I HATE YOU
I WISH YOU WERE DEAD!

Living with long term chronic conditions
Supporting whānau to support their teenager
In our kōrero today....

• We will be brutally honest and upfront

• We talk about specific people in different roles that have helped or hindered our journey

• If you recognise yourself in this story, please don’t get offended

• Our whanau story, our whanau experience, our whanau journey

• Use our story to take an honest look into your own approach:
  • Can you do things better?
  • What learnings can you take from this?
  • How can you apply them to your own work?
<table>
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  • Managed with flixotide  
  • 1-2 hospital admissions | • Diagnosed with hayfever  
  • Multiple hospital admissions (10-20) per year  
  • Diagnosed with brittle asthma  
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  • Multiple medications  
  • 2 life threatening attacks  
  • CAMHS referral for anxiety |
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<th>At high school</th>
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It’s about the whole person and their whole world
On a good day

- Family
- My health
- Friends
- Sports
- School
When the bad days turn into weeks and months....

- Disobedient
- Refusal to take medications
- Hiding her symptoms
- Delaying medical help
- Disengaged
- Defiant
- Lying
- Running away
- Breaking furniture
- Physically abusive
- Violent outbursts
- Thoughts of self-harming

A SENSE OF HOPELESSNESS
You can only be so strong for so long
Until you reach the point
Where you break.
Physically.
Mentally.
Emotionally.
Broken.
Te taha hinengaro
Psychological health

Te taha whānau
Family health

Te taha tinana
Physical health

Te taha wairua
Spiritual health
Emotional and mental wellbeing of the whānau
At intermediate school

- Increasing hospital admissions (4-6 per month)
- Massive asthma attack (2 collapsed lungs, 2 respiratory arrests)
- Hypoxic brain injury
- PICU/Starship/Wilson Centre
- Rehabilitation
- Ongoing chest infections requiring IV antibiotics
- Ongoing fatigue
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- Multiple medications
- Long term steroid use
- Frequent absences from school
- Intermittent CAMHS input

At high school

- Ongoing fatigue
- Chronic pain
- Allergies have worsened
- Ongoing chest infections
- Portacath inserted
- Asthma flare ups continue
- Lower back pain (query slipped disc, associated to long term steroids)
- Minimal CAMHS input
Emotional wellbeing of us as parents

Emotional wellbeing of our children
If the parents are strong, the whanau is strong.

If the whanau is strong, the children are strong.
Asking for Help

• Paediatric Social Worker
• Referral to Children’s Team
• Referral to CAMHS
  – Discussion on what had and hadn’t worked in the past
• Referral to Family Works
• Referral to Stand Children’s Services
5<sup>th</sup> time lucky!

- The psychologist supported James and I as parents and as individuals
- She was a mind reader!
- She gave us ‘little tweaks’ to help refine our strategies and tactics
- She was accessible anytime – we felt supported
- She cared about us
• An amazing social worker
• In it for the long haul
• Adaptable and flexible
• In our own way, in our own time
• Caring, supportive, loving workforce
• We never felt like a ‘tick box’ whanau
Why does it seem like when you take one step forward you are pushed two steps back?
In my own words

By Tomairangi Pihema-Brown
I hate being in hospital. When I’m in isolation, they just give me the pills and then forget about me.
In hospital there’s nothing to feel happy about. I just look forward to Shortland St. I count down the hours
I want the doctors to not just fix me up with pills. They discharge me too early. I hate when they say “oh you just called in for a visit” or “You missed us!” I hate that. It’s annoying
I don’t spend enough time with my mum and dad and if I do it’s because I’m in hospital
I don’t like how everyone says “You always start fights”
I don’t like when my sister says “It’s better when you’re in hospital.”
It makes me feel angry and I just want to punch her.
I feel angry and shamed out because I have to have mum or dad with me for school trips and sports
All I want is to eat, sleep and go to school. Not medicines, not appointments.
I can’t even enjoy night time. I don’t even get to sleep. Asthma is always there
I don’t know what I want to change at home. I don’t want anything to change at home. I just don’t want to be in hospital.
I was awake till 4am. Then I went to sleep. My sleeping is all mixed up. I sleep at daytime and stay awake at night.
I hate Dad because it’s all his fault.
But I don’t know why it’s all his fault.
The only time I get to myself is when I run away
Respect Our Rights

Our rights as parents vs Our rights to parent

Our rights to be a family

Our rights to decide how the professionals can best help us

Our rights to care for our daughter
What would help?

Every child with a long term chronic condition requiring significant hospitalisations, medication regimes or absences from school should receive culturally appropriate psychological and social support from 10 years of age.
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- Several bouts of bronchiolitis

### As a preschooeller
- Diagnosed with asthma
- Managed with flixotide
- 1-2 hospital admissions

### At primary school
- Diagnosed with hayfever
- Multiple hospital admissions (10-20) per year
- Diagnosed with brittle asthma
- Serious bout of pneumonia
- Diagnosed with bronchiectasis
- Multiple medications
- 2 life threatening attacks
- CAMHS referral for anxiety
- Coping strategies
- Anger and frustration
- Self esteem and fitting in
- Looking after themselves
  - Feeling included
Parents, grandparents, caregivers

CAMHS support early:
Coping strategies
Understand what’s going on in their child’s mind
Strategies to keep themselves well
Supporting their other children
Work-life balance and stress management
Keeping the whanau safe
The siblings

CAMHS support:
• Coping strategies – they feel worried and stressed as well.
• Feeling included and valued

Support groups:
• Where they can have fun, enjoy themselves and not worry too much!
PRE-EMPT THE CHAOS
BE PROACTIVE
SUPPORT THE WHANAU
WORK HOLISTICALLY
Where are we now?

• In a much better space!
• We feel like a ‘normal’ family
• We are back in charge
• We can make decisions
• We feel like we are in control
• We can talk, laugh, growl, punish
• We speak up and speak out
• WE CAN COPE