



Combined sensory loss

Acquired deafblindness

COMBINED SENSORY LOSS – ABOUT ACQUIRED DEAFBLINDNESS

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This leaflet was compiled by staff at Statped, National Professional Unit for Dual Visual and Hearing Impairment and Deafblindness, Bergen: Evabritt Andreassen, Harald Haldorsen, Anny Koppen, May Bente Matre and Hanna Taranger.

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This leaflet provides brief information for people wanting to know more about deafblindness in various contexts, including as a service user, service partner, family member or acquaintance.

We cover topics such as where you can find help, how we can best communicate together, which assistive devices are available and how you can obtain these assistive devices.

The National Advisory Unit on Deafblindness (NKDB) is part of the Norwegian specialist health service. It consists of four centres with regional tasks, two centres with nationwide tasks and a coordinating unit – all affiliated with the Northern Norway Regional Health Authority.

These centres provide services to the deafblind throughout the country. They also collaborate with municipal operators and form part of a comprehensive and multidisciplinary service provision. You will find more information about the National Advisory Unit on Deafblindness near the back of this leaflet.

ABOUT DEAFBLINDNESS

Humans are equipped with various senses, which may be divided into near and far senses. The near senses are what you can feel on and with your body, while the far senses are vision, hearing and smell. Vision and hearing are considered the most important because they play a crucial role in development, orientation and communication. We refer to deafblindness when these two far senses are severely impaired.

Deafblindness is a severe combined vision and hearing impairment. It is a distinct disability. A minority of people who are deafblind are completely deaf and comple-

tely blind. Deafblindness occurs when a person's vision is so poor that it can barely compensate for their hearing loss and their hearing is so poor that it can barely compensate for their vision loss.

DIFFERENT CATEGORIES OF DEAFBLINDNESS

A distinction is made between congenital deafblindness and acquired deafblindness. Congenital deafblindness is deafblindness that occurs before the child has developed language. Many in this group have multiple disabilities, which can further complicate the condition.

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Acquired deafblindness is combined sensory loss that occurs after language development. People with acquired deafblindness are a heterogeneous group including people in all age groups and different life situations.

Having deafblindness does not necessarily mean that the person is completely deaf and completely blind. Many people who are deafblind have residual hearing and/or vision, and often one or both sensory losses are progressive.

COMMON CAUSES OF ACQUIRED DEAFBLINDNESS

- Usher syndrome, type 1, 2 and 3
- other rare syndromes
- rare infectious diseases
- random combinations of various injuries or diseases that affect both vision and hearing
- age-related vision and hearing impairments

In some cases, it can be difficult to find the diagnostic cause of deafblindness.

CONSEQUENCES OF DEAFBLINDNESS

Deafblindness creates many challenges. It affects social life, communication, access to information, orientation and the ability to

move around freely and safely. Deafblindness also has psychological consequences such as grief and anxiety, existential concerns and identity crises. If compensatory measures are not implemented, there is a great risk of deprivation and lack of opportunities to realise the potential of the individual concerned. People with deafblindness require specially adapted assistive technology to compensate for their visual and hearing impairments to the greatest extent possible. Although assistive devices are available for visual and hearing impairments, the challenge is often the combination. In other words, the hearing aids are often not adapted to the visual situation and the visual aids are often not adapted to the hearing situation.

Finding out about the services that are available can be difficult. Many people are reliant on a doctor in their local community having knowledge of deafblindness for them to get information about opportunities, rights and where to go for help. General practitioners often have a poor understanding of syndromes that can cause deafblindness. Some people receive a misdiagnosis and inadequate information, which can cause problems additional to the deafblindness.

COMMUNICATION WITH PEOPLE WHO ARE DEAFBLIND

Communication must be adapted to the individual. Be creative and try different methods to ensure that communication is as good as possible.

We can often combine methods to make it easier to communicate. Let the person with deafblindness decide the form of communication, and other factors such as their location in the room and distance from other communicators.

Communication can occur by using:

- sign language
- tactile signing
- fingerspelling
- hands-on signing
- writing with a black marker pen on white paper
- computer and tablet – large text
- screen reader
- spoken language using assistive technology
- haptic signals

The following tips can help to improve communication:

- Make sure the room is quiet and there is no background noise.
- Make sure the room is well lit and that the light is not dazzling.
- When choosing where to sit, make sure your face is illuminated.
- Let the person with deafblindness choose where they want to sit.
- Speak clearly and one at a time.



ASSISTIVE TECHNOLOGY

People with deafblindness have the right to an interpreter and companion service.

Professionals must provide an interpreter if they cannot communicate in the required form of communication. Interpreters can be ordered through the interpreting service at the assistance centres operated by the Norwegian Labour and Welfare Administration (Nav). Interpreters should be ordered well in advance.

