

# A Good Senior Life with Dual Sensory Loss

Nordic Centre for Welfare and Social Issues

Inspiration booklet





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Nordic Centre for Welfare and Social Issues

A Good Senior Life with Dual Sensory Loss

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Photo: Lasse Winther Wehner

## A Good Senior Life with Dual Sensory Loss

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## Elderly people with severe dual sensory loss – a public health problem?

Getting old means decline of various functions previously taken for granted. For many, life will be influenced in a negative way and the need for change may cause stress. Both old people themselves, but also those around them, occasionally experience dual sensory loss as part of natural aging and out of their control. This does not necessarily mean disregarding the possibility of influencing the negative consequences. The attitude that it is pointless to do something due to age is a questionable one, both from a human and a social perspective. Often, small and seemingly simple measures may contribute to keeping important functions as vision and hearing, and thus quality of life, for a longer time. Surely that is important, not the least at a time when the number of elderly people is increasing rapidly, along with rising healthcare costs.

*P. O. Edberg*

*Expert on dual  
sensory loss*

It is fairly common for elderly people to experience severe dual sensory loss. During recent years, various Nordic studies have revealed that this is true for at least 5-10% of all people over age 65. The person affected will, among other things, experience difficulty communicating with others. To a great extent, this influences the potential for active participation. The risk of isolation is apparent with all the consequences that entails. Therefore, people with a severe degree of dual sensory loss need to have their lives organized in accordance with their specific needs. In order for that to happen, knowledge and understanding is required from both professionals and close persons/relatives.

It is usual that a person has had a hearing loss for a long time, but his eyesight has compensated for loss of hearing. Suddenly it doesn't work anymore to read other people's lips, perceive facial expressions or see written communication. Cognitive capacities are tested, working memory functions are overloaded and one's energy is reduced. Many people experience a rapid deterioration of hearing at this stage. The reason is that the person has not previously been aware that the vision has compensated for the hearing loss. The person is not either prepared for the negative consequences this radical life adjustment brings. One becomes dependent on other people, people who often lack knowledge of what it means to live with severe dual sensory loss. This in turn can mean that one risks being treated incorrectly and without adequate support.

Increased knowledge among actual players/professionals on the effects of severe dual sensory loss means that the people in question can be identified and that adequate measures may be offered at an early stage, with all the positive side effects. Many people then get out of isolation and exemption from activities and social contexts or of being dependent on others in everyday life. Sometimes, very small changes in life can make a big difference. As an example, support with regard to cleaning the earmold of the hearing aid, changing batteries, or getting correct assistive devices, will result in such a huge and important difference. An environment that understands the need to find solutions in order to communicate, and provides time for this, is another example that can result in a major difference for quality of life and perceived health.

Getting an accurate assessment of the dual disability and the consequences hereof is very important when it comes to elderly people. Expressions of forgetfulness, withdrawal,

confusion and aggression are consequences that may arise after prolonged social isolation, which in turn can lead to erroneous assessments and, at worst, misdiagnosis. As an example, a wrong diagnosis of dementia may influence the content of life, even until the end of life, in a devastating and deeply unethical way. A humble approach from the environment when it comes to the risk of misinterpretations of behaviour and symptoms is therefore very important, not the least in order for each person being able to get appropriate support and intervention.

The average age for people with severe dual sensory loss in Sweden was in year 2008 just above 80 years. The capacity, at that age, to get motivation and get to grips with different rehabilitation measures on basis of the needs severe dual sensory loss entails, may be limited. For many, the energy tends to be devoured by other biologically and socially determined changes in life. Therefore, it is important to discover and be aware of the dual disability, not only for the person himself, but also for his/her surroundings as soon as possible. By preventing the negative consequences with appropriate rehabilitation measures in time, the vision and hearing function may be maintained longer with good quality of life as a result.

