

The 2004 Libby Harricks Memorial Oration



Honouring the Deafness Forum's first president & profoundly deaf achiever Elisabeth Ann Harricks AM 1945 – 1998

Introduction to the 6th Libby Harricks Memorial Oration

Dr Jenny Rosen, Chairperson, Libby Harricks Memorial Oration Committee



Today's orator Dr Peter Carter, Ms Margaret Robertson and Deafness Forum Board Members, fellow members of the Libby Harricks Memorial Oration Committee, ladies and gentlemen. On behalf of the Libby Harricks Memorial Oration Committee of Deafness Forum, it is with very great pleasure that I welcome you all to this 6th Libby Harricks Memorial Oration.

Previous Orations have either been organised as independent events, or have benefitted from association with a related occasion. For example Professor Bill Gibson spoke at the International Federation of Hard of Hearing Conference (IFHOH) in Sydney in 2002 and Professor Paul Mitchell at the XXVI International Congress of Audiology in Melbourne in 2002. This year we are privileged to feature the 6th Libby Harricks Memorial Oration as an integral part of a Deafness Forum event, the 3rd National Deafness Sector Summit.

Once more, I must thank the hard working Libby Harricks Memorial Oration Committee, and the always supportive staff of the Deafness Forum national secretariat without whom this Oration series would not happen.

We are indeed privileged to have Dr Peter Carter with us today to present the 6th Libby Harricks Memorial Oration.

I understand that Dr Carter is originally from Brisbane, so perhaps in some respects this can be seen as a 'home' event. However, since completing his basic medical training in Sydney in 1972, it appears that Peter has excelled not only in the medical sphere, but also as a sailor, with both strands intertwined throughout his career.

After three years as a medical officer in the Royal Australian Navy (1973-1975) Peter appears to have managed to combine preparing for his First Part Examination of the Royal Australasian College of Surgeons with obtaining a Sailing Bosun's Certificate, and qualifications in diving. It appears that he also happened to sail from Brisbane to Port Moresby.



He completed his Fellowship of the Royal Australasian College of Surgeons FRACS Otolaryngology in 1981, and subsequently spent a year as Teaching Fellow, Otolaryngology at St Vincents Hospital, Sydney. From 1983 to 2001 Peter was a Visiting Medical Officer, Otolaryngology at four major Sydney hospitals: Prince of Wales, Randwick; Sydney Childrens Hospital, Randwick; Children's Hospital, Camperdown and St Lukes Hospital, Sydney. From 1988-1992 he headed the Department of Otolaryngology, Head and Neck Surgery Prince of Wales Children's (later Sydney Children's) Hospital Randwick, and from 1996-2000, similarly led the Otolaryngology team at the Prince of Wales Hospital. From 1992 to 2000, he was on the Court of Examiners, Royal Australasian College of Surgeons.

Perhaps more importantly in terms of today's Oration, from 1983 to 2001 Peter was also Visiting Otolaryngologist at Brewarrina Hospital, NSW, Aboriginal Medical Service, Redfern, and Norfolk Island Hospital. From 1995-2000 he chaired the Aboriginal and Rural Health Group of the Australian Society of Otolaryngology, Head and Neck Surgery. During 1995-1996 he was the Otolaryngology Representative on the NSW Health Department Working Party on Ear Disease in Aboriginal Children, which resulted in Guidelines published in the Medical Journal of Australia, May 1996 vol 164 (Supp). In 1998 he was the Otolaryngology Representative on the Commonwealth Department of Health Steering Committee for Systematic Review of Otitis Media in Aboriginal and Torres Strait Islander Populations. Peter has been involved in numerous research projects with this population, and is widely respected for his work in this specialised area.

In 2001 Peter retired from full time practise in Otolaryngology and spent 2002-2003 sailing with his wife Ruth firstly to Hobart, then back up the east coast to Cape York and thence a full navigation of the Australian continent, stopping to complete various locums here and there along the way.

We are indeed fortunate that he has returned in time to prepare his presentation, 'A Sorry Business: Lack of Progress in Aboriginal Ear Health'. Would you please welcome Dr Peter Carter.

