

# Watch this space

Epilepsy Queensland 50th Anniversary  
Celebrations 2019



## Tenth Annual Queensland Epilepsy Symposium

# Thinking outside the box!

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Thursday 31 October 2019  
State Library of Queensland



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**'UNDERSTANDING EPILEPSY'  
and the  
'ADMINISTRATION OF MIDAZOLAM'  
WORKSHOPS**

**Brisbane and Gold Coast**

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## LIVEwires

Newsletter of the Family Support Program



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## HOW DIGITAL RECORDS CAN TRANSFORM LIFE FOR A CHILD WITH PROFOUND HEALTH NEEDS

Caring for a child with severe and profound disabilities is complicated, emotionally draining, and taxing in ways difficult to measure. It can also be the most rewarding part of your life. But the reality is that you have little choice in the matter. We are all driven to protect and care for our children, and we want the very best for them, no matter the circumstances, and that includes the very best health care. In this essay, we talk about the realities of caring for our daughter in a complex system and give some examples of issues we have come across about digital records in complex care. We also think about what the future could look like if consumer voices in this space are heard and acted on.

This story is about Daelle, who is 20, and lives with severe and profound intellectual and physical disabilities and has complex health issues. She is loving, unique, inspiring and courageous. She lives with a genetic condition causing severe intellectual disabilities, uncontrolled epilepsy, and a number of physical disabilities including cerebral palsy and cortical vision impairment. Daelle approaches her life with a limitless joy and appreciation of the moment. She has great and endless love, holds no grudges, and has infinite patience. Because of the severity of her intellectual disabilities, Daelle doesn't have the decision-making capacity she needs to make a range of choices and actions like being able to communicate she is hungry or thirsty or tired or being able to pull up a blanket if she is cold or deciding and communicating her own health care needs. Her uncontrolled seizures means all her vital medical information needs to go with her at all times. Any moment with Daelle can become a medical emergency. Daelle's disabilities have resulted in some very big decisions about complex life-changing surgeries, medication, and therapies. Two of the most important factors for her care are the ability to communicate her current

reality and her relevant medical history to her many clinicians, allied health workers, support organisations, and carers; and how we manage the continuity of her care through all the people in her life who support her daily living: her parents, extended family, carers and support staff, allied health support, clinics and doctors, hospitals, and the multitude of organisations in which she receives care and support. This is no easy task when a person has multiple complex needs and no functional communication. Daelle can't communicate anything about her healthcare, even her name. She relies on advocates like us to consider her wishes and navigate these complex systems with her. Clearly, a good digital health record system would be invaluable in supporting Daelle.



When you are a "frequent flyer" of the health care system, you see both the best and worst parts of it. While Daelle has had some amazing, quality care, we also see where improvements can be made to the system for those who need it the most. Daelle's life is affected by many different government departments and agencies, including Education, Health, Disability Services, Centrelink, and the NDIA. Each agency has its own information systems, records management, and communication methods.

continued...



Basic information about Daelle is not integrated or shared between these systems, and most of these systems don't have a way to talk to each other about Daelle and her history, needs and preferences. There is no communication, and no continuity of care.

Having to manage so many different departments, agencies, and records, none of which talk to each other (even within Departments sometimes!) adds a huge burden of complex administration and management to people with disabilities and complex health needs (and their families and supporters). This work is unpaid, unsupported, and unrecognised. It is also more difficult as the person you are supporting leaves childhood and becomes an adult, and agencies require complex processes or supporters to continue to manage things. It would significantly ease that burden if we didn't have to provide the same information to multiple sources, and instead had access to a system like My Health Record, and other digital communication.

Imagine if we could agree that her school could have been given access to Daelle's seizure management plan and medications list through her digital health record; if we could allow limited access to Daelle's NDIA planner to access her digital health record as evidence for her NDIS plan goals; if there was one central digital place to record Daelle's decision-making supporters and medical evidence that she lacks legal capacity; if we could get new prescriptions electronically, allowing paper-free changes to her medications to be monitored by doctors and supplied by pharmacists. Imagine if her hospital records were digitally available to give specialists access to medical information, scans, having to show doctors results on our phones. For used a simple mobile app have not been able to share with medical practitioners. Daelle's health safer and



and tests, rather than pictures of x-rays and test several years, we have also for seizure tracking, and it or use it collaboratively This would certainly make easier to manage.