On the basis of the demographic facts identified by several Nordic studies in recent years, and in view of the consequences in form of reduced quality of life for the individual suffering from severe dual sensory loss, it should be in the interest of society to meet the needs better than today. The regular occurrence, and the steadily rising number of elderly people in our society, means that it should rather be regarded as a public health problem than as a problem of individuals. With such an approach, we should be able to create structures in the health and social care sector in order to prevent and delay disability in older people. The increased limitations reduced vision and hearing brings with it must not be an obstacle to a good life!

## Not being able to hear, not being able to see – what is done and what should be done for people with deafblindness?

Seriously impaired vision and hearing, or even being totally deaf and blind, places high demands on the individual and the surrounding world. The goal must be that persons with deafblindness, whether it be congenital or acquired, will get as good a life as possible, here and now and in the future. Since people with deafblindness are equally different from each other as the rest of us, an individual approach is required in order to create contact, social interaction, communication, and thereby quality of life, between the deafblind person and others in society.

*Barbro Westerholm  
Member of Parliament  
(Folkpartiet)  
Social policy  
spokesperson*

There are no exact figures on how many people with deafblindness there are in Sweden. There might be approximately 2,000 persons under 60 years of age, of which 400 have acquired deafblindness before they developed language. We do not know for sure how many of them have become deafblind late in life, but the Swedish Agency for Public Management has estimated the number over 75 years of age to be approximately 30 - 40,000 persons. There is a large group that has not got the same attention as young people with deafblindness.

There are relatively few politicians on a national and a local level in Sweden who have spoken for the cause of the deafblind. However, there have been certain achievements that have led to the Swedish state allocating funds to support people with deafblindness. But these efforts are far from fulfilling the existing needs of deafblind people to lead a life similar to other people's lives.

The Swedish Agency for Public Management has, at the request of the Government, analysed the use of funding and submitted a report to the Government in March 2011 on what has to be done for more effective use of the funds.

Since the analysis of the Swedish Agency for Public Management, the Government has given the National Board of Health and Welfare the task of finding a player to take on national responsibility for professional support, information and so on, within the area of deafblindness. The Board finds there is a need for a national function in terms of professional support to, first of all, the county councils, but also to other responsible leading players.

There is also a need to gather, develop and disseminate information, to promote the development of methods and to establish forms of cooperation for intensive user participation. Here, it is important that the national function is able to support municipalities, county councils and other relevant players in the provision of courses and education, e.g. with regard to the attitude towards, and the support to, people with deafblindness when it comes to rehabilitation and care. It is encouraging that the Government emphasizes this. It is also encouraging that the Government, in the assignment to the National Board of Health and Welfare, especially stresses the importance of user participation.

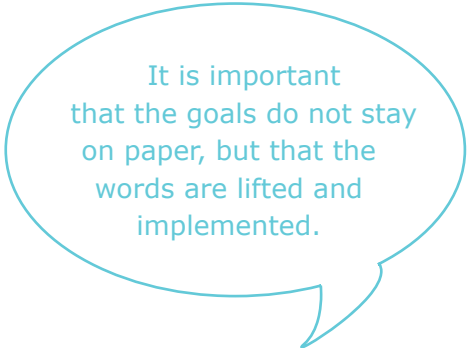
The Government finds there is even a continued need for a player with national responsibility to provide interpretation services for elected representatives in organizations for the deaf, hard of hearing and people with deafblindness; and that meets the requirements for state support to disability organizations. The assignment to the National Board of Health and Welfare involves support being provided on the same terms as support to other disability organizations. This applies to the execution of association activities and opinion-making efforts. Here, I would like to add that it is important that the National Board of Health and Welfare in this context also addresses issues such as: What is deafblind interpretation seen from the perspective of people with deafblindness? How can people with deafblindness achieve full participation, equality, independence and empowerment in society? How do the authorities prioritize with regard to the activities people with deafblindness get the opportunity to participate in?

