



USHER SYNDROME INFORMATION KIT

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FOREWARD

Many people, including doctors and other health professionals, have never heard of Usher syndrome. In the past there was very little information or support available for people with Usher syndrome and their families. While more information and support is now available, there remains a need to increase awareness, networks of support and services specifically for people with Usher syndrome and their families.

In 1992 funding was granted by the ANZ bank for an Usher syndrome Project which found that people with Usher syndrome required more information about all aspects of the syndrome and as a result, an “Usher’s Information Kit” was developed. The term “Usher’s” was used as this term is used interchangeably with the term Usher syndrome and was more popular at that time. This kit was revised several times with assistance from Myra Homes from the Retinitis Pigmentosa Society of Victoria and Teresa Cumpston-Bird from the Victorian Deaf Society. The last revision of the Usher’s Information Kit was undertaken in 2007. For information about the Usher syndrome Project conducted in 1992 contact the Manager Deafblind Services at Able Australia.

With the development of Usher Kid’s Australia, it was recognised that the existing Usher’s Information Kit:

- did not provide adequate or current information for families with children diagnosed with Usher syndrome
- had out of date information for adults with Usher syndrome
- did not address the varying issues facing people with Usher syndrome and their families depending on age of diagnosis

Funding was granted by the Australian Communities Foundation in January 2016 to develop this new Information Kit to address the lack of a current and single information source for:

- families of children with Usher syndrome
- adults with Usher syndrome
- professionals working with children and adults with Usher syndrome

It is important to note that services and governments change, as do intervention approaches as new research is undertaken. Every effort was made to ensure that information in this kit was current at the time of publication, however it is important to check for yourself to ensure the information is still current at the time of reading.

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HOW TO USE THIS INFORMATION KIT

This kit is designed to be used by different people including people with Usher syndrome, families of children with Usher syndrome and professionals working with people with Usher syndrome. The sections at the start of the kit have relevance to all of these groups, and the later sections have information specific for:

- adults with Usher syndrome
- parents and family members
- professionals

All sections may be of interest and relevance to people from each of these groups at different times.

WHAT IS DEAFBLINDNESS?

While many people with Usher syndrome do not consider themselves to have deafblindness as they have good functional vision and hearing, there is value in recognising that the term "deafblind" refers to any degree of combined vision and hearing loss, sometimes called dual sensory impairment.

While it is entirely up to individuals and their families whether they consider themselves to have deafblindness or not, there is generally value in receiving services from organisations who specifically work with people with deafblindness.

These organisations will have staff with a greater understanding of the implications and impact of dual sensory impairment than single sensory or more general disability services. People with Usher syndrome may also gain practical and emotional support, and a reduced sense of isolation by connecting with others with dual sensory loss who experience similar daily challenges, even if their deafblindness is not caused by Usher syndrome.

Deafblind International (Deafblind International, n.d.) use the following description to define deafblindness: "The term deafblindness describes a condition that combines in varying degrees both hearing and visual impairment. Two sensory impairments multiply and intensify the impact of each other creating a severe disability which is different and unique.

All people who are deafblind experience problems with communication, access to information and mobility. However, their specific needs vary enormously according to age, onset and type of deafblindness.

People who are deafblind are unable to use one sense to fully compensate for the impairment of the other. Thus they will require services which are different from those designed exclusively for either people who are blind or people who are deaf."

WHAT IS USHER SYNDROME?

Usher syndrome is the most common genetic cause of combined hearing impairment and vision impairment. More than 400,000 people are affected by this disorder worldwide. It was previously estimated that 3 - 6% of children born deaf have Usher syndrome, however these estimates focus on children with Usher type 1 and not Usher types 2 and 3.

Kimberling et al (2010) found 11% of all children diagnosed with a hearing impairment carried a gene for Usher syndrome and it is now estimated the prevalence may be as high as one in 6,000.

Usher syndrome is a genetic condition characterised by hearing loss or deafness, the progressive loss of vision and in some cases, vestibular dysfunction. The loss of vision is caused by an eye disease called Retinitis Pigmentosa (RP), which affects the light sensitive area of tissue on the back of the eye (the retina).



Although Usher syndrome brings challenges, people with Usher lead fulfilling and independent lives. People with Usher can and do have relationships, get married, have children, go to university, travel, go to work and enjoy numerous leisure pursuits.

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There are three main types of Usher syndrome - Type 1, Type 2 and Type 3. Each of these types has a number of different genes responsible for causing the syndrome.



TYPE 1:

- Type 1 is comprised of 5 different subtypes; 1B, 1C, 1D, 1F and 1G depending on the specific gene mutation.
- People diagnosed with Usher syndrome type 1 are profoundly deaf at birth and have a dysfunctional vestibular system.
- Due to the vestibular dysfunction, a child with Usher syndrome type 1 will usually take longer to sit up and develop walking at a later stage than a typically developing child.
- Gradual vision loss occurs due to Retinitis Pigmentosa (RP). The severity and onset of RP varies between individuals but commonly develops before the age of 10. Vision problems are initially characterised by night blindness or tunnel vision but this also varies between individuals.

TYPE 2:

- Usher syndrome type 2 can be grouped into 3 subtypes, 2A, 2C and 2D.
- In Usher syndrome type 2, the severity of hearing loss from birth can range from very mild to severe. Those with Usher syndrome type 2 do not have a dysfunctional vestibular system.
- Vision loss due to the RP does not usually develop until late adolescence or in some cases until the late twenties.



TYPE 3:

- Usher syndrome type 3 is very rare compared to the other Usher syndrome types and only one subtype has been discovered so far, with the majority of people with USH3 living in Finland.
- A person with Usher syndrome type 3 is born with normal hearing and close to normal balance, however hearing gradually deteriorates with age.
- A measurable hearing loss usually occurs by puberty and vision starts to deteriorate during the teenage years and may progress during life.

Information from What is Usher syndrome? (Usher Syndrome Coalition (n.d.a), What is Usher Syndrome? (Usher Kids Australia, n.d.), What is Usher Syndrome (Sense, 2016), and Usher Syndrome Type 1 (Lentz, J. & Keats, B. J. B., 2016).

GENETICS OF USHER SYNDROME

Usher syndrome is a genetic disorder and is inherited in an 'autosomal recessive' manner. Basic inheritance genetics tells us that:

- Each person receives 23 chromosomes from each parent: 22 being non-sex (autosome) chromosomes and one sex chromosome to give a total of 46 chromosomes.
- These 46 chromosomes are located in every cell in the human body and contain the approximately 20,000 genes which act as blueprints for how our bodies grow, develop and function.
- Mutations in at least ten different genes are known to cause Usher syndrome, although in each family, only one of the Usher syndrome genes is involved.
- Usher syndrome occurs when a child inherits two faulty copies of an Usher syndrome gene, one from each parent. This is called autosomal recessive inheritance.
- For a couple to have a child with Usher syndrome, the mother and father must both be 'carriers' of a fault on the same Usher syndrome gene. Carriers of Usher syndrome also have one functioning copy of the Usher syndrome gene, and therefore are healthy (and do not have Usher syndrome).
- When both parents are carriers of a fault on the same Usher syndrome gene, each child has a 1 in 4 (25%) chance of having Usher syndrome, a 1 in 2 (50%) chance of being a carrier of Usher syndrome (like the parents) and a 1 in 4 (25%) chance of being neither affected by Usher syndrome nor a carrier of Usher syndrome.

Information from What is Usher Syndrome? (Usher Kids Australia, n.d.)

DIAGNOSIS

It is important to consider Usher syndrome in any child who is having considerable problems hearing, since this may be evident before the symptoms of vision impairment caused by RP develop. Early diagnosis in children is important so that a child's developmental and educational needs can be met. Figures from the USA and Scandinavia suggest that 3 to 6% of all people born deaf have Usher syndrome. In Victoria, a recent survey of people with RP showed that 8% have Usher syndrome.

While in the past diagnosis normally included extensive hearing and vision assessments, diagnosis in children is now undertaken primarily through genetic testing. Anecdotally, diagnosis can take longer for adults who may not be aware that their vision is deteriorating, and think accidents which occur as a result of reduced peripheral vision, are due to clumsiness.

Information from Early Diagnosis Is Critical for Children with Usher syndrome (Dunning, M. n.d.), and Usher Syndrome – Symptoms and Causes (Retina Australia, n.d.)

GENETIC TESTING AND GENETIC COUNSELLING

Genetic testing is the only way of getting a definitive diagnosis of Usher syndrome. Genetic testing usually involves having a sample of your blood or tissue taken. The sample will contain cells containing your DNA and can be tested to find out whether you are carrying a particular mutation and are at risk of developing a particular genetic condition.

