

Identification of deafblind dual sensory impairment in older people

By Diane Roberts, Thomas Scharf, Miriam Bernard and Peter Crome

Key messages

- Rising life expectancy and increasing numbers of older people in the population means a growing number of individuals are affected by dual sensory impairment.
- Raising general awareness of problems and potential solutions is essential to maximising individual quality of life and minimising social isolation.
- Dual sensory impairment in older people may be seen as 'normal' and not identified as problematic or as a disability.
- Simple interventions, such as ensuring regular sight and hearing checks or holding conversations in well-lit areas, can be very effective in improving the quality of life of people with dual sensory impairment.
- Families, carers and other 'non-specialists' can play a crucial role in early identification, hopefully leading to appropriate and timely interventions.

Introduction

This briefing focuses on issues relating to the identification of people over the age of 60 in the UK who have dual sensory loss in the form of a combined hearing and sight impairment (deafblind). People are defined by the Department of Health (DH) as deafblind '...if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility...'.¹

What is the issue?

In practice, the comprehensive description of 'deafblind' may be misleading as the severity of impairment for each separate sense, and the relationship between the two, can vary considerably between individuals. The term therefore ranges between the partial and complete loss of one or both senses. The 'Coppersmith Matrix', which shows the potential intersections of sight and hearing impairment provides a simple visual explanation of this.² It is, however, usually people with more complex and extensive needs who register for specialist services and are clearly identified as 'deafblind'.

Many of those who fall into this category will be congenitally deafblind, i.e. from birth or early childhood, while others may have acquired this form of dual sensory loss during adulthood. The briefing concentrates, however, on those who develop a combined sight and hearing impairment after the age of 60. Dual sensory loss in this age group is often not labelled as 'deafblindness' or recognised as an identifiable disability. The briefing also includes those with an existing sight or hearing impairment where development of an impairment to the second sense places them within the deafblind continuum. The prevalence of dual sensory impairment in the older population, particularly in less acute cases, is extremely difficult to quantify but is estimated to be substantially higher than recorded numbers would indicate.³ It is therefore likely that the same older people who fall into the category 'deafblind' in the context of this briefing are also in contact with other health and social care professionals. Such professionals should therefore be well-placed to provide a mechanism for early identification of individuals with the disability of deafblindness. A key issue, however, is the potential impact of ageism in that sensory impairment generally is assumed to be an inevitable and inescapable element of growing older. There is, therefore, a high potential that both 'non-specialist' professionals and older people's informal carers may not identify dual sensory impairment as a disability requiring investigation and possible intervention.

This briefing is intended to raise awareness among those who do not have specific technical knowledge of deafblind issues and interventions. This includes both health or social care practitioners and also any others in formal or informal contact with older people.

It therefore makes a distinction throughout between those with 'specialist' technical knowledge of deafblindness and those without it, the 'non-specialists'. Specialists are also not commonly involved until an individual has been identified as deafblind and, as a result, tend to deal with more complex requirements. By contrast, non-specialists have the opportunity to identify problems at a much earlier stage and have a key role to play in raising awareness of how the potentially adverse effects of deafblindness on older people's quality of life can be mitigated. Their early identification of disabling dual sensory loss has the potential to involve specialists at a stage when interventions may be less intrusive while still providing a robust basis for enhancing and maintaining older people's independence and autonomy. This briefing therefore examines issues which may lead to health or social care interventions, but with a particular focus on ways in which non-specialists can promote early identification of problems arising from dual sensory impairment, thereby leading to timely introduction of suitable support and coping strategies.

Why is it important?

Loss or reduction of sight and hearing acuity in old age is common and most often perceived as a 'normal' feature of ageing rather than a potentially disabling sensory loss. With growing numbers of people over the age of 60 and rising life expectancy, the proportion of older people who experience both sight and hearing loss is also increasing. In particular, there has been a significant increase in the number of people living to 'old' old age, i.e. 85+, when deafblindness is most likely to be problematic.⁴ While the statutory guidance issued in 2001¹ clearly sets

out that local authorities are obliged to record those people they have identified as deafblind, this does not include all of those who have difficulties created by dual sensory impairment. One of the problems is that there is no common understanding of how the DH definition should be applied³ and, thus, many older people affected by a combined sight and hearing impairment are not officially recorded. Over a decade ago the estimated total number of recognised deafblind people in the UK was 24,000: a figure which rose to nearly 250,000 when estimated numbers of those aged 60 and over with a combined sight and hearing impairment were included.⁵ These figures are now considered to be not only a serious underestimate but likely to rise dramatically as the most vulnerable proportion of the population, those aged over 85, is projected to treble by 2050.⁴ Such an increase raises several points relevant to the context of this briefing:

- There is an increasing awareness of the basic human rights of older people⁶ and, in particular, an emphasis on facilitating the preference of older people to retain independence for as long as possible.⁷
- The identified benefits for older people of living independently in their own homes, requires resources to be directed to the maintenance of a domestic environment which encourages and facilitates individual independence.⁸
- The cost of health provision and of care packages is of continuing and increasing concern in light of the demographic changes outlined above.⁹ Any steps which can be taken to reduce the financial costs of care without compromising the quality of care are therefore to be welcomed.

What does the research show?

This section draws primarily on studies undertaken in the UK to ensure the greatest relevance to briefing users, though some studies undertaken elsewhere are also noted. However, in line with the predominant view of dual sensory impairment in older people as an inescapable and normal part of ageing, there is comparatively little research evidence which deals directly with its identification before a crisis point is reached and specialists become involved. Rather, most research focuses on what are usually negative outcomes for older people in health and social terms, but tends not to make any specific link between the outcome and its origin in dual sensory impairment. An example would be some of the research studies on falls and their prevention. Such studies often focus on the health impact of falls and on the physical environment in which falls occur, rather than on any underlying contribution from dual sensory impairment. Research which considers the ways in which problems arising from dual sensory impairment may show in individual lives is therefore also considered. By concentrating attention on apparently unconnected outcomes rather than the nature of interventions, this briefing explores how earlier identification of dual sensory impairment in older people might be achieved.

Vulnerability and isolation

Many studies show that the combined loss of vision and hearing has a greater impact than that of either impairment alone, since the person affected cannot use one or other sense to compensate for the loss. People who have adjusted to hearing impairment, for example, may lose the ability to lip-read as their sight fails, and individuals with visual impairment may lose the ability to hear clearly.¹⁰ In both

cases, there is likely to be increased isolation arising from the loss of not only essential information and interactive routes like conversation, but also more solitary leisure activities such as reading, listening to the radio or watching television. The influence of a combined dual sensory impairment on sight and hearing may also make the person more physically vulnerable. In some cases the domestic environment may present physical obstacles or difficulties and require changes to make it safer or easier. While it is important to obtain appropriate diagnosis and treatment for conditions giving rise to sensory loss, the social aspects are often masked by a focus on the medical aspects of impairment and are separated from associated outcomes, such as falls.¹¹ Falls are a recognised source of anxiety in older people and are also a potential trigger for isolation as reduced mobility often follows, all factors which are recognised by health and social care professionals. Dual sensory loss is, however, recognised by deafblind specialists as a clear underlying cause of falls in older people and a greater awareness among non-specialists would act as a preventive measure.¹²

For people with dual sensory impairment the potential for isolation increases as their impairment becomes more severe. Visits outside the home or from family and friends may become increasingly difficult when ease of travel and communication are lost, for example. As a result, such visits may diminish in frequency, leading to a loss of social interaction and potentially a loss of information about the world outside the home. Older people, their families and carers may also display unwitting ageism and assume that such isolation is an inescapable consequence of ageing, with the result that its effect on mood and motivation are rarely questioned.¹³ However, studies have

shown that while visual impairment clearly increases the risk of depression and, to a lesser extent, so does hearing loss, combined dual sensory loss has an even greater effect.¹⁴ Depression, when identified, is usually considered a medical problem and therefore capable of treatment. However, the combination of assumptions about the natural course of ageing and dual sensory loss means that the depression which can result is often ignored until it becomes severe. Disability in any form, but particularly the combination of vision and hearing loss, results in an increased risk of developing depressive symptoms and disorders which, in turn, can lead to illness, further physical impairments and other restrictions on activities of daily living.¹⁵

Much of the existing research focuses on events which have the capacity to make older people vulnerable in ways which may lead to an increased need for social care provision and a reduction in independence.¹² A comparative European study of how vulnerability may be generated in older people noted the interaction between reserve capacity and environmental challenge.¹⁶ Reserve capacity refers to the resources available to the person through tangible facilities, inner resilience or social networks, while environmental challenge relates to the difficulties presented by the environment in which older people live. This can refer to social spaces and provisions such as public transport or, equally, to individuals' own domestic surroundings. By considering the ways in which differences between reserve capacity and environmental challenge are managed by older people, it is possible to identify whether appropriate support is best delivered informally or, as is usually the case in a crisis situation, through a

professional route. Either route can increase the reserve capacity and thereby enable individuals to meet their own personal environmental challenges. This is no less true for older people with dual sensory impairment than it is in any other context. Enabling people to reduce the environmental challenge through comparatively minor interventions such as changes to lighting or furniture layout, for example, demonstrates this. Combining this with interventions to reduce isolation and thereby maximise reserve capacity has the potential to make a substantial impact in maintaining independence.