If I should wish for more than what the Government has written in their assignment to the National Board of Health and Welfare, then that would be getting better control of the situation of elderly people with deafblindness. They do not

even appear as figures in the statistics, but I know they are out there and that the isolation from information society can be difficult. Some years ago, I heard of an elderly man with deafblindness who shot himself with his shotgun because life no longer was worth living in his isolated situation. There is need for increased knowledge on deafblindness within the elderly care services of Sweden and among close family members. The National Knowledge Centre for Deafblind Issues (Nationellt Kunskapscenter för Dövblindfrågor) has published the educational material "Äldre med kombinerad syn- och hörselnedsättning – dövblindhet" ("Elderly people with dual sensory loss – deafblindness") to be used in the municipalities, but it does not seem to have been taken in use widely. One might ask oneself whether this is due to lack of interest or lack of knowledge on elderly people with deafblindness and their requirements.

The goal of the state for an easier life for people with deafblindness is clear, but now it is important that the goals do not stay on paper, but that the words are lifted and implemented.

The so-called player in the Government's assignment to the National Board of Health and Welfare must become a powerful centre with the necessary resources for providing the tools needed by county councils and municipalities in order to make a good life possible for people with deafblindness at any age and regardless of their address. But tools alone do not suffice, there must be politicians, officials and practitioners in the social services, health and social care, who are knowledgeable enough about the needs of people with deafblindness and who show real commitment to improving their situation. They must be awakened in order to become a driving force on the issue. Driving forces are very much in demand these days. Here, the user organizations play an important role through giving a clear picture of how it is living with deafblindness and what needs to be done.



It is important  
that the goals do not stay  
on paper, but that the  
words are lifted and  
implemented.

## The challenge of progressive dual sensory loss

Elderly people often experience problems with vision or hearing. A group of these elderly people even experience dual sensory loss; the hearing cannot compensate for the impaired vision and vice versa – together they form a dual and extraordinary disability, which may lead to serious consequences for quality of life if there is no intervening support.

*Henriette Hermann  
Olesen*

*Specialist manager  
Nordic Centre for  
Welfare and Social  
Issues*

Severe dual sensory loss is also called deafblindness.

Older people who have acquired deafblindness have usually lived a long life without any form of sensory loss. The acquired sensory loss often has serious consequences, but is rarely regarded as something that requires special attention by the person in question or others. "It is probably just a matter of age that the person is not able to keep up with or participate in society", many people think – also the elderly themselves.

The practical consequences are mostly experienced in important areas of functioning, such as communication, acquisition of information, orientation and mobility, and activities of daily life. The consequences show as isolation, and that you misinterpret a lot of things and you are not understood in full. This may lead to less visible effects, namely limited security, integrity, participation and independence.

### LIMITED INFORMATION INFLUENCES INDEPENDENT EVERYDAY LIFE

We live in an information society with increasing levels of visual and auditory information, which we receive through, for example, newspapers, internet, radio and TV. Being able to keep up with the massive information in our society is vitally important in order to get the necessary basis for making own

decisions and maintaining independent living. Access to information is also important in order to be able to maintain communication with others and to be able to participate in discussions and conversations.

However, many people with deafblindness experience great difficulty in keeping up with media coverage and in acquiring the necessary information. If you experience, as a close family member or staff, that the elderly person begins to seem less interested in what is going on in the outside world – and if the elderly person to a lesser degree participates in discussions and conversations – then it is important for the elderly person that you, as a close family member or staff, not just figure that beginning to be less interested in information about the surroundings is a normal consequence of ageing. A minor, but yet considerable, contribution would be to help the elderly person having his hearing and vision checked. If there are problems with the two senses, then there are several possibilities for the elderly person himself, his close family members or staff, to gain knowledge and support to make the elderly person able to acquire information again.

