

How digital records can transform life for a child with profound health needs



WRITTEN BY

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David Bunker has worked over the past 15 years in advancing the digitization of the health system in Australia. He spent a decade in the national electronic health program and held a significant role in the development of the My Health Record.

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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.

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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. 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.

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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 for 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, and tests, rather than having to show doctors pictures of x-rays and test results on our phones. For several years, we have also used a simple mobile app for seizure tracking, and have not been able to share it or use it collaboratively with medical practitioners. This would certainly make Daelle's health safer and easier to manage.

We do see hope on the horizon. Last year Daelle had a bad seizure...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.

Another important area where digital records could save time is in the administration of healthcare. We really need to think more about the patient's experience in healthcare and how this could save money and time for our already busy healthcare system. In our experience, interactions with health services of 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.

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.

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