A Sorry Business: Lack of Progress in Aboriginal Ear Health

Delivered by Dr Peter Carter FRACS at the 3rd National Deafness Sector Summit, Brisbane 16 May 2004



Impaired hearing can have effects extending well beyond the ability to communicate, adversely affecting self esteem and sense of well being. If Libby Harricks had any such feelings it is impossible to tell from her life story, for she triumphed over her profound hearing loss, using the principle of self help (and all available technology) to make a tremendous contribution to the lives of others with hearing impairment. It is a great privilege to have been asked to deliver this oration, named in her honour.

Profound hearing loss is indeed 'The Hurt That Does Not Show,' but moderate, even temporary conductive hearing loss, particularly in the childhood years, is more insidious, subtly undermining the ability to learn, to develop social skills, confidence and self respect. Such is the case in many of the Aboriginal communities in Australia, where the incidence of ear disease in the form of purulent discharge from children's ears ranges from 4% in Western NSW to over 60% in the Tiwi Islands, NT. The World Health Organisation defines ear discharge rate above 4% as a massive public health problem.² By contrast, in non-indigenous Australian children the incidence of discharge is less than 1%.



Chronically Discharging Ears are but one aspect of Indigenous Health Problems

Chronic Suppurative Otitis Media – Discharge from the ears - is a vast problem, but then in these same communities the ear disease in children is a silent partner to crisis levels of life threatening kidney failure, heart disease and diabetes in adults, even young adults. Community general health statistics, particularly those for respiratory illness, closely follow those for ear disease. Consider these recent mortality figures for Indigenous Australians: (Figure 1)

Indigenous people are highly over-represented in deaths caused by diabetes, respiratory diseases, neoplasms (including cancers), diseases of the circulatory system (including heart disease), and external causes such as accidents and suicide.

e 1 The six main causes of death of Aboriginal and Torres Strait Islander (ATSI) peoples 1999-2001 compared with non–Indigenous Australians ³					
Cause		ATSI Female Standardized Mortality Ratio		ATSI Male Standardized Mortality Ratio	
Diseases of circulatory system (inc. heart disease)		2.8: 1		3.2: 1	
External causes (inc. accidents, suicide etc)		3.2: 1		2.9: 1	
Neoplasms (inc. cancers)		1.6: 1		1.6: 1	
Diseases of respiratory system		3.9: 1		4.4: 1	
Endocrine, nutritional and metabolic diseases (inc. diabetes)		11.7: 1		7.9: 1	
Diseases of the digestive system		4.8: 1		4.8: 1	

Was It Always So?

Descriptions of the health of Indigenous Australians at the time of European colonisation are patchy at best, but the hints are intriguing.

Tom Austen in his book 'A Cry in the Wind – Conflict in Western Australia 1829-1929' quotes from the 1830 diary of one George Moore, a settler on a grant of 12,000 acres on the Upper Swan. The natives, he said ...were slender-limbed, broad-chested, strong and quick minded.⁵ Obesity had not yet appeared.

The Eora people of the Sydney region were noted by those of the First Fleet to be strong and well nourished. One such man so impressed Captain Arthur Phillip with his physique and courage that the cove where he stood his ground became 'Manly'. Professor Max Kamien of the University of Western Australia believes the health of Aboriginals at the time of European contact was "almost certainly better than that of the English, whose occupation of Australia led to the Aborigines' rapid decline."⁶

Florence Nightingale, who made care, compassion and cleanliness the catchwords of nursing in the Crimean War, turned her attention to reform in the colonies. In England in 1860 she devised forms to be completed by colonial officials in charge of 'natives', requesting sickness and fatality figures for Aboriginal children, and details of hospitalised Aboriginals. Western Australian Colonial Surgeon John Ferguson sent her no information on Aboriginals admitted to hospital - there were none. "(That) would render the hospital wards unhealthy for Europeans". In outpatient Aborigines, he noted tuberculosis, syphilis, alcohol problems and significantly, the introduction of diseases 'more fatal to Aborigines than Europeans!⁵ This was 30 years after European displacement of Aborigines in the Swan River region.

