

# WHY COMMUNITY MATTERS

By Dr Sue Jackson



## Why the Australian Pituitary Foundation community matters for pituitary patients and their families

A pituitary condition can disrupt the rhythms of life, imposing a sometimes-unpredictable new order that can be difficult to adjust to. The disruptions can be so significant that the person with the condition can end up feeling alienated and confused by the changes they're experiencing, misunderstood and disbelieved by others. This article looks at the importance of the Australian Pituitary Foundation community in reducing these patient experiences.

### Starting from diagnosis

For some people diagnosis can take years. It can be a strange sort of relief to know that all that time and many visits to the doctor have finally been vindicated – see, there is/was something wrong! Whether your diagnosis was quick or slow, it can be stressful, shocking and/or traumatic to be told that you have a brain tumour. Pituitary tumours are mostly benign (i.e., non-cancerous), but you may not know that when your diagnosis is first communicated to you. Say 'tumour' to most people and they hear 'cancer'. For all that doctors aim to be very careful in how they provide the diagnosis to patients, it's inevitable that there are going to be some people who end up feeling shocked and, possibly, traumatised by their diagnostic experience. Stress is highly communicable; as humans we're wired to pay attention when other people are stressed, because if something is affecting them it might have implications for us too, so any shock and trauma felt by the patient and their family may well ripple out to friends and acquaintances too.

### Sharing matters

When you've experienced something particularly stressful and/or traumatic, it can be particularly helpful to be able to talk to others who understand what's happened to you. In talking to other members of the Foundation it can be a relief to know that you're not the only one who's had to wait a long time for a diagnosis, and you can get information and advice about what you might expect to happen next. But it offers more than that. Judith L Herman in her book *Trauma and Recovery* talks about the importance of community in helping people to recover from traumatic experiences. On page 101, she observes that,

*'In ordinary bereavement, numerous social rituals contain and support the mourner ... By contrast, no custom or common ritual recognizes the mourning that follows traumatic life events.'*

She goes on to talk about the importance of the community in helping people to understand what's happening/happened to them and coping with it. But pituitary conditions are complex conditions not easily understood by the general population. Unlike cancer, most people won't have heard of the pituitary or understand what it is, what it does, how important it is, or that the diseases associated with it can have far-reaching effects. Someone who is traumatised, shocked and/or stressed can't take in information properly. So, a patient's understanding about their condition and its treatment might be quite limited in the early days. It's a problem telling others about something you don't really understand yourself. For conditions as complex as pituitary conditions, this can be a significant problem which can involve more than just telling your boss (if you have one) why you need time off work. Not all healthcare professionals understand pituitary conditions, and you may need to advocate for yourself about your condition in non-endocrine focussed healthcare services.

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It feels unfair that on top of everything else, from early in their treatment, pituitary patients need to be working towards becoming expert in their condition knowing what tests to expect, what results to ask for and what they mean. And that's even more important for those who're not being treated in a specialist centre. There's help and support available from the Foundation to help you navigate the process of treatment so you have a better idea of what's happening to you. And you can use that information to help you explain to others.

## **Challenges associated with pituitary conditions**

Pituitary conditions can take people into unknown territory. The various conditions and their treatments can change how someone looks, as well as how they react and respond to things. Some people will end up with crushing fatigue that limits what they can physically do and brain fog that affects their mental functioning. Pituitary patients can be shocked and surprised anew when confronted by reactions that they don't recognise in themselves. They can start to wonder if they're going mad on top of everything else they're dealing with. Their family and friends can find it very confusing and difficult to understand too. And then there's the rollercoaster that is fluctuating symptoms.

We're used to the idea that being ill is a steady state (you have a cold or a broken leg all day), the idea that someone might have a condition that fluctuates such that what they can do in the morning is very different to what they can manage to do later in the day, and that that can shift and change from day to day is bewildering and confusing for all concerned whether at home in the workplace or in educational settings.

As a species we're very good with cyclic change – in health terms, we're used to the idea of getting ill and getting better again. Even with cancer these days, we're used to the idea that it can be curable albeit if detected early enough and after some gruelling treatments, and we expect those who survive to get back to pretty much how they were before. And that goes double for common illnesses such as colds and flu and the aftermath of accidents resulting in broken bones where the treatments are largely much less demanding on the patient. But a pituitary condition is a long-term health condition that can't be cured. The idea that someone might be so affected by their condition that the outcome is uncertain and 'getting better' might mean that their condition is ameliorated by drugs but that they can't get back to normal functioning can be profoundly unsettling for patients and their family, friends and the wider community such as work colleagues.

## **Chronic stress arising from uncertainty**

Humans aren't good with uncertainty. It's much easier to support someone through something if you know how long it's going to last for and what to expect along the way. When someone is ill with flu, we tend to shift to dancing attendance on the person who isn't well. But the timescales involved in pituitary conditions can leave family members wondering about the sustainability of this approach to providing support. The lack of certainty about how someone is going to be thanks to their condition and its treatment is a form of chronic stress affecting the patient and the people they live with. It's psychologically wearing not to know how someone is going to be, whether they will be able to do their share of the usual household tasks, and whether someone else is going to have to take up the slack again. It's difficult to always have a question hanging over social events, not knowing if they'll be able to go or if they're going to have to be excused from it again.

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It's very hard to be disconnected from yourself and your family, thrown out of all your everyday routines and habits and methods of engagement and profoundly unsure about how long that situation will last. Death is straightforward – the person isn't there anymore – but someone who is profoundly changed but still present; that's quite a conundrum for all concerned. It doesn't help that we lack social representations of what to expect and how to deal with it. There aren't any popular shows, films or books that feature characters and their families having adventures or solving mysteries whilst at the same time living with and supporting someone with a pituitary condition. That lack of social representation is a problem because it means that the wider community has no idea what the patient and their family are dealing with. It can contribute to social isolation because without those stories of what life is like the wider community are largely incapable of imagining what support is needed. And if they can't imagine it, they're very unlikely to offer it and/or understand why it might be needed.

## **Finding a community**

The Australian Pituitary Foundation offers a community that genuinely understands what it's like to live with a pituitary condition. They have a lot of useful information as well as other people to talk to. Some of those people are healthcare professionals whom you can ask for advice about how to understand what's happening to you and what might be next on your treatment journey. But there are other people who've been on this journey before you who will also have insights to share. There's a tremendous psychological relief that comes with knowing that it's not just you and your family that finds it difficult to understand and to live with.