

# Journey to A Cochlear Implant

Janeen Jardine

Program Manager  
Mater Cochlear Implant Clinic  
Brisbane Australia

*Dignity — The spirit of humanity, respecting the worth of each person*

*Quality — The spirit of professionalism*

## To Date

- The Healthy Hearing Newborn Hearing Screening Program commenced in 2004 in Queensland
- Many have proceeded to receive a Cochlear Implant
- Significant change in practice
- Looked at 3 cases of children who have proceeded to implant at the MCIC
- Asked a series of questions looking at the feelings around diagnosis, frustrations, staff support and suggestions for improvements

# Case 1

Born at 39/40 First baby

Apgar 9,9 no complications

Breast feed

Referred for hearing aids at 6/52 but not fitted until 12/52

No developmental concerns

Bilateral severe sensorineural hearing loss

Clinical Findings - Mild enlarged vestibular aqueducts

All investigations for genetic cause NAD

Refugees from Iraq

Non English speaking

## Case 2

Born at Gold Coast Hospital (full-term + 2 days; 3.51kg ).

Apgars 8 and 9.

No Complications but required oxygen

Went to ward as normal.

Breast feed 4 weeks

Small PDA

OT assessment – appropriate cognitive and fine motor skills

Bilateral severe to profound sensorineural hearing loss

Family history: Father's cousin has congenital hearing loss (unknown degree).

Genetic-Connexion 26

First child (but both parents have another child to different partners).

## Case 3

Unplanned pregnancy

Term birth at home 2.2 kg

Nil complications

No screening    Nil vaccinations    No Guthrie

Mother has an anxiety disorder

Does not approve of the medical model and intervention

Followed the philosophy of attachment parenting

Frequent ear infection but no medical intervention

First diagnostic test 25 July 2012 at age 2

Profound sensorineural hearing loss

Fitted with hearing aids 2 weeks later but reluctant to wear them

MRI - suggestive of congenital CMV infection

Nil developmental delay

# Feelings about initial diagnosis

It felt strange

I was shocked

I didn't know how to deal with this situation

Did not believe the diagnosis I felt very sad

Before we could make a decision we needed to study our religious beliefs and values within our culture

Always doubtful of diagnosis and not trusting of the medical field maybe they have made a mistake

Was this just for research

I felt lots of pressure new culture no chance to start our new life

Did not trust people

Always believed that if we could wait maybe 5 years he would get better and his hearing would improve

# Feelings about initial diagnosis

I was completely and utterly devastated

I was in absolute shock not only was it a hearing loss but a profound hearing loss

I was the mother of a disabled child and at that moment I did not know what could be done but I just thought she is not going to lead a normal life

I didn't want any thing to do with my baby

I breastfeed but it was very difficult

I felt lost until my next appointment

# Feelings about initial diagnosis

Feeling of disbelief and numbness mixed with relief  
Spent past six months trying to find out what was wrong  
Was my child Autistic because of his delayed speech

In truth I was far more traumatised by the invasive methods of western medicine than the diagnosis

Watching him being put to sleep and having blood drawn hurt me so much it became unbearable

I was defensive and hyper vigilant that my child would never feel I felt at the hands of the medical system

I did not wish him to be labelled  
I felt angry



# Strengths and frustrations

Staff explained everything to us but I needed and wanted lots of proof

They let us know what was going to happen and what they could provide

Car Parking

It was very hard to explain this to all my community but I know that my extended family will support us

It was very hard to listen with my head and not my heart

I would like more time and not need to decide now

I do not feel very different between now and the initial day of diagnosis still very sad

# Strengths and frustrations

The wait from the screening to the audiology appointment was unbearable

I wanted to see someone straight away

The nurses body language made me worried about the result I knew there was something wrong although told to go home and massage my babies ears as it might just be fluid

The times of the appointments was frustrating

It was difficult to fit in a normal life for my 7 yr old

The staff at MCIC from start to finish have been the best I could of asked for

I felt every one focused on helping us so I don't think anything needs changing

# Strengths and frustrations

First and foremost are the staff who have been wonderful

Long wait to see medical staff – waiting for 2 hrs at a medical clinic was very frustrating

Expensive parking

Time of appointments

Long way to travel

The medical system did not match my beliefs

# Similarities

- Need for information( Hyde et al)
- Sense of relief when given appropriate information
- Need for appointments to be soon after diagnosis
- Frustration with travel
- Financial concern
- Sense of grief
- Acceptance that a Cochlear Implant was required

## Differences

- Time frame to implantation
- Rate of acceptance for treatment
- Cultural
- Family
- Bonding
- Anger

# Time frame for Initial Appointments

	Case 1	Case 2	Case 3
AABR 1	2/7	2/7	nil
AABR 2	8/7	5/7 Outpatient	nil
Diagnostic ABR	2/52 3/52 4/52	2/52 4/52 12/52	23/12 24/12
Childhood Hearing Clinic	7/52	8/52	2 yr 2/52
Hearing Aid Fitting	3/12	2/12	24/12

# No Of Appointments prior to Implant

	Case 1	Case 2	Case 3
Medical	9	8	6
Allied Health	50	21	11
Admissions	2 Sedation ABR Grommets	1 Grommets	2 Sedation ABR Grommets
Age at Implant	13/12	10/12	28/12

# Conclusions

- Based on this brief look we need to be always considering our process and practise
- Body language matches our words
- Concern re interrupted bonding
- Time between screen and diagnosis is stressful
- Information is provided in a timely manner
- Continual reflection
- Different for every individual family



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# Questions