Early Devastation

The inadvertent introduction of diseases, noted in John Ferguson's reply to Florence Nightingale, was far more devastating in numerical terms than the sporadic early massacres and even the later sustained attempts at genocide, as seen in the Kimberley and in the three waves of pastoral wars in Arnhem Land.⁷ The smallpox epidemic of 1789 killed most of the Eora people of the Port Jackson region and went on to kill an estimated half of the indigenous

inhabitants of south-east Australia. Chicken pox, measles, rubella (German measles), whooping cough, mumps, diphtheria, and scarlet fever were all sources of great morbidity and mortality for children in those days before immunisation, but in Aboriginal communities the adults also had no immunity and vast numbers died. Tuberculosis was a less obvious killer than epidemics of influenza, but by the late 1800s figures from Port Pearce in South Australia showed almost 30% of deaths due to this disease.

Population Recovery

When the human rejects from England were first exported to Botany Bay in 1788, approximately 150,000 to 300,000 Australians are estimated to have lived in this 'Terra Nullius'. It is unknown just how low the population fell, but by the1930s it seems likely that the decline stopped.⁶ In 1981, 160,000 people identified as Aboriginal in the Census, and since then the increase has been dramatic, as shown in Figure 2.

Figure 2 shows that 410,000 people identified as of Aboriginal and/or Torres Strait Islander origin in the 2001 Census. This was a 16% increase since the 1996 Census. Three-quarters of this growth over the five years from 1996-2001 can be explained by demographic factors (births and deaths), with the remaining increase the result of other factors (such as improved Census collection methods and increased tendencies of people to identify as Indigenous).⁸

Figure 2 Census count of Indigenous population, 1991-2001 ⁶						
		1991		1996		2001
Recorded by the Census		265,500		353,000		410,000
Increase on previous census (per cent)		17.0		33.0		16.0
% of the total population (per cent)		1.6		2.0		2.2

Health Parameters Worsening 1970-2000

Despite improvements in Aboriginal mortality and increasing population over the past 30 years, many aspects of Aboriginal health have worsened.

In his book 'Why Warriors Lay Down and Die' Richard Trudgen describes an American-Australian Scientific group commenting in Arnhem Land in 1948 that in no instance was an obese adult encountered, and that scabies was rare. Trudgen's findings were similar in 1973 in Milingimbi, Arnhem Land, but by the end of the twentieth century he noted dramatic deterioration. Now scabies is endemic. Obesity, so common now in Australia, is even more so in Indigenous Australians at 63% compared to the overall national figure of 50%.³ Diabetes, renal failure, heart attack and stroke are major killers. "Yolnu are now dying in early to mid forties or even younger... life seems to lurch from one funeral to another."⁷

Figures from the Australian Bureau of Statistics over the past decade confirm this continuing 25 year difference in life expectancy between Indigenous and Non–Indigenous Australians. (Figures 3 & 4)³



Figure 3 Median age at death (male), 1990-2001³





Figure 4 Median age at death (female) 1990-2001³

Why is there such illness in so many Australians?

There are many known contributing factors to all this illness and shortened life:

- Diet based on cereal and sugar: This dietary preference, the legacy of hand-outs of white flour, tea and sugar over generations, leads directly to obesity, diabetes and coronary artery disease, making sugar a more pervasive and lethal substance of abuse than alcohol, tobacco or drugs.⁶
- Alcohol: does great damage to mind and body in many Aboriginal Australians (and in other Australians), yet Indigenous Australians are actually less likely (44%) to consume alcohol than Non-Indigenes (62%), and the proportion of at-risk drinkers is approximately the same in the two populations, at 10-11%¹⁰ Aboriginal drinking of alcohol seems to be more public in its immediate and longer term effects.

Smoking: a strong risk factor for cancer, coronary artery disease and stroke, is twice as common in Aboriginal and Torres Strait Islander people, 49% of whom smoke compared to 24% of the general population.¹⁰