Another important area where time is in the administration need to think more about in healthcare and how this time for our already busy healthcare system. In our experience, interactions with health services or government require us to ring, go to an office, or rely on the post. We rarely receive a personal response, and we can't ask complex questions. In all of Daelle's life, only two doctors have ever given us their individual work email addresses. Email about complex medication and diet management, which often needs only small changes cuts down on unnecessary office visits and means Daelle's treatment is more agile and able to react week to week rather than month to month. This kind of consultation and complex care management needs to be a part of our whole health system, and our digital health records should be keeping up with how people now work and live online.

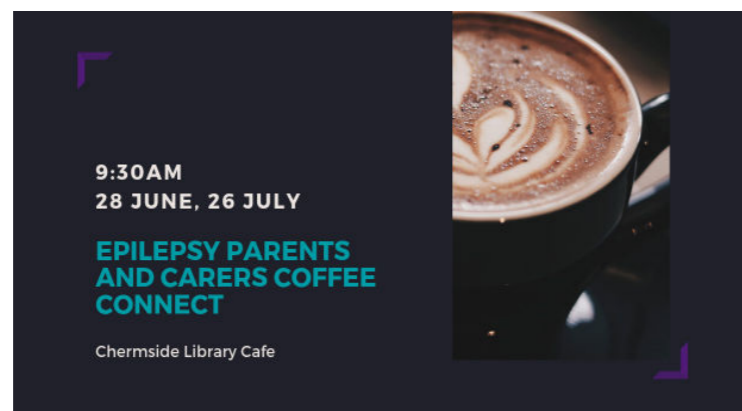
digital records could save of healthcare. We really the patient's experience could save money and

We do see hope on the horizon. Last year Daelle had a bad seizure whilst in the care of a new support worker, which resulted in an ambulance trip to emergency. The emergency doctors accessed Daelle's My Health Record and immediately knew her medications, her specialists, what her underlying conditions is, and had our contact information. We received an SMS indicating the hospital had accessed her record in line with our privacy preferences. This gives us a window into what it will be like when healthcare embraces the digital age, and gives us hope for Daelle's care in the future.

Written by

David Bunker

& Michelle King



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As the NDIS has been a progressive roll out, some people are at the stage of a yearly plan review. Below we have put together 5 hot tips for preparing for your review meeting.

1. Knowing what to expect in your plan review meeting, is helpful to prepare for the meeting. The NDIA have advised that these things will be discussed during your meeting...
  - What worked well in your plan?
  - What goals did you achieve?
  - What didn't work as well?
  - Is there any change in your circumstances?
  - What questions do you have about how your plan is managed?
  - Would you like to change how you manage your funding?
  - What are your new goals for your next plan?
2. A report from the treating therapist that outlines progress and alignment to goals is helpful. This report should also provide recommendations for continuing therapy needs.
3. When discussing therapy needs with the Planner, make sure to discuss the need for an allocation for reports within the funding. This way, you will have additional funding for the development of reports, without cutting into valuable therapy hours.
4. Some Assistive Technology suppliers – such as some companies who supply monitoring devices and other aids, are not registered with the NDIA. As such, it is important to consider either plan management or self-managing this part of your plan. This will enable greater access to purchase these items.
5. When considering the epilepsy related needs, we recommend that you include:



### Capacity Building – Improved Daily Living Supports:

- Assistive Technology assessment (5-8hrs depending on complexity); or monthly subscription costs for previously recommended aids (as relevant)
- Training for support workers/carers about understanding epilepsy; enhancing quality of life; seizure first aid; administration of Midazolam (as needed) (2.5hrs per session + travel);
- Development/review/update of Epilepsy Management Plan (2-3hrs depending on complexity)
- Information, phone and referral services to enhance capacity building for epilepsy management (approx. 5-10hrs)
- Group or individual based programs to enhance independence, social connectedness, safety and capacity building for person living with epilepsy (EQI are progressively rolling out various sessions through the year on topics such as – self-care and wellness workshops; learning & memory; employment supports etc. approx. 10hrs)

If you have any questions, or would like to share your experiences of your review meeting, for EQI to share with other families going through similar situations, please contact a member of the services team on 07 3435 5000.