

***Views from the other side: The Human Side of Hearing Loss.***

*Editorial comment by Graham Weir*

*The following two stories by Queenslanders, Peter and Jill Lindley, (both with hearing impairment, Peter with a profound loss since childhood and Jill, a late onset, moderate loss), give us a fascinating insight into the daily struggles that can accompany family life with significant hearing loss. Unusually, both are deeply involved in advocacy work on behalf of local and national consumer groups for the hearing impaired. From this unique perspective, their insights into their own struggles and the accessibility barriers faced by many of their peers - and the gaping holes that they see from their side of the service delivery fence, will hopefully make us all more humble and considerate of how we can put a greater effort into helping to make our communities better places to live for those we profess to serve for our livelihood.*

**The Vicissitudes of Life: Experiences of a Consumer and Significant Other**

*Peter and Jill Lindley*

***Peter's Story...***

What I have documented in this paper in no way attempts to provide a professional research example of a hearing loss. It is an attempt to compile the experiences of someone who has lived with a profound sensori neural hearing loss for 64 years. In addition, I have attempted to provide an objective analysis of those experiences and, hopefully, evidence from the literature to support what I have said.

**Introduction to a Personal Experience**

"I operate on the periphery of what goes on every day, and I often feel confused and vulnerable. Due to my hearing impairment, I cannot make accurate judgments about verbal events, which affect me constantly. In attempting to interact with people, I frequently experience significant levels of stress, through not knowing if my judgments or responses to situations are accurate, and if those judgments or responses are going to result in adverse outcomes". I make these statements as a result of living with a profound hearing loss since childhood.

As a complication of illness, I lost my hearing suddenly when I was 7. Hence my ability to communicate orally. My parents had been advised to send me to a mainstream school, rather than a school for the deaf, so that I would acquire normal social skills within a hearing world. This, to some extent has been the case. However, my formal education essentially stopped at that time. There were no teachers with understanding of, or expertise in education of a profoundly deaf child. I did not comprehend myself, why some people I could understand, others I couldn't. My job prospects have been limited and the enjoyment and benefit of all the things that hearing people take for granted has been severely curtailed.

## Living With Hearing Loss and Stress

I have lived with the experience of the lack of understanding of the implications of a sensori neural loss by my peers. It has been clear from the behaviour and comments of others, that their perception of me has been one of a person with a diminished mental capacity, or a manipulative anti social person – with the result that rejection has been part and parcel of my life. The resulting constant emotional turmoil, perception of my world being ‘different’ and stress of living as a deaf, orally communicating person in a hearing world was constant.

Antony Kidman, 2005, quotes Selye’s definition of stress as ‘the common or non specific response of the body to any demand’, and demonstrates how chronic stress can have adverse effects on a person’s mental and physical health. It seems obvious to me, that a person with impaired hearing, who lives with constant fatigue, confusion and apprehension on an almost daily basis is subjected to chronic (or bad) stress for long periods of time.

## Hearing Handicap

My own experiences of hearing handicap have been many and varied as there have been (and often still are) innumerable barriers to effective communication in every day life. I have been unable to participate in, and therefore belong to groups. For example, I am an avid builder of models, ships, planes etc, I would have loved to be able to share my interest with the local Modeller’s club, who said they understood my communication needs. Unfortunately, after a few meetings of having no idea what was going on, and feeling excluded I left. The same occurred with my interest in bird breeding. Until very recent years a visit to the cinema, attendance at meetings of any sort, was a waste of time.

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I attempted to gain education as a mature age student, but my lack of even the most basic qualification of ‘Scholarship’ meant that was a failure. What education I had was gained from books. I became interested in history, anthropology and similar subjects, and developed what I have been told is a very broad vocabulary. What I did not know until many years later, was that in conversation I used the language of books, which was often not common usage. Added to this was the fact that I had never heard words pronounced, so did not know that the pronunciation I used was ‘unusual’. Over the years, I experienced odd reactions if I managed to participate in conversation. I can understand why now – but at that time it was just more evidence to me of being misunderstood.

So - it seems to me that the principal handicap with which a hearing impaired person has to contend is the lack of understanding of the implications of hearing loss, especially if it is of the sensori neural type, implications which I did not fully understand myself! This lack of understanding breeds attitudes of indifference, through a failure to understand the consequences of disability and handicap. In my own experience, those attitudes have fueled in me anger, resentment and at times a desire to physically lash out.

