

# Deafblindness

This factsheet will be useful to anyone who wants to find out more about deafblindness.

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**i** If you'd like this factsheet in Braille, large print or audio, please contact our Information Line - see last page for contact details.



## What is deafblindness?

Deafblindness is a combination of sight loss and hearing loss that causes difficulties with communication, mobility and accessing information. It is also known as 'dual sensory impairment', 'dual sensory loss' and 'multi-sensory impairment'.

Most people who are deafblind are not totally deaf and blind – they have a little hearing or sight (or a little of both). However, deafblindness has a significant impact on a person's life because of the way that sight loss and hearing loss affect each other – even if, individually, each impairment is mild.

Sense, a national charity supporting and campaigning for deafblind people, estimates that there are around 358,000 people in the UK who are deafblind.

## What are the different types of deafblindness?

There are two types of deafblindness:

- **congenital deafblindness** is present from birth or develops in early life, before a child has developed language
- **acquired deafblindness** develops later in life.

## What are the main causes of congenital deafblindness?

Congenital deafblindness can be caused by:

- problems associated with premature birth (birth before 37 weeks of pregnancy)
- genetic conditions, such as Down's syndrome or CHARGE (a rare disorder that affects many parts of the body)
- an infection picked up during pregnancy, such as rubella (German measles), which in the past was the most common cause of congenital deafblindness, but thanks to the childhood vaccination programme, the virus has now been almost totally wiped out in the UK
- health problems caused by drinking alcohol or taking certain drugs during pregnancy
- cerebral palsy – a problem with the brain and nervous system that mainly affects movement and co-ordination
- severe infections in early childhood that damage the brain, such as bacterial meningitis.

## What support do people who are congenitally deafblind need?

People who are born deafblind may have needs that can't be met by services run specifically for people who are either blind or deaf. They may need specialist support.

Children with deafblindness may also have other disabilities such as:

- learning difficulties
- epilepsy
- feeding problems
- severe physical disabilities
- difficulty moving around.

They need specialist services to meet their needs.

### Communication and learning

Communication and learning can be significant challenges for children who are deafblind. They may not understand the concept of language because they haven't been exposed to it. A child's mental and physical development may be slower if they are not being stimulated enough. So it's important that children who are deafblind get the right support to learn early on – from their parents, family, teachers and intervenors (see opposite).

One-to-one work with children who are deafblind helps them understand the human interaction that is the basis of communication. Children may learn to use symbols, objects, sign language, Braille and other methods of communication.



Sense ([see page 7](#)) has a Children's Specialist Services team that can advise families on ways to communicate with their child and how to access the services their child needs. Visit [sense.org.uk/content/children-and-young-people](https://www.sense.org.uk/content/children-and-young-people)

### Intervenors

A specially trained intervenor provides dedicated one-to-one support to someone who is congenitally deafblind. They help the person to experience and take part in the world around them, encourage their independence and support their communication. They can provide support in a person's home, in their local community, or in an educational or work setting.

Some local authorities (councils), Health and Social Care Trusts in Northern Ireland and other organisations, such as Sense ([see page 7](#)), provide intervenors for people who are eligible for this support. The person's local council or trust will pay for this (see 'What help is available from social services?', [page 5](#)).

## What are the main causes of acquired deafblindness?

There are many causes of acquired deafblindness, including:

- Usher syndrome (see below)
- sight and hearing loss as a result of the ageing process
- damage to the brain, such as from meningitis, a stroke or a severe head injury
- people who have been born deaf or blind subsequently losing their sight or hearing through accident or illness at some point later in life.

### Usher syndrome

Usher syndrome is a genetic condition that affects vision, hearing and, in some cases, balance. In most cases, hearing loss or deafness is present from birth and sight loss starts in late childhood.

The sight loss, which develops over a number of years, is caused by an eye condition called retinitis pigmentosa (RP). As the sight loss gets worse, it can become difficult for the person to communicate, access information and move around safely.

For a child to have Usher syndrome, both parents must either 'carry' the gene with a mutation (they won't show any symptoms of the disorder) or have the same type of Usher syndrome themselves.