It is important to be able to keep up with daily information, such as:

- Knowing which activities are going on out there. Participation in social activities is a prerequisite for being able to maintain an active social life, but if you, due to deafblindness, are not really able to understand information (such as postings on a crowded notice board or a shared verbal message), then you soon have limited social interaction without wanting to.
- Being able to keep up with who is at work if you live in a nursing home. You are dependent on the staff and are connected to them, but you do not know whether they are at work or will come to work because the information is not available due to the sensory loss. This may result in insecurity and isolation.
- Being able to keep up with what your family is up to. It is difficult to keep up, in case of hearing loss, with regard to the telephone or visits. Sometimes vision does not allow reading of letters and emails. Information about someone being ill or deceased, grandchildren, who have graduated etc., might be missed. This results in you not being able to participate in conversations with, and about close family members, and you become an outcast and are rejected by the family.

Several types of initiatives may contribute to the inclusion of people with deafblindness. Knowledge about deafblindness is the first step. This knowledge may support the people around the elderly in adapting time, pace and approach. Increased access to interpretation and guidance services, other personal assistance, such as contact persons and reading and secretary assistance, may improve the access to information. Furthermore, there are many adaptations and technical assistive devices with regard to magnification, lighting, reading out loud, tactile markings and so on, that make it easier for the deafblind person to get direct access to ordinary information and knowledge from the internet.

### THE SENSORY LOSS AFFECTS COMMUNICATION WITH THE SURROUNDINGS

For seeing and hearing people, communication takes place via vision and hearing. We also use our body to express ourselves, and our eyesight registers the expressions. Among deafblind people, it is often necessary to use the tactile senses to a higher degree in communication. It might be in the form of physical support by touching the item the communication is about, or by touching people in order to keep the contact with them or to regulate the distance to them in order to facilitate remaining vision or hearing. It may also be physical support by marking possible signs in the communication. This physical approach to communication is not natural for very many seeing and hearing people. It can also be regarded as weak and helpless. Therefore, the contents of the conversation or the discussions might be influenced by this attitude, without this being justified.

Communication in everyday life is fast; many people speak fast with a lot of content. Deafblindness is accompanied by a reduced ability to pick up and understand parts of the communication. To get the whole picture, you must often ask for repetition and slower speech. There may well be a conflict between hectic everyday life for staff or close family members and the elderly person with vision and hearing loss that needs more time than others to understand what is being said. Yet, it is important to take the time needed to avoid misunderstanding, insecurity, social uneasiness and isolation.

Too high a speed also increases the risk of being misinterpreted by people around you; making them believe you are having cognitive difficulties in keeping up. At the same time, it is extremely difficult to slow down and repeat things several times – you get inhibited and the communication suffers. This

can mean that people around you try to avoid too much communication with the elderly person.

A severely impaired communicative function leads to difficulties in understanding and being able to influence your situation. This in turn may be experienced as degrading, and the consequences can, at worst, be misinterpreted and, due to ignorance, lead to inappropriate efforts from other people.

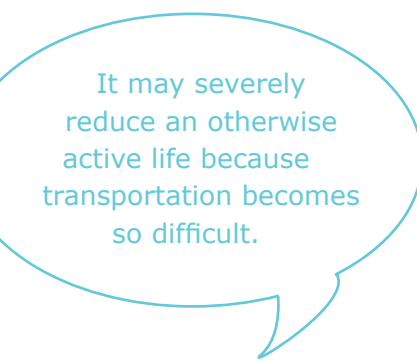
Several types of measures can contribute to including the elderly person with deafblindness in the communication. Knowledge on deafblindness is the first step. This knowledge can support the elderly person's surroundings to adapt with regard to time, pace and repetition. At the same time it is an advantage for the elderly person himself, his close family members and staff, to get guidance on how communication is supposed to function, so the person with deafblindness is not exempt from the opportunity of learning, influencing, discussing and being happy.