Dependence and Loss of Control: A sense of control over one's own life is an essential for good mental and physical health. This concept is central to the problem. There is a downward spiral, a cascade of disasters evident in Arnhem Land leading to dependence on welfare, loss of status and self respect, leading to a sense of hopelessness which progresses to self destructive behaviour - neglect of responsibility, drug abuse, violence, homicide, incest and suicide. (Trudgen)' In 1983, Yolnu people themselves carried out nearly all work in their communities, but only a decade later, by linking Commonwealth funding to a system of tendering for contracts, this had all gone to outsiders. Paradoxically it was federal government policy, disastrously implemented, that contributed to this dependence on welfare in Arnhem Land. The Aboriginal Development Commission (ADC) in 1983 linked additional funding for Aboriginal housing to acceptance by the Ramingining council of outside contractors to speed the building process. The Yolnu building team, who had constructed all cyclone standard steel framed housing at Ramingining until then, was disbanded. Richard Trudgen gives other examples. In 1975 a loan application from the Galiwin'ku Yolnu council for developing the fishing industry led to the ADC bringing in a consultant, who recommended one large modern trawler rather than the fleet of small boats. which were then destroyed. The large trawler required a licenced captain so an outsider was employed. The various clans could not work together on one boat under him, they no longer had any sense of 'ownership' of the industry, and within six months the whole fishing enterprise collapsed. The slide from self respect to hopelessness, from responsibility to neglect, was well underway.



Standard of Living: Lack of housing or overcrowded houses, inadequate sanitation, lack of water for personal washing and for laundry, all contribute to health statistics reminiscent of eighteenth century London. This is fertile ground for ear infection, and the infection can reach 95% of the nose, pharynx and ears of Aboriginal infants by the age of two months.¹¹ The benefits of clean water extend to swimming pools, as demonstrated by a recent study in two remote Western Australian communities which showed a marked reduction in skin infections and perforated eardrums six months after opening of public swimming pools.¹⁹

Close living means neonates are heavily and frequently exposed to the bacteria carried by others, causing constant inflammation and damage, leading to chronic infection. By contrast, in Non-Aboriginal children where the exposure to bacteria is less, the immune response is not overwhelmed, and can eradicate the bacteria, limiting damage.

 Lack of Access to Medical Care: In many remote areas, but particularly the Kimberley, Arnhem Land and Central Australia, access to Aboriginal Health Workers and health clinics can be difficult, nursing and medical officer visits may be infrequent, and referral to major centres costly and culturally disruptive. Life preserving medical technology such as a dialysis machine for end renal failure simply does not reach many a remote patient. What about other Indigenous Communities?

Wherever Indigenous peoples have been displaced by European colonisation the same factors have come together to sap health and morale: loss of independence, reliance on welfare, high carbohydrate low protein diet, alcohol, overcrowding and inadequate water and sanitation.

Much greater progress has been made, however, by the Inuit of Canada, the Native Americans of USA and the Maoris of New Zealand than by Aboriginal Australians. (Figure 5)

Figure 5 Comparisons of life expectancy for Indigenous peoples in Australia, Canada, New Zealand and the United States of America $^{\circ}$





Specific Consideration of Ear Disease Does Moderate Conductive Hearing Loss Matter?

Given this array of appalling statistics, does a moderate reduction in hearing in childhood years matter, particularly as the ear disease tends to clear with the onset of adolescence? There is a close link between hearing loss and learning delay, between treatment of ear disease and improved psycholinguistic function. The associated hearing loss has a life-long impact, as it occurs during speech and language development and the early school years.⁴ For Aboriginal children in remote areas, English may not just be a second language, but fourth or fifth, and given that almost all schooling is in English, hearing loss forms a formidable barrier to learning. School becomes a place of humiliation and boredom, and the pattern of educational, economic and social disruption is set. This becomes a contributing factor to the high imprisonment rate of Aboriginal youth.

Although there is improvement in ear disease during adolescence, hearing loss can persist into adult years. Ward et al found 15.5% of indigenous university students had a unilateral or bilateral hearing loss.¹⁵

* Yiparinya school in Alice Springs is an exception, where classes are taught in four Australian languages, only one of which is English.



Figure 6 Large wet perforation



Normal ear drum

Types of Middle Ear Infection Chronic Suppurative Otitis Media (CSOM)

Continuing discharge through a persisting hole in the eardrum, termed Chronic Suppurative Otitis Media, is the common form of ear disease affecting Aboriginal children. Although damage to the inner ear can occur causing some permanent inner ear deafness, the hearing impairment is usually due simply to inefficiency of vibration of the perforated, wet ear drum – Conductive Hearing Loss. The hearing impairment is less when the pus clears, and may be minimal if the hole is small.