The psycho – social problems of impaired hearing have been well documented ie intense concentration and fatigue / stress and anxiety / difficulties in family relationships / isolation / negative self image / irritation from others when they have to repeat themselves etc. I have lived them.

## In The Workplace

Whilst family and contemporaries gained higher education and professional status, I remained at the blue collar level – very conscious of my ‘lesser’ status, frustrated by it and angry that it was so. For 33 years I worked in the rehabilitation wards of a large public hospital on a lower rung of the existing ‘pecking order’. I can state quite categorically that during those 33 years, I can count on the fingers of one hand, the number of times a health professional said to me “how can I help meet your communication needs?”

My tenure at the hospital was among the most traumatic years of my life. I would have preferred to move to a less stressful job, but my fear of not being able to obtain other employment resulted in remaining where I was, because ‘who was going to employ a profoundly deaf man?’ Within the hospital environment, first and foremost I had a responsibility to the patients, of which I was very conscious. The daily challenge of ‘keeping up’ coupled with the health care workers lack of understanding of my communication problems – (after all, I spoke as a person with no outward signs of a disability) was at times overwhelming. Sadly, I noted that the hearing impaired patients in the wards experienced the same lack of understanding of their communication difficulties and needs.

The result of my constant and seemingly unwinnable battle to maintain some sense of equilibrium, forced me to eventually seek help in dealing with the emotional trauma and stress. These days, I would probably be referred for anger management, though even today, I find myself wondering if the professional staff would have the insight to consider the ‘why’ of the anger. I approached a number of psychologists in both the public and private sectors, to no avail. They regretfully admitted that they could not help, because they knew next to nothing about sensori neural hearing loss or its implications. I approached the Deaf Society of the day, with the same result.

I obtained some peer support from the Association of Better Hearing (as Better Hearing Australia was known then.) Other than that, I made my way through an emotional minefield on my own, developing through ‘trial and error’ a range of strategies, many of them inappropriate and often causing more problems than they solved - as I sought to survive in a hearing world.

However, had it been there I would gladly have accepted counselling and rehabilitation to help me develop strategies to more effectively negotiate a hearing world. Such professional services still do not exist, outside of hearing aid fitting services. At age 59 I was made redundant and told that I was not redeployable / trainable for any other position due to my deafness. At that time I applied for the disability pension. I was told by the reviewing officer, that given my level of hearing impairment I could have spent my life on the pension.

## **Limitations in Current Hearing Health Care.**

The current medical model of hearing health care in Australia is of a very high standard. Unfortunately, it only targets the receptive component of hearing loss – ie what goes in – utilising the marvels of technology, hearing aids, cochlear implants etc. The expressive component of a hearing loss ie how to live with and manage it – has to date been virtually ignored, yet it is a vital component of hearing health care.

A rehabilitation unit would not dream of discharging a patient who has had a stroke and been left with poor function eg mobility / dexterity – without looking at ways of assisting that person to manage that change in function. Yet the hearing health care system sends the hearing impaired person on their way with a hearing aid as if this remedied the problem. – even though it is widely recognised that it is an aide only!

Dr Bill Noble, from the University of New England, states that there should be available methods to supplement pure tone audiometric data, to evaluate hearing disability and handicap i.e. *“without direct inquiry into the lives and circumstances of people who manifest signs of impairment on these tests, little useful knowledge is gained about disabilities -functional hearing incapacities in the everyday world and none whatsoever about handicaps – the disadvantages for everyday living, experienced as a consequence of the impairment.”*

Additionally, the medically assessed degree of hearing impairment does not necessarily serve as an indicator of how an individual will cope with the loss. ANY disruption to communication function can have adverse consequences, whatever the degree of hearing impairment. It has been documented that hearing loss can, as a result of subsequent isolation and lack of mental stimulus, contribute to cognitive decline in the elderly. Additionally, Morgan et al, University of Queensland 2002, in “The Impact of Hearing Impairment on Quality of Life of Older People” found that “hearing impairment was found to significantly affect subjects quality of life on the mental health scale.” They go on to suggest that “the need for medical professionals to seriously consider the impact of hearing impairment on the mental health of older persons.”

The overall aim of this paper, has been to demonstrate how stress, caused by an inability to hear well in a hearing world, with the related problems it can cause can contribute to mental ill health issues. This needs to be addressed. In doing so, I have used my own experiences. However, I would like to cite a reference related to hearing health, stress and mental ill health. Research literature from Eriksson-Mangold M and Carlsson states “it was suggested that insecurity in social settings and diminished hearing for contextual sounds, could cause a perceived loss of control, which could induce stress reactions”.

