What does good care look like for a deafblind person?

A report written for the Care Quality Commission (CQC)

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1.0 Background

1.1 What is deafblindness?
Deafblindness is a combination of both sight and hearing difficulties. There are around 250,000 people in the UK who have a serious impairment of both vision and hearing. There are three common terms for people with co-occurring hearing and visual impairments: deafblindness, multi-sensory impairment and dual-sensory impairment.

Most of what we learn about the world comes through our ears and eyes, so deafblind people can often face problems with communication, accessing information and mobility.

There are many causes of deafblindness. These include infections during pregnancy, premature birth, birth trauma and rare genetic conditions. Any of us can become deafblind at any time through illness, accident or as we grow older.

When someone is born with combined sight and hearing difficulties this is called congenital deafblindness. Conditions that can cause this include congenital rubella syndrome or CHARGE syndrome. People who are born deafblind often have additional disabilities, including learning and physical disabilities. If people develop sight and hearing problems later in life, this is called acquired deafblindness. This may be due to an accident, illness or as a result of ageing.

In some cases, people may be born with a genetic condition such as Usher syndrome, which may mean that they progressively lose their sight and / or hearing.

For more details on different types and causes of deafblindness visit the Sense website.

1.2 About Sense and the work we do
Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. We also support people who have a single-sensory impairment with additional needs.

We believe that every deafblind person has the right to choose the support and lifestyle that is right for them; one that takes into account their long-term hopes and aspirations.

We offer high quality, flexible services across the UK, using skilled staff and a dedicated network of volunteers. By offering a range of housing, educational and leisure opportunities, we can tailor the support we offer to the individual needs of each person, so that everyone can live as independently as possible and participate fully in their local communities.

Our services include on-going support for deafblind people and their families. These range from day services, where deafblind people have the opportunity to learn new skills to Sense-run houses in the community, where people are supported to live as independently as possible. Our communicator-guides offer support to deafblind people living in their own homes and our dedicated Information & Advice Team provide support and guidance on all issues relating to deafblindness.
2.0 Best Practice Case Studies

The following case studies have been developed to demonstrate the different needs of deafblind people accessing health and social care settings. They illustrate simple best practice techniques which can be used to enhance their experiences.

2.1 Beryl: the experiences of an older person in a residential care home

Following a nasty fall, Beryl moved into a residential care home at the age of 87. She had been widowed 3 years previously. Her family lived nearby but were no longer able to provide the level of support that she required.

A few weeks after Beryl had moved into a care home the staff noticed that she was becoming more and more withdrawn and that she rarely ventured outside of her room, choosing instead to sit in her chair in silence. Her family noticed this too and began to worry that she was showing the early stages of dementia. During this time, a new member of staff, Becky, came to work at the home and Beryl was one of her clients. She also identified that Beryl was reluctant to leave her room and didn’t enjoy having her dinner in the dining room with the other residents. In addition, she noted that Beryl didn’t seem very steady on her feet and that she often tripped – something which had previously been attributed to her recovering from her fall. In her previous job, Becky had undergone dual-sensory loss awareness training and she began to wonder whether Beryl might be struggling with her hearing and vision, and not the early stages of dementia as her family feared.

The next time Becky saw Beryl she broached the topic of the difficulties she had observed and worked through the Sense Sensory Impairment Screening Tool. Over the next thirty minutes Beryl shared how she had been noticing that she was struggling to see as well as she used to be able to and that she wasn’t very confident outside of her room as she was worried that she might fall and hurt herself again; whilst her experience in hospital had been a good one she didn’t particularly want to return. She also reported that she found it hard to follow the conversation in the dining room and didn’t want to appear rude to the other residents, which is why she avoided the communal areas of the home. When Becky had spoken to Beryl’s family previously they had mentioned that she used to be an avid reader and was also a fan of watching soaps on television – two things which the home hadn’t noticed her doing during her time with them. Becky asked Beryl about this and she reported that her eyesight meant she wasn’t able to read comfortably and that she was worried that if she watched the television she would need the volume turned up too loud and it would disturb the residents in adjoining rooms to hers. When asked why she hadn’t told anyone about the difficulties she had been experiencing, Beryl said that she hadn’t wanted to worry anyone or be a nuisance, especially to her family who were so busy and had already had to spend a lot of time caring for her following her fall.

