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Navigating the healthcare maze

A new model of care for epilepsy.

Waiting up to 17 years before being offered life-changing surgery is the reality for people with uncontrolled epilepsy. A new way of caring for people with this most severe form of epilepsy promises to speed up access to treatment, clearing a path through the often-daunting maze of health services.

Epilepsy affects around 1 in 26 Australians at some time in their life. Refractory epilepsy is at the severe end of this chronic condition, where people fail to respond to medication, leaving them unable to control their seizures.

Possible treatments are often buried in a maze of decision-making that has proven difficult for patients and healthcare professionals to navigate. For people with refractory epilepsy, life becomes a confusing and frightening journey through the health system.

Developing the new care model

I was fortunate enough to lead a team from Macquarie University, Cardiff University (UK) and

Sydney hospitals, Royal Prince Alfred Hospital, Royal North Shore Hospital and Westmead Hospital, to develop a new model of care to support and guide people with chronic neurological conditions, their families and care teams.

During the course of the study, researchers interviewed one woman who had refractory epilepsy for 27 years but had only recently been fully diagnosed. She had been prescribed many different medications and had numerous misdiagnoses and all the while experienced debilitating seizures that did not respond well to anti-epileptic drugs, disrupting her work and family life.

Researchers also spoke to a man who, after living with refractory epilepsy for many years, had finally undergone surgery but this had proven unsuccessful. He was left confused and disappointed and described the enormous emotional effort now required to remain hopeful of future success in the face of more surgery.

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These cases are not unusual. It is currently taking a very long time for patients to move from first diagnosis, through a range of complex assessments, to an eventual full diagnosis of refractory epilepsy with more clear routes of treatment such as a surgical procedure—up to 17 years in Australia and up to 22 years in the United States. The journey is not a smooth or straightforward one, with many periods of delay, uncertainty, treatment gaps, disrupted home and work life, and concerns about the health system.

For the first time in neurological and brain research fields, this new model, called the PRIME Model, hopes to address this complexity and time lag. PRIME stands for Patient Reported, ImpleMentation sciEnce (PRIME). It will help to identify new pathways through the health system, avoiding system gaps and fractured journeys through care, and providing tools to overcome breakdowns in communication between patients, their families and healthcare professionals.

A new starting point—ask the patient

We believe that care should start from the point of asking patients what they believe to be important for their own health and wellbeing along with what they understand about their treatment and options. This then leads to determining pathways through the different clinical services and medications available for their unique set of circumstances.

The model also identifies where gaps lie in treatment and where there are breakdowns in communication, for example between the patient and their specialist doctor. The model places a strong emphasis on the patient's individual situation—including whether they are alone or well-supported; their comorbidities; and their expectations for care and wellness.

For example, Indigenous Australians living in remote communities will need care plans that

consider not only their individual profile but also cultural issues and geographic isolation.

An 'implementation science' approach

To develop this model, researchers took a unique approach. They recognised the need to give patients a voice; to give weight to the emotional toll of a chronic condition on people and their families; and to apply an 'implementation science' approach.

Implementation science is exactly what it sounds like—it is the skill of putting theories or ideas that have proven, through evidence, to be worthwhile into real world practice. It is about ensuring that well-evidenced advances in medicine and health services actually make it to the people who need them most, at the right time, and in the right place. Implementation science also looks at what barriers there might be to the widespread uptake or dissemination of new ideas, techniques or treatments and how these might be overcome.

For instance, surgery for people with refractory epilepsy has been available for decades, and yet it takes so long for Australians with the condition to come to a surgical intervention. Researchers asked why?

They also acknowledged that people with a whole host of brain and neurological disorders would benefit from being educated about their condition and treatments and being involved by clinicians in decision-making. This builds confidence and trust, without which people can suffer anxiety, which in turn leads to poorer health outcomes.

There is a known relationship between physical and psychosocial domains in epilepsy—and the PRIME model has the capacity to incorporate these factors into a care plan.

Professor Rapport says that 'next steps' will be to refine the model and test it through a pilot randomised control trial. 



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The official magazine of the
Australian Healthcare and Hospitals Association

ISSUE 52 / February 2019

PRINT POST APPROVED PP:100009739