

# It all adds up

A guide for healthcare staff on supporting patients with a dual sensory loss



**sense**  
for deafblind people

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There are many easy ways in which you can support your patients to continue to maintain their independence and a healthy lifestyle.

# Maintaining independence and quality of life

**As we get older many of us will start to develop problems with our hearing and vision. Sense has estimated that at least one in every 20 patients aged over 75 will have a significant hearing and sight loss.**

This loss might make it difficult for people to hear their name being called in reception, access information on living healthily or manage their health conditions. It could lead to them finding it increasingly difficult to get to their appointments at all. They may also start to find daily living tasks difficult, and can feel isolated and depressed.

Sense recognises that colleagues in health settings are often working in pressured situations. However, there are many easy ways in which you can support your patients to continue to maintain their independence and a healthy lifestyle. For example, aim to provide large print information as standard

on common health conditions and healthy living.

You could also work with your patients to find the best way to support them with communication and attending appointments. There are also lots of places that you can refer your patients for additional support in their homes and communities. This booklet suggests many simple adjustments and changes which are easy to do but can substantially improve the quality of life of older people with sensory impairments.



# Supporting patients with a dual sensory loss

## 1

**One in twenty of your patients over the age of 75 are likely to have a moderate or severe hearing and sight loss. This combination of sensory impairments – which is called deafblindness or dual sensory loss – can have a serious impact on people’s lives and health.**

This has been demonstrated by findings published in the Chief Medical Officers Report<sup>1</sup>:

- 7-10% of all years lived with a disability can be attributed to ‘sense organ diseases’ (i.e. causes of sensory loss) in those aged 70 or over. This is comparable to other conditions such as diabetes, Alzheimer’s, dementia and cardiovascular disease.
- In the 55–84 age group, those with a hearing or vision loss were found to be more than twice as likely to have Alzheimer’s or another form of dementia.

- 69% of those reporting a dual sensory loss have two or more additional long term conditions.
- Only 64% of people who have a dual sensory loss feel confident in managing their own health.
- In terms of health related quality of life, having a dual sensory loss has a significant impact, greater than having a single sensory loss.
- People with a dual sensory impairment are more likely to experience anxiety and depression than those with a single sensory impairment.

Older people with dual sensory loss also have higher rates of a range of conditions – including stroke, arthritis, heart disease, hypertension, falls and depression.

Support is available to older people who have a dual sensory loss which can help keep them active, independent and healthy. However because their needs often haven’t been identified many do not receive appropriate services. This booklet includes information on how you can help identify older people with dual sensory loss and make sure they get the support they need.

## What is a dual sensory loss?

When someone has a combination of hearing and sight impairments this can cause problems with mobility, communication and access to information. Many older people have some level of hearing or sight loss, but a loss in both senses makes it much harder to compensate. They may:

- Find it difficult to receive information about healthy lifestyles, or managing medication and long term conditions
- Find healthy eating difficult, as shopping and cooking become a challenge to do safely
- Struggle to communicate with others, and so become ever more isolated from friends and family
- Not feel safe to go outside, making exercise difficult
- Find it hard to read, watch television, listen to the radio, or keep their minds active.

It’s not hard to see how this could add up to poor health outcomes.



<sup>1</sup> Annual Report of Chief Medical Officer, 2012, On the State of the Public’s Health; [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/298297/cmo-report-2012.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/298297/cmo-report-2012.pdf)

## Identifying patients with a dual sensory loss

Patients may:

- Not respond when they are sent written information
- Have to be told several times that it is their turn to see the doctor
- Give answers that don't relate to the question they were asked
- Nod and smile in conversation, even when they don't understand
- Walk slowly, or with less confidence, or bump into things
- Read in an unusual way, for instance holding the paper close to their face
- Ask you to repeat what you have said, or complain that you are mumbling
- Not recognise staff they have met often

