

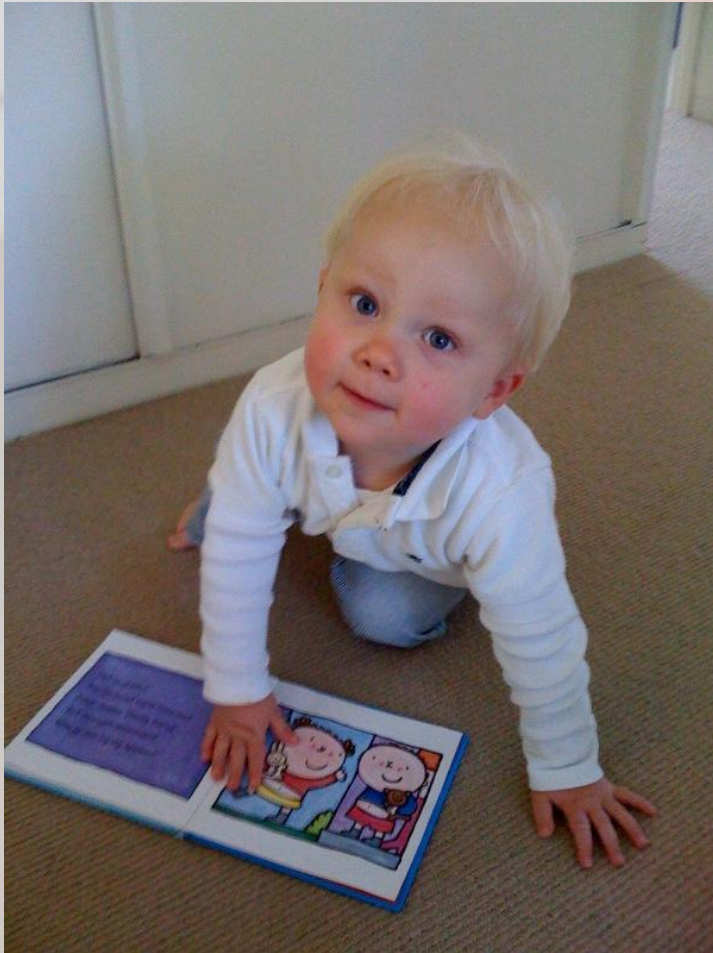


Neither Hear Nor There

About a child with Single Sided Deafness

Kirsten Buwalda, November 2008

Hi, my name is Quinten ...



... I am 22 months old and one of my ears does not work. I often cry when it is noisy or when I think I hear my Mummy but cannot find her. Also whilst I like to look at books, I cannot say many words at all. We have been to many doctors but they say they cannot help me....

Single Sided Deafness (SSD)

Description

- Profound unilateral hearing loss is a specific type of hearing impairment when one ear has no functional hearing ability. People with profound unilateral hearing loss can only hear in mono.

Impacts

- Poor sound localisation
- No or delayed speech development
- Social isolation
- Stress, irritable
- Head shadow
- Inability to filter out background noise

What a day!

- “My bedside alarm goes off at 6:30am, but I sleep through it because I happen to be lying with my left ear — my hearing ear — to the pillow”
- “...he’s walking on my right and the noise from the nearby traffic is all but drowning out the sound of his voice. I smile and nod — and hope he doesn’t notice that I have no idea what he’s on about...”
- “Putting the receiver down I discover that my boss has patiently been trying to get my attention to tell me he needs me in a meeting — once I have my ear to the phone, I can’t hear anything else...”
- “I have no choice but to sit in the only available chair — at the left-hand end of the table — meaning that my deaf ear is facing the room and subsequently the meeting is really hard work...”
- “Crossing the road always require my full attention as the traffic is approaching me on my deaf side. Trying to follow a conversation amongst a group of people *and* cross the road is impossible”
- “At the bar, I only ask for a Coke, but I’m careful to pay with a note so that it doesn’t matter that I can’t hear the barmaid when she tells me the price...”
- “I miss out on the big joke that everyone laughs at, but it avoids a lot of embarrassment I feel when I try, and fail, to keep up with the conversation”
- “she can hear the sound ‘moving’ across the cinema. I try and imagine what that must feel like, but to me all the sound comes from the same direction”
- “I can’t hear the waitress, of course, but as I’ve already told Heather what I want, she orders for both of us”
- “Heather tells me that she worries that I can’t hear the smoke alarm when I’m asleep. It worries me too...”