There are increasing numbers of private providers of genetic testing. It is recommended that genetic testing is undertaken by a service which also offers genetic counselling and provides follow up information and support as this process can be very stressful for families and involves the extended family also.

Genetic counselling provides an individual or family with information and support regarding health concerns which run in their family. Genetic counselling may involve the diagnosis of a genetic condition, the provision of information and supportive counselling (advice and guidance) by a team of health professionals, so that families and individuals may be better able to adjust to diagnosis.

Follow-up counselling is available to ensure on-going support, review previous information or to answer new questions as they arise.

Adapted from What is Genetic Testing? (Centre for Genetics Education, 2014), Genetics – Genetic Testing and Genetic Counselling (National Health Service, 2014), and Get genetic testing for Usher Syndrome (Usher Syndrome Coalition, n.d.)

COMPONENTS OF USHER SYNDROME

SENSORINEURAL HEARING LOSS

The term sensorineural hearing loss describes two different problems: sensory loss involving the inner ear and neural loss involving the hearing nerve.

In the past, sensorineural hearing loss was referred to as "nerve deafness". In most cases the problem stems from the inner ear rather than from the hearing nerve. However, the two problems are grouped together, because the inner ear and the hearing nerve are connected and need to work together.

The 'downstream' neural parts of the hearing system need input from the 'upstream' sensory parts in order to grow and stay healthy.

Congenital hearing loss resulting from Usher syndrome is present at birth
Adapted from Sensorineural hearing loss (Cochlear n.d.a)

RETINITIS PIGMENTOSA

Retinitis Pigmentosa causes cells in the light-sensitive retina, located at the back of the eye, to degenerate slowly and progressively. The condition can vary greatly in onset and progress.

Generally, symptoms develop between the ages of 10 and 30 years. Some of the first symptoms may include the following:

- difficulty seeing at night or in dimly lit areas (night-blindness)
- a narrowing field of vision known as tunnel vision
- light and glare sensitivity

Information from Retinitis Pigmentosa (Vision Australia, n.d.)

VESTIBULAR DISORDER

Usher syndrome Type 1 causes vestibular dysfunction. The vestibular system includes the parts of the inner ear and brain that process the sensory information involved with controlling balance and eye movements. In addition to impairments of motor development and balance, vestibular deficits may also cause poor gaze stability that impacts on children's ability to learn to read.

People with Usher syndrome Type 2 have also reported experiencing disequilibrium (loss of steadiness, or imbalance) and vertigo. Benign Paroxysmal Positional Vertigo (or BPPV) is the most common cause of vertigo, a false sensation of falling or spinning.

Benign – it is not life-threatening

Paroxysmal – it comes in sudden, brief spells

Positional – it gets triggered by certain head positions or movements

Vertigo – a false sense of rotational movement

BPPV is a mechanical problem in the inner ear. It occurs when some of the calcium carbonate crystals (otoconia) that are normally embedded in gel in the utricle become dislodged and migrate into one or more of the 3 fluid-filled semicircular canals, where they are not supposed to be. When enough of these particles accumulate in one of the canals they interfere with the normal fluid movement that these canals use to sense head motion, causing the inner ear to send false signals to the brain.

Information from About vestibular disorders (Vestibular Disorders Association, n.d.)



LIVING WITH USHER SYNDROME

This section outlines the hearing, vision and psychosocial effects of Usher syndrome and some of the strategies and approaches used to address these.



EFFECTS OF DEAFNESS AND HEARING IMPAIRMENT

The terms both deaf and hearing impaired are used here to distinguish between those who have profound deafness and communicate using sign language and those with a mild to severe hearing impairment who communicate orally and aurally. Again it is recognised that it is up to individual preference how people identify themselves, and the terms they choose to describe their deafness or hearing impairment. Please also note that while here the term "deaf" with a lower case "d" is being used, many people who are deaf prefer to use the term "Deaf" with a capital "D" to denote their cultural identity as a member of the Deaf community.

Deafness and hearing impairment can have a range of consequences if not addressed. The effects of hearing loss differ from person to person, but most people with deafness or hearing impairment experience some social, psychological and physical issues as a result of their deafness or hearing impairment.



The psychological effects of hearing loss can include problems concentrating, anxiety, depression and low self-esteem. Physical consequences can include headaches, tense muscles, stress and increased blood pressure. There can also be social consequences which can include isolation and communication problems.

Specific issues which can arise from a mild to severe hearing impairment include difficulty hearing:

- the radio and television
- announcements over public address systems
- in background noise such as at shopping centers and noisy cafes
- in group conversations

Adapted from Effects of hearing loss (Hearnet Online, n.d.a)

HEARING IMPAIRMENT INTERVENTION

HEARING AIDS

Hearing aids are electronic devices worn by people with mild to profound Hearing Loss. They use a microphone to detect sounds that are then changed and amplified to comfortable levels to help wearers hear better. It's important to note hearing aids do not restore hearing back to normal. Instead, they provide the wearer with better access to sounds and an improved ability to understand speech.

Making the decision to have hearing aids is only a small part of the hearing loss management journey to have better hearing. An audiologist can work with you to help your brain to make sense of the new information being sent by the hearing aids.

Some adults with Usher syndrome who do not have adequate hearing to receive speech sounds still wear hearing aids to detect environmental sounds such as traffic and closing doors. Hearing these sounds can help people feel more safe and secure.

Adapted from Hearing aids (Hearnet Online, n.d.b)

COCHLEAR IMPLANTS

A cochlear implant is a device that replaces the function of the inner ear of people who are deaf or have moderate to profound hearing impairment and receive little or no benefits from wearing hearing aids. Unlike hearing aids, which make sounds louder, cochlear implants do the work of damaged parts of the inner ear (cochlea) to provide sound signals to the brain.

Many people have cochlear implants in both ears (bilateral). Listening with two ears can improve ability to identify the direction of sound and separate the sounds you want to hear from those you don't.

One of the largest differences between adults with Usher syndrome Type 1 and children born with Usher syndrome Type 1 now is that most adults do NOT have cochlear implants as these are a more recent development. These adults grew up deaf and their primary communication method is Auslan (sign language used by the Australian Deaf Community). Children born with Usher syndrome Type 1 now will typically receive cochlear implants in infancy and grow up with speech as their primary means of communication.

Some adults with Usher syndrome Type 1 do have cochlear implants but as they received these later in life, they do not use them to understand speech, but rather to detect environmental noises such as traffic and doors closing. Hearing these sounds can assist people to feel more safe and secure.

Adapted from Cochlear implants and cochlear implant technology (Cochlear, n.d.b)

OTHER INTERVENTION FOR HEARING IMPAIRMENT

Early childhood educators and teachers trained in working with children with hearing impairments, audiologists and speech pathologists all provide support and intervention for children to develop speech and listening skills. For older children and adults audiologists and technical support staff can recommend adaptive listening devices for school, work and social contexts as well as aural rehabilitation advice and information.

There is value in connecting with support groups or joining mailing lists of services for people with hearing impairments to keep up to date with the latest technologies and services available to improve access to communication for people with hearing impairments.

EFFECTS OF VISION IMPAIRMENT

NIGHT BLINDNESS:

One of the first indications that a person with Usher syndrome's vision is affected is the onset of night blindness. Signs of night blindness include:

- being unable to see when coming in from bright sunlight
- tripping over things when the light changes or light is dim
- staying near a light in a dark room or at night
- moving a person speaking to them so light falls on their face
- avoiding conversations in a darkened area
- staggering or losing balance after an oncoming car has passed if walking outdoors at night
- problems reading in dimly lit areas

GLARE SENSITIVITY:

People with Usher syndrome also commonly experience glare sensitivity. Signs of glare sensitivity include:

- squinting and shading eyes in bright light
- complaining that the light hurts their eyes
- wearing sunglasses even inside, but especially in bright sunlight
- avoiding participating in outdoor activities when the sun is very bright
- stopping abruptly when transitioning from inside to outside a building (when faced with bright light)

Strategies to minimise the impact of glare are:

- wear sunglasses in bright environments
- wear peaked caps in bright environments
- allow time for eyes to adjust when moving from one environment to another
- close blinds and curtains to reduce glare from windows
- position person with Usher syndrome with their back to the source of the glare

Adapted from Information about Usher Syndrome (Texas School for the Blind and Visually Impaired, 1996)



VISION IMPAIRMENT INTERVENTIONS

ORIENTATION AND MOBILITY

People with retinitis pigmentosa will experience issues with orientation and mobility resulting from restricted visual fields, issues with glare and night blindness and will benefit from working with an orientation and mobility specialist. Orientation and mobility specialists can assist with:

- choosing an appropriate mobility aid, such as a long cane
- training in use of mobility aids
- safe travel at night time
- using residual vision to optimise safety and independence
- catching public transport
- learning the best way to get to school, work, community facilities or other places you want to travel to regularly
- getting assistance when travelling alone
- environmental assessments for school and work
- information for family and friends

OTHER INTERVENTIONS FOR VISION IMPAIRMENT

There are a number of services available specifically for people with vision impairment which people with Usher syndrome may benefit from over the course of their lives. In addition to orientation and mobility, these include braille training, support from visiting teachers with specialist knowledge in vision impairment training in use of adaptive technology, occupational therapy to develop independence in daily activities, and access to relevant information and advocacy. These areas are covered in more detail in later sections.