### **BEING ABLE TO ORIENTATE AND MOVE AROUND FREELY IS A HUMAN RIGHT**

Travelling by bus or train can suddenly become confusing for the vision and hearing impaired person, since you are no longer able to see the schedules, the bus numbers and the automatic ticket machines. It is also unsafe to travel where there are many people who move around at high speed. For some people it will require all their energy, and therefore they choose not to participate in social life outside of the home unless they get support for other means of transportation. It may severely reduce an otherwise active life because transportation becomes so difficult. This limitation in travelling outside the home cannot be good for anybody's quality of life. Unfortunately, being limited in travelling outside your home is regarded as a natural part of ageing, but maybe it is not by free will that the elderly person with deafblindness stays at home.

Many elderly people with acquired vision and hearing loss have previously lived a life where shopping has been a natural ingredient. Several of the elderly citizens have children and grandchildren who they love to buy presents for. When they are affected by vision and hearing loss, this part of life suddenly becomes very limited.

Just moving to and from your own room at the nursing home can be difficult. The physical environment at the nursing home can be different from one day to the next – from hour to hour. There are many assistive devices that



It may severely reduce an otherwise active life because transportation becomes so difficult.

have to find their place or furniture that is moved around. This may restrict the elderly person in being able to orientate and thus it becomes a natural reaction that the elderly person stays in his room.

Not all elderly people find it natural to stay in their rooms or apartments – this may also be due to some other limitations. Isolation and passivity may be a result of the dual sensory loss.

Several types of efforts may contribute to the elderly being able to move around and orientate themselves freely. Knowledge on deafblindness is the first step. This knowledge can support the people around the person with deafblindness in adapting with regard to arrangement of the physical environment. At the same time, it is an advantage for the elderly person himself, his close family members or staff, to get guidance on how the person can orientate in other ways. Guidance and contact services may also be an option.

### **QUALITY OF LIFE AND MENTALITY ARE AFFECTED BY THE SENSORY LOSS AND LACK OF KNOWLEDGE FROM OTHERS**

When communication fails, or when the acquisition of information is limited, you often lose the ability to influence people and situations. Self-determination, social contact, the possibility of participating actively and a lot more, are limited. If the elderly person himself, a close family member or staff, do not discover and do something about the deafblindness, then intellectual ability and cognitive capabilities are often misunderstood, and the elderly person is regarded as helpless and less equal.

At the same time, the cognitive capabilities of the elderly person are influenced by limited communication, social participation, independence and acquisition of information. This is due to lack of challenges.

Failing vision and hearing make previous activities and skills difficult to perform. It is frustrating for the elderly person with deafblindness, and, at the same time, it is a factor that makes others jump to the conclusion that the elderly person has reduced cognitive capabilities.

Many elderly people with a vision and hearing disability become afraid of not sitting properly at the table, and of spilling, and therefore they avoid social settings in connection with dining. This leads to isolation and misunderstanding from others; making them think the elderly person prefers to be left alone.

This may lead to a change of identity. It may also lead to changed behaviour of elderly people with deafblindness, which may be mistaken for cognitive debilitation. Stress and deprivation may occur, and this influences the cognitive functions. In addition, increased passivity, isolation, lack of information etc., may also lead to lifestyle diseases and health issues.

In order to understand the capabilities of other human beings, one must take a look at the demands of everyday life and use knowledge about the sensory loss. Knowledge about and early intervention, with regard to being deafblind, may limit the extent of the consequences.

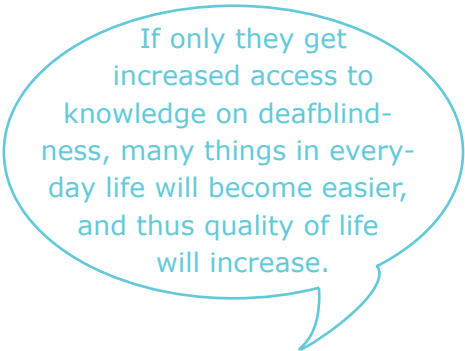
### KNOWLEDGE IS A NECESSITY

Elderly people with deafblindness must have access to knowledge on deafblindness. Many older people with deafblindness do not discover the sensory loss or take it seriously. They blame ageing for the emerging symptoms. If only they get increased access to knowledge on deafblindness, many things in everyday life will become easier, and thus quality of life will increase.