Source: Ray Gillies Jones, *A personal introduction to single sided deafness*, 2008

Quinten's Journey

31 Jan 2007
I am here!

March 2007
One ear does not work – but not to worry... !?

3 February 2007
SWISS test – I failed?

June 2007
I cry a lot and do not say anything - Mum not sure

September 2007
Finally support - Shepherd Centre

September 2008
Dr Chang – can they fix it, really?

March 2008
Pepsi (the dog) – my first word!

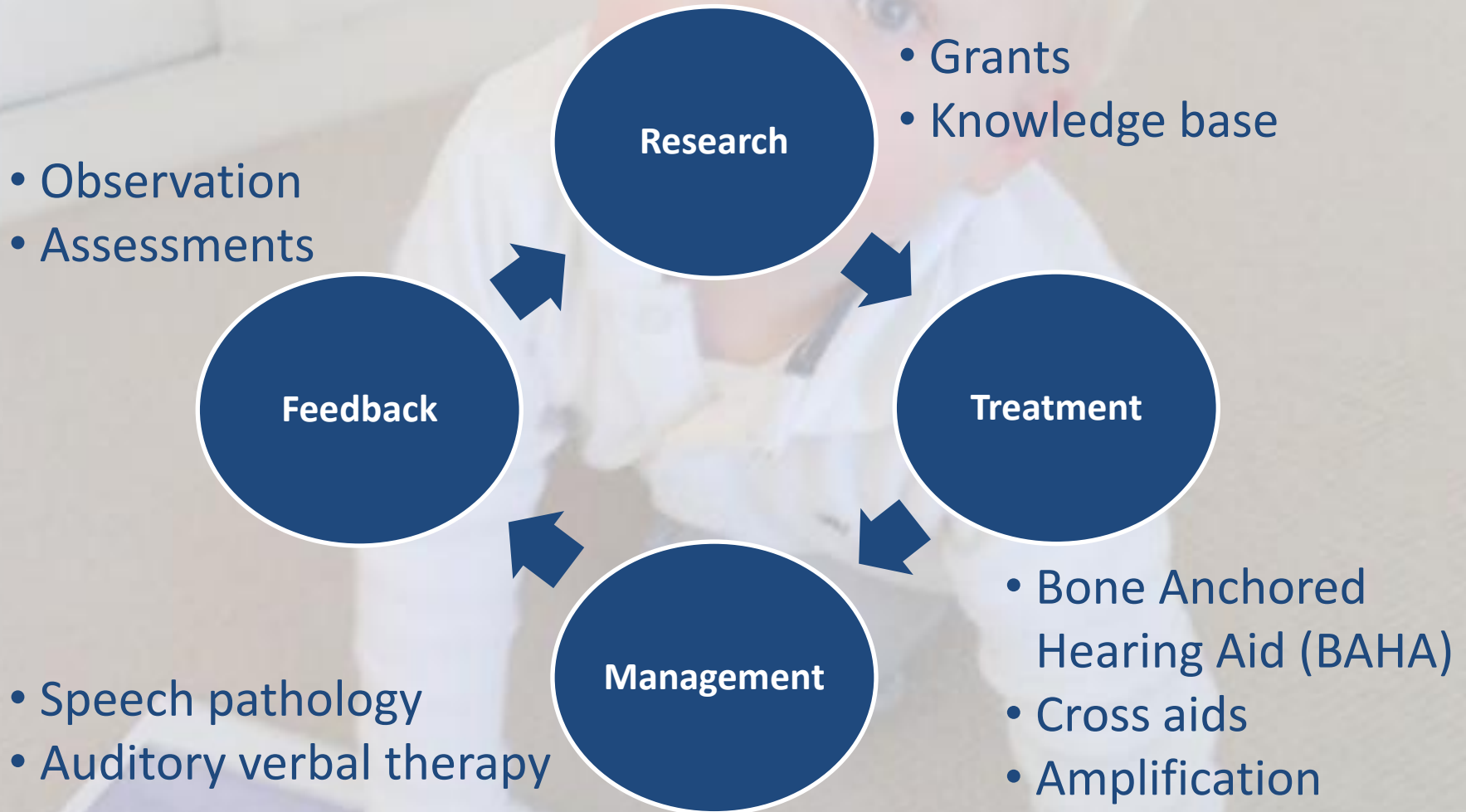
To date
Waiting, waiting, waiting...