If a person with Usher syndrome has a child with an unaffected carrier of the same Usher gene, then the child has a 50% chance of developing Usher syndrome.

### Living with Usher syndrome

A diagnosis of Usher syndrome may be devastating for the individual and their family. It's likely that the individual will have had deafness or hearing loss from birth, and coming to terms with losing their sight as well can be very hard. However, with the right training, support and assistive equipment ([see page 6](#)), many people with Usher syndrome lead independent and fulfilling lives.

As their vision gets worse, many people with Usher syndrome will learn new forms of communication or adapt their communication method. For example, they can use adapted forms of sign language such as hands-on or visual frame, or learn the Deafblind Manual Alphabet.



To find out more about these communication methods, see our factsheet *Communicating with people who are deafblind*.

## What support do people with acquired deafblindness need?

People with acquired deafblindness may find it difficult to do everyday things, such as shopping and dealing with mail. Such difficulties can cause feelings of depression and isolation, so it's important that people get the right support.

The following groups of older people who are deafblind all need different types of support:

- people who have developed hearing loss and sight loss as they've got older
- people who have adapted to blindness or partial sight during their lives, and are now losing their hearing
- older people with hearing loss who are now losing their sight
- older people who have had hearing loss and sight loss for most of their lives.

### Communicator guides

A communicator guide is someone who supports a person who has developed deafblindness to take an active part in everyday life. They:

- provide one-to-one communication support and guiding
- provide practical help with everyday tasks such as shopping, dealing with mail and paying bills
- assist people to lead independent and fulfilling lives at home and in their community.

Some councils, Health and Social Care Trusts in Northern Ireland and other organisations, such as Sense ([see page 7](#)), provide communicator guides.

They should be seen as an addition to, rather than a substitute for, other services such as a home help or social worker visits. The person's local council or trust may cover the cost of the communicator guide (see below).

## What help is available from social services?

Councils, or Health and Social Care Trusts in Northern Ireland, can provide help and support for disabled people and their carers. In England and Wales, councils now have a legal duty to provide support to those who need it and have eligible needs.

The way that councils and trusts make a decision about the help and support they can provide is by carrying out an assessment.

In England and Wales, councils must carry out a health and social care assessment for any adult who appears to have needs for care and support, to find out which social services, if any, will benefit them. The assessment must make sure that the person being assessed has their needs and wishes heard.

Similar assessments are carried out in Scotland and Northern Ireland.

Assessments for deafblind people must be carried out by a professional with specific training and expertise relating to people who are deafblind. They will assess the needs of a deafblind person in relation to:

- communication
- one-to-one support and social interaction
- support with mobility
- assistive technology
- rehabilitation
- their current and future needs.

If a deafblind person is assessed as needing care and support, the council or trust must make sure that appropriate care and support is provided. This may include healthcare, one-to-one support, equipment or residential care.

The council or trust will allocate the deafblind person a sum of money to cover the cost of their support, which is known as their 'personal budget'. This can either be held by the council or trust, who can arrange the support on the person's behalf, or be paid to the person so they can buy their own support.

Contact your local social services department for more information about assessments and the types of support that may be available to people who are deafblind. You can find the contact details by searching online or by looking in your local telephone directory.

 You can find out more about the health and care assessment from Citizens Advice – visit [citizensadvice.org.uk](https://citizensadvice.org.uk)

## What equipment can help?

There's a range of equipment that can help people who are deafblind to live independently.

- **Alerting devices for the home** – these let people who are deafblind, or have hearing loss, know that an alarm or bell is ringing – for example, a smoke alarm or doorbell. These devices can alert people through a vibrating pager, watch or pad, and/or a flashing light.
- **Computing aids** – these can convert text into Braille, change text into large print, change the colours on the screen and even 'speak' text through loudspeakers or hearing aids.
- **Assistive listening devices** – these help people with hearing loss hear the sounds they want to focus on (see our factsheet *Assistive listening devices* for more information).
- **Magnifiers** – these range from reading glasses to video magnifiers, which amplify images from a camera onto a screen.
- **Mobility aids** – these include walking sticks, canes and guide dogs.
- **Telephones and textphones** – telephones for people with hearing loss and/or sight loss are amplified and have large numbers and letters; textphones are designed for people who are deaf and don't communicate by speech.