At the same time, it is important that close family members and staff have access to knowledge on deafblindness. Thereby, they can make everyday life easier for many older people with deafblindness and contribute to a good quality of life.

This knowledge is not widely known. We try to do something about that with this publication. Only a few resources are required to help the older person with deafblindness to a good life, and in order to maintain the good contact between close family members and the older person.

We hope that this knowledge will be spread to many places – such as hospitals, nursing homes, home care, vision centres, hearing centres and organizations for older people.



If only they get increased access to knowledge on deafblindness, many things in everyday life will become easier, and thus quality of life will increase.

# Acquired deafblindness and dementia – a special challenge

The major cause of acquired deafblindness in elderly people is a combination of age-related vision and hearing loss.

*Trine Skov Uldall*

*Area Consultant –  
Acquired Deafblindness  
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Technologies and Social  
Psychiatry*

When vision and hearing loss occur at the same time, they reinforce each other and form together quite a unique disability, namely acquired deafblindness. A person who is “only” vision impaired will be dependent on hearing in order to compensate, and vice versa. When both senses are affected, even a minor hearing loss and a minor vision loss can give serious problems in everyday life.

Deafblindness does thus not mean that one is totally deaf and totally blind. We use the term deafblindness when the combined hearing and vision loss causes serious problems in everyday life with regard to information, communication and the possibility to move around freely. For most people the deafblindness is progressive, which means that vision and/or hearing deteriorate with time. This deterioration typically takes place gradually and can be difficult to register for the person and his environment. Maybe one experiences increased occurrences of tiredness and drops out of more and more activities. Elderly people with acquired deafblindness are at a high risk of experiencing social isolation because of the massive communication problems. They have limited possibility of participating in and following conversations, and difficulties in keeping up with what happens in the surroundings.

This demands courage and especially acknowledgement of one’s disability, to continuously make the environment aware of the dual sensory loss and the considerations that must be met by the environment. There might be considerations such as speaking clearly in a normal voice, standing with the light falling on your face, supplementing with large black letters on white paper, turning down background noise such as radio and TV, or by using supportive signs or haptic signs that are perceptible on the body. On the whole, one must, as a deaf-blind person and as a relative or staff, be ready to make use of alternative communication forms.

## **LIVING WITH ACQUIRED DEAFBLINDNESS PLACES GREAT DEMANDS ON COGNITION AND REQUIRES MUCH MENTAL ENERGY**

Everything becomes more difficult and more confusing when one lives with acquired deafblindness. Even quite ordinary everyday activities, such as shopping, taking a walk, reading the newspaper, keeping up in conversations and seeing who greets you in the streets becomes difficult.

Compensating for acquired deafblindness requires you to be good at concentrating and at remembering where you put your things, or remembering what to do and when, and remembering how to find your way. Furthermore, it requires that you can think logically and are able to lay an appropriate strategy, learn new strategies as well as learn new skills, e.g., with regard to the use of assistive technology devices. Continual adjustments have to be made and learned in step with deteriorating vision and hearing – in step with changes in the environment and in relation to the given situation or context you are in – in that way you can be more deafblind in some situations than in others. It costs huge amounts of energy to carry out necessary and desired activities of everyday life. The possibility of being active and independent and to keep updated on what is going on, both in your vicinity and in society as a whole, is limited.

Cognitive functions such as memory, concentration, sense of space and learning ability are thus necessary in order to be able to compensate for your disability when you suffer from acquired deafblindness. Unfortunately, these are the functions hit by deterioration when you suffer from dementia.