Support and awareness

The Joseph Rowntree Foundation enquired into the general support needs of older people¹⁷ and found that many needs can best be met by 'that bit of help' which is not the subject of professional social care or health interventions. Small-scale actions by a range of people and organisations with whom older people have contact in daily life are, therefore, valued very highly by older people. This confirms much of the common sense knowledge about the needs of older people generally, including those with acquired deafblindness. Changes in vision and hearing which arise during the ageing process do not usually occur suddenly, and they tend only to become problematic when the combination prevents or hinders the safe completion of everyday tasks and activities. Even minor falls and other accidents resulting from dual sensory impairment will tend to come to the attention of a variety of people including neighbours, relatives or other informal carers, medical practitioners, managers of sheltered housing schemes, or shop assistants – none of whom are likely to be deafblind specialists, but all of whom are capable of identifying the need for assessment.^{18, 11}

Raising awareness among those who come into contact with older people is important, as are simple, non-technical and non-specialist forms of assistance. For example, one study¹⁹ indicates how minor alterations to individual behaviour can have a substantial impact in terms of minimising social isolation. By providing examples it shows how an awareness of the basic needs of those with combined sight and hearing loss can lead to an enhanced level of communication. It indicates how conversations can be physically arranged to allow light to fall on the face of the speaker to facilitate lip reading and how sound interference from the environment can be minimised. It therefore demonstrates how, if suitable hearing aids and spectacles have been provided and are used, simple interventions can allow older people who have an impairment in the deafblind range to interact more easily with those around them.

Implications from the research

For organisations

Of major concern for organisations like local authorities who come into contact with older people with dual sensory impairment should be their responsibility to ensure that clients are provided with a specialist assessment of their needs.¹⁸ The National Service Framework for Older People demands respect for individual needs, while the Fair Access to Care Services²⁰ regulations impose an obligation to ensure that appropriate specialist assessment is conducted. However, while public policy emphasises autonomy and choice, tensions may arise between individual and organisational measures of success.²¹ For example, organisational success may be measured by evidence of

individual choice about care even though some individuals may be happier with a professional exercising judgement on their behalf. Although the Single Assessment Process has the potential to provide services in a coherent and integrated way, it remains unclear how effectively it will be used. If changes are seen as too radical or difficult to implement by the various professions involved, then organisations may fail to deliver the best outcomes. The philosophy of implementation needs to be client-centred in a way that conflicts with some traditional tenets of these professions, yet is fundamental to the success of the holistic nature of assessment proposed.²²

For the policy community

Clear guidelines from the DH¹ and the introduction of the Single Assessment Process (SAP) for older people²¹ mean that current legislation and regulation in this area potentially provides a sound basis for the delivery of a comprehensive service for older people with dual sensory impairment. What the research indicates, however, is that this is not always used to best effect.²⁰ Early identification of dual sensory impairment and comparatively inexpensive interventions could provide long-term cost savings by, for example, reducing some acute hospital admissions. The comparative costs of care for older people are discussed fully in *Fit for the Future* which also identifies ways in which costs can be reduced by the use of new technologies and more proactive and local preventative measures.²³ In addition, two initiatives have been launched which support this agenda: the DH's Partnership for Older People Pilot (POPP) initiative and the Department for Work and Pensions' Link Age Plus pilots. Further information about these initiatives can be found in the *Useful links* section of this briefing.

For practitioners

Two of the major providers of information on deafblindness are the charities Deafblind UK and Sense (see *Useful links* for information on these and other organisations). Sense has developed a campaign to promote the early identification of dual sensory loss in older people and provides a toolkit which identifies a number of behaviours indicating possible combined sensory loss. This is freely available from their website for use by anyone supporting older people in any capacity.¹⁸ This type of checklist of behaviours allows practitioners, carers and other non-specialists to assess whether further specialist investigation may be required. Sense's material points out the statutory responsibilities of local authorities, but also argues that practitioners in direct contact with older people need to become more aware of possible dual sensory impairment. In this context, the current emphasis on multi-disciplinary working should also provide an enabling climate in which practitioners in the various disciplines can communicate to best effect. Practitioners therefore need to use aids such as the toolkit to identify more easily the types of behaviour that may indicate a problem with single or combined sight or hearing impairment and to consider possible ways in which problems may be overcome. Some of these responses may need specialist involvement. However, the availability of such interventions, perhaps through rehabilitation services, has not been addressed within this briefing as there is likely to be local variation. Practitioners should ensure they are aware of local provision in response to the statutory obligations outlined in the DH guidance.¹ These guidance notes also include a useful appendix showing descriptors for both congenital and acquired deafblindness.