My own experiences have been of high levels of tension and stress, feelings of apprehension and frustration, in many situations when I have verbal contact with people. I am well aware that the primary cause is the sense that my daily interaction in my world is out of my effective control.

### **The Way Forward**

The issue I want to highlight, is that hearing health i.e. physical, psychological and mental health should be the objective of best practice. This includes direct intervention such as counselling and rehabilitation services for existing problems - and just as importantly - **prevention** of psychological and mental health disorders.

Graham Weir M.A - in Psychological Adjustment to Hearing Loss (1995), illustrates the similarities between good nutrition for physical health and good communication for mental health. His concept of what constitutes “ a good communication diet” provides a frame of reference for rehabilitation counselling for people with a hearing loss, as a way of promoting and maintaining good mental health.

## To Conclude

However, despite not having the opportunity to achieve academically, I have lived my life determined to do what others did, being usefully employed. Despite feelings of low self esteem and little confidence, I became equally determined to do what I could to make a difference, becoming passionate about speaking out on behalf of hearing impaired people - lobbying for communication access – challenging discrimination. I have been and continue to be a volunteer in a number of organisations supporting people who are hearing impaired.

Peter Berger in 1977, postulated twenty five theses, related to the role of the consumer of health services, and the importance of their contribution towards the development of such services. These theses were widely circulated during the International Year of the Disabled 1981.

To quote two of these theses:

- Thesis 14. Every human being knows their own world better than any outsider (including the expert who makes policy.)
- Thesis 15. Those who are the objects of policy should have the opportunity to participate, not only in specific decisions, but in the definitions of the situations on which these decisions are based.

He goes on to add – that what people say about their own reality must always be taken with great seriousness – not only because this is morally right, but failure to do so may lead to great and sometimes catastrophic practical consequences. I believe this to be just as relevant today as it was then.

There are 3.55 million Australians who are Deaf, hearing impaired or have a disorder of the ear (Access Economics Report 2006). We all have a story to tell – we hope the decision makers listen to and act on what consumers have to say. The need for Deaf and Hearing Impaired people to have the opportunity to live a life in which they can reach their full potential, demands it.

Peter Lindley  
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## *Jill's Story...*

### ***THE SIGNIFICANT OTHER - A CONSUMER PERSEPECTIVE***

#### **The Beginning**

I have read many articles about the challenges faced by hearing impaired people, but little on the those faced by family / spouse – 'the significant other/s'. An article I read a few years ago, was titled "Ten Ways to Drive the Hard of Hearing Crazy". I sat down and wrote my own "Ten Ways to Drive the Hearing Crazy" to address the imbalance, and let off some steam!!!. The following is an expanded article about some of the issues faced in the journey of being a 'significant other'.

I have a moderate hearing impairment. My husband is profoundly deaf, losing his hearing suddenly at the age of 7. In our relationship, he and I have lived with the challenges that have been a result of a decision made at that time to send him to a mainstream school, so that he would learn to socialise in a hearing world, even though that meant he would not receive an education. I have seen that for a highly intelligent and articulate man, that lack of a piece of paper has been an ongoing source of feelings of poor self worth, poor self confidence and poor self esteem.

Add to that, the lack of the incidental learning, subtle nuances of socialisation normally acquired during the years of formal education – and you have someone who has learnt to look within himself for ways of coping, developing an 'aloneness' a self reliance to help him deal with the frustration and anger engendered by his daily experience.

#### **Life Together.**

As he has lived on the 'outer' of the hearing world, so I have often felt the frustration and aloneness of being on the outer of his world. As those things that molded him were outside my experience so the things of the hearing world that molded me were outside his. There were many times when I felt like pounding him on the chest and crying "let me in!" I felt that there was no one I could turn to who could help, even if I could have overcome the sense of disloyalty to him, of making my distress 'public'.