## **WHAT IS DEMENTIA?**

Dementia is a condition characterized by impairment of cognitive functions and behaviour due to damage or disease affecting the brain. Dementia is thus always caused by disease, and it is a myth that dementia is a natural part of aging. The risk of developing dementia increases with age. The most common cause of dementia is Alzheimer's disease, but more than 200 different diseases may eventually lead to dementia. Only a few of the diseases leading to symptoms of dementia can be cured, but symptomatic relief is often possible. Therefore, it is important to precisely determine which disease has caused the dementia and to establish a plan for the treatment.

1. Formerly known as  
Videnscenter for Døvblind-  
blevne (The Information  
Centre for Acquired  
Deafblindness)

## COMMON CHARACTERISTICS OF ACQUIRED DEAF-BLINDNESS AND DEMENTIA

For several years, ViHS<sup>1</sup> has had special focus on acquired deafblindness and dementia. In cooperation with the consultant services of Centre for the Deaf and neuropsychologist Peter Bruhn from the Memory Clinic at the University Hospital of Glostrup, we have collected experiences from the practice of the deafblind consultants and put special focus on the problems involved in the assessment of dementia in people with combined vision and hearing loss.

Often, people with acquired deafblindness, as a consequence of the deafblindness and the energy it demands to see, hear and keep up, may find difficulty in remembering, finding things, differentiating people from each other, orienting in time and space, picking up what is said and keeping up to date on everyday issues. Likewise, they may misinterpret visual information or experience hallucinations. Other frequent consequences are a reduced level of activity and withdrawal from social activities. Also, depressed mood or genuine depression may occur. These are all characteristics that may also be seen in people with dementia.

It can be difficult to discover early signs of dementia in elderly people with acquired deafblindness, just as the elderly person may be mistakenly identified as having dementia, without the existence of a diagnosis. The elderly person himself or a relative might also be worried about whether it could be a case of dementia.

An example of this is a woman with known acquired deafblindness, who every week takes the local bus to a club for elderly people she has frequented for several years. She usually finds the way herself. "I kind of have the route in my head and I use my cane, and, as an example, I am able to see the colour of the house where I know the bus usually stops," she has explained. Recently, there has been roadwork in the area and the bus stop has been moved. She has not been able to find the new bus stop on her own in spite of her husband having guided her there several times. Now, she also finds difficulty in finding her way at the local grocery store. These problems might be a consequence of a progression of the deafblindness, and that she no more has the same capacity to compensate. But it might also be a sign of cognitive problems, e.g., because of beginning dementia. At the doctors it is decided to start an examination and a year later the woman gets a diagnosis of dementia.

A man with acquired deafblindness tells that he has pro-

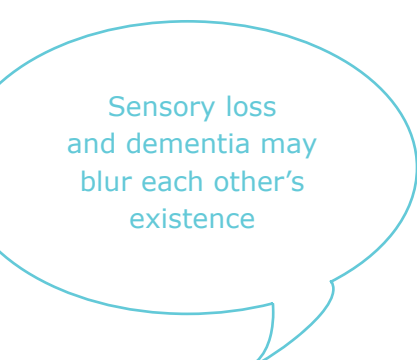
gressive memory difficulties. As an example when he has been at the doctors. His GP is good at using the man's hearing technology devices, and the man is able to hear what the GP says. Anyhow, he is not able to remember the information when he comes back home and has to tell his wife about the course of events. Recently, he has had many similar experiences, and he is beginning to get worried about whether he is getting dementia. However, after a discussion at the doctors, this is rejected. On the other hand, an examination of his eyesight shows that his eyesight has deteriorated. He thus has to concentrate even more in order to hear without the aid of lip reading. This effort gives less energy to also remember the substance of what he has heard.