One of the major issues raised in research is the need to recognise the additional problems created by dual sensory impairment rather than simply seeing such problems as the sum of those created by vision or hearing impairment.¹⁴ Recognition that deafblindness creates a much more difficult living environment for older people, who may also have additional health problems, is key to providing a better basis for early identification. Heightened awareness and empathy with older people experiencing dual sensory impairment is, therefore, necessary for practitioners to produce the most timely and supportive solutions.¹⁴ It should be emphasised that research does not suggest that all practitioners should be deafblind specialists. Rather, specialists have a particular role which could be enhanced by increasing the capacity of other people to recognise the existence of dual sensory impairment and request specialist assessment.

For users and carers

It was noted earlier that it is often in the small ways that the greatest assistance can be given. There are several ways in which both users (older people with a dual sensory impairment) and carers (including anyone with whom there is day-to-day contact) could be more aware of approaches to creating a supportive environment.

First, older people can take practical self-help steps such as:

- having regular sight and hearing tests
- ensuring they have adequate supplies of hearing aid batteries
- ensuring suitably fresh batteries are installed in the hearing aid
- carrying appropriate reading aids in public places.

Second, older people and others can develop greater recognition of how appropriate lighting and acoustics can make communication easier and more effective.

Third, both formal and informal carers should take time to check that arrangements and instructions are clearly understood by the person with dual sensory loss.

All of these actions are important and relatively straightforward to implement. They are also comparatively inexpensive and involve a wide range of individuals. However, to better identify people who require more specialised support, it is essential that anyone in regular contact with an older person with disabling dual sensory impairment, is not only aware of potential behaviours which may be displayed and indicate that intervention may be necessary, but is also prepared to suggest or request specialist assessment before a crisis point is reached.^{18, 19}

Useful links

Deafblind UK – charity offering a wide range of services to support people with a combined sight and hearing impairment. The organisation offers training to professionals and others.
www.deafblind.org.uk

Deafblind International – Bagely, M. (1998) 'Communication and people who have lost vision and hearing in later life', from expert meeting on older people with vision and hearing loss, Copenhagen, Denmark 18–24 March 1998.
www.deafblindinternational.org

Department of Health – has several items of useful guidance. In particular, 'Think dual sensory: good practice guidelines for older people with dual sensory loss' (1995).

Joseph Rowntree Foundation – commissions and produces research reports on a variety of social issues. These are also published as short summaries in their Findings series. These can be downloaded at www.jrf.org.uk

Link Age Plus – an initiative to make information and support for older people easier to obtain. Further details can be found at www.communities.gov.uk

Partnerships for Older People projects – two-year partnership projects led by local

authorities and primary care trusts. Represent a range of preventative interventions and initiatives. Further details can be found at www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/DH_4099198

RNIB (Royal National Institute for the Blind) – charity working with and providing information for blind and visually impaired people. www.rnib.org.uk. Use 'Audience' quick link to 'older people' from the home page. A variety of factsheets are available.

RNID (Royal National Institute for the Deaf) – charity working with and providing information for deaf and hearing impaired people. Also has a factsheet on deafblind people. www.rnid.org.uk

Sense – charity working with and providing information for those with dual, deafblind, sensory impairment. www.sense.org.uk. Produces a variety of reports, factsheets and information sources including a toolkit, 'Fill the Gaps' for use by those working with or in contact with older people www.sense.org.uk/fillinthegaps

Thomas Pocklington Trust – charity commissioning research and providing housing, care and support services for people with sight loss in the UK. www.pocklington-trust.org.uk

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Research briefing 15: Helping older people to take prescribed medication in their own homes (2005)

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Knowledge review 13: Outcomes-focused services for older people (2007)

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Social Care Institute for Excellence

Goldings House
2 Hay's Lane
London
SE1 2HB

tel: 020 7089 6840
fax: 020 7089 6841
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www.scie.org.uk