Otitis Media with Effusion (OME) (Glue Ear)

Following clearance of the pain and fever of a middle ear infection, fluid may continue in the middle ear deep to the intact ear drum for many weeks. This OME may eventually lead to a recommendation for placement of ventilation tubes - grommets the commonest children's surgical procedure performed in Australia. Indigenous children develop glue ear as do other Australians and the problem tends to be poorly diagnosed and managed, in part because of its hidden nature compared to the very common and obvious discharging ears (CSOM), and in part because of the isolation of some of the communities.

Otitis Media with Effusion not only impairs hearing but can rarely progress to retraction of the eardrum into the middle ear cavity, in turn causing erosion of the sound conducting ossicles and even progressing to cholesteatoma (essentially deep ingrowth of skin) and deep infection which can be life threatening. These complications can be prevented or treated by timely medical intervention.

What needs to be done?

Focus on medical treatment of this ear disease should not allow us to downplay the profound influence denial of cultural identity continues to have on the overall health of Indigenous Australians. Improvement there requires recognition by all Australians, and particularly the Federal Government, of the history of dispossession, conflict and racial intolerance. 'To understand this history is to build the supports of the bridge that is reconciliation.'⁵

Again, ENT specialists naturally turn their attention to specific interventions – cleaning of infected ears, surgical repair of long term perforations, and use of antibiotics as appropriate, leaving the wider 'standard of living' indices to others. While these medical measures, carefully applied and followed through, are effective for individual children, overall community ear health will improve only when all Indigenous communities, remote as well as urban and rural, have Government support, financial and practical, to supply the following:

- Health Infrastructure Locally accessible health clinics with Indigenous staff able to diagnose and treat Chronic Suppurative Otitis Media.
- Clean water reticulated to houses sufficient for drinking, personal washing, laundry and sewerage.
- Housing, adequate in numbers and size to avoid overcrowding, acknowledging problems associated with home shifting and sharing for cultural reasons – e.g. temporary home abandonment after death of a family member – 'Sorry Business.'
- Carbohydrate reduction in diet, particularly by exclusion of processed sugar.
- Community reduction of smoking, control of access to alcohol and active containment of other drugs of abuse.¹³

Specific Medical Measures Vaccination

Given the almost universal colonization of the nasopharynx of Aboriginal neonates by pneumococcus, there is an emerging and important role for the new pneumococcal vaccine, and this is an area of active research.^{20,21}

Antibiotics

Orally administered antibiotics are effective for acute otitis media but prolonged and repeated courses may be required. Single dose azithromycin is effective for clearance of streptococcus from the respiratory tract but again, colonisation quickly recurs.¹⁴ There is a further compelling reason for treating these bacteria, as skin streptococcal infection of scabies sites are a potent cause of later kidney failure and rheumatic heart disease through the body's immune response to the streptococcus.

Topical Antibiotics applied to the middle ear

My experience with Aboriginal children in the previous Sydney practice and in the rural NSW centre of Brewarrina was that repeated syringing of discharge from the ear canals followed by application of surface medication (steroid with Antibiotic) reliably achieved dry ears. In Brewarrina, nurse Judy Caswell would clear the infection by 2-3 of these once-daily treatments, with repeat course of cleansing if and when discharge recurred. In 2001, a review of all available evidence¹³ found no strong evidence of the efficacy of this topical treatment, and identified the need for further research.

East Arnhem Runny Ears Study – Antiobiotic/steroid drops Joe Daby, senior Aboriginal Health Worker, and I undertook a pilot study coordinated by nurse Jo White in Numbulwar in late 1998 in the Gulf of Carpentaria. That project was quite encouraging with 90 per cent of the ears being clear within three days using syringing followed by Sofradex insufflation technique. Irrigation with Betadine appeared to be quite an effective way to clean out the profuse ear discharge, including insects, preparatory to placement of the Sofradex medication.



Funding was obtained for a larger study to determine the efficacy of ear cleaning, comparing a technique of:

- (a) Dry mopping the ears and placing Sofradex drops with
- (b) A washout technique combined with pushing the Sofradex drops through the hole using a rubber bulb on the otoscope.

