PRIMARY PROGRESSIVE APHASIA- THROUGH THE EYES OF PARTNERS

THE POWER OF PEER SUPPORT

Forward:

Primary Progressive Aphasia (PPA) is a neurodegenerative condition that originates in the language part of the brain. PPA affects an individual's language skills. Symptoms start small, like momentarily forgetting occasional words or mispronouncing longer words. Overtime language skills worsen, making conversation more and more difficult for people with PPA. As communication always involves at least 2 people, PPA affects everyone in the family, not just the individual with the diagnosis. Life for the partners of people with PPA changes dramatically. As well as dealing with the grief of their partners' diagnosis, they are left managing the practical side of living in a PPA household. Whilst information and resources for managing these practicalities can be helpful, emotional support is essential. Aotearoa New Zealand is lucky to have an online support group for the partners of people with PPA. Gary Sutcliffe and Robyn Commins, both partners of people with PPA, started this monthly support group over two years ago. Gary shares with us his and his wife, Janell's, journey so far as well as why he co-facilitates this group.

My wife was diagnosed with PPA in December 2021, two years after retiring from a busy administrative role in a growing accountancy practice. Janell started working in the practice in the mid-1990's. At this time there were just 4 people working there. By the time she retired in December 2019, there were 14.

Janell had an extraordinary memory, remembering all her clients (up to 2,000) and often their partners too. I remember doing an IQ exercise several decades ago. Janell was at the higher end of the scale whereas I was barely average!

We married in 1974 and in 1976 headed off on our OE to the UK and Europe. Although we did the planning together, Janell was the primary organiser. After 18 months away we returned home to settle and have our two children. We now have five granddaughters.

It would be fair to say that Janell was the quintessential working mother who handled everything. She organised the kids, prepared virtually all the meals, did most of the housework and worked a 40-to-45-hour week. Everything inside the house was her domain; everything outside was mine (probably many men reading this can relate to that).

On retiring at the age of 69, there was no evidence as to what was to follow a few years later. In hindsight, there were some signs around mid-late 2020 that not all was well with Janell's confidence in speaking. However, over the next 12 months, her speech and language started to deteriorate, and it seemed obvious to some that something was not right. After family encouragement/insistence, we sought professional help. Janell had a neurology assessment and was given a diagnosis of Primary Progressive Aphasia.

It was recommended by a dementia specialist that we contact Aphasia NZ. We discovered the lovely Christa (a Speech Language Therapist based in the Waikato) who was running online education sessions and had just started an online support group for people with PPA. We joined the group around March/April of 2022.

And, to the purpose of this paper.

In late 2022, Christa spoke to Robyn, whose husband John has PPA , and I about the prospect of having a support group for the partners of people with PPA.

My work background included peer support within the mental health sector. I understood the power of peer support and in sharing your experiences with those on a similar journey. Members of peer support groups learn from each other while receiving comfort and an understanding that they are not alone on this journey.

So, in September 2022, with support and encouragement from Christa, Robyn and I started the online support group for partners of people with PPA. From small beginnings, the partners support group now has over 20 members from across Aotearoa. Our monthly meetings regularly have between eight and twelve participants.

Here is what some people have said about the group:

- *I appreciate the group very much and I'll attend when I can. Thanks for your help and support*
- *I have made friends in this group, and it is lovely to be able to stay connected with everyone*
- *This group is really helpful in getting a realistic perspective on the journey by gathering others' experiences.*
- *I am lucky to be a confident operator, but I find day/night caring for my dear characterful husband greatly challenges my composure and patience ... my own sanity! The opportunity to share with others who are tussling with the same ordeals is surprisingly comforting. Like a warm blanket.*
- *This Group gives me a sense of camaraderie. It connects me to kindred spirits that are at different stages of the journey and, as such, helps me along the way. On a practical level, this Group is a forum for shared experiences and challenges. I learn from my colleagues' different approaches to similar challenges.*
- *I gain a lot of strength and confidence from my association with the other people in the groups who all share very similar difficulties to my own.*
- *The benefit of the Partners Group is that the focus is on the Partner. There is lots of help, although not always easily accessible, for the person with PPA, but there is not much out there for carers. Sure, you can get respite, but that's not easy. Leaving your loved one, whom you have been in a relationship with for some 40-50 years for many of us, is not easy. People will say 'you need a break' and assume that you can just leave your dear loved one with complete strangers. Even in the first instance, for a few hours a day, let alone overnight or several nights, is not easy. We often have to get desperate to take that difficult step.*

  But having the Partners Group we support each other, and sometimes gain the strength to take those hard steps along the way and accept that 'your long-time mate' is no longer the person they were and that you have to move on. As others have done this before you, as evident in the group, I find it very rewarding helping others that have come after me and are now very sad, bewildered, and often struggling to accept what their life has become, in a relatively short space in time. Furthermore, what their life will be like in the future, on their own.

And from a daughter who often joins her Mum at group sessions:

- *My Mum who is supporting my Dad day to day has found the PPA partners group great. Just to know that there are others out there managing the same issues, and to get a glimpse of what might be to come is very helpful. This insight gives us time to process the possible future and to also be grateful for the present. The pooling of real information and ideas is invaluable.*

Inevitably, at some point during the PPA journey, the spouse's role changes from that of a partner to that of a carer. Nobody signs up for this change and the transition can be confusing and painful. Knowing that there is a community of people also making this painful transition can be empowering for the partners of people with PPA. Connecting with others in this community can ease some of the pain. If you would like to know more about joining the Partners of People with PPA Support Group, please contact AphasiaNZ.