

# Condition Insight Report (CIR)

## Deafblindness

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Completed in collaboration with  
Sense

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# Overview

## What is the condition usually called / any abbreviations used?

Deafblindness

## Brief overview of the condition

Deafblindness is a combination of sight and hearing loss that affects a person's ability to communicate, access information and get around.

It's also sometimes called "dual sensory loss" or "multi-sensory impairment".

A deafblind person won't usually be totally deaf and totally blind, but both senses will be reduced enough to cause significant difficulties in everyday life.

These problems can occur even if hearing loss and vision loss are mild, as the senses work together and one would usually help compensate for loss of the other.

The most common condition affecting both senses, and sometimes balance is Usher syndrome.

## What is the generally preferred term for someone with this condition?

An individual living with deafblindness.

# Presenting Symptoms

There can often be variation in the ability of someone to use the senses they have left in different environmental conditions. Some symptoms which can be experienced are:

- Changes to their vision in darker or very bright environments
- Loss of a visual field
- Distorted vision
- Difficulty with depth perception and focusing on moving objects
- Difficulty navigating around familiar and unfamiliar spaces. People may require red and white canes or guide dogs, when others will require human support to navigate around.
- An individual might have good visual acuity, and so can see an object presented in front of them, but they may have loss of peripheral vision so may be unable to see things on the floor in front of them for example.
- To compensate for loss of one sense with another, they will use other senses such as touch, body awareness in space, balance, smell or taste to get the information. Many deafblind people will need assistive technology or aids to access written information and some will require human support.
- Those with hearing impairments, who use hearing aids, may be able to have one-to-one conversation in a quiet room but will struggle to hear speech in a room with background noises or when outside.
- Struggle with localisation of sound and not be able to keep eye contact or direct to where a sound originated.
- May not be able to hear sound at a certain pitch and won't be able to rely on cues from environmental noises; equally they won't be able to safely compensate for this by using visual cues.
- People with Usher Syndrome may have affected balance

# Fluctuations



For people with Usher Syndrome (a genetic condition that causes deafblindness) sight can vary significantly given the time of day. Some people with Usher Syndrome experience night-blindness and this impacts daily activities more so in the winter for example, when it gets darker much earlier. This must be explored with the individual.

It should be noted that for some deafblind people, they may experience deterioration over time: certain genetic conditions that cause deafblindness can get progressively worse, such as Usher Syndrome and CHARGE Syndrome.

## Think about exploring things like:

- Is it central or peripheral vision that is impacted?
- Do they have any restrictions with moving objects or depth perception?
- What impact does changing light have on their eye sight and how do they manage this?
- If they use aids to support any hearing, are these effective in all environments?
- **How has the condition been over the past 12 months?**  
What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?

# Reliability

What specific areas should be covered to ensure a complete, reflective report?

**S**AFETY



Do they have any symptoms which could cause a safety consideration?

When considering safety, don't assume no injuries means no restrictions - what adaptations are in place to keep the individual safe in their environment?

Remember reduction or loss of one or both senses will pose a safety risk to individuals. Review safety guidance for more information as needed.

**T**IMELY



For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

You need to explore how the individual is managing the reduction of two senses as any compensation methods are likely to take additional time to complete.

**A**CCCEPTABLE  
STANDARD



How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Ensure you cover the hearing and sight loss for each activity. Both are equally important and the impact of having the loss of both senses needs to be explored.

Remember as well that their ability needs to be considered under the PIP specific guidance. This includes remembering to consider the environment the individual is in for any assessment so assumptions are not made about a broader ability.

**R**EPEATEDLY



Are they able to repeat a task as often as required? Is this the same every day?

Remember that light can have a big impact on individuals with sight impairment, you need to explore any aspects which affect their ability to complete tasks and how it might change during a day and whether they can repeat any task in the same way as often as required.

# Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

Many disabled people prefer to talk about their abilities and the ways they cope, and this can mask the ways in which they struggle. For deafblind people, communication/engagement and mobility are areas where issues are likely to be understated, especially the details of variability. These are also areas where issues may not always be apparent without further questioning; for example, in a face-to-face assessment in the home, an individual may seem comfortable navigating and independently carrying out tasks, but the consideration of whether this is due to familiarity must be taken into account. In particular, coping in unfamiliar situations should be explored.

When completing an Initial Review (IR) on claimants with deafblindness, consider if/ how they are going to manage the route of assessment advised.



# Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?



## During face to face interactions

- If a deafblind person needs to wait for their assessment, **they may need assistance getting to a seat.** They should be asked if they require any help.
- Assessors should be mindful that when they call a deafblind person for their assessment, **they may not hear their name has been called** or be able to see which room they need to go to for the assessment. Particularly if they do not have support with them, **guidance and assistance should be offered** at this stage. Similarly, it should be offered when leaving the assessment room.
- When a deafblind person attends an assessment with communication support, **the DA should be talking to the deafblind person, rather than their interpreter/communication support.** Asking the deafblind person how best to support this, e.g. in terms of lighting or positioning in the room, is best practice.
- **An assessor should not assume abilities based on physical impressions** – they should always ask what the experience of the individual has been, and whether this varies in different circumstances.

It is important to keep in mind that lip reading is not accurate. Even the best lip-readers only catch less than half of the words said to them.

## To make it easier to lip read:

- Ensure that you are facing the person
- Don't cover your mouth with your hands or clothing
- Use natural facial expressions and gestures
- Speak clearly but not too slowly
- Don't exaggerate your lip movements



# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 1: Preparing food

Not being able to see temperature gauges, location of items, timings, whether a food is in date will impact their ability and this cannot always be mitigated with aids due to additional impact of hearing loss. Some may struggle to chop items safely and many will need support to prepare and cook meals. Ensure to cover any balance restrictions for those with usher syndrome.

### Remember in PIP...

Are they safe in the kitchen? Have they had any incidents with cutting or burning? How do they tell if food is cooked or in date? Do they require assistance or supervision or have they adapted to safely using aids?

## Activity 2: Taking nutrition

Many are likely to be independent with this task but this will depend on how they are/have adapted to their sensory loss. Some will be able to make use of aids to support them to manage their restrictions.

### Remember in PIP...

Are they able to chew, swallow and bring food to their mouth? Do they regularly spill food that requires them to change clothing? Do they have any aids to overcome this?

## Activity 3: Managing therapy and monitoring a health condition

Whilst individuals may have input from therapy services to support with the management and learning skills to manage any changes to their sensory loss this is likely to be short term. Some will have medication such as eye drops but many may have no therapy or medication unless there are other conditions.

### Remember in PIP...

If they are prescribed multiple different tablets, can they determine which medication they should be taking at what time? Do they have any aids to support with their visual impairment? Do they receive any therapy in the home environment?

# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 4: Washing and bathing

Sight loss in a wet environment can be challenging for many and they will manage this in different ways. Some may struggle with depth perceptions or central vision and rely on aids to guide them and keep them safer in this environment, others may not require this. Also, if someone has a hearing impairment, they may be limited in hearing a fire alarm when their aids are not in use.

Also ensure to cover any balance restrictions for those with usher syndrome.

### Remember in PIP...

How does someone get in and out of the bath? Are they safe? Have they had any falls or do they use any aids? Could they hear a standard fire alarm in they were in the bath or shower without hearing aids?

## Activity 5: Managing toileting needs and incontinence

There is no physical limitation unless there is a comorbidity but many have different ways to manage their sight loss in this environment. For those who have comorbidities and may be incontinent this can be a challenging task which requires support. Ensure to cover any balance restrictions for those with usher syndrome.

### Remember in PIP...

Although mobilising to and from the toilet is not considered within the scope of the activity, you must explore how someone sits on, stands from, and cleans themselves after using the toilet. If they experience incontinence, how do they manage this? Do they require support?