This main project was commenced in four communities: Ramingining, Yirrkala and then Galiwinku on Elcho Island and Milingimbi. All were in East Arnhem Land and all involved the same two investigators. Once Joe and I had done the initial treatment over three days, video documenting the progress, a different team came in to reassess the same children a week later, video their ears again and document any improvement. Further assessment was carried out at two months.

In Central Australia, copious pus was common, often containing four or five dead flies. In East Arnhem Land in the Dry season, the discharge tended to be scantier than in Central Australia or even in Numbulwar, further down the Gulf. Because of this drier more viscous discharge, the irrigation was not as useful as cleaning with paper wicks. This paper wick technique is very easy to do: a piece of tissue is rolled in the hands and then placed in the ear canal. (Figure 7 & 8)



Figure 7 Paper wick technique



Figure 8 Paper wick technique

Five or even ten tissue wicks may be required until they come out dry, and it is very easy to demonstrate this to the parents. In this Study, by random allocation, Sofradex drops were placed and either pushed in by (a) gentle finger pressure on the ear canal, or (b) gently blown through the perforation and down the natural tube into the back of the nose. All this was video recorded.

So what did we achieve? The results have been guite interesting, but ultimately disappointing. In the pilot study we had 90 per cent clear within three days. In the East Arnhem Study, about 80% of the ears improved quickly during the week of treatment, but when Peter Morris, paediatrician and coordinator of the study, went back to the communities a week later, only about one third were dry. Also, there was no difference in effectiveness of the two techniques. When the team went back in after two months to the communities, just about all the ears were wet again. Regular intensive treatment can be successful, but occasional intervention is not enough.¹⁶ The challenge now is to demonstrate sustained improvement from regular treatment, to clarify how often that is required and then to transfer those skills to the health workers on site in the communities. This implies regular visits by ear health personnel – nurses, audiologists and ENT specialists – a massive problem, given the vast distances involved, and the isolation of some of these communities.

Surgical Repair of the Eardrum

As many of the children with discharging ears have only small holes in the ear drum, clearance of the discharge can dramatically improve hearing and remove the barrier to learning. In some however, there remains a large hole in both eardrums with significant hearing loss. These children require help either by sound amplification or by surgery to repair the tympanic membrane (Tympanoplasty or Myringoplasty).

Graft breakdown rates are high in young children, so we tend to defer surgery until teenage years or older, but this leaves children with hearing loss in the vital learning years. A recent report on myringoplasty results from the Kimberley region showed at six months after surgery, 53% of ears still had intact eardrums and had achieved good hearing. It did also confirm success was more likely in adults and children over 10 years.¹⁷

Other Sound Measures

Restoring health and hearing is the goal, but other measures are also important:

- Reduction of background noise in the classroom. Wooden floors, scraping chairs, corrugated iron roof and walls, rattling fans or wheezing air conditioner and twenty noisy children – even those with normal hearing struggle under such conditions.
- Effective communication strategies: Some female community elders dealing with children command respect and attention by rank, supported by the language the children understand, in a booming voice if necessary. It can be very difficult for a teacher with a soft voice in English to command attention. Direct eye contact may improve intelligibility, but to insist upon it is to directly invade privacy.
- Hearing Aids worn behind-the-ear are very effective for moderate conductive hearing loss, but there are multiple difficulties employing them effectively in children who may not perceive that there is any problem in hearing their friends or family, and who resist being identified as being 'different' by wearing the aids. The hearing aids will only function when the canal is dry, and this is the time when they are least required. There may be no secure place at home for the device,



which may quickly succumb to the attention of siblings or the family dogs. These are problems familiar to audiologists dealing with children of all cultures, but regular servicing and replacement of the units is particularly difficult in remote communities. The use of bone-conducting hearing aids avoids the pus problem, and holding the aids at school improves their longevity. It does not improve their acceptance.

- The 'Surround Sound' classroom device provides uniform soundfield amplification throughout the classroom, by FM transmission from the teacher's microphone to wall speakers. It can increase the teacher's effectiveness with the entire class, not just those with hearing loss. Other major advantages are that it does not require any student acceptance, it is not damaged by the pus and it does not identify and shame the youngsters with the hearing loss. It is provided through Australian Hearing a great initiative. There are some problems: it requires significant financial input from the school, it does not assist the child once out of the classroom and it requires cooperation, even enthusiasm from the teacher who must remember to wear the microphone, check its function, maintain its battery and check the volume and function of the wall mounted amplifier.
- Personal FM systems are similar to the above but the volume can be tailored to the need of the individuals who wears the receivers, allowing more effective amplification. It has the same demands on the teacher as the surround system but may also arouse resistance in the child, who may be embarrassed by wearing it.