Over the next few weeks, things began to change for Beryl; the home arranged for her to have hearing and vision tests which revealed that she had a moderate age-related hearing loss in both ears and the beginnings of macular degeneration. She was provided with some hearing aids which the staff helped her manage and these meant that she could participate more confidently in conversations in the communal areas of the home. Her local Sensory Impairment team also issued
her with a TV listener meaning that she could listen to her television at a volume that wouldn’t disturb anybody. Beryl moved rooms so that she was nearer to the dining room and lounge and didn’t need to navigate any stairs to meet up with other residents. Becky helped Beryl to get used to her new surroundings by walking her through the routes to the lounge and dining room and pointing out key landmarks on the way, within a few weeks Beryl was confident to leave her room unaided. Beryl’s family also arranged for her to have a subscription to a Talking Books service.

When the home managers saw the effect of the small changes that they had made for Beryl they decided that all staff should be trained in sensory loss awareness. Following the training, a number of other residents were also identified as having dual sensory losses and were supported accordingly.

2.2 Stephen: the experiences of an adult as an inpatient

Stephen, aged 47, has Usher Syndrome (Type 2) and has been admitted to hospital for a routine operation for gall stones. Stephen has had a severe hearing loss since birth and communicates using a combination of hearing aids and lip reading. He also has difficulties with peripheral vision, wears glasses and struggles to see clearly in poorly lit environments.

During his pre-op assessment, Stephen was asked what his communication needs would be during his time in hospital – he explained that he wouldn’t need an interpreter but that he would need the hospital staff to use good communication tactics. These tactics included getting his attention before starting a conversation, ensuring that they faced him when speaking to him, making sure that their faces were well-illuminated, and that they spoke clearly and not too quickly. The nurse carrying out the pre-operative assessment noted these needs on Stephen’s admission chart.

When Stephen arrived at the ward to be admitted two weeks later, the nurse checked his hospital notes and saw the communication needs that had been outlined during the pre-op appointment. She showed Stephen to his bay and as she went to write his name above the bed; she asked if Stephen would be happy to have his communication needs included on the sign so that others would know to speak clearly when they approached his bed. Stephen agreed and she wrote ‘Please speak clearly to me, I have a hearing and vision loss’. She also made arrangements for him to have a bedside light that he could use whenever he wanted to ensure that he could see clearly. When the time came for the nurse to finish her shift she ensured that Stephen’s communication needs were included in the handover notes.

During his time in hospital, Stephen found that the staff used good communication tactics when they spoke to him, but he also felt confident to ask for things to be repeated or for someone to face him when they spoke to him as he could refer to the sign above his bed. When the consultant began his rounds of the ward, he asked Stephen whether it would be ok if his medical students also attended. Stephen asked that the consultant didn’t stand at the end of the bed where it would be harder for him to see him but that he would sit on the chair next to his bed and near to the lamp so that Stephen could use lip-reading to support what he was hearing with his hearing aids.

When the time came to go into theatre, Stephen was allowed to keep his glasses and hearing aids on until he was fully unconscious so that he was aware of what was happening. They were also
replaced once his surgery was completed so that as he came round he was able to see and hear as clearly as possible.

When Stephen left hospital he was given a number of different medications to take. Before he left, one of the nurses sat down with him and explained each step and provided him with a printed copy of the information in large print so that he could refer to this if necessary. Because of the excellent awareness of his communication needs when in hospital and on discharge Stephen felt well informed about his health and empowered to manage his aftercare independently and effectively.

2.3 Charlotte: the experiences of a child as an inpatient

Charlotte, aged 7, lives with her parents and two brothers. Charlotte has CHARGE syndrome, a rare genetic condition, and as a result is profoundly deaf and vision impaired. She also has a heart condition which means that she often has to be in hospital for days at a time. As Charlotte can’t hear or see very well her family communicate with her by using touch.