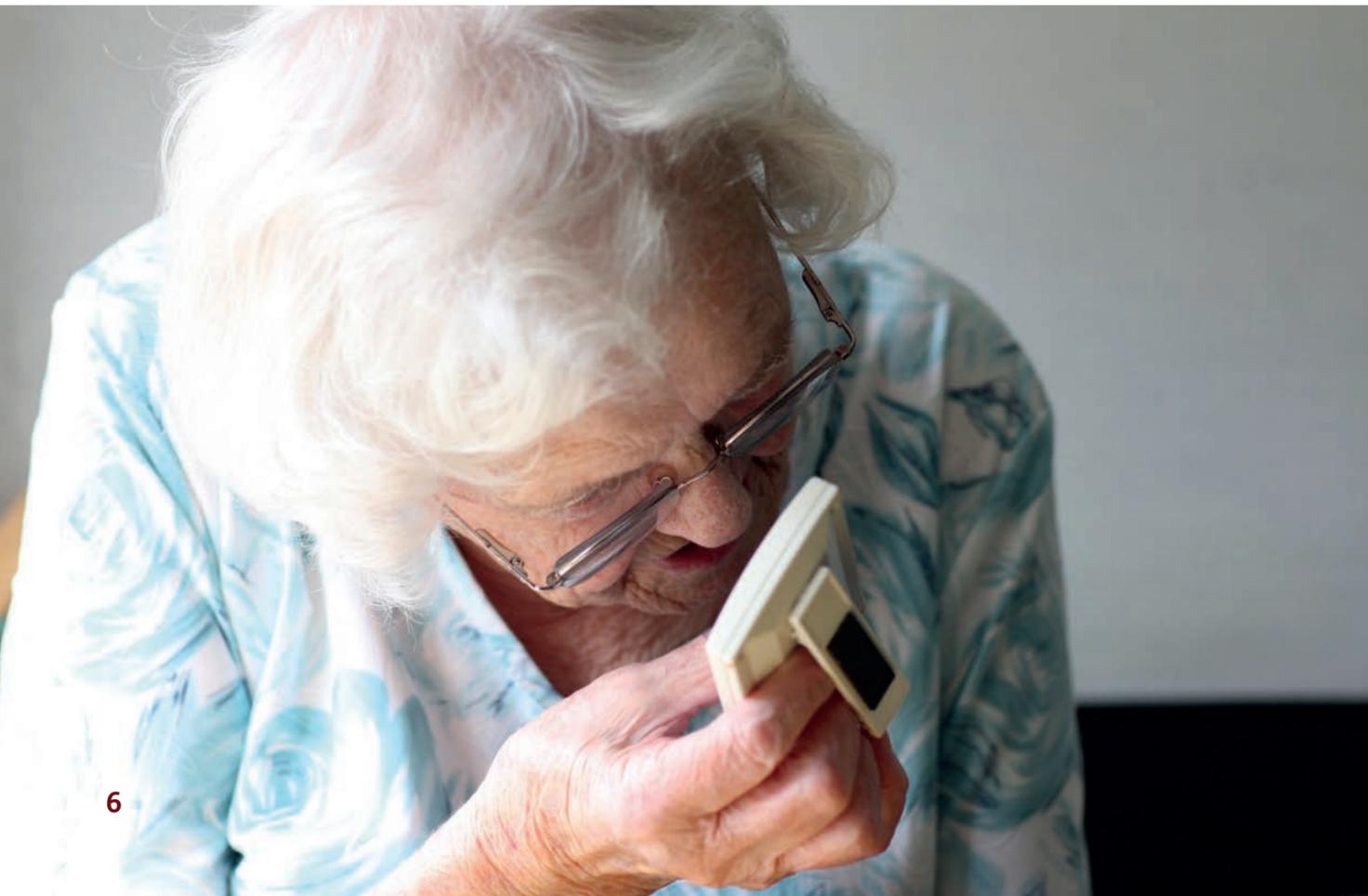
- Prefer to talk to staff they have met before because familiar voices are easier to understand
- Find it difficult to find their way to the right room
- Not come to the surgery at all because it is too difficult.