Just as the early signs of dementia can be difficult to detect in people with acquired deafblindness, both vision, hearing and dual sensory loss may be overlooked in people affected by dementia. If a person with dementia develops one or more sensory losses, the strategies, assistive devices and routines, one previously has relied on in everyday life, will no longer function optimally, and your abilities may gradually appear reduced, which can be misinterpreted as a progression of the state of dementia.

A person with dementia may gradually lose the ability to orientate and to use the visual indicators that previously have been useful with regard to finding your way. These difficulties may also occur because of a progressive loss of eyesight, which makes it difficult to use the known strategies. Thus, reduced functional ability does not necessarily have to be due to deterioration of the dementia disease.

An elderly man in a nursing home, who has a diagnosis of Alzheimer's, is becoming regarded as being more and more demented, partly because he can no longer feed himself and must be fed. One day, a newly appointed home carer comes to help the man to eat. Previously, she used to work with people with reduced vision. She has noticed that he has a dining light in his apartment (an assistive device to ensure good lighting in his dining area). She puts the light at his plate during meals so it lights up the plate. When the light is lit, the man takes the spoon and starts to eat by himself.

As explained above, sensory loss and dementia may blur each other's existence. It is therefore vitally important that signs of both cognitive and sensory problems be taken seriously and revealed in respectively elderly people with sensory losses and in elderly people with dementia, in order to implement relevant compensation, support and treatment.



Sensory loss  
and dementia may  
blur each other's  
existence

The sooner this revelation can take place, the better the starting point.

### **SPECIAL ATTENTION IS NEEDED**

It is important that care staff are informed about the typical consequences of acquired deafblindness and the early signs of dementia, and that the staff are aware of both conditions being able to deteriorate over time and to obscure each other.

The person with dementia and his close family have to be especially aware of the progressive deterioration of vision and hearing. Likewise, the person with deafblindness must seek a doctor's advice if he is worried about developing dementia, just in order to get the right assessment and treatment. Symptoms of dementia may in fact look like symptoms of other diseases; such as depression. As mentioned, dementia is not a sign of you being old. Dementia is a sign of an underlying disease which has to be checked, and in turn this requires special assessment performed by dementia experts.

In a person with dementia, you should, as far as possible, try to get information on the person's sensory loss and on basis of that determine whether further assessment is necessary. If the citizen has earlier been diagnosed with a vision or hearing loss, the development of sensory loss should be monitored. In case of a reduced level of functioning, you should be aware of, whether it is one or the other disability that is the cause, and whether you eventually might be able to support the citizen better through the use of compensatory measures. It might, as an example, be in the form of reduced background noise, the establishment of tactile markings, better lighting or changes in mode of communication. It might be a good idea to introduce potential assistive technology devices for vision and hearing while the person is capable of learning how to use them. The person might need help in order to use assistive devices in everyday life. Seek help with professionals who know about vision loss, hearing loss or acquired deafblindness, when living with a dual sensory loss.

### **A DEVELOPMENT PROJECT ON THE ASSESSMENT OF DEMENTIA IN PEOPLE WITH ACQUIRED DEAFBLINDNESS**

The first step in the assessment of dementia is a clinical and objective examination of cognitive functions, e.g. the MMSE<sup>2</sup> and a clock test (see figure 2). This type of test plays a vital role with regard to revealing whether it is a case of dementia.

The major problem in the examination of persons with

acquired deafblindness is that the commonly used and recommended cognitive tests are dependent on functional vision and hearing. Both auditorily presented material and visual tasks are very significant sub-tasks in the tests. An important part of the assessment of dementia based on traditional procedures renders a precise diagnosis of dementia in people with acquired deafblindness impossible.

Neuropsychologist Peter Bruhn, the Memory Clinic at Glostrup Hospital, is, in cooperation with the deafblindness consultants at Center for the Deaf and ViHS, working on the development of a tactile test battery for the assessment of dementia in people with acquired deafblindness. That is to say, the cause is typically age-related combined reduced vision and hearing or e.g. Usher