As Charlotte goes into hospital on a regular basis, it is important that she feels safe and secure and that she understands what is happening to her. When Charlotte was first diagnosed as having a dual sensory loss, a member of Sense’s Children’s Specialist Services team worked with her family to support them to develop communication. They also visited the hospital and talked to the professionals who look after Charlotte about her individual needs as well as giving them a copy of their ‘Multi-sensory impaired children in hospitals’ booklet for additional advice.

As she is such a frequent visitor to the hospital most of the staff now know Charlotte and her parents well. They always ask Charlotte’s parents if there is anything that she particularly likes or doesn’t like at the moment and the best ways to communicate with her. Over the years the staff have established ways to communicate effectively with Charlotte; including using ‘objects of reference.’ For example, whenever a nurse is going to undertake routine observations they hand Charlotte the blood pressure cuff so that she understands what is about to happen. The staff have also developed a communication passport for Charlotte in which her parents and staff at the hospital who have worked with her have written down all of Charlotte’s likes, dislikes, objects of reference and more. This enables other staff who may not have met Charlotte before to be able to find out about how to communicate with her simply by reading the communication passport.

Whilst hospital visits are always stressful because they mean that Charlotte is ill, the readiness of the staff to understand Charlotte and want to communicate with her rather makes it a more positive experience. Their dialogue with her parents empowers them as they respect their expert knowledge of their daughter but also reassures them that she is in safe hands.
2.4 Lloyd: the experiences of an adult in primary care

Lloyd, aged 25, is deafblind. He communicates using deafblind manual but also has a laptop with assistive technology and an attached refreshable Braille display. Lloyd receives 5 hours a week of support from a communicator guide but otherwise lives alone.

Lloyd has diabetes so often requires blood tests and check ups with his GP. In the past, Lloyd has had difficulties with booking GP appointments and having access to a qualified and NRCPD registered deafblind manual interpreter. It is important that Lloyd has a registered interpreter at his appointments so that he can fully participate in the appointment and access all of the information that he needs without miscommunication and with the assurances of confidentiality and impartiality.

When Lloyd registered with his new GP surgery he asked if he could have an introductory appointment with his GP to discuss his communication needs. The GP obliged and between them they came up with an action plan on how to support Lloyd and best meet his needs:

- The surgery now has the appropriate contact details to be able to arrange for a registered interpreter to attend appointments for Lloyd and whenever he books an appointment they arrange this accordingly.
- Lloyd is allowed to book a double appointment slot as it allows more time for him to communicate via his interpreter
- If Lloyd has a blood test the surgery will email him the results to save him having to attend the surgery or wait for his communicator guide to be able to read the printed results posted to him
- Whilst the GP surgery has a telephone based appointment booking system, Lloyd is able to request and arrange his appointments via email
- If Lloyd’s GP needs to refer him to another clinician he always ensures to include Lloyd’s communication needs in the referral letter so that they can put appropriate arrangements in place

Sometimes Lloyd needs appointments at short notice which means it isn’t always possible for a communicator guide and/or interpreter to be arranged. In these situations, Lloyd’s GP will visit him at home and communicate with him by typing on his laptop and using the Braille display. He has also taken the time to learn the deafblind manual alphabet so can introduce himself when Lloyd opens the door to him; something which is not only useful but also reassuring for Lloyd.

The person centred approach to Lloyd’s care has meant that he is able to access primary care services in an effective and appropriate way; he is much more able to manage his diabetes and feels that he has control of his own health, as well as needing fewer GP appointments. In addition to Lloyd having the support that he requires, the surgery now has a much greater understanding of the needs of people with sensory loss and make sure that they record all communication needs where appropriate. Staff have also recently undertaken sensory loss awareness training which is now included in their induction package and a number of patients have commented that they have noticed a significant improvement in the care they receive as a result.
2.5 Other
The below case studies are published in Sense literature and publications which have been included for additional information.