So we lived with the consequent misunderstandings, on a daily basis, as in his 'aloneness' he was not aware of leaving me out, did not understand. He was just living the life that was 'normal' for him. He had no other frame of reference. This aspect of his way of functioning was in contradiction to the generous, loving and caring person that he is. I struggled with making sense of that contradiction, with the consequent frustration and stress. His view of me is that I am 'volatile' and he finds that difficult to cope with, understandably. My response is, that I found that sometimes I could get through the barrier with a 'volcanic eruption'! So - as a child who wants attention uses whatever behaviour achieves that result, I used what worked - to some extent!! Like him, using an inappropriate strategy, born of frustration as I struggled to survive as a partner in the relationship. With hindsight, I can see the way in which this has impacted on all aspects of our relationship. Added to the fact that we came from the different planets of Mars and Venus – the challenges have been formidable!!

He has a number of health problems which have meant frequent dealings with a health care system that has demonstrated lack of understanding of the fact that he is profoundly 'deaf', because he

does not sign!. When he is admitted to hospital, I experience a high level of frustration and anxiety, as we have experienced medication and treatment errors result from this lack of understanding.

One of his ways of coping is to bluff, make light of the problem, so that he will be accepted, and not be seen as being a 'difficult' patient. He jokes with the staff about it. But I see under the joking the vulnerability and insecurity and I experience that also. I know that the bluffing is a response to a lifetime of coping with negative reactions – I have seen the obvious impatience when he asks for repetition, the brusque "it doesn't matter" when he struggled to understand. Bluffing is a two edged sword, helping to avoid the distress of put downs – but I have seen it create its own misunderstanding.

I look with some wistfulness at those who are able to participate in free flowing conversation – the subtle sense of intimacy and camaraderie that this engenders. I have found that for myself and other 'significant others' this is a common thread ie a loss of intimacy and spontaneity – one has always to think about and plan communication – and forget it when the hearing impaired person is tired or stressed!

As I see members of the Deaf signing community able to achieve this free flow I have felt some envy. However, his past experience of wanting to appear 'normal' in the hearing community has created an insurmountable barrier to his learning to communicate in this way.

When we are in a group setting with family and friends, his way of coping is to control the conversation. I learned very early in our life together to gauge how well he was coping by the number of times he would change the topic! As soon as he lost the thread of the interaction, off the conversation would go on another tangent. Widely read and articulate, he was not lost for topics. My participation became minimal. I went through a period when I realised that I was losing social skills and could not cope socially if he was not there to carry the conversation!!

We 'significant others' also deal with feelings of responsibility - the feeling that the onus is on us to make the relationship work. After all, the deafness of our spouses is not their fault! So we feel guilty when we feel frustrated and get angry. There was a time when I tried to be his shadow – there to pick up on misunderstanding. I had to learn that we both have to live with this unpredictability and vulnerability.

There is also the problem that we are never sure, when or whether our hearing impaired partner has heard AND understood. This insecurity is exacerbated by the frequent accusations that we have not told them something important. The issues we deal with are particularly relevant where partners have a severe to profound hearing loss, where hearing aids are of limited help.

He had a cochlear implant, October 2008. One of the driving factors in his decision to have this, has been the hope that it will help to address some of the communication challenges of daily life and in our relationship. This in itself has been a journey into the unknown for both of us, as we do not know anybody who has had an implant following 64 years of profound deafness. Another step in our challenging journey together.

We are now dealing with the unrealistic expectations of others. Whilst some implantees can hear recognisable speech immediately after activation of the electrodes, this has not been the case for him. He is having to relearn the meaning of sounds that he has not heard for 64 years - a process that may take at least 12 months and is proving very challenging. Also, wonderful though the technology is – it does not restore 'normal' hearing.

Like him, I recognised that change will only come about as we participate in being a part of the change that we wish to see. Some years ago I realised that saying 'someone should do something' achieved nothing. It was important to be that 'someone' - and have participated with Peter as a volunteer, in a number of organisations supporting people who are hearing impaired.

### **My dream**

I have observed over the years, barriers that exist between the Deaf and hearing impaired communities, in my home state ( and no doubt elsewhere). I see there a focus on what is different, not the similarity of issues. I dream that one day, there will be an acknowledgement of the fact that we all face communication challenges – albeit responding to and managing them in different ways. I dream that Deaf and hearing impaired people will feel that ALL communication options / choices are acceptable – that we are ALL working toward a common goal – living our lives – reaching our full potential.

I would like to see professional counselling services readily available and accessible, where those professionals have an in depth knowledge, beyond the aetiology - of the implications of deafness and hearing impairment - and the ability to address the personal/ interpersonal and social relationship issues, to prevent isolation, the breakdown of those relationships, and potential emergence of mental health issues such as depression and anxiety states.

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