## Activity 6: Dressing and undressing

For those with no sensory loss it is easy to determine if a garment is suitable to wear, clean, the right way round, and easier to handle fastenings. For many with sensory loss this becomes more challenging.

### Remember in PIP...

Explore if someone has the ability to select appropriate clothing for the environment. If they have a longstanding visual impairment, have they established a way to reliably manage this activity? How do they tell if clothes are clean or dirty?

# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 7: Communicating verbally

Some deafblind people will require interpreters with additional skills, which can include British Sign Language interpreters who use visual frame or hands-on BSL or deafblind manual interpreters. Some will be able to lip-read, but might require good lighting and to sit right opposite the person who is speaking or be closer to them to be able to see. Other people will be able to use clear speech.

### Remember in PIP...

The person must be able to both **express** and **understand** verbal information. Lip reading is not considered an acceptable way to communicate. You must explore how someone manages when communicating out of the home. Do they utilise specialist BSL/ISL? Do they have bilateral hearing loss or unilateral? Can they manage with background noise?

**You must also consider if the visual impairment is to the extent they cannot utilise an interpreter to communicate. Always explore reliability here.**

## Activity 8: Reading and understanding signs and symbols

Their ability to read will depend on their level of sensory loss and will vary for many depending on the conditions around them such as lighting.

### Remember in PIP...

How do they manage to read? Can they read normal size font? Do they require aids other than spectacles in order to read? Even with these aids, what can they read? Do they have any adaptations to post such as braille or enlarged font?

## Activity 9: Engaging with others face to face

Many can find social environments very daunting and anxiety provoking due to their sensory loss and many need support to communicate in these environments due to struggling to lip read. It can lead to engagement occurring in more 121 settings for some.

### Remember in PIP...

Although hearing or visual impairment alone are not covered within the scope of this activity, we must consider the detrimental impact of the impairments and this leading to potential anxiety. If someone does report difficulties with engaging, who can support them? Who do they engage with on a regular basis? If someone specific supports, why is this? How do they feel engaging with unfamiliar people?



# Functional Impact

*A brief summary of the functional impact those living with this condition may experience*

## Activity 10: Budgeting

The ability to manage this will be different for each individual.

### Remember in PIP...

Visual restriction is not considered within the scope of this activity. However, consider the detrimental impact both a visual and hearing impairment may have had on someones ability to learn and consequently manage their finances. Do they do this independently? Could they understand change in a shop? Do they do online banking or shopping?

## Activity 11: Planning and following a journey

Deafblindness has significant impact on an individuals ability to go out. Sight and hearing are the two distance senses which are important for a person's ability to navigate around safely. Deafblind people are not able to compensate an impairment of one sense by greater reliance on the other, meaning that many have support to get out.

### Remember in PIP...

Within the scope of the activity, someone must be able to plan and follow both familiar and unfamiliar journeys. This must include the ability to follow a diversion. Ensure you explore if someone can hear a train announcement for example. Even if someone drives, this does not necessarily mean they can plan and follow journeys unaided, as public transport must be considered.

## Activity 12: Moving around

This will depend on individuals comorbidities. Ensure to cover any balance restrictions for those with usher syndrome.

### Remember in PIP...

Remember that any safety due to their sensory loss will be covered in A11, here you should seek to determine if there are comorbidities which affect their physical ability to move around on flat surfaces and management of kerbs.



# Additional reading or other resources

## EXTERNAL

- Sense provides a number of resources for information on different aspects of deafblindness. These can be found here: [www.sense.org.uk/content/about-deafblindness](http://www.sense.org.uk/content/about-deafblindness)
- For further information see NHS Conditions and Treatments: <https://www.nhs.uk/conditions/deafblindness/>

## INTERNAL

- Desktop Aid – Activity 11, Activity 6, Vision

## Version control