2.5.1 Mary
Mary moved into a residential home when she lost all her remaining sight after a brain operation. She’d been almost deaf since the age of 12 but had always led a full and rewarding life. She’d married, had two children, enjoyed working at a local shop and enjoyed a lively social life. Now the unthinkable had happened and she had been left completely deafblind. At first, her family and the staff in the home where she lived, struggled to find a way to reach her. “We started to realise that Mum was changing” said her son Jim. “She was becoming very disorientated and was increasingly withdrawing into her own mind.” Fortunately Sense had known Mary for some time and were able to offer guidance and support. They provided a communicator guide, Nikki, for three hours each week funded by the local authority. She worked with Mary on a one-to-one basis helping her to develop a new form of communication by using cut-out wooden letters to spell words. Equally importantly, Nikki was able to train and support the other staff working with Mary in how to communicate with and support her. This was enormously beneficial. “Mum became a lot sharper in herself and was much happier” said Jim. “She didn’t talk to the voices in her head nearly as much and she really appreciated being able to talk to the other staff in the home.”

2.5.2 Barbara
Barbara has been living in a residential home for two years. When she first moved in she got on well with staff and other residents and enjoyed taking part in activities. Although she was quite deaf, she could communicate well provided the person was facing her in a well lit room. In the last few months she has become more withdrawn. New staff complain that she is difficult and bad tempered. Staff ask for advice from a specialist in sensory loss who says that Barbara’s sight has deteriorated so that she is finding lip reading difficult. This is making it frustrating for her. They find that she can still see well enough to read large letters with the help of a magnifier. Staff began to use an A4 pad and marker pen to communicate with her. She becomes less frustrated, and talks to staff and residents again.

2.5.3 Janet
Janet is a care worker providing support to people in their own homes. She visits Ethel once a week to help with cleaning and shopping. Normally Ethel is very friendly but recently Janet notices she seems very confused and even a simple conversation is difficult. She also notices that Ethel has begun to lose things, especially if she has moved something. She is concerned that the confusion is because Ethel doesn’t see and hear well, not because of dementia. Janet tells her manager that she
thinks some specialist help is needed. When she is working, Janet also makes sure she leaves things exactly where she found them, and that she uses good clear speech when talking to Ethel.

2.6.4 Luna

Luna, 78, has a hearing impairment and only a tiny amount of residual vision in her right eye due to glaucoma linked to diabetes. She can hear speech if someone speaks slowly and clearly to her. When her sight and hearing deteriorated she lived with two of her daughters for a while but then decided to move into a residential home. She’s very pleased with her ground floor room and the staff have made a concerted effort to meet her particular needs – including receiving deafblind awareness training from Kent Association for the Blind (KAB). Luna also receives the support of a communicator guide – Jackie – from KAB. Jackie enables her to get out and about, go shopping, collect her pension, have a cup of coffee in a local café. She has a strong bond with Jackie and still keeps in close contact with her former guide. Luna speaks of them with a smile on her face. Now Luna has the care and environment that suits her. She regularly attends a craft class and is taking computer lessons. As a religious person, she is supported by her local church which escorts her to and from services. All these arrangements have allowed Luna to keep much of her independence and to choose how she wishes to live her life.
3.0 Ingredients for good care

3.1 Healthcare

The following sections outline Sense’s recommendations on quality standards for commissioners, health services and other professionals when providing care and support for deafblind people. For more information on deafblind people’s experiences of healthcare, please see our report ‘Who Cares’ and the report from a recent engagement event held by NHS England and Sense, regarding the development of their Accessible Information Standard.

3.1.1 Commissioners

NHS England, CCGs and Health and Wellbeing boards should:

- Be aware of and understand the impact of deafblindness, and make it a requirement of funding that the needs of all deafblind people are being met.
- Ensure services are commissioned to be accessible (physical and environmental access).
- Build the needs of deafblind patients into quality assurance inspection checklists.
- Ensure deafblind patient’s needs are included in local Joint Strategic Needs Assessments (JSNA), including the number of deafblind people identified in compliance with Deafblind guidance.
- Ensure deafblind patient’s voices are heard when consultations take place, putting steps in place to ensure consultation exercises are accessible.
- Ensure contracts for interpreting include organisations that can provide for the communication needs of deafblind people.
- Ensure quality standards for healthcare services, listed below, are made a requirement for all commissioned services.
- Be aware that those who are deafblind may need longer appointment times and allow services to accommodate these needs, possibly within tariff negotiations.