There may be other reasons for the indicators listed above, but don't immediately assume that confusion is dementia related, or that a cautious walk is a sign of arthritis. It may be that sensory loss is a factor.

Some older patients may not recognise that they have a problem with their hearing and their sight. Sensory loss may come on gradually and people will adapt their behaviour to take account of sensory changes, sometimes without realising.

Make an effort to identify patients with a dual sensory loss and – with their permission – refer them to social services for an assessment. It will make their lives easier and improve their physical and mental health.

Many of your patients in the 50 – 70 age group will have older relatives with sight and hearing problems. They may not have recognised this, or know what to do about it. You can make them aware of the support available if the issue comes up, or display a copy of Sense's 'Enjoy Life' poster (enclosed) in the waiting room or reception area.



# Making your services more accessible

## 2

Often simple, low-cost changes can help people with sensory impairments access your service more easily. This checklist will allow you to look at your setting and decide if there are any adaptations you could make.

### The environment

- Are all areas well lit? Are there any dark corners or big changes in light level between corridors and rooms?
- How easy would it be for someone with limited vision to move around, could they find doorways, banister rails, etc?

Look for:

- Colour contrast between banister rails, door frames and walls
- Are the labels on doors in large lettering with colour contrasted backgrounds?
- Are floors and walkways kept clear of obstructions?
- Does background music or radio make it difficult for hard of hearing patients to hear their name called?
- Is there a loop system in reception? Do staff know how to use it and is it maintained regularly?

- Is there a glass screen between patients and reception staff? If so, could reception staff come out from behind it if it makes communication difficult?
- Could appointments be announced via a visual display, as well as having names called?

### Staff

- Do all staff know how to use clear speech?
- Do staff know how to guide a patient?
- Is there a system for booking longer appointments for people whose communication is slower?
- Do reception staff make sure patients have heard when their name is called?
- Do reception staff know how to use a text phone/receive a Text Relay call?

### Information

- Do you record the communication and information needs of patients?

- Can you send letters to patients in different formats if they need it – for example via email, or in braille or audio?
- Do you offer a range of different ways for patients to contact you – for example telephone, text message and email?
- Do you have patient information available in different formats – for example braille or audio? This is especially important for commonly used information such as self-care information or introductions to your service.
- Do you have a website that is accessible to those using screen readers, including documents available for download?

For more information about making your service accessible take a look at the quality standards included as a pull-out at the back of the booklet. Many of the things included in this checklist will be addressed by NHS England's Accessible Information Standard.



# Communicating with patients with a dual sensory loss

## 3

### Clear speech

Most older people with a dual sensory loss continue to use speech for communication but may find it increasingly difficult to hear. Here are some basic tips for good communication:

- Make sure you have the person's attention before you start

- Good lighting is important. Don't have the light behind you – for example, don't sit with the window behind you
- Speak clearly
- Speak a little more slowly than usual but keep the natural rhythm
- Speak a little louder, but don't shout as this will distort your voice and lip patterns
- Keep your face visible. Don't cover your mouth with your hand, or speak while looking down.

### Other tips

- Take your time. Pauses will allow the person to work out what you said before you start the next sentence.
- Repeat phrases if needed. If this doesn't work, try re-phrasing the whole sentence – some words are easier to lip read than others.
- Make the subject clear from the start.
- Use short sentences.
- Be aware that if the person is smiling and nodding it doesn't necessarily mean they have understood.

### Deafblind manual and block

Some people lose too much hearing and sight to continue using speech. They may use a tactile communication system. There are two main methods: block and the deafblind manual alphabet. These are easy for you to learn, but they will be quicker if you organise an interpreter or communicator guide. More information can be found on pages 17 and 18.