- **Tactile (touch) markers** – as well as labelling things in Braille, tactile markers can be used to help people who are deafblind identify objects or areas. These markers include tactile stickers, liquid plastic that sets hard, or anything that feels different to the touch.

 You can find out more about hearing loss products in our **Products and technology** range.

## Where can I find out more about deafblindness?

### Deafblind UK

A charity providing support services to deafblind people.

Deafblind UK Head Office  
National Centre for Deafblindness  
John and Lucille van Geest Place  
Cygnet Road  
Hampton  
Peterborough  
PE7 8FD

Telephone/textphone: **01733 358 100**

Fax: **01733 358 356**

Online contact form:

[deafblind.org.uk/contact-us/](https://deafblind.org.uk/contact-us/)

Email: [info@deafblind.org.uk](mailto:info@deafblind.org.uk)

Website: [deafblind.org.uk](https://deafblind.org.uk)

### Sense

A national charity that supports people who are deafblind, have sensory impairment or complex needs, to enjoy more independent lives.

Sense  
101 Pentonville Road  
London N1 9LG

Telephone: **0300 330 9256**  
**020 7520 0972**

Textphone: **0300 330 9256**  
**020 7520 0972**

Fax: **0300 330 9251**

Email: [info@sense.org.uk](mailto:info@sense.org.uk)

Website: [sense.org.uk](https://sense.org.uk)

### Information you can trust

The Information Standard certifies us as producers of high-quality, evidence-based information.

Thank you to **Sarah White, Policy & Partnerships Manager (Health) at Sense**, for helping us to review and update this factsheet, published August 2017.

### Did you find this factsheet helpful?

We'd love to know what you think of this factsheet – please email us at [reviewpanel@hearingloss.org.uk](mailto:reviewpanel@hearingloss.org.uk)

If you'd like to join our Readers' Panel, to help us create new publications and improve existing ones, please let us know.

## Further information from Action on Hearing Loss

Our expert information covers everything you need to know about:

- hearing loss and deafness
- tinnitus
- ear problems and treatments
- hearing aids and cochlear implants
- useful products and technology
- communication tactics and support
- benefits and grants
- your rights.

Visit our website [actiononhearingloss.org.uk](https://actiononhearingloss.org.uk) or call our Information Line ([see last page](#)) for information, support and publications. You can also find out about services in your area, our hearing research, and how you can get involved.

## Please help us support others

We provide our leaflets, factsheets and Information Line service free of charge to anyone affected by deafness, tinnitus or hearing loss in the UK. We rely on the generosity of our supporters to help us do this. We would be very grateful if you would consider making a donation – of as little or as much as you can afford.

Please send a cheque, payable to Action on Hearing Loss, to:

**Freepost RTLX-CZKX-BTTZ**  
**Action on Hearing Loss**  
**1-3 Highbury Station Road**  
**London N1 1SE**  
(No stamp needed)

Donate online at [actiononhearingloss.org.uk/icanhelp](https://actiononhearingloss.org.uk/icanhelp)  
Or make a donation over the phone by credit or debit card:

 **0203 227 6182**  
 **0203 227 6185**

Thank you.

Our purpose is to help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way.

To find out more about what we do and how you can support us, go to [actiononhearingloss.org.uk](http://actiononhearingloss.org.uk)

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### Action on Hearing Loss Information Line

Telephone **0808 808 0123**  
Textphone **0808 808 9000**  
SMS **0780 000 0360**  
(standard text message rates apply)  
Email **[information@hearingloss.org.uk](mailto:information@hearingloss.org.uk)**

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### Join us



Action on Hearing Loss



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**Action on Hearing Loss is the trading name of The Royal National Institute for Deaf People.**  
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