3.1.2 Health services

Services should:

- Ensure all professionals have basic deafblind awareness training.
- Take steps to identify their deafblind patients, including older people who may not yet recognise that they have a combined sensory loss. Support them to access the support they need to lead full and active lives.
- Put in place systems that alert all healthcare staff to an individual’s communication and access requirements. For hospital inpatients this should include a sign above the patient’s bed highlighting their needs, as well as information about communication and sensory needs being shared during handover.
- Medical records should include information about the way deafblind people need to be contacted (moon, braille, large print, audiotape etc) and services should ensure that deafblind people are contacted in a format that is accessible.
- Understand systems and requirements for booking appropriate communication support (interpreters) and have a commitment to doing so. Be flexible as to which agency and
communication professional is used, as communication needs can be very person specific. Decisions should be made in partnership with the individual.

- Except in an emergency, no procedure should be carried out on a deafblind person without it being fully explained in a way that is clear and accessible to the deafblind person.
- Ensure professionals are aware of legal requirements for reasonable adjustment and put these in place to support the deafblind person.
- Provide signposting information as to where additional support can be accessed, and ensure staff are aware of their duty to support deafblind people.
- Have information available in formats that are accessible to all patients, e.g. Braille, audio, large print, moon etc.
- Have communication boxes available to support the staff in their work, these could include hearing aid batteries and tubing, signage on needs for above beds, objects of reference, communication cards (Block/deafblind manual alphabet) etc, on children’s wards these could also include some sensory toys.

### 3.1.3 Healthcare professionals

Staff should:

- Have received deafblind awareness training.
- Seek to understand an individual’s needs, and work with the individual and their family to establish a suitable communication method (accessing interpreters where required).
- Establish a partnership approach to healthcare.
- Ensure individuals have the opportunity to explore, map and experience the environment they are in, enabling them to be as independent as possible. For example, making sure individuals know where the toilet/reception desk/nurses station are located etc.
- Ensure individuals are fully aware of the nature of their condition, treatment and on-going care.
- Assume capacity, unless officially informed otherwise.

### 3.1.4 Adjustments for specific groups

Whilst the above standards apply to all deafblind people there are some additional recommendations that may be considered for older people and children and young people.

#### 3.1.4.1 Older People

If a service works with a high volume of older people they may want to include some additional quality standards looking at identification and support, and consider more than basic deafblind awareness training for staff. This is because by far the largest group of deafblind people are people over 70 years old, and one in twenty of patients over the age of 75 are likely to be classed as deafblind. Furthermore, deafblind older people have higher rates of a range of conditions, including stroke, arthritis, heart disease, hypertension, falls and depression. Sense estimates the cost of treating these additional conditions to be £365,000,000 per year.

Support is available to deafblind older people that would help keep them active, independent and healthy so it is important that they are identified and informed of the services available.
Identifying deafblind people can be challenging. Older people are less likely to come forward asking for help and less likely to know what is available. Too often, they and their families think sensory loss is only to be expected at their age and therefore they do nothing to seek support.

If deafblind patients are identified and encouraged to seek the right help, their quality of life and health will be improved.

Quality Standards

- All staff to receive training on deafblind awareness (with focus on older people) and early identification of sensory loss.
- Implement simple functional screening for dual sensory loss in all older patients, where consent is given.
- Consider the implementation of a “Sensory Friends” or “Sensory Champions” initiative where at least one practitioner in each team has more in-depth training and knowledge in working with people with dual sensory loss.
- Ensure consideration is given to the possibility of sensory loss where an individual is showing signs of an increased number of falls, malnutrition, confusion or withdrawal from socialising.