# Additional support

## 4

Some people will need extra support to get to the surgery and make best use of their appointment. Some will also need support with communication and accessing information during their time at the surgery.

This support can be provided by a Communicator Guide. Communicator Guides are trained to act as the eyes and ears of the person they are supporting, helping them to get around safely, access information, communicate and be as independent as possible.

For those with very specific communication needs – such as British Sign

Language, hands-on sign language and advanced deafblind manual alphabet – they may also need an interpreter. Please bear in mind that even if a person normally uses a member of their family as an interpreter, they may not want to do this for medical appointments.

### Your duties

As an NHS provider you have two duties in relation to supporting individuals who are deafblind/have a dual sensory loss to access services. These are the provision of

hospital transport, and the duty to make a reasonable adjustment under the Equalities Act – for example, providing an interpreter or Communicator Guide to support an individual during an appointment.

However, there may be people who are unable to access your services even when you have complied with both of these duties. This might be, for instance, a person who requires a Communicator Guide to navigate around a hospital, get from their home to their appointment or to communicate with the hospital transport driver.

In these cases, the local authority should provide the **additional** support needed to access your service. You may need to work together with colleagues in the local authority to ensure each individual gets the right support for them.

You can book a Communicator Guide to support someone with an appointment through Sense or Deafblind UK – contact details are on page 14. Most local areas will have a contract for interpreting services, but Action on Hearing Loss may well be able to help you if you are unsure.

### In the community

Even if someone's underlying sensory loss cannot be treated, there is a range of support available which can help them enjoy life:

- Equipment such as magnifiers and listening devices can make the most of remaining senses, and items such as vibrating pager doorbells can help maintain independence around the home.

- A support worker, called a Communicator Guide, can make a significant difference to a person's ability to get out of the house, do their own shopping, engage in leisure activities and maintain their independence.
- Friends and family can learn new ways to communicate – which could be as simple as writing things down in large letters.



Additional support is available through social services. There is a statutory requirement for social services to identify deafblind people in their area and offer them a specialist assessment. Even people who cannot get free services are entitled to an assessment and advice about where to get the right support. Most social services have a sensory team, usually with a deafblind specialist worker.

Identifying deafblind people can be a challenge. Older people in particular, are unlikely to come forward asking for help or know what help is available. Too often individuals and their families think of sensory loss as an inevitable part of ageing only to be expected at their age and do not look for help.

If you identify your older deafblind patients, and encourage them to seek the right help, you will improve their lives and their health.



# Useful organisations

## 5

### Sense

Sense is the national charity that campaigns and supports people with deafblindness of all ages. Sense provides training to professionals and support, information and services to deafblind people.

As well as this pack, Sense produces a range of other information and services. You may find the following useful:

- **Enjoy Life** is aimed at the relatives and carers of older people who don't see and hear too well – giving tips about how to help and where to go for more support.
- **Seeing Me** is aimed at social care professionals, who are supporting older people with dual-sensory impairments, offering tips for best practice services.
- **Communicator Guides** can support people who acquire sight and hearing loss later in life. They support the individuals by acting as their eyes and ears and can help the individual access the community, work and social groups. They can also support them to access medical appointments.
- Other Sense services include residential care, advice on assistive technology, social prescribing and befriending.

### Sense

101 Pentonville Road  
London N1 9LG  
Tel: 0300 330 9256 (voice and text)  
Fax: 0300 330 9251  
Email: [info@sense.org.uk](mailto:info@sense.org.uk)  
Web: [www.sense.org.uk/olderpeople](http://www.sense.org.uk/olderpeople)

### Deafblind UK

Deafblind UK provides training to professionals and a range of support to deafblind people – including Communicator Guides, a befriending scheme, helpline, weekly news bulletin in a range of formats, and advice and support.

