffed by people

who understand where they fit in as part of a wider support network with the carer and client's needs at the centre of the care configuration.

After 9 months of hospital and rehab, dad was lucky enough that just as his rehab allocation was timing out, a level 4 Home Care Package came up with a large interstate organisation that the social worker said was fairly new to Melbourne. She was sage enough to advise us that level 4 packages don't come up often and, because we knew Dad couldn't stay at home without that level of support, we took it.

What was great about our provider being new to the area is that they didn't have many services; we were able to on-board new ones and through a process of trial and error have arrived at the stage where dad has a fantastic team of allied health professionals and carers that continue to support him to remain at home and to make gains in his life that defied all initial expectations of dad's initial medical team.

Definitely there have been some fairly significant challenges to our relationship with our package provider/administrator. What has ultimately made the package work has been the strength of the relationships of the direct service providers; the managers of those services; the allied health professionals; dad's personal trainers and carers; and local related businesses. Their flexibility and willingness to troubleshoot; to share dad's goals – this is what we'd want from our package provider and more.

It's here that I'll use some of COTA's specific questions to guide how our experience is going to inform **whether we choose to stay with our current provider or not in 2017.**

What we would like in a provider:

- To have established a **respectful, collaborative relationship which recognises dad's needs and wants as central to how the package is administered.** Since we started with our package administrator we've had upwards of 6 successive care advisers there because of the high staff turnover. Currently we don't even know the name of our current care adviser; they have changed that often. It's difficult to feel a sense of trust, of being known and understood, when you and your contact person within the organisation are always just being introduced.
- We'd want an **ally and an advocate** in our care adviser because the organisation is large and there are many areas such as procurement, billing and accounts. When things go wrong, it's often not been clear, or perhaps our care adviser has been too new and fresh to feel confident advocating strongly to get the solutions about why 'X' service was cancelled or why 'A, B, C' invoices haven't been paid, or reimbursed months after paperwork was submitted.
- **Good communication and for them to be upfront about costs and what it is you are actually getting for those costs.** Currently 45% of dad's package

goes to an organisation that on a day-to-day basis we have almost nothing to do with. His direct service providers are all 3<sup>rd</sup> party contractors. It's hard to justify that level of expense when dad's needs for those government funds are so great and likely to get greater as he continues to age at home.

- Our consideration about whether to stay or go in 2017 is not only about cost, although certainly this is important when you have hit the limit of funds available to provide essential service from your package and there's no room to move because almost half of it is going towards the provision of invisible 'administration' services.
- We do not expect perfection, but **we do expect a robust process to be in place when things go wrong** and ideally a willingness to acknowledge mistakes when they're made, if only so that the service, where it's lack lustre, can continue to improve.
- In answer to the question on what advice we'd give to aged care providers about how to prepare for a consumer driven aged care system: **consumers have the potential to be the greatest champions of your service** (and, of course, the opposite of this is also true). We will increasingly get better at sharing our experiences about the quality of the services we're receiving from respective aged care providers, so it's in all of our interests that you do the best possible job.
- **Investing in quality staff, training them adequately and empowering them to act as advocates on behalf of your clients is essential.** Quality staff that are able to build relationships based on trust, respect and the understanding of individual goals and challenges in the wider context of the family/home they're living within.
- **Being proactive about seeking feedback on how people are finding their service provision to avoid falling into a reactive, complaint-based paradigm.** The quality of our relationships, the quality of the service and the quality of the communication will determine where consumers go.
- **'Why is it important to you to have choice and control over your support arrangements?'** Because everyone is an individual and the fact that you are the recipient of Government support doesn't mean that you should be in anyway less empowered. It is also a fact that when you have more control over your care decisions, the outcomes will be better. An Aged Care Approvals Round (ACAR) cannot define an individual nor can a job description tell you whether a health practitioner, or a carer's individual approach is going to be a good fit for the consumer. Therefore, to get the best outcome for the consumer, individual choice of practitioner is so important.

Just as my dad's condition doesn't define him, nor does my, or my mother's role as carers define us. We are still principally partner and daughter respectively – but it's true that every minute spent going over the same ground; initiating new staff into who we are and what dad's needs are; or seeking clarification from DSS when another new care adviser at the organisation has given us the wrong information (or failed to pass on essential information at all), all of this takes away from our primary roles as family members and as

individuals in our own right. So, what our package administrator does or doesn't do, *really matters*. It has had a tremendous impact on our lives in both the positive and negative sense at times.

Dad could not do this without the supports he receives through his Home Care Package, he absolutely couldn't. The gains that he's made, he would not have made had he gone, as our rehabilitation consultants at the Royal Melbourne recommended, directly to an aged care home. We absolutely would not be in the position that we are today without the services that he receives.

Dad's stroke changed everything for him and in other ways nothing at all. He's still the same bloke, who likes the same things and who rightly expects to have the same say about his life, in spite of the fact he needs more support than he has in the past to achieve decent quality of life. It's nothing more than anyone would expect, surely.