PSYCHOSOCIAL IMPLICATIONS

Usher syndrome has long term psychosocial implications for both the person with Usher syndrome and their family and social networks. Initially families need to come to terms with the diagnosis and will benefit from undertaking genetic counselling to better understand the genetic nature of the syndrome. Families face the challenge of how they tell their extended family networks as well as members of the immediate family and the psychological and practical implications for all of them. Also, having many medical and therapy appointments can be time consuming and challenging to coordinate with family life.

Times of transition can be particularly difficult for people with Usher syndrome. These transitions may include starting school, entering the work force, changes in employment, changing roles within families, and parenting. Preparing for times of change and transition can help to reduce the psychosocial impact of these challenging times.

Seek support from professionals experienced in working with people with dual sensory loss, as well as from those who may have been through a similar situation and can share insights from their own experience. Making connections with support groups, networks, peers and mentors can significantly reduce the isolation experienced by those with a rare syndrome and can lead to long term practical and emotional support, particularly at challenging times.

In later years individuals are likely to experience grief and loss as their vision deteriorates as well as potential embarrassment and stigma due to requiring special aids and equipment.

Developing positive coping strategies for managing stress and challenging situations will be valuable and can be worked on with a psychologist or counsellor.

The list of organisations at the end of this document includes some groups in Australia who can provide links to support networks including Usher Kids Australia and Deafblind Australia. There are also increasing numbers of Usher syndrome and deafblind specific groups and blogs on social media which can provide useful information and support.

RESEARCH

Many research groups both in Australia and overseas are trying to better understand Usher syndrome. This section focuses predominantly on medical research, but has a section at the end on non-medical, social research.

GENE-SPECIFIC GENE THERAPY TRIALS

This is where a good copy of the gene is inserted into the eye to repair or increase the function of the gene.

In the USA, patients are being enrolled in an early trial that will evaluate the safety and effectiveness of a therapy for people with Usher Type 1.



STEM CELLS

Stem cells have the potential to be turned into many different cell types i.e. heart, nerve, eye tissue. There are two kinds of stem cells from humans:

1. embryonic stem cells
2. non-embryonic "adult" stem cells which have originated from human tissue such as an individual's skin sample.

The use of stems cells obtained from “skin” samples do not have the same ethical issues as the use of embryonic stem cells.

Skin samples from individuals with specific eye problems are grown in the laboratory, turned into stem cells and reprogrammed to become retinal tissue i.e. rods and cones which are damaged in RP.

This allows researchers to study the cells at the back of the eye without actually needing to take a sample from the eye.

This will help researchers better understand how Usher syndrome occurs, possibly develop new treatments and test new drugs that might minimize vision and/or hearing loss.

There are other emerging stem cell technologies. Using genetic “cut-and-paste” technology, researchers can cut out “genetic changes” and replace it with a healthy piece of DNA. Researchers are hopeful that one day this could be used to reverse these genetic/DNA changes and essentially stop further vision loss.

Stem cells also offer the potential for cell replacement therapy. At present early human clinical trials have commenced using both embryonic and skin derived stem cells for types of Retinitis Pigmentosa. This would benefit those people in whom the retinal layer is lost, damaged, or not working.

DRUG THERAPY

Early human clinical trials using drug therapy for Retinitis Pigmentosa are also underway. Rescula (isopropylunoprostone eye drops) and Valproic Acid are being tested to assess their effectiveness and safety.

MEDICAL TECHNOLOGY / BIONIC EYE

These advanced technologies use very small implants which either sit on or under the retina, or at the back of the head. This form of technology is more suitable for people with advanced RP (barely able or unable to see light) in both eyes.

There are several research groups in Australia involved with this work.

You can read more about the progress of their research here:

<http://www.bionicsinstitute.org/research/bionic-vision/Pages/bionic-vision.aspx>
<http://www.monash.edu.au/bioniceye>

INFORMATION FOR THOSE DIAGNOSED MANY YEARS AGO

There is a misconception that “nothing can be done and so there’s no reason for ongoing eye specialist care”. Whilst glasses may not make your vision much better, they can help your vision to be the best it can be.

Low vision aids and technology can help you best use your remaining vision.

People with Usher syndrome or Retinitis Pigmentosa can be prone to swelling of the macula (affecting central vision) or developing a cataract. Treatment for these conditions is available if needed and may make some difference.

Ongoing follow up with your eye specialist is important to ensure you have access to all the necessary social supports, education, and services that are available.

WHAT YOU CAN DO

Knowing the genetic change(s) causing your RP is an important first step. It is important to undertake genetic testing to assist in research and if you are interested in being involved in clinical trials (O'Donnell, n.d.).

It is advisable to investigate avenues for genetic testing with either your eye specialist, genetic eye clinic or genetic testing service in your State. See support services listed at the end of this kit for services in your area. You can register with the Australia Wide Inherited Retinal Disease Register <http://irdregister.org.au>

Stay in touch with your eye specialist and/or genetic eye clinic in your state, as this can help researchers identify potential participants for future clinical trials which will come to Australia.

Participate in research studies, as it is only through research that we will eventually develop new treatments. Environmental factors such as smoking, drinking alcohol in excess and a poor diet contribute to further vision loss. A good healthy and well balanced diet are recommended.

Further information:

The Usher Syndrome Coalition, and Usher Kids Australia keep people with Usher syndrome and their families notified of any progress made in research into Usher syndrome. Go to:

<http://www.usher-syndrome.org/what-is-usher-syndrome/>

and

<http://www.usherkidsaustralia.com/research.html>

Adapted from Usher Syndrome, with an eye research perspective (Royal Victorian Eye and Ear Hospital, 2015)

PSYCHOSOCIAL RESEARCH

It is important to note that as well as medical research there is much psychosocial research occurring around the world which involves people with Usher syndrome or deafblindness in general. Studies and topics of research include International Study of Support and Sensory Loss, Parenting with Usher syndrome, experience of children of parents with Usher syndrome, mental health of people with deafblindness, tactile sign language, and other topics relating to the lived experience of people with Usher syndrome or those with dual sensory loss / deafblindness. For more information about current research contact the Deafblind International Research Network <http://www.deafblindinternational.org/networks.html>

FUNDING AND SERVICES

GOVERNMENT BENEFITS AND PAYMENTS

There are a number of different funding options provided by the Federal Government to support people with disabilities and their families and carers. You and your family may be eligible for payments such as Disability Support Pension – Blind, Mobility Allowance, Carer Payment, Carer Allowance, Carer Adjustment Payment, Carer Supplement. More information about available funding and eligibility can be found through the Department of Social Services. Changes to government departments and funding are made from time to time so please check with government departments or service providers for most current information. For information about Department of Social Services Benefits and Payments current at July 2016 go to: <https://www.dss.gov.au/about-the-department/benefits-payments>

BETTER START FOR CHILDREN WITH A DISABILITY

The Better Start for Children with disability initiative provides funding for early intervention services for children with certain disabilities including deafblindness. Children eligible for Better Start must be under the age of 6. Children registered with Better Start can access up to \$12,000 (maximum \$6,000 per year) to pay for early intervention services and specialist equipment. These services include:

- audiology
 - occupational therapy
 - orientation and mobility
 - orthoptics
 - physiotherapy
 - psychology
 - speech pathology
- As the National Disability Insurance Scheme (NDIS) is rolled out across Australia, children supported through Better Start will transition to the National Disability Insurance Scheme (NDIS). See below about the NDIS.

For more information about Better Start see: <http://betterstart.net.au/>



NATIONAL DISABILITY INSURANCE SCHEME

The National Disability Insurance Scheme (NDIS) is the new way of providing individualised support for people with disability, their families and carers in Australia. The NDIS provides eligible people a flexible, whole-of-life approach to the support needed to pursue their goals and aspirations and participate in daily life. The NDIS is rolling out in stages across Australia until its full implementation in 2018. For more information about the NDIS including when it will be rolled out in your area go to: www.ndis.gov.au

MY AGED CARE

The My Aged Care website has been established by the Australian Government to help people navigate the aged care system. My Aged Care is part of the Australian Government's changes to the aged care system which have been designed to give people more choice, more control and easier access to a full range of aged care services.