### National Centre for Deafblindness

John and Lucille van Geest Place  
Cygnet Road  
Hampton, Peterborough  
Cambridgeshire PE7 8FD  
Helpline tel/text: 01733 358100  
Email: [info@deafblind.org.uk](mailto:info@deafblind.org.uk)

### Action on Hearing Loss

Action on Hearing Loss supports deaf and hard of hearing people at home and at work, and offer courses for people who are interested in working with deaf people. They provide communication services, outreach and support, rights and welfare advice, employment advice, a helpline, help with equipment and typetalk – which allows deaf people using text phones to communicate with hearing people by telephone.

### Action on Hearing Loss

19-23 Featherstone Street  
London EC1Y 8SL  
Tel: 0808 808 0123  
Text: 0808 808 9000  
Email: [informationline@hearingloss.org.uk](mailto:informationline@hearingloss.org.uk)  
Web: [www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)

### RNIB

RNIB provides support to people with sight problems including a guide to adapting to sight loss, practical support and advice, a helpline, welfare rights advice, a talk and support service, and a talking book service.

### RNIB

105 Judd Street  
London WC1H 9NE  
Tel: 0303 123 9999  
Email: [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)  
Web: [www.rnib.org.uk](http://www.rnib.org.uk)

### Local sensory team

Most local authorities have a sensory team. They are usually the people responsible for providing specialist assessments for people with deafblindness. Your local authority website should have the contact details.

### Local societies for the blind

Many areas have a local society for the blind who may be able to help. Ask your sensory team what is available in your area.

### Accessible information

RNIB have transcription services to produce information in Braille or audio.



# Things to do now

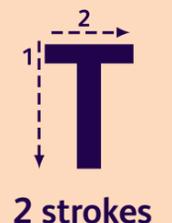
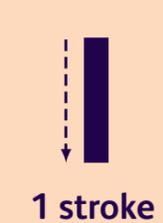
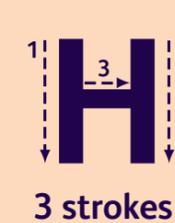
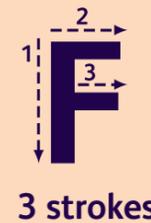
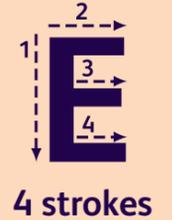
# 6

- Find out how to contact the sensory team in your area. Try the local council website or ring Sense for help. Put their number on the It All Adds Up poster enclosed and put it up as a reminder.
- Contact your sensory team and ask what services are available in the local area. In some areas there are social events for people with a dual sensory loss, local societies with support services, or specialist befriending schemes.
- Invite your sensory team or Sense to come and speak to your team about deafblindness and what support they can offer.
- Think about the patients you see. Do any of them have a significant sight and hearing loss? Or are they caring for