3.1.4.2 Children and Young People

When we talk about children and young people with combined hearing and sight problems we often used the term Multi-Sensory Impairment (MSI). This is because the combination often causes additional difficulties such as problems with balance and spatial awareness. MSI is a very rare disability, particularly in children and there are an estimated 4,000 children with MSI in the United Kingdom. And it is really important to remember that every child has different, individual needs, and some children with the same diagnosis can vary enormously in their abilities and character.

Quality Standards

Many MSI/deafblind children and young people will have ongoing health needs and so these additional standards focus on diagnosis, ongoing support and transition in to adult services (please remember these standards are in addition to those listed above)

Diagnosis

- Diagnosis and support is sensitively delivered, appropriate follow up information and further sources of support and peer/family networking is provided.
- Support is joined up – with other agencies (Education, Social Care and the voluntary sector)
- Provision of a key-worker to co-ordinate, advise and provide emotional support to families.
- Provision of multi-agency early intervention (e.g. Early Support Programme) including early stimulation provision on ward as well as community based provision. This would include liaison with education providers and referral to specialist advisory teachers in sensory impairment (Hearing impairment, visual impairment and MSI)
Ongoing care and support

- Delivered in venues that are physically accessible – level access, tactile markers etc.
- Provision of a key-worker approach to co-ordinate, advise and provide emotional support to family
- Support is joined up – with other agencies (e.g. education, Social Care and the voluntary sector)
- Signposting and access to specialist tertiary monitoring services as appropriate (e.g. CHARGE, Alstrom, Bardet Biedel, Wolframs, Usher etc).
- Access to Emergency information – passport type (such as an ‘All about me’ or ‘communication passport’) – with flagging systems for priority access through A&E and planned hospital admissions.
- Provision for support for family during planned hospital admissions Provision for accessing appropriate education during planned and longer unplanned admissions.
- Discharge is planned with appropriate community support in place prior to discharge to ensure patients and parents have right skills required when discharged with complex medical needs (CPAP, suction, Trache, NG-tube etc)
- Appointments are extended to give time for familiarisation and communication.
- Appointments may need to be provided at a more frequent interval than other patients to be able to notice changes in health status and for children and young people to develop understanding of appointment – e.g. provision for appointments to follow a routine format for procedures so that the child/young person understands what is happening and what to expect next – increasing compliance and effectiveness of appointments overall.
- Appointments are co-ordinated – where the child/young person sees more than one health professional consideration is given to co-ordinating appointments where possible.

Transition to adult services

- Transition to adult services is planned with health plans in place.
- Planned transitional arrangements to meet adult health practitioners and familiarise with new environments.
- Provision to support CYP to take ownership of own healthcare and planning (where suitable).
- Health needs and future planning is considered as part of wider multi-agency provision and transition planning (from 14+).

Audit and review

- Targeted audits about user satisfaction and patient experience.
3.2 Social Care

Many deafblind people require support from social care services; ranging from support at home or to leave the home, to residential facilities. For more information on the different types of support that deafblind people need watch our report on See Hear.

The majority of the information in this section is based on information included in our Seeing Me publication. We will also be submitting a more detailed piece on social care as part of our consultation response so please refer to this for more information.

3.2.1 Service user plans

Care plans should be drawn up with the involvement of the service user. This is not possible unless meaningful communication has been established. It must also be recorded in a style that is accessible to the service user.

Other useful resources include one page profiles and passports.

3.2.2 Social contact and activities

Keeping active is vital to keeping healthy, especially as we get older. Enabling people to maintain leisure and social activities and cultural interests will require thought about what support the person needs to do this.

One of the greatest challenges for older people with hearing and sight loss is to fill the time when reading, television and other activities may be difficult or impossible. However, it is possible to adapt activities, for example large print knitting patterns and audio taped books. RNIB sells a number of tactile games, such as dominoes and playing cards which can be played with sighted and hearing people too.

Some museums, galleries and cathedrals offer ‘touch tours’ for people who cannot see exhibits. Don’t assume a person has to give up activities they once enjoyed or is not able to participate; look for ways to make them accessible, and ask for specialist help if necessary. Look for new activities that they may enjoy. There may be social clubs for people with sight loss or even people with both hearing and sight loss.