My Aged Care is made up of a website and a contact centre which provide information on aged care for yourself, a family member, friend or someone you're caring for.

You can expect My Aged Care staff to provide: information in languages other than English if you need an interpreter and in other formats if you request it. You can receive help to find Government-funded aged care services and prompt resolution of any complaint or concern you have with My Aged Care. My Aged Care can help you find information about the services you need and what you need to do to receive them.

For more information go to: <http://www.myagedcare.gov.au>



THERAPY CHOICES

The Therapy Choices website was developed to help people with a disability and their families, better understand the roles of the many allied health professionals/therapists who are available to provide supports under the NDIS. The information in this site is equally relevant to those with disabilities not in the NDIS also. This site also provides examples of national not-for-profit organisations and government programs which support daily living activities.

<http://www.therapychoices.org.au/index.html>

SERVICES

As a person with Usher syndrome you will require a variety of different specialist services. For a list of services relevant to people with vision and hearing impairments, deafblindness and genetic disorders please see the end of this document.

ADVOCACY

Having a disability or a family member with a disability means that at certain times you will need to advocate for your own, or your family members needs to be met. This may include being able to access a public or community facility or a public or private service or business and could include lighting, tactile ground surface indicators, accessibility of printed or other visual information, or face to face communication. Sometimes it is helpful to discuss an advocacy issue or get support in dealing with the situation with someone experienced in advocacy. You may also wish to raise an issue with an advocacy organisation to follow up with systemic advocacy to make a situation better for many people who experience the same issue as you do.

For a list of organisations that provide advocacy specific to people with sensory disabilities, please see the list of services at the end of this document.

DISCRIMINATION

Australia has laws to protect people from being discriminated against on the basis of age, race, gender and disability. If you believe you or your family member has been discriminated against because of a disability, you can get information and advice or make a claim of discrimination by contacting the Equal Opportunity or Human Rights Commission in your State. See list below:

National

<https://www.humanrights.gov.au/>

Australian Capital Territory

<http://hrc.act.gov.au/>

New South Wales

<http://www.antidiscrimination.justice.nsw.gov.au/>

Northern Territory

<http://www.adc.nt.gov.au/>

Queensland

<https://www.business.qld.gov.au/business/employing/employee-rights-awards-entitlements/anti-discrimination-eeo>

South Australia

<http://www.eoc.sa.gov.au/>

Tasmania

<http://equalopportunity.tas.gov.au/>

Victoria

<http://www.humanrightscommission.vic.gov.au/>

Western Australia

<http://www.eoc.wa.gov.au/>

INFORMATION FOR ADULTS WITH USHER SYNDROME

EDUCATION

If you are interested in undertaking training or study after you finish secondary school, most tertiary institutions such as TAFEs and universities have a service specifically for students with disabilities to help them access their course and complete the assessments required. These services are sometimes called the Disability Liaison Unit or Disability Support Services. A staff member will work with you and your teachers to help work out the best way you can access the course and meet the course requirements. Things to consider may include need for interpreters, receiving power point presentations or class notes in advance, additional time for assignments or exams, and disability awareness education for teachers and students about your specific needs.

EMPLOYMENT

There are many disability employment services around Australia in both regional and metropolitan areas. These services can provide assistance in determining skills and training needs, developing job readiness, and in job seeking. For information about employment services for people with disabilities see <https://disabilityemployment.org.au/>

If you are starting a job or have a job and require funding for interpreters or specialist equipment in order to be able to do your job, you can apply for funding through Job Access. See <http://www.jobaccess.gov.au/about-jobaccess>



PROFESSIONALS YOU MAY SEE

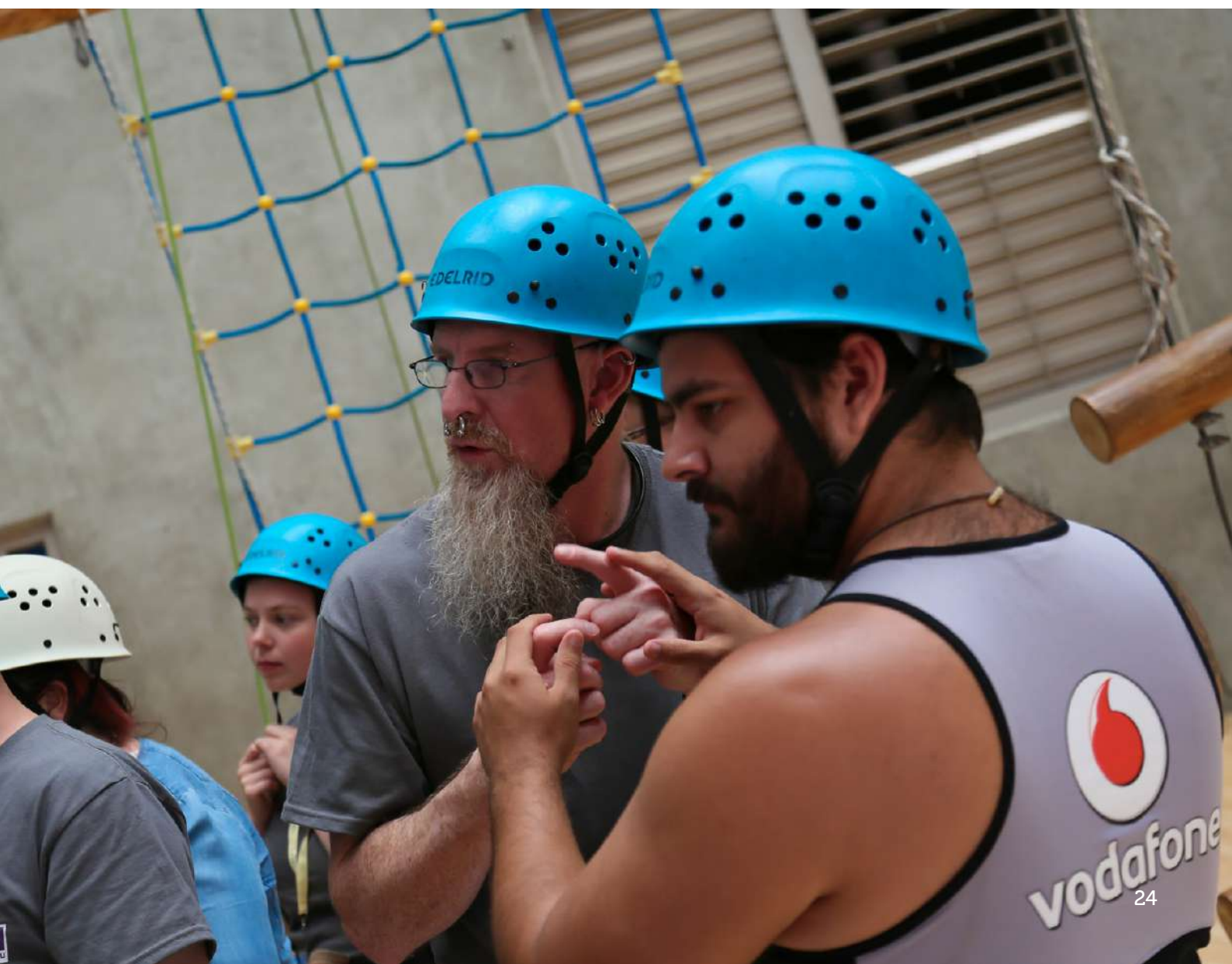
DEAFBLIND CONSULTANT

While the term “deafblind consultant” is more common outside Australia, there are some deafblind consultants in Australia, predominantly in Western Australia. There are some professionals who do the role of a deafblind consultant, but may have a different title such as case manager. Deafblind consultants work specifically with people with dual sensory loss and have a good understanding of the impacts of a combined vision and hearing loss, such as the need to use specific communication methods, strategies and techniques, and the need for orientation and mobility support. They can link people with Usher syndrome with appropriate services and networks, and can anticipate and advocate for appropriate adjustments needed in class rooms, work places and other settings to ensure the person with Usher syndrome has full access.

DEAFBLIND COMMUNICATION GUIDE

Deafblind communication guides, also known as intervenors, and support workers, have specific skills in supporting people with dual sensory loss to access their environment. This may include support dealing with mail, attending medical appointments, doing grocery and other shopping, attending special events such as weddings, funerals, or parties, and support accessing recreational facilities such as swimming pools, sporting events or anywhere the person with Usher syndrome or deafblindness wants to go.