The SSD - Dilemma

- The NSW Statewide Infant Screening – Hearing (SWISH) Program aims to identify babies born with significant hearing loss and introduce them to appropriate services as soon as possible
- About 1 to 2 babies out of every 1000 babies born will have a significant hearing loss and 5 cases of SSD were detected recently in NSW alone*
- Early detection and intervention are critical since the first months and years of a child's life are essential to the establishment of sound, social behaviour and speech
- However in the case of infants and children with SSD, no treatment or management is made available
- Australia is home to Cochlear, the world leader in hearing aids such as the BAHA, which use is heavily promoted overseas but not in Australia!!!

* Source: NSW Health - http://www.health.nsw.gov.au/resources/Initiatives/swish/swish_hearingcheck.pdf, November 2008

Integrated approach required



BAHA – a logical solution?



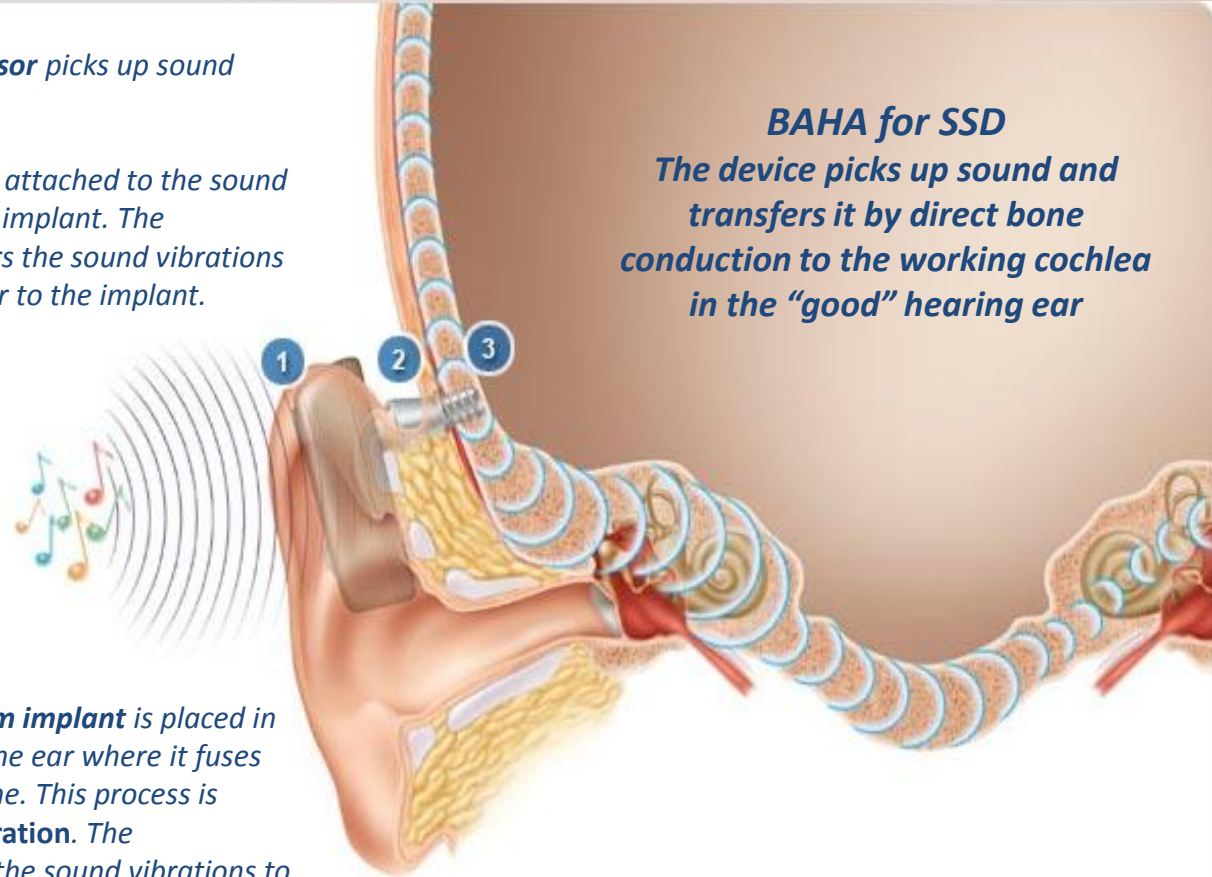
Source: Cochlear – *When hearing aids are no longer enough*, May 2007