Think about the social activities available to service users. Do they all assume the ability to hear in a noisy environment? Has communication support such as a loop or communicator guide been provided where appropriate?
3.2.3 Food, meals and mealtimes

For people with sight loss, eating can be difficult. Dining rooms can be noisy, making speech difficult to understand. If a person always sits in the same place this can make it easier for them. Think about making the most of people’s remaining vision by serving attractive food on a contrasting plate and placemat in a well-lit environment. If a person’s hearing and sight loss is severe, make sure they know the food is there and don’t take the plate away until you are sure they have eaten enough.

3.2.4 Specialist equipment

Service users should have the specialist equipment they require to maximise their independence. For people with a dual sensory loss this will include a range of high and low tech equipment. Loop systems can help anyone who uses a hearing aid to hear speech or the TV. Magnifiers can help with reading. Tactile markers, vibrating alarm clocks, task lighting, the list is endless. A specialist assessment may be necessary to identify the best solutions.

3.2.5 Information and communication

3.2.5.1 Written information

It is important that information and correspondence is provided in an accessible format. For example, letters, care plans, information about activities, menus, etc. should be available in large print, braille, tape or disk as appropriate for the individual. Many visually impaired people have enough vision to read printed information if it is large and bold. No single size is suitable for everyone, but most people prefer their large print in the range of 16 to 22 point. Arial is an example of a clear font. You can word process simple large print documents yourself. If a person requires information in braille, audio tape or disk formats, you can use any number of transcription services. If in doubt, contact your local sensory team or other specialist sensory agencies such as Sense, Deafblind UK or RNIB.

NHS England is developing an information standard regarding accessible formats and communication support. For more information visit their website.

3.2.5.2 Communication

When speaking to someone with a dual sensory loss it is important to use excellent communication tactics. With regard to older people, remember that those with dual sensory loss often have problems with communication. If we use common sense, clear speech and courtesy we can help an older person to understand what is being said. Simple solutions can improve the environment
dramatically. Just because someone is smiling and nodding it doesn’t mean that they’ve understood. You can also ask the person how they would like to be communicated with and what would make it easier for them.

For more information on different communication methods and tactics visit the Sense website.

3.2.6 Environment

The ability of a person with hearing and sight loss to move around with or without support should be considered in the context of the whole environment. There are aspects of the environment that can be adapted to aid the individual’s feeling of confidence and improve the chances of independent mobility.

3.2.6.1 Lighting

Good lighting is essential; strip lighting or low energy halogen bulbs cast no shadows and illuminate a whole area. Stairways in particular should be well lit. An 11 watt fluorescent task lamp provides a source of good personal lighting.

3.2.6.2 Noise

Avoid unnecessary background noise. The radio, the television; a vacuum cleaner, all create an environment where it is difficult to identify specific sounds or understand speech. Background noise will also cause problems for people using hearing aids. If the only place to meet people is a room where the TV is on all the time this will cause problems for anyone with a hearing impairment. Having the radio on while you work will make communication harder.

3.2.6.3 Colour contrast

Door handles, door frames, light switches and placemats at meal times in contrasting colours can be useful aids to vision. The edge of steps should be highlighted either by an edging strip in good strong contrasting colour or by hazard tape. Ensure the internal decor is suitable – no fussy confusing patterns with doorways painted a blending colour. Instead have plain or very simple patterned walls with doorways and skirting boards picked out in a bold contrasting colour.

Staff should wear clothing which gives them a strong outline and contrast. No spots, stripes or flowery patterns. Plain un-patterned clothing in strong colours is best.
3.2.6.4 Obstacles

Environmental obstacles can be dangerous for people with little or no vision. For example doors left half open; buckets, wastepaper bins, handbags, left where they will cause someone to fall; things like shelves which jut out from the wall at head height; and low items like coffee tables in the middle of the room. It is important that these obstacles are removed where possible or if they are essential then they remain in a consistent location so that the deafblind person can navigate accordingly.