While deafblind communication guides are often fluent in Auslan, they should not be booked as a substitute for an Auslan interpreter. Typically a deafblind communication guide and an interpreter would be booked for meetings or medical appointments. The deafblind communication guide will often provide transport support and orientation and guiding on arrival, and the interpreter is responsible for interpreting what is said and signed during the appointment. The person with Usher syndrome may debrief with the deafblind communication guide after the appointment.



AUDIOLOGIST

Audiologists provide clinical services in hospitals, community health centres, hearing aid clinics, private practice, university clinics and in some medical practices. Audiologists are hearing health practitioners who provide services to people of all ages, from babies to older adults. Audiologists also provide advice to other practitioners and organisations about hearing care. You can get information about hearing aids and other amplification devices from an audiologist.

See <http://audiology.asn.au/index.cfm/consumers/learning-about-audiologists/what-is-an-audiologist/>

BRAILLE INSTRUCTOR

Braille is a system of raised dots that can be read with the fingers by people who are blind or who have low vision. Braille is not a language, it is a code in which many languages, including English, can be written and read. Learning braille is a personal choice and is typically only undertaken by adults with Usher syndrome once their vision has deteriorated to the point that reading print has become extremely difficult. There are not a lot of braille instructors in Australia. To locate your nearest instructor, contact your local deafblindness or blindness service. See services listed at the end of this kit.

EAR NOSE AND THROAT SPECIALIST

An ear, nose and throat specialist (ENT), also called an otolaryngologist, is a doctor trained in the medical and surgical treatment of the ears, nose throat, and related structures of the head and neck. An ENT will be involved in the correct diagnosis of hearing loss and also in the surgery required for a cochlear implant. Getting a cochlear implant is a personal choice and many adults with Usher syndrome who have grown up culturally Deaf will choose not to get a cochlear implant. See <http://www.entassociates.com/what%20is%20an%20ent.htm>

GENERAL PRACTITIONER / DOCTOR

It is recommended that you find a general practitioner (GP) you feel comfortable with. If you use an Auslan interpreter it is useful to always book double appointments with your GP to allow for extra time required when using an interpreter. It is good to use the same GP so you do not need to repeatedly explain what Usher syndrome is or how they need to work with an interpreter or address other communication needs you may have.

INTERPRETERS

Many adults with Usher syndrome Type 1 will frequently use Auslan interpreters. It is good to develop good working relationships with a number of Auslan interpreters and let them know your preferences with regard to positioning, lighting, and specific signs you use or prefer. When meeting with a professional, always let them know they will need to book an Auslan interpreter for you and if it is a meeting with multiple people or a meeting longer than one hour that they need to book two interpreters. If a service provider is booking an interpreter for you always let them know your preferred interpreters.



OCCUPATIONAL THERAPIST

Occupational therapists work with people with vision impairments. They can help people regain or enhance their daily lives after specific events such as vision loss.

They can assess and modify clients' homes and community environments to improve their safety and independence.

See <https://www.otaus.com.au/about/what-do-occupational-therapists-do>



OPHTHALMOLOGIST

An ophthalmologist is a medical doctor who has undertaken additional specialist training in the diagnosis and management of disorders of the eye and visual system. An ophthalmologist will be involved in the diagnosis and ongoing monitoring and treatment of retinitis pigmentosa.

See <http://www.asoeye.org/what-is-an-ophthalmologist>

ORIENTATION AND MOBILITY SPECIALIST

Orientation and mobility specialists work with people of all ages, who are blind or have low vision. They offer training in the use of mobility aids, orientation to the environment, skills and needs assessments, vision education and development of sensory awareness.

Orientation and mobility specialists teach people the skills and concepts they need to move safely and confidently through their environment, be it moving from the bed to the toilet during the night, getting to school, catching a train and a bus to get to work, going bushwalking or taking a world tour.

See <https://omaaustralasia.com/>

PSYCHOLOGIST

People with Usher syndrome typically experience grief and loss as their vision deteriorates resulting from retinitis pigmentosa. It can be valuable to see a psychologist or counsellor to help cope with feelings arising as a result of having Usher syndrome and to develop strategies to manage these feelings.

The Better Access Initiative supports people with mental health issues, which could include symptoms of grief and loss resulting from disability, to attend up to 10 sessions with a psychiatrist, psychologist or some social workers. For more information about the Better Access Initiative see <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat>

SPEECH PATHOLOGIST

Speech pathologists study, diagnose and treat communication disorders, including difficulties with speaking, listening, understanding language, reading, writing, and social skills. Speech pathologists can develop communication aids to support interaction in the community as well as providing aural rehabilitation to support people to minimise and repair communication break downs.

See https://www.speechpathologyaustralia.org.au/SPAweb/General_Information/What_is_a_Speech_Pathologist/SPAweb/General_Information/What_is_a_Speech_Pathologist/What_is_a_Speech_Pathologist.aspx?hkey=7e5fb9f8-c226-4db6-934c-0c3987214d7a

TECHNOLOGY SPECIALIST

With increases in the use of technology, there are many devices which can assist people with Usher syndrome to be more independent. These include specialist devices for vision, for hearing, for computing and e-communication. It is good to put yourself on the mailing list of services who sell or give advice about technology to find out about new products and any expos, where you can look at and try technology, which are happening in your area. See list of services at the end of this document who may be able to link you with technology services.

INFORMATION FOR FAMILIES

PROFESSIONALS WHO WILL BE INVOLVED WITH YOUR CHILD

Over the course of your child's life they will see many specialists and professionals with varying frequency depending on their developmental and educational needs. The below lists professionals which all children with Usher syndrome will see at some stage. They are listed roughly in the order in which they will become involved. It is important to note, there are some professionals which appear in the Information for Adults section which do not appear in this list, as improved diagnosis and medical intervention have led to the experiences of children and adults with Usher syndrome being quite different at this point in time. There are currently very few deafblind consultants in Australia, and the majority work predominantly with adults. However, it is worth investigating if there are any deafblind consultants working with children in your area, as they will have a better understanding of the complexities of dual sensory impairment and be able to provide practical support and strategies for managing the challenges presented by Usher syndrome.

As your child gets older and is looking to transition to tertiary study or employment, input from a deafblind consultant will be valuable. Deafblind consultants have a good understanding of the progression of Usher syndrome and will be able to provide practical advice, suggestions and referrals to optimise smooth transitions to tertiary study and employment.

GENERAL PRACTITIONER

It is recommended that you find a General Practitioner (GP) you feel comfortable with as it is valuable to stay with one GP for ongoing support as your child ages and referrals for specialists are required. Staying with the same GP will also stop the need to repeatedly explain what Usher syndrome is and its implications.

AUDIOLOGIST

Audiologists provide clinical services in hospitals, community health centres, hearing aid clinics, private practice, university clinics and in some medical practices. Audiologists are hearing health practitioners who provide services to people of all ages, from babies to older adults. Audiologists also provide advice to other practitioners and organisations about hearing care.

See <http://audiology.asn.au/index.cfm/consumers/learning-about-audiologists/what-is-an-audiologist/>

EAR NOSE AND THROAT SPECIALIST

An ear, nose and throat specialist (ENT), also called an otolaryngologist, is a doctor trained in the medical and surgical treatment of the ears, nose throat, and related structures of the head and neck. An ENT will be involved in the correct diagnosis of hearing loss and also in the surgery required for a cochlear implant.

See <http://www.entassociates.com/what%20is%20an%20ent.htm>

OPHTHALMOLOGIST

An ophthalmologist is a medical doctor who has undertaken additional specialist training in the diagnosis and management of disorders of the eye and visual system. An ophthalmologist will be involved in the diagnosis and ongoing monitoring and treatment of retinitis pigmentosa.

See <http://www.asoeye.org/what-is-an-ophthalmologist>



OPHTHALMOLOGIST

An ophthalmologist is a medical doctor who has undertaken additional specialist training in the diagnosis and management of disorders of the eye and visual system. An ophthalmologist will be involved in the diagnosis and ongoing monitoring and treatment of retinitis pigmentosa.

See <http://www.asoeye.org/what-is-an-ophthalmologist>

CASE MANAGER / KEY WORKER

It is likely that your child will have a team of therapists such as a speech pathologist, occupational therapist, and physiotherapist working with them as part of an early intervention team. There will typically be one key contact person you have in this team. They may be an early childhood educator, or one of the therapists in the team, and will most likely provide some level of case management or case coordination to ensure the intervention team is working in a coordinated way.