In certain contexts, the interpreting service also offers digital interpretation (screen interpretation, and image interpretation).

Many useful assistive devices are available that can make everyday life easier for people with acquired deafblindness. Assistive devices can support communication, make acquiring information easier and more efficient, and enable people to move around independently. Most assistive devices are developed to help with either vision problems or hearing problems.

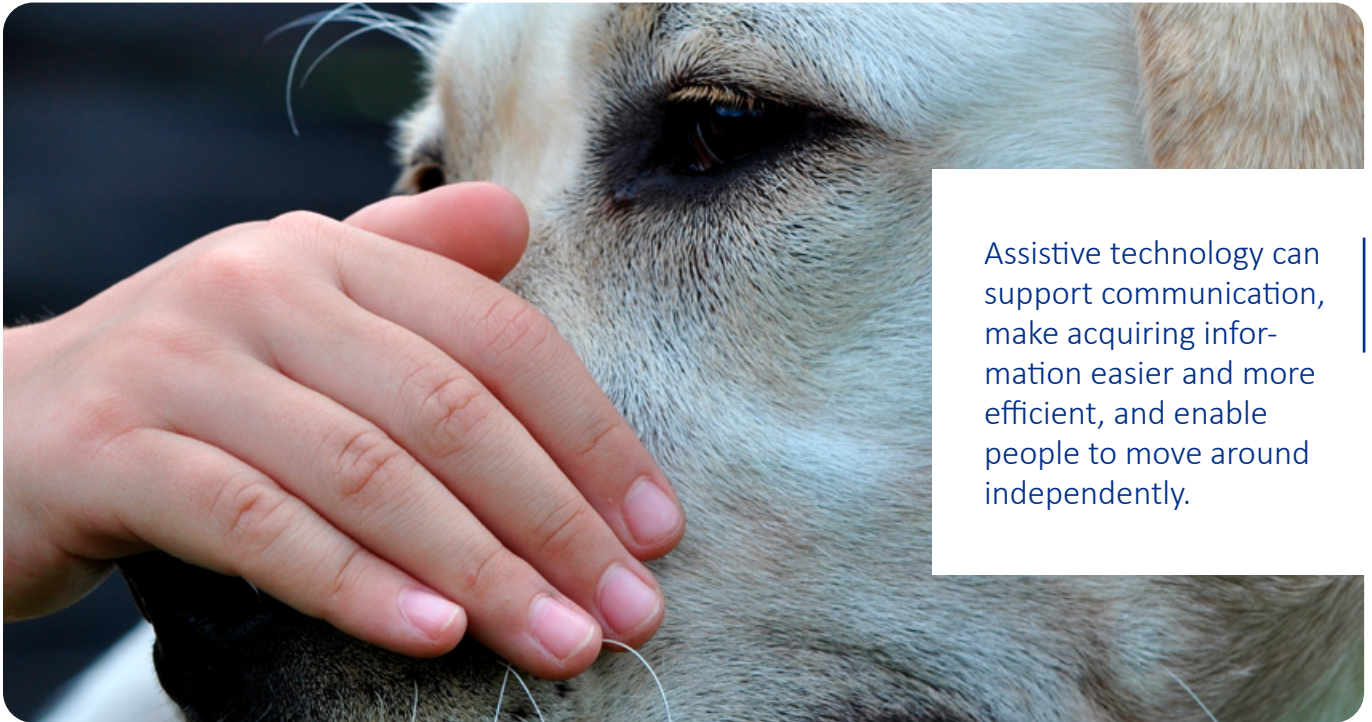
When allocating assistive devices to a person with deafblindness, it is important to consider the combined sensory loss. The Nav assistive technology centres in each county are responsible for allocating the assistive technologies.

Examples of assistive devices that many people with deafblindness use:

Assistive technology for hearing impairments

- speech amplifiers
- FM systems
- audio induction loops for telephone, radio and TV
- vibration and light alert assistive devices for doorbells, telephones and fire alarms
- hearing aids with accessories

A cochlear implant (CI) is an advanced form of hearing assistive device. The internal part is surgically implanted in the cochlea. This technology is mainly offered to people with such severe hearing impairments that



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they cannot perceive speech with a regular hearing assistive device.

In Norway, most children with severe hearing impairments are offered a CI. However, various factors determine how beneficial these are for an individual.

While cochlear implants do not restore normal hearing, most people who undergo this operation experience a major improvement in their hearing compared to using a regular hearing aid.

Assistive technology for visual impairments

- properly adapted lighting
- magnifying glasses and filter glasses
- screen reader
- special equipment and computer software
- Digital accessible information system (DAISY)
- various household devices
- guide dogs
- various assistive devices for mobility
- braille display

Developments in information technology and computers are worthy of special mention as these have been of significant benefit to people with deafblindness. Information and communications technology (ICT) has given many people better opportunities to obtain information and maintain contact with the outside world. Adaptations, special software and additional equipment enable blind and severely visually impaired people to use the internet, social media and email to the same extent as other people. For more information about assistive technology, please contact the support representatives for visual and hearing assistance at the municipalities.