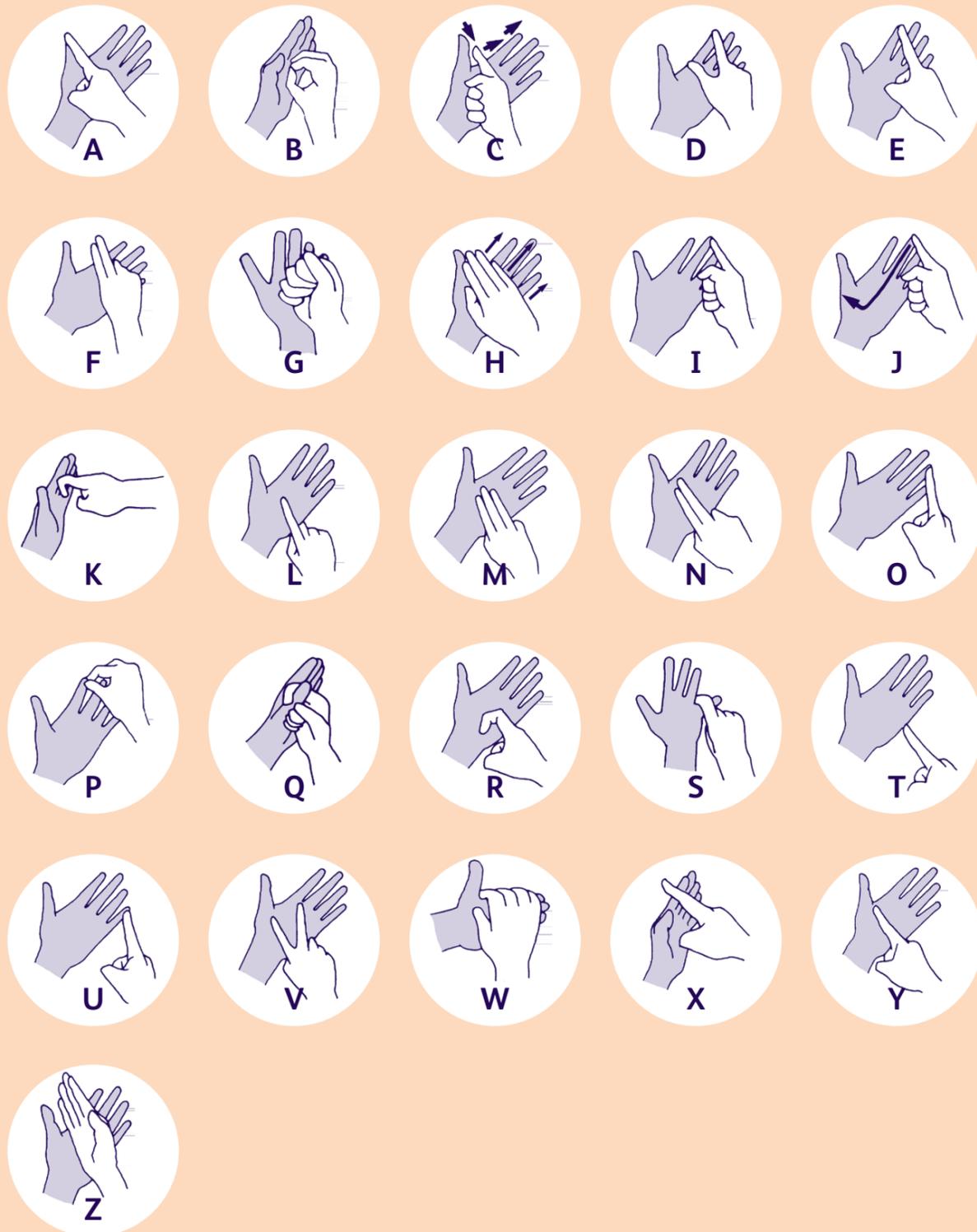
relative who has a dual sensory loss? Make sure they have had an assessment from a deafblind specialist.

- Think about your services. Use the quality standards provided at the back of this leaflet to ensure best possible service and access for your patients who have a dual sensory loss.
- Deafblind Awareness Week is at the end of June each year. Why not have an information display in the surgery about dual sensory loss during that week? Contact Sense for materials.
- Organise some dual sensory loss awareness training for your staff. Sense can help with this.

# Teach yourself the block alphabet



# Teach yourself the deafblind manual alphabet



## About Sense

Sense is the leading national charity that supports and campaigns for children, adults and older people who are deafblind or have sensory impairments. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have sensory impairments with additional disabilities.

Sense offers information and advice to carers of older people, it also offers guidance to a range of professionals who may meet older people with sensory impairments.

## Sense

101 Pentonville Road  
London  
N1 9LG

Tel: 0300 330 9256 (voice)

Text: 0300 330 9256

Fax: 0300 330 9251

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

Website: [www.sense.org.uk/olderpeople](http://www.sense.org.uk/olderpeople)

Patron: HRH The Princess Royal

Produced with funding support from the  
Department of Health