SPEECH PATHOLOGIST

Speech pathologists study, diagnose and treat communication disorders, including difficulties with speaking, listening, understanding language, reading, writing, and social skills. Children with Usher syndrome will see a speech pathologist for support in developing speech and language skills which can be delayed due to hearing impairment.

See https://www.speechpathologyaustralia.org.au/SPAweb/General_Information/What_is_a_Speech_Pathologist/SPAweb/General_Information/What_is_a_Speech_Pathologist/What_is_a_Speech_Pathologist.aspx?hkey=7e5fb9f8-c226-4db6-934c-0c3987214d7a

OCCUPATIONAL THERAPIST

Occupational therapists help children achieve their developmental milestones such as fine motor skills and hand-eye coordination.

Educating and involving parents, carers and others to facilitate the normal development and learning of children is also part of their role. Occupational therapists will be involved to assist children with Usher Type 1 to improve and manage balance issues caused by vestibular dysfunction.

See <https://www.otaus.com.au/about/what-do-occupational-therapists-do>

PHYSIOTHERAPIST

Physiotherapy is a healthcare profession that assesses, diagnoses, treats, and works to prevent disease and disability through physical means. Physiotherapists are experts in movement and function who work with children and their parents, assisting them to overcome movement disorders. Physiotherapists will be involved to assist children with Usher Type 1 to improve and manage balance issues caused by vestibular dysfunction.

See http://www.physiotherapy.asn.au/APAWCM/Physio_and_You/physio/APAWCM/Physio_and_You/physio.aspx?hkey=25ad06f0-e004-47e5-b894-e0ede69e0fff

ORIENTATION AND MOBILITY SPECIALIST

Orientation and mobility specialists work with people of all ages, who are blind or have low vision. They offer training in the use of mobility aids, orientation to the environment, skills and needs assessments, vision education and development of sensory awareness.

Orientation and mobility specialists equip children with the skills and concepts they need to move safely and confidently through their environment, be it moving from the bed to the toilet during the night, getting to school, catching a train and a bus to get to work, going bushwalking or taking a world tour.

See <https://omaaustralasia.com/>

PSYCHOLOGIST

People with Usher syndrome typically experience grief and loss as their vision deteriorates resulting from retinitis pigmentosa.. Older children and family members of children with Usher syndrome may benefit from seeing a psychologist or counsellor to help manage feelings of grief, loss, isolation, and frustration, and develop coping strategies.

The Better Access Initiative supports people with mental health issues, which could include symptoms of grief and loss resulting from disability, to attend up to 10 sessions with a psychiatrist, psychologist or some social workers. For more information about the Better Access Initiative see <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat>

INFORMATION FOR PROFESSIONALS

GENERAL INFORMATION ABOUT USHER SYNDROME

Please see the first sections in this kit which provide information about:

- What is Usher syndrome
- Diagnosis
- Living with Usher syndrome
- Research

WORKING WITH AUSLAN INTERPRETERS

If you are going to have a meeting with an adult with Usher syndrome Type 1, they will most likely require you to book an interpreter.

For more information about booking an Auslan Interpreter, including contact details for booking agencies please go to:

<https://aslia.com.au/booking-an-interpreter/>

When working with an Auslan Interpreter it is important to:

- Ensure you, the person with Usher syndrome and the interpreter are positioned for best communication. Ask the person with Usher syndrome and the interpreter what positioning will work best for them
- Always address the person with Usher syndrome directly. E.g. say "Good to see you again. How have you been going with the exercises I taught you?". Do NOT say "Please ask Sue how she is going with her exercises".
- Allow more time for the session as using an interpreter will slow the interaction down, and people with Usher syndrome experience more communication break downs.
- Pause after each key message to allow the person with Usher syndrome to make any comments or ask any questions they may have.
- Ask for key information to be repeated back to you to ensure the message has been received correctly.

PROFESSIONALS WORKING WITH HEARING, SPEECH AND LANGUAGE

While all children with Usher syndrome will require some input from speech, language and hearing professionals, many professionals working in these areas will not have worked with a child with dual sensory loss before. The below article was written specifically for speech, language and hearing professionals to better understand Usher syndrome.

See <http://www.asha.org/aud/articles/Ushersyndrome/>

INFORMATION FOR INTERPRETERS

Usually interpreter bookings will state if the person has a vision impairment and if so if they require a certain type of signing to be used e.g. visual frame, tracking or tactile. For information about these different forms of signing and key issues to be aware of when interpreting for someone with Usher syndrome, see below link to Australian Deafblind Council Interpreter Guidelines: <http://www.deafblind.org.au/interpreter-guidelines.asp>

PROFESSIONALS WORKING WITH VESTIBULAR DISORDERS

If you are referred a child with a diagnosis of Usher syndrome Type 1, you are likely to observe delays in motor development. It is important to be aware that people with Usher syndrome Type 1 experience vestibular disorders, so an understanding of how this impacts on development is essential to providing appropriate interventions. For professional resources and support see:

<http://vestibular.org/resources-professionals>

<http://www.asha.org/aud/articles/CentralVestib/>

PROFESSIONALS WORKING WITH CHILDREN

As Usher syndrome is not common, it can be challenging for professionals to gain an understanding of all the aspects of the syndrome and how they impact on children's development. Wallber (2009), and Fainberg (2016) give an overall summary of Usher syndrome as well as management suggestions, particularly with relation to hearing impairment. Wallber (2009) lists a number of useful strategies for families and educators in an appendix at the end of the article.

INFORMATION FOR EDUCATORS, EMPLOYERS AND WORKSHOP FACILITATORS

LIGHTING

Lighting is important to optimise visual function. Lighting should be consistent and cool white light from fluorescent globes is usually ideal.

Bright light can cause glare, so it is important that student's backs are to windows or that glare from light coming through windows is prevented by lowering blinds.

People with Usher syndrome experience significant difficulty moving between dark to light settings or light to dark e.g. coming in and out of a cinema, so in these situations it is important to either allow time for the students vision to adjust or provide guiding until their eyes adjust (see section on guiding).

SEATING

Positioning of students is important. Close to the front is optimal to maximize auditory and visual input, but always check with the individual, where they want to sit and why.

POSITIONING OF TEACHER OR SPEAKER

As much as possible, it is best if the teacher can typically stand or position themselves in the same location and always face the class and individual with Usher syndrome when speaking.

POSITIONING OF FURNITURE AND OTHER OBJECTS

Furniture should be positioned for ease of access. It should be stable and free of sharp edges. Avoid moving class room furniture where possible and do not place objects on the floor. If furniture does need to be rearranged, let the student know ahead of time.

PRESENTING VISUAL INFORMATION

Some students with Usher syndrome will prefer to get any written information being presented to the whole class ahead of time in the format they prefer. Some students will prefer white on a black background to reduce glare.

ASSISTIVE TECHNOLOGY

There are now a variety of devices to assist with accessing visual and auditory information. Ask the student or their parents if they have any technology they will be using in the classroom and if there is anything you need to be aware of with regard to this technology.

Any extra information or negotiation such as changing of seating positions should be done ahead of time and privately with the student without drawing attention to them in front of other students.



STUDENT SUPPORT SERVICES

Most States have specific support services for students with vision and hearing impairments. See the end of this kit for details of services in your State.

See also <https://nationaldb.org/library/page/2178>

and

<http://www.brandonuteachertools.net/ussher-syndrome.html>



RELEVANT SERVICES AND NETWORKS

INTERNATIONAL

WORLD FEDERATION OF THE DEAFBLIND

The World Federation of the deafblind, WFDB, is a global non-governmental advocacy organisation by and for people with deafblindness.

WFDB was established in 2001 and consists today of 75 national and associated member organizations from 62 different countries from all corners of the world.

Relationships have been established with The World Blind Union (WBU), The World Federation of the Deaf (WFD), Deafblind International (DbI) and The World Association of Sign Language Interpreters (WASLI).

<http://www.wfdb.eu/>

DEAFBLIND INTERNATIONAL

Deafblind International (DbI) is the world association promoting services for people who are deafblind. DbI brings together professionals, researchers, families, people who are deafblind and administrators to raise awareness of deafblindness. Central to our work is to support the development of services to enable a good quality of life for children and adults of all ages who are deafblind.

<http://www.deafblindinternational.org/index.htm#>

DEAFBLIND INTERNATIONAL USHER NETWORK

Deafblind International has a number of networks including one specifically for people with and those working with people with Usher syndrome. For more information about this network go to: <http://www.deafblindinternational.org/networks.html>

SENSE

Sense is an organisation based in the United Kingdom that supports and campaigns for children and adults who are deafblind or have sensory impairments. They have extensive information about Usher syndrome on their website and run webinars about Usher syndrome which can be accessed from Australia.

https://www.sense.org.uk/content/usher-syndrome?gclid=CjwKEAjwiMe8BRD0ts3Vtv-ohWgSJAAZurk10aEeGhkujT56j0snVkagWI6AKBms-AC8kcehTCKNQhoCtHTw_wcB

USHER SYNDROME COALITION

The Usher Syndrome Coalition aims to raise awareness and accelerate research for the most common genetic cause of combined deafness and blindness. The Coalition also provides information and support to individuals and families affected by Usher syndrome.