- green card for concession fares on public transport
- transport service (TT) card
- reading and secretarial assistance
- basic benefit, assistance allowance, work assessment allowance and disability benefit
- assistance schemes, such as
 - functional assistance in the workplace (Nav)
 - user-controlled personal assistance to provide greater flexibility in dealing with services and everyday life
- carer certificate for people with disabilities
- municipal services such as home-based healthcare and personal support contacts, etc.

OTHER RIGHTS AND SUPPORT MEASURES

- adaptation courses at Eikholt National Resource Centre for the Deafblind
- adult education courses

You can read more about legislation and rights for people with deafblindness on dovblindhet.no and eikholt.no

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NATIONAL ADVISORY UNIT ON DEAFBLINDNESS

The National Advisory Unit on Deafblindness (NKDB) provides services to people with severe combined visual and hearing impairment / deafblindness, their families and networks and public and private organisations and groups.

Most people who receive services from the advisory unit have progressive conditions. Most people need advice, guidance and support from the advisors and other professionals at the advisory unit so they can make choices regarding their own future based on knowledge, understanding and insight.

The services are based on collaboration between NKDB, the municipality and the county authority.

For best possible habilitation and rehabilitation outcomes for people with deafblindness, specialised services are required from professional environments that have broad knowledge of the consequences of combined sensory losses, and how these can best be managed.

NKDB has specific knowledge of severe combined visual and hearing impairment defined as deafblindness.

The services are both individual and system-oriented:

- Services for individuals involve direct contact with people with deafblindness and their relatives and people close to them. The services are based on specific expressed needs and aim to enable the person to live as independently as possible.
- System-oriented services are services of a more general nature that are offered to municipalities, county authorities and the specialist health service, as well as the social and cultural environments of which people with deafblindness are part.



WHAT THE ADVISORY UNIT CAN ASSIST WITH

Assessments

- that form the basis for identification of deafblindness
- in connection with changes in an individual's
 - life situation
 - level of vision and hearing function
- aimed specifically at topics or issues raised by the support network or the person with acquired deafblindness

Identification of deafblindness is administrated by the National Interdisciplinary Team for Diagnosis and Identification of Deafblindness (NTT).

NTT

This interdisciplinary team consists of professionals from various fields of medicine, psychology and special education. The main tasks of NTT are to:

- quality-assure the sufficiency of medical and functional assessments and diagnostics conducted by the ordinary health service system
- diagnose and identify deafblindness in people with rare conditions and syndromes

Counselling and guidance

NKDB offers individual counselling and guidance based on the needs of the person with deafblindness.

Counselling and guidance can be provided directly to people with deafblindness. We can also provide counselling and guidance to relatives, municipal or county service providers and other professional bodies that provide services to the target group.

Individual plans

The advisory unit cooperates with the municipalities on the compilation and follow-up of individual service plans.

Training and courses

Provisions offered by NKDB include:

- habilitation and rehabilitation courses
- assistance with developing communication skills
- course and training for the network, including in collaboration with other agencies, such as assistive technology centres, other competence centres and municipal or county bodies

Courses and workshop are offered as required to

- people with acquired deafblindness and people close to them
- local service providers
- municipalities that have users with severe visual and hearing impairment / deafblindness due to age-related conditions
- other bodies

We also offer teaching and guidance to universities and university colleges.

Other professional assistance

- statements in connection with supportive documentation for applications for training, assistive technology, adaptations and services
- establishing contact between various service and user networks
- facilitating contact between people with acquired deafblindness

CONTACT US

The regional centres have a particular responsibility for the follow-up of people with deafblindness in their region, in cooperation with the respective municipalities.

The regional centres welcome direct enquiries from people with deafblindness, their relatives and professionals.

You will find contact details on this page.

You can read more about deafblindness on

dovblindhet.no

statped.no

signo.no

eikholt.no

REGIONAL CENTRES

The regional centres welcome direct enquiries from users, their relatives and relevant professionals. They perform assessments and provide guidance and training. They spread knowledge about deafblindness, give advice about relevant services and inform about the legal rights of people with deafblindness.

