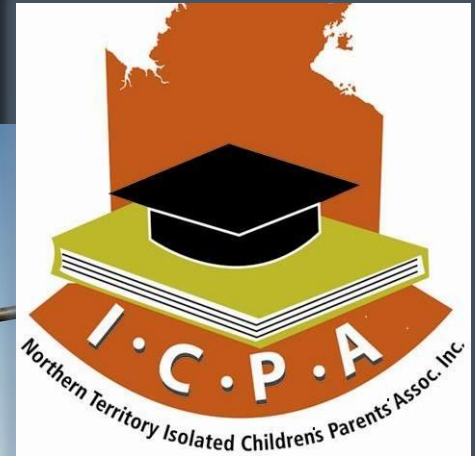


Health & Education: working together for isolated children in the bush.



Distance Education is often the only way for isolated children to be educated during their primary years.



There are typically between one and four children in the home classroom. The majority of the teaching is delivered by a Home Tutor (often the Mum), supported by some daily online lessons through School of the Air.

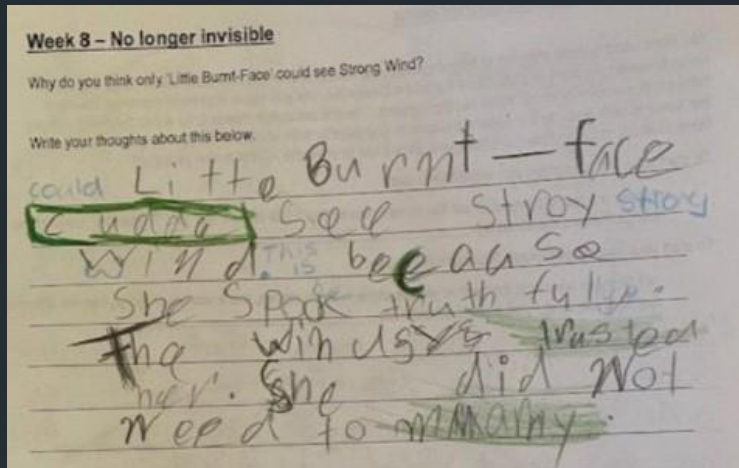
Our story:
Zahli – Oct 2020, aged 8 was
diagnosed with Sydenham's
Chorea – a neurological
manifestation of Acute Rheumatic
Fever.



Sydenham Chorea:

- Sydenham chorea is a rare neurological disorder characterized by sudden onset chorea, usually in childhood. Chorea is defined as random-appearing, continuous (while awake), involuntary movements which can affect the entire body. This often includes the face and tongue. Symptoms in arms and legs are often worse on one side of the body. Additional symptoms of Sydenham chorea may include slurring of speech and difficulty maintaining steady hand grip. Anxiety, sadness, inattention, and obsessive compulsive thoughts and behaviors may also occur. Sydenham chorea most often affects children over the age of 5 years and adolescents. Sydenham chorea usually develops within weeks to months following group A beta-hemolytic streptococcal infection and may occur as an isolated finding or as a major complication of acute rheumatic fever. It is considered an autoimmune disorder, meaning it occurs when the body's immune system (which normally responds to foreign substances) mistakenly targets part of the body, disrupting normal function. — (rarediseases.org)

Effects:



- Over a period of months before diagnosis, Zahli's handwriting deteriorated. In the weeks before, she became increasingly fidgety, inattentive and had difficulty focussing on set tasks. She was repeatedly dropping things, such as her pencil.
- Her condition then deteriorated rapidly and she was rushed to Katherine hospital and immediately sent to Darwin. Within a very short time, she became unable to walk unaided, she could not feed herself, she needed assistance to do basic tasks such as brush her teeth, she had a diminished capacity to put sentences together in a meaningful way, eventually becoming non verbal and wheelchair bound. Extensive tests lead to the diagnosis of Sydenham Chorea as a complication of ARF.



Treatment & Prognosis:

Zahli's SC was able to be alleviated with high dose short term steroid treatment over a few weeks. There have been very limited studies to show the long term effects of Sydenham's. One third of children will have a reoccurrence between 1.5 yrs and 2.5yrs after the initial onset. Many children report they have continuing issues with their fine motor skills, memory, and fatigue. Researchers have noted an association between recurrent SC and the later development of the abrupt onset of obsessive-compulsive disorder, attention deficit/hyperactivity disorder, tic disorders, and autism, which they call PANDAS, or Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus infection. Further studies are needed to determine the nature of the association and the biological pathways that connect streptococcal infection, autoimmune response, and the later development of these specific behavioral disorders.

Zahli will need prophylactic Penicillin until she is 21 to prevent additional manifestations of rheumatic fever.



Moving Forward: What does Telehealth mean to us?

- *Regular video consultations with Zahli's Paediatrician to monitor her condition.
- *Video consultation with the Paediatric Neurologist located in Sydney.
- *Neurological assessments can be done at home and recorded to be sent to Zahli's healthcare team.
- *Fine and gross motor skills can be monitored by the Allied Health Team through telehealth against base line assessments, and adjustments and assistance methods implemented by her Occupational Therapist.
- *Appointments can be made with the least amount of disruption to Zahli's schooling and day to day activities, resulting in a better quality of life.
- *Problems can be assessed in a timely manner to minimise residual symptoms impacting Zahli's education.



What we can do better:

- Video consultations for isolated children needs to be seen as a typical way to provide healthcare.
- Healthcare professionals need to have a better understanding of lifestyle and distance for geographically isolated families – and their lack of access to healthcare. Not all remote children have access or are permitted to utilise community clinics.
- A dedicated, secure, professional video conferencing system needs to be implemented – currently we use private Zoom accounts and WhatsApp linked to individual mobile numbers. Possible privacy issues and diminished continuity of care.
- Should be used in conjunction with face to face consultations. Health Professionals should be visiting isolated children when practical. I.e. when there is the ability to have a face to face consultation, there should be allowances for practitioners to incorporate a pastoral property into their travel to community clinics