BAHA – how it works

1. A **sound processor** picks up sound vibrations.

2. An **abutment** is attached to the sound processor and the implant. The abutment transfers the sound vibrations from the processor to the implant.

3. A **small titanium implant** is placed in the bone behind the ear where it fuses with the living bone. This process is called **osseointegration**. The implant transfers the sound vibrations to the functioning cochlea



BAHA for SSD

The device picks up sound and transfers it by direct bone conduction to the working cochlea in the “good” hearing ear

Source: Cochlear – *When hearing aids are no longer enough*, May 2007

Soft band BAHA - for an early start



- Children's skulls are thinner and their bone is softer than an adult's
- Therefore, clinicians recommend waiting for BAHA implant placement until the child's skull is thick and strong
- The soft band BAHA is an elastic band with a sound processor connected to a plastic snap connector sewn into the band

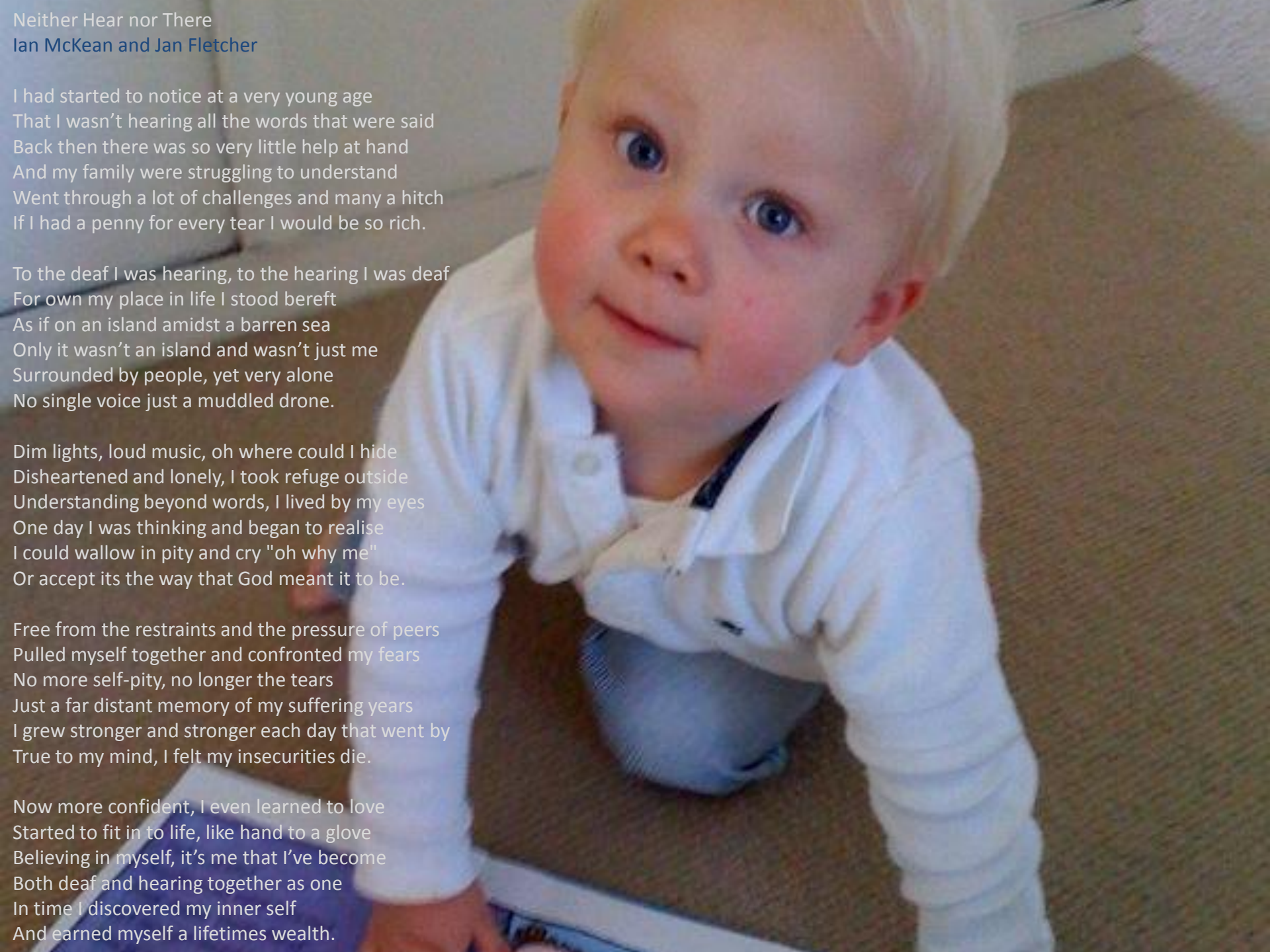
Shepherd Centre

- Charity founded in 1970 for deaf and hearing-impaired children to learn to listen and speak so they can reach their individual potential
- Involvement of family, peers, education and wider community in child development
- Assistance and knowledge for parents to make appropriate decisions and choices about amplification and hearing devices for their children
- Guidance and support both on an individual and family basis as well as in group settings
- The Shepherd Centre program, structured around typical child development sequences, is based on family involvement and parent and professional teamwork.

Source: Shepherd Centre – <http://www.shepherdcentre.com.au> , November 2008

Help Quinten and children with SSD