<http://www.usher-syndrome.org/about-the-coalition/>



NATIONAL

DEAFBLIND AUSTRALIA

Deafblind Australia (formerly Australian Deafblind Council) was set up as an advocacy organisation for people with deafblindness and their families and as a network for people with vision and hearing impairments and deafblindness, freelance professionals, family members and carers, professionals involved with people with deafblindness, organisations who provide services to people with deafblindness and other interested people.

www.deafblind.org.au

BLIND CITIZENS AUSTRALIA

Blind Citizens Australia (BCA) is the united voice of Australians who are blind or vision impaired. BCA aims to achieve equity and equality by our empowerment, by promoting positive community attitudes, and by striving for high quality and accessible services which meet our needs.

www.bca.org.au

DEAF AUSTRALIA

Deaf Australia is the national peak advocacy and information organisation in Australia for Deaf people who are bilingual – using both English and Auslan (Australian Sign Language).

Deaf Australia work under the understanding that many Deaf Australians have varying degrees of fluency in both Auslan and English, but primarily use Auslan as their native or preferred language.

They advise government, industry, and service providers about the needs and views of Deaf people, and work to improve Deaf people's access in a range of areas.

www.deafaustalia.org.au

DEAFNESS FORUM

Deafness Forum advocate and seek solutions on issues for Australians with hearing loss.

www.deafnessforum.org.au

ABLE AUSTRALIA

Able Australia is one of Australia's leading not-for-profit organisations, delivering high quality, person-centred services to people living with multiple disabilities, including deafblindness and those in need of community support.

Established in 1967 as the Victorian Deaf Blind and Rubella Children's Association, Able Australia has since grown into a diverse and dynamic organisation supporting more than 4000 people in Victoria, the ACT, NSW, South Australia, Tasmania and Queensland.

www.ableaustralia.org.au

AUSSIE DEAF KIDS

Aussie Deaf Kids aims to empower parents raising a child with hearing loss through online support, information and advocacy.

They are committed to improving the outcomes of deaf children by:

Providing online parent-to-parent support on a variety of platforms. The support needs to be empathic, informative and supportive of the choices families make.

Providing an independent information resource for families raising a deaf child in Australia through our website www.aussiedeafkids.org.au. The guiding principle is an intuitive website that provides comprehensive, yet parent-friendly, information from birth to the post-school period. The information should be relevant, meaningful and evidence-based to assist parents to make informed choices about raising their deaf child.

Advocating for the rights of deaf and hard of hearing children and their families to receive the services and support they need to achieve their potential.

Collaborating with parents, consumer organisations, service providers and academics to improve services and support for families.

<http://www.aussiedeafkids.org.au/>



VISION AUSTRALIA

Vision Australia is a leading national provider of blindness and low vision services in Australia. Supporting more than 27,500 people of all ages they aim to create equal opportunity so people who are blind or have low vision can gain an education, employment and be as independent as they choose.

<https://www.visionaustralia.org/>

CENTRE FOR EYE RESEARCH AUSTRALIA

The Centre for Eye Research Australia was established in 1996 and is now the leading eye research institute in Australia. Their goal is to eliminate the major eye diseases that cause vision loss and blindness in Australians.

<http://www.cera.org.au/>

RETINA AUSTRALIA

Retina Australia provide information and support to individuals and families affected by Retinitis Pigmentosa as well as other retinal dystrophies. They are completely funded by public donations and they also help to raise funds to finance scientific research into the causes, prevention and cure of Retinitis Pigmentosa and other retinal dystrophies.

<http://www.retinaaustralia.com.au/>

GUIDE DOGS AUSTRALIA

Guide Dogs Australia represents Australia's six state-based Guide Dog organisations. Together, as the nation's leading providers of orientation and mobility services, including Guide Dogs, they assist people who are blind or have a vision impairment gain the freedom and independence to move safely and confidently around their communities, and to fulfill their potential.

<http://www.guidedogsaustralia.com/>

ROYAL INSTITUTE FOR DEAF AND BLIND CHILDREN [RIDBC]

Services are provided from 17 permanent sites and serve children, families and adults throughout Australia. Using face to face services combined with modern technology, RIDBC connects people across Australia to the expert therapy and services they need. Vision Loss and Blindness as well as Hearing Loss and Deafness services include Early Learning Program, RIDBC VisionEd Preschool and School Support Service. RIDBC also provides integrated cochlear implant services through the RIDBC Sydney Cochlear Implant Service.

<http://www.ridbc.org.au/>

DEAF CHILDREN AUSTRALIA

Deaf Children Australia aim to provide children and young people who are deaf or hard of hearing, and their families, with the opportunities and skills to face life's challenges and to celebrate their potential.

Deaf Children Australia works hard to provide families and children with the opportunity to access unbiased information, become more connected with each other, participate in peer to peer support, access community, recreational and youth activities, engage in individually tailored support, and develop skills in advocacy, relationship building and influence.

<http://deafchildreनाustralia.org.au/>

VICTORIA

ABLE AUSTRALIA

Able Australia's Deafblind Services provide case management, respite, counselling, technology training, art therapy, music therapy, and 1:1 outreach support, as well as a recreation program.

www.ableaustralia.org.au

DEAFBLIND VICTORIANS

Deafblind Victorians is a self-advocacy group of people with deafblindness.

<https://deafblindadvocacy.wordpress.com/>

THE VICTORIAN DEAF SOCIETY [VICDEAF]

VicDeaf provides services to people who are Deaf or hard of hearing.

<http://www.vicdeaf.com.au/>

THE GENETIC SUPPORT NETWORK OF VICTORIA

The Genetic Support Network Victoria (GSNV) is a vibrant and active organisation committed to promoting the interests and well-being of people affected by genetic conditions. The Network is proud to be associated with a wide range of support groups throughout Victoria and Australia as well as peak professional bodies such as Victorian Clinical Genetics Services.

<http://www.gsnv.org.au/>

STATEWIDE VISION RESOURCE CENTRE [SVRC]

The SVRC supports over 500 students with vision impairments (blindness and low vision) in Victorian schools. Funded by the Department of Education and Training (DET), the SVRC is the leading centre of educational expertise and provider of materials in alternative format for eligible students with vision impairments in Victoria.

<http://svrc.vic.edu.au/index.shtml>

VICTORIAN DEAF EDUCATION INSTITUTE

The Victorian Deaf Education Institute (VDEI) was established in 2010 as a branch of the Department of Education and Early Childhood Development (now the Department of Education and Training), to deliver excellence in deaf education throughout Victoria. VDEI also works closely with the Royal Institute for Deaf and Blind Children in Sydney.

<http://www.deafeducation.vic.edu.au/Pages/home.aspx>

AURORA SCHOOL

Aurora School is an innovative educational organisation that provides optimal learning environments for Deaf and Deafblind children and their families across the State of Victoria. Communication, Language and Literacy form the foundation of programs that support each child's whole development. The addition of an Inclusive Community Kindergarten supports access to the broader environment.

<http://www.auroraschool.vic.edu.au/>

EARLY EDUCATION PROGRAM FOR CHILDREN WHO ARE HEARING IMPAIRED [EEP]

The objective of the EEP is to promote communication, speech and social development of children, by reducing the impact of hearing loss. The EEP uses a family-centred approach. The whole family, rather than just the child, is considered when programs are designed. Individual programs include emotional support at the time of diagnosis as well as individual language, listening and speech sessions provided by teachers of the deaf. A language playgroup and a weekly parent support and education session are available to families who wish to attend.

<http://www.eep.org.au/index.htm>

TARALYE

Taralye is founded on the premise of “parents helping parents” and this vision has remained core to our family centred practices to the present day. Taralye advocates for early diagnosis of hearing loss, prompt fitting of hearing aids and/or cochlear implants and high quality early childhood intervention services.

<https://www.taralye.vic.edu.au/default.aspx>

VICTORIAN CLINICAL GENETIC SERVICES [VCGS]

Victorian Clinical Genetics Services (VCGS) delivers expert genetic testing and genetic support services to thousands of families in Victoria, throughout Australia, and around the world.