What ENT specialist services are provided at present? 'Where appropriate primary health care interventions have failed, timely referral to otolaryngologists for assessment and surgical interventions can improve hearing outcomes.'¹³ What access to such specialist care is there for children in remote Aboriginal communities?

There are regular outreach clinics organized individually by specialists in each state. Travel and associated costs are sometimes covered by them, or in some cases by state governments, e.g. Rural Health section of NSW Health Department provides air travel to Brewarrina clinics through the Royal Flying Doctor Service. Rural Aboriginals may have access to an ENT specialist in their area, with the referrals facilitated by Aboriginal staff at an AMS Clinic (Aboriginal Medical Service) or by local medical practitioners, but there are many rural and remote communities not served by specialist visits, regular or otherwise.

Northern Territory The director of ENT specialist services in NT, Gus Hunter, and his unit provide operative surgical services in both Darwin and the East Arnhem Hospital at Gove, together with outreach clinics to multiple communities. Joe Daby, Senior Aboriginal Health Worker, chairs the Northern Territory Hearing Program Coordinating Committee, visiting, teaching and working with the wide network of Aboriginal Health Workers. Successful management of discharging ears using several days of treatment, repeated as necessary, must come though the work of these members of the communities – ear health knowledge passed on through same language, same culture, same place.

The Ear Health and Education Unit under Peter Morris, Paediatrician, at Menzies School of Health Research in Darwin is examining the role of polyvalent pneumococcal vaccine in reducing chronic ear discharge, while the role of antibiotics, oral or applied to the ear, is also being studied. While the aim is research to widen the base of 'evidence- based' medicine, the research is accompanied by treatment.

Queensland An excellent outreach program directed by Chris Perry, ENT specialist, stumbled and almost fell due to cessation of funding, but now regular community visits and operating sessions are likely to be resumed to remote communities. Western Australia. In addition to regional and remote clinics provided by ENT specialists in WA, there are a number of promising projects involving mainly private donations:¹⁸

- Lions telemedicine project video otoscopic images of eardrums sent via e-mail from Aboriginal health workers and nurses in remote areas for assessment by ENT specialists in Perth
- Lions Hearing Aid Bank enabling young Aboriginal adults to access hearing aids
- Variety Club touring 'ear bus' with ear nurse specialist for urban and regional communities, with plans for day-surgery Operating Theatre bus for remote areas.

Conclusion

1967 marked an essential step forward in reconciliation. It was in that referendum that Aboriginal people were finally acknowledged as full citizens by other Australians. Faith Bandler, who had worked so hard to see that referendum emphatically endorsed, put it well - "You will not be free until we are..."

"We must remember the past, earn the privilege of the present, and face the future with confidence".

The large number of children with discharging ears and poor hearing, the recurrence after apparent successful treatment, and the deluge of sorry statistics can promote despair. When it seems that nothing works, the tendency is to do nothing - and indeed that does not work.

In the ear clinic at the Aboriginal Medical Service at Redfern, when progress seemed slow, the answer was to focus, to concentrate on one child with chronic ear discharge, to work with the mother to give whatever time and follow up was necessary to get that lad's ear dry, grafted and healed. Whatever it took - for the good result gave energy to us, joy to the mother and self confidence to the child.



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Notes





Libby's Story



Libby's story is one of courage and triumph over adversity by utilising the knowledge of her own severe hearing loss to help others.

Libby started to lose her hearing following a bad dose of flu in the English winter soon after her marriage in 1969. Having returned to Australia in 1970 she began to find difficulty in understanding conversation and instructions, particularly on the telephone which was very important in her profession of pharmacy.

In spite of advice to the contrary, Libby tried hearing aids and found they helped. Had she heeded the negative advice, Libby believed she might never have embarked on the road to self-help, which so enriched her own life and that of many others.

She thought her two boys quickly learnt to sleep through the night and her friends remarked they had loud voices, which was the boys' mechanism for coping with a deaf mother!