- We are seeking for funding to
 - support an immediate and integrated approach for Quinten including
 - Treatment with a (soft band) BAHA
 - Management support by the Shepherd Centre
 - Research for SSD
 - establish guidelines, protocols and policies across various stakeholders including Australian Hearing, Cochlear, The Shepherd Centre, Medicare, Health Funds, surgeons and audiologists



Neither Hear nor There
Ian McKean and Jan Fletcher

I had started to notice at a very young age
That I wasn't hearing all the words that were said
Back then there was so very little help at hand
And my family were struggling to understand
Went through a lot of challenges and many a hitch
If I had a penny for every tear I would be so rich.

To the deaf I was hearing, to the hearing I was deaf
For own my place in life I stood bereft
As if on an island amidst a barren sea
Only it wasn't an island and wasn't just me
Surrounded by people, yet very alone
No single voice just a muddled drone.

Dim lights, loud music, oh where could I hide
Disheartened and lonely, I took refuge outside
Understanding beyond words, I lived by my eyes
One day I was thinking and began to realise
I could wallow in pity and cry "oh why me"
Or accept its the way that God meant it to be.

Free from the restraints and the pressure of peers
Pulled myself together and confronted my fears
No more self-pity, no longer the tears
Just a far distant memory of my suffering years
I grew stronger and stronger each day that went by
True to my mind, I felt my insecurities die.

Now more confident, I even learned to love
Started to fit in to life, like hand to a glove
Believing in myself, it's me that I've become
Both deaf and hearing together as one
In time I discovered my inner self
And earned myself a lifetimes wealth.