3.2.7 Orientation

Orientation is the ability to locate ourselves within our environment. Both within the home and outside there are a variety of clues which can help a person identify where they are and therefore move around independently.

There are many naturally occurring clues that can provide useful information. Inside the home one might consider a typical route from the bedroom to the bathroom – the table by the door, the door, the radiator, the corner outside the bathroom etc. The positioning of furniture can be an important orientation clue. For example, chairs and other furniture can be used to divide a large room into a more easily understood smaller area. If furniture is used as a location clue then it is important that it is not moved around regularly.

Outside in the garden perhaps there are different sorts of paving, a lawn, a gate etc. It can be useful to follow a route blindfolded and write down all the clues that you used to locate your position.

Sound can also be a useful location clue for a person with enough hearing. It may not be a good idea to have the radio on all of the time but if it is always located in the kitchen then that is a good guide to where that room is.

Other senses such as smell can also be used, for example it may be a good idea to have a bowl of pot pourri in the bedroom so that when the person can smell it they know that they are in the bedroom. Objects of references can also help someone to orientate themselves; for instance hanging a wooden spoon on the kitchen door, a sponge on the bathroom door and a remote control on the lounge door could all help someone to differentiate between rooms and their purposes.

The aim should always be to enable the person to move around their environment, either inside or outside the home, as independently as possible. There are a number of techniques which will help the person to feel confident. It is important to develop a trusting relationship between the person and the carer who is helping to develop mobility skills. Learning how to trail a route is an important step. Pick a short route and encourage the person to hold one hand ahead while trailing the back of the other hand against a wall. Help them to explore the texture of the wallpaper and any other clues on the route. You might like to use a border strip of wallpaper or, for a more temporary learning period, a strip of Velcro.

More complicated routes can be broken down into easier stages. For example, a walk from the kitchen to the lounge: Walk the entire route pointing out all of the clues along the way. Divide the route into stages. Support the person in learning the first stage of the route. When they can achieve that part independently, move onto the subsequent stages.
3.2.8 Older people

Care homes for older people will almost certainly have service users who have a dual sensory loss. It is not possible to meet the National Minimum Standards issued by the Department of Health and the National Assembly for Wales without taking account of their needs.

In December 2013, NICE released their new Quality Standards on the mental wellbeing of older people in care homes which included the below. See the Sense website for more details.

- Organisations providing care must ensure that staff are trained to be alert to specific needs arising from sensory impairment in older people in care homes and to record them in a care plan.
- Social care, health and public health practitioners are alert to and recognise specific needs arising from sensory impairment in older people in care homes and record them in their care plan.
- Local authorities and other commissioning services only commission services from providers that can produce evidence of protocols for training staff to be alert to specific needs arising from sensory impairment in older people in care homes and to record them in a care plan.

In 2012, Sense conducted a joint study with Bupa to investigate the identification and assessment of the needs of older people with combined hearing and sight loss in residential homes. Key findings included:

- Many residents reported hearing difficulties when in groups and background noise; a consideration when many activities were held in groups, e.g. talks, quizzes and social gatherings. Others were not able to take part in activities which required good vision.
- Of the seven homes asked, only one reported having a hearing loop system fitted. Other than this, none of the homes had any adaptations specifically for people with sight and/or hearing loss.
- Most staff felt that they had not met many people with a combination of hearing and sight loss.
- None of the staff interviewed were aware that the local authority has a duty to provide an assessment for people with combined hearing and sight loss under the Deafblind Guidance.
- All but one member of staff said they would welcome further training in the needs of people with hearing and sight loss.

The full report with more findings is available here.
4.0 Resources

Listed below are links to some of the resources available from Sense that are available free of charge. For more information please contact our Information and Advice Team.

General

http://www.sense.org.uk/publications

Children and Young People

http://www.sense.org.uk/content/resources-professionals-working-children-and-young-people

www.sense.org.uk/hospitalspack

Older People

www.sense.org.uk/olderpeople (including training for care staff)


http://www.sense.org.uk/publications/enjoy-life