The more the doctors said nothing could be done to help, the more Libby looked towards self help and so she learnt to lip read, a tool she relied on heavily in her quest to help others.

Libby's will to win led her, with the help of others, to get involved with the setting up of a support group, which became SHHH – Self Help for Hard of Hearing people. The American founder, Rocky Stone, was invited to Australia in 1982 and did a lecture tour entitled "The Hurt That Does Not Show" which cemented the bonds between the US and Australian groups and helped the local SHHH develop.

Libby, with others, then began SHHH News, a quarterly publication, and with Bill Taylor set up the first Hearing Information and Resource Centre at "Hillview", Turramurra with support from Hornsby/Kuringai Hospital. This centre provided reliable information on, and demonstrated, assistive listening devices for hearing impaired people. Through this interest, Libby became an enthusiastic user of technology and with her handbag full of electronic aids was enabled to join in a full social life with family and public.



Libby became President of SHHH in 1986 and began to develop her role as an advocate for hearing impaired people generally. She became involved in ACCESS 2000, under the Australian Deafness Council, and a member of the Disability Council of NSW. Her horizons broadened further as Vice President of the Australian Deafness Council and then as the first, and two terms, President of the newly formed national peak body in deafness, the Deafness Forum of Australia. In this latter role Libby made a huge contribution to bring together all the different organisations into a central body, and actively lobbied on behalf of Deaf and hearing impaired at the highest level – the archetype of a successful achiever despite her profound hearing loss.

For her work on behalf of hearing impaired people Libby was made a Member of the Order of Australia in 1990. Later she was appointed by the Government to the Board of Australian Hearing Services and was asked to represent the needs of hearing impaired on the Olympic Access Committee.

Unfortunately, Libby faced another hurdle when she was diagnosed with breast cancer in 1995. Following surgery, she continued her family and volunteer work with undiminished vigour. She would wickedly show off her wig at public functions after her chemotherapy, and talked openly of her "mean disease". She died peacefully on 1 August 1998 and was honoured by hundreds who attended her Thanksgiving Service on 6 August.

In her own words, Libby related her outlook:

"I look back over these years since I became hearing impaired and realise that any efforts that I have made have been returned to me threefold. I have found talents I never knew I had, I have gained so much from the many people I have met and worked with to improve life for people with disabilities and through self help I have turned the potential negative of a profound hearing loss into a positive sense of purpose and direction in my life".



Introduction

Deafness Forum is the peak body for deafness in Australia. Established in early 1993 at the instigation of the Federal government, the Deafness Forum now represents all interests and viewpoints of the Deaf and hearing impaired communities of Australia (including those people who have a chronic disorder of the ear and those who are DeafBlind).

Structure

The representational base of the Deafness Forum is divided into five Sections:

- a) Hearing Impaired Section persons with a hearing loss who communicate predominantly orally,
- b) Deaf Section i.e. the Deaf Community those persons who consider themselves to be members of that community by virtue of its language (sign language known as Auslan) and culture,
- c) Ear Disorders Section persons with a chronic ear disorder (such as Tinnitus, Meniere's Disease or Acoustic Neuroma) and
- Parents section parents or legal guardians of persons who are Deaf or hearing impaired,
- e) Service Providers section service providers to the Deaf and/or hearing impaired communities.



Objectives

The Deafness Forum exists to improve the quality of life for Australians who are Deaf, have a hearing impairment or have a chronic disorder of the ear by:

- advocating for government policy change and development
- making input into policy and legislation
- generating public awareness
- providing a forum for information sharing and
- creating better understanding between all areas of deafness.

Community Involvement

The Deafness Forum is consumer-driven and represents the interests and concerns of the entire deafness sector, including:

- the Deaf community
- people who have a hearing impairment
- people who have a chronic ear disorder
- the DeafBlind community
- parents who have Deaf or hearing impaired children in their families

The Libby Harricks Memorial Oration program is supported by the Libby Harricks Memorial Fund of the Deafness Forum of Australia. Donations to this fund are tax deductible. Please see enclosed donation form for full details.

Donations should be made payable to Deafness Forum. Additional donation forms and general information regarding deafness can be obtained from:

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Notes





