



ROYAL NEW ZEALAND
FOUNDATION OF
THE BLIND

TE TUĀPĀPĀ O TE HUNGA KĀPŌ O AOTEAROA

Navigating the Challenges of Deafblindness

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Who is deafblind?

- Simple definition: Vision impairment or blindness, and hearing impairment or Deafness, coming together to have a significant impact over and above that of a single sensory impairment
- Can mean no functional vision or hearing, but often does not – many deafblind people have functional vision, hearing or both
- Regarded as a separate disability in its own right, not a subgroup of blindness or deafness
- Very varied group of people
- A very conservative estimate suggests 1,500 deafblind people in Aotearoa New Zealand; this does not take into account large numbers of older people with acquired severe vision and hearing loss, so true figures almost certainly higher

Why does it matter?

Implications of living with deafblindness in our society include:

- Communication
 - May use communication methods that aren't known by many people
 - May need to change communication as vision and hearing change
 - May find communication hard in some environments
- Travel
 - Inaccessible environments
 - Difficulty accessing environmental information with impaired vision and hearing
- Access to information at every level
- Time and effort needed to do things, especially in the presence of societal barriers

What do I do?

Communicate

- Essential for good assessment
- Be aware that deafblind people use communication a wide variety of communication methods
- Speech is a common communication method. Use clear speech:
 - Try to find somewhere quiet – background noise can make it impossible for some people to hear you
 - Get the deafblind person's attention
 - Find a good position – some deafblind people need you to be at just the right distance to see your face
 - Stand with the light on your face; if the light is behind you your face will be in shadow
 - Speak clearly, but don't overdo it – really exaggerated lip movements are hard to follow
 - Speak at a moderate speed – fast speech can be tricky for people
 - Never shout – some people will want you to speak up a bit, but shouting will just distort your voice
 - If the person doesn't understand, try repeating it; if they still don't get it, find another way to say it
 - Don't all talk at once
- Be aware that you will need support to communicate with some deafblind people – New Zealand Sign Language interpreter, other communication support professionals (pure NZSL interpreting not suitable for some deafblind people), whānau support, etc.
- Find out what format written information is needed in – e.g., large print, braille, plain English, signed DVD
- Allow enough time for communicating – much more than for assessments with sighted hearing people

Build trust

- Essential for good communication
- Be aware that many techniques for building rapport are inaccessible to some deafblind people – facial expressions, body language, tone of voice
- Misunderstandings happen more easily; make sure people are really clear what you've agreed to
- Allow enough time for building trust – again, may be much more than for assessments with sighted hearing people

What do deafblind people need?

- Ordinary human needs
- May be met in different ways for deafblind people

Chris's story

- Born deafblind, no vision or hearing, uses tactile sign
- Lives in staffed house with 24 hour support; personal care needs met but risks isolation without additional support
- Has additional NASC-funded hours for accessing his world – hands-on experience of the world and the society he lives in, to learn things that sighted hearing people take for granted
- Opens his social world, increases his confidence and decision-making skills, increases his control over his own life

Lorraine's story

- Born deaf, losing vision during adulthood, uses speech
- Home help for practical tasks
- Community worker for accessing community
- Communicator Guide to overcome barriers to communication, travel and access to information at important events (hospital appointments, meetings): when getting the communication right is vital, Lorraine needs a highly-skilled worker she can rely on utterly to communicate clearly with her, and who can see when she's missing something and help fill in the details
- Different sources of support needed to meet different needs in different settings; one can't substitute for the other

Mrs Armitage's story

- In her 80s, deaf, lost much of her vision, has additional health needs
- Uses speech herself; finds following speech hard now she's lost vision; has tried various alternative communication methods
- Finds communication with anyone other than her husband stressful

- NASC funds someone to come in when Mr Armitage is out, to ensure safety, but not to communicate, as it's too stressful for Mrs Armitage
- Very different from Chris' and Lorraine's packages which aim to increase social contact; indicates just how varied deafblind people's specific needs can be, and how creative we have to be in meeting them

Who can help?

Deafblind Services, Royal New Zealand Foundation of the Blind

Works with deafblind people of all ages. Services include:

- Information and advice
- Specialist assessment
- Support to develop new or adapted ways of communicating
- Support to access other services, and service coordination
- Social and leisure activities
- Training for professionals and others

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