A subsidiary of the Murdoch Children’s Research Institute, VCGS provides both clinical and laboratory pathology services for genetic diagnosis, as well as screening and counselling, through a team of clinical geneticists, genetic counsellors, laboratory scientists, metabolic physicians, social workers and support staff.

<http://www.vcgs.org.au/>

MONASH GENETICS CLINIC

Monash Genetics Clinic provides for the diagnosis, management, counselling and support of adults and children with a wide range of genetic disorders and also includes prenatal diagnosis for various genetic conditions.

<http://www.monashhealth.org/page/Genetics>



NEW SOUTH WALES

ABLE AUSTRALIA

Able Australia's Deafblind Services have a Community Development Worker based in New South Wales to provide information and support to individuals with deafblindness and their families.

<http://www.ableaustralia.org.au/>

DEAFBLIND ASSOCIATION NSW

DBANSW is a voluntary, not for profit organisation which aims to create safe and comfortable environments that enable individuals who are deafblind to access the community.

www.dbansw.org.au

THE SHEPHERD CENTRE

The Shepherd Centre has been providing children in NSW and the ACT with hearing loss with the tools they need to learn to listen and speak since 1970. Their Early Intervention program is world-renowned for its results. More than 90 per cent of children with hearing loss who graduate from the program attend school with listening and language skills on par with those of their hearing peers.

<http://shepherdcentre.org.au/>

SAVE SIGHT INSTITUTE

Located within the University of Sydney on the Sydney Eye Hospital campus the Save Sight Institute is involved in a number of aspects including research, patient care and teaching. Save sight cares for more than 6,000 patients with eye disorders.

<http://www.savesightinstitute.org.au/>

PARENTS OF DEAF CHILDREN

Parents of Deaf Children (PODC) is a non-profit organisation, supporting families with babies, children and teenagers with hearing loss in NSW. The organisation offers a range of information, support and capacity building services for parents and carers, respecting the method or methods of communication that the family has chosen for their child. PODC can assist families with free decision making and planning support prior to attending your NDIS planning meetings. Their support also extends to helping families to connect with others in their local area via POD groups (parent groups) and can advocate on behalf of families with government departments and service providers.

<http://www.podc.org.au/>

DEAF SOCIETY OF NSW

Provides services to people who are Deaf and hard of hearing.

<http://deafsocietynsw.org.au/>

GENETIC ALLIANCE AUSTRALIA

Genetic Alliance Australia, formerly Association of Genetic Support of Australasia (AGSA), was formed in 1988 to provide peer support and information for individuals and families affected by a rare genetic condition/rare disease.

<http://www.geneticalliance.org.au/index.php>

WESTERN AUSTRALIA

WEST AUSTRALIAN FOUNDATION FOR DEAF CHILDREN

The West Australian Foundation for Deaf Children (Inc) promotes and supports education and learning opportunities for Deaf and Hard of Hearing children and young adults.

<http://www.wafdc.org.au/>

TELETHON SPEECH AND HEARING CENTRE

Telethon Speech & Hearing Centre for Children is a non profit, charitable organisation that exists to support families, children, adults and carers and offers early intervention and school support programs for hearing impaired children, as well as specialist paediatric audiological services.

<http://www.tsh.org.au/>

LIONS EYE INSTITUTE

The Lions Eye Institute is a not for profit organisation that conducts scientific research into blindness prevention and also help patients with high quality eye care. Their large clinic contains a day surgery unit and a laser vision centre. This combined with the research conducted, helps to provided techniques and ideas to help benefit people suffering with blinding eye conditions.

<https://www.lei.org.au/>

VISABILITY

VisAbility, formerly the Association for the Blind of WA, is a provider of disability services specialising in supporting people who are blind or vision impaired.

<http://www.visability.com.au/>

WA DEAF SOCIETY

Provides services to people who are Deaf and hard of hearing.

<http://www.wadeaf.org.au/>

GENETIC SERVICE OF WESTERN AUSTRALIA

The Genetic Paediatric Clinic is part of Genetic Services of Western Australia (GSWA). It is a state-wide service based at King Edward Memorial Hospital/Princess Margaret Hospital in Perth. It provides diagnosis, assessment and genetic counselling to parents/families of children with a range of genetic conditions. These services are provided through a multidisciplinary team that includes clinical geneticists and genetic counsellors, working closely with DNA and cytogenetic laboratories and other associated disciplines.

<http://www.kemh.health.wa.gov.au/services/genetics/>

GENETIC AND RARE DISEASE NETWORK

Genetic and Rare Disease Network (GaRDN) works to empower individuals and their families to reach positive health outcomes. We inform health professionals and the wider community on the perspectives and experiences of those affected by genetic and rare diseases. We connect key stakeholders and service providers with people affected by genetic and rare diseases.

<http://www.geneticandrarediseasenetwork.org.au/>

SENSES AUSTRALIA

Senses Australia is a not for profit organisation. Their services help over 650 children, adults and older adults with a range of disabilities. Senses Australia also provides support and services for families, other health professionals, service providers and teachers.

<http://www.senses.org.au/>

QUEENSLAND

ABLE AUSTRALIA

Able Australia's Deafblind Services have a Community Development Worker based in Queensland to provide information and support to individuals with deafblindness and their families.

<http://www.ableaustralia.org.au/>

HEAR AND SAY CENTRE

Hear and Say provides services and programs to over 1,800 children, young adults and families across six centres as well as e-Auditory-Verbal Therapy and e-Audiology programs for rural and remote areas. They aim to help all children to hear, listen and speak so they can attend a regular school, have wider career choices and can fully participate in their community. Hear and Say combines state-of-the-art hearing technology (digital hearing aids and implantable technology such as cochlear implants) with the Auditory-Verbal Therapy approach.

<https://www.hearandsay.com.au/>

QUEENSLAND EYE INSTITUTE

The Queensland Eye Institute is Queensland's only academic research institute devoted to eye related health and diseases.

<http://www.qei.org.au/>

DEAF SERVICES QUEENSLAND

Provides services to people who are Deaf and hard of hearing.

<http://www.deafservicesqld.org.au/>

GENETIC HEALTH QUEENSLAND

Genetic Health Queensland (GHQ) is a statewide service that provides diagnosis, counselling, and management advice to individuals and families who have, or are at risk of having, a genetic or inherited condition. A team of medical specialists (clinical geneticists) and genetic counsellors work together at GHQ to look after patients and families all over Queensland.

<https://www.health.qld.gov.au/ghq/patients/default.asp>

SOUTH AUSTRALIA

ABLE AUSTRALIA

Able Australia's Deafblind Services have a Community Development Worker based in South Australia to provide information and support to individuals with deafblindness and their families.

<http://www.ableaustralia.org.au/>

DEAF CAN DO

Deaf Can Do, The Royal Deaf Society of South Australia provides services to people who are Deaf and hard of hearing

<http://www.deafcando.com.au/>

CAN DO 4 KIDS

CanDo4Kids works directly with children and young adults with sensory impairment disabilities, such as blindness and deafness, by focusing on what children "can do" and helping them to reach their full potential.

<http://www.cando4kids.com.au/>

CORA BARCLAY CENTRE

The Cora Barclay Centre is a dedicated Listening & Spoken Language program providing intensive, evidenced-based intervention through Auditory-Verbal Therapy, student support services, social participation programs, and ongoing monitoring and assessment to children from birth to 18 years and their families. The aim of the Centre is to help children who are deaf or hearing impaired achieve life-long social and emotional wellbeing and economic independence.

<http://corabarclay.com.au/>

SOUTH AUSTRALIA CLINICAL GENETIC SERVICES

The South Australia Clinical Genetics Service provides a clinical genetics and genetic counselling service within South Australia. The Paediatric & Reproductive Genetics Unit provides diagnostic and counselling services for genetic disorders which occur during prenatal development or childhood, and for prenatal genetic testing

<http://www.wch.sa.gov.au/services/az/divisions/labs/geneticmed/>

TASMANIA

TASMANIAN CLINICAL GENETIC SERVICES

The Tasmanian Clinical Genetics Service (TCGS) provides a clinical service for the diagnosis, management, counselling and support of individuals and families with a wide range of genetic disorders. The TCGS is staffed by Genetic Counsellors, who are based at the Royal Hobart Hospital, and by Clinical Geneticists, contracted from the Royal Children's Hospital and the Peter MacCallum Hospital in Melbourne, who visit Tasmania to conduct monthly clinics in conjunction with the genetic counsellors.

https://www.dhhs.tas.gov.au/service_information/services_files/RHH/treatments_and_services/genetic_counselling

TASMANIAN DEAF SOCIETY

TasDeaf provides services to Tasmanians who are Deaf or hard of hearing including information, advocacy and interpreter bookings.

<http://tasdeaf.org.au/>

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