[Regional Centre for the Deafblind, Universitetssykehuset Nord-Norge HF](#)

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PO Box 88, 9038 Tromsø
Visiting address: Grønnegata 83
Phone: +47 476 85 163
E-mail: regionsenteretDB@unn.no
www.unn.no
Region: Nordland, Troms, Finnmark and Svalbard

[Statped, Units for Dual Visual and Hearing impairment and Deafblindness, Bergen](#)

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PO Box 113, 3081 Holmestrand
Visiting address: Solheimsgaten 13, 5058 Bergen | Phone: 02196
E-mail: post@statped.no
www.statped.no
Region: Møre og Romsdal, Vestland and Rogaland

[Statped, Units for Dual Visual and Hearing impairment and Deafblindness, Oslo](#)

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PO Box 113, 3081 Holmestrand
Visiting address: Gamle Hovsetervei 3, 0768 Oslo | Phone: 02196
E-mail: post@statped.no
www.statped.no
Region: Trøndelag, Innlandet, Oslo and Akershus

[Signo Deafblind Centre](#)

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Molandveien 44, 3158 Andebu
Phone: +47 909 96 038 / 940 57 062
E-mail: post.ssk@signo.no
www.signo.no
Region: Agder, Buskerud, Telemark, Østfold and Vestfold

CENTRES WITH NATIONWIDE SERVICES

The Eikholt National Resource Centre for the Deafblind offers assessment of combined vision and hearing and habilitation/rehabilitation.

The focus is on opportunities through knowledge about one's own sensory loss. They also provide training in various forms of assistive communication. Eikholt offers testing and training in the use of various assistive technologies, including IT/iPad and iPhone.

The centre also offers courses and training for families and networks.

[Eikholt National Resource Centre for the Deafblind](#)

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Helen Kellers vei 3, 3031 Drammen
Phone: +47 32 88 90 50
E-mail: post@eikholt.no
www.eikholt.no

[Statped, Statped – National Professional Unit for Dual Visual and Hearing Impairment and Deafblindness](#)

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PO Box 113, 3081 Holmestrand
Visiting address: Gamle Hovsetervei 3, 0768 Oslo
Phone: 02196
E-mail: post@statped.no
www.statped.no

The unit has a nationwide function when it comes to vision assessments for people with deafblindness/combined sensory loss.

THE COORDINATING UNIT

The central task of the Coordinating Unit is to coordinate the activities of the National Advisory Unit on Deafblindness. The unit contributes to enhanced cooperation between user and service organisations, performs regular public relations efforts and promotes research and development. The Coordinating Unit contributes to network building and provides advice to service users and providers.

[National Advisory Unit on Deafblindness, The Coordinating Unit](#)

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Universitetssykehuset Nord-Norge HF,
PO Box 88, 9038 Tromsø
Visiting address: Grønnegata 83
Phone: +47 476 85 163
E-mail: dovblindhet@unn.no

The National Advisory Unit on Deafblindness has a shared website:
www.dovblindhet.no

OTHER CONTACTS

Nav assistive technology centres, which offer interpreters and carers for the deaf and deafblind, are in all counties.

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www.nav.no
Phone: +47 55 55 33 33

[Advisory Centre for Vision and Hearing, Oslo](#)

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PO Box 99 Økern, 0509 Oslo
Visiting address: Kabelgt. 2, 0509 Oslo
Phone: +47 23 47 85 00
SMS: +47 911 57 575
E-mail:
radgivningskontoret@hel.oslo.kommune.no

[Advisory Centre for the Hearing Impaired, Bergen](#)

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Damsgårdveien 40, 5058 Bergen
SMS: +47 480 73 824 / 409 15 816
E-mail:
radgivning.horsel@bergen.kommune.no

[Advisory Centre for the Hearing Impaired, Stavanger](#)

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PO Box 8069, Forus,
4068 Stavanger
Visiting address: Haugesundsgata 27,
4014 Stavanger
Phone: +47 51 50 67 96
SMS: +47 478 03 541
E-mail: horsel@johannesls.no

[Resource Centre for Hearing and Vision, Trondheim](#)

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Visiting address: Erling Skakkes gate 40,
7012 Trondheim
Phone/SMS: +47 952 63 922
E-mail: rhs@trondheim.kommune.no

Most municipalities have support representatives for visual and hearing assistance. This is a voluntary scheme. Please contact your municipality for information.

Every municipality also has a coordinating unit for habilitation and rehabilitation. This unit facilitates interdisciplinary and cross-sectoral collaboration for those requiring long-term and coordinated services.

USER ORGANISATIONS

[The Norwegian Association of the Deafblind \(FNDB\) – including the section for the congenital deafblind](#)

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PO Box 5922,
Majorstuen, 0308 Oslo
Visiting address: Sporveisgt. 10
Phone: +47 22 93 33 50
E-mail: fndb@fndb.no
www.fndb.no

[The Norwegian Association for Combined Visual and Hearing Impairment/Deafblind \(LSHDB\)](#)

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Skippergata 33, 0154 Oslo
Phone: +47 22 41 34 24
E-mail: kontor@lshdb.no
www.lshdb.no

For more information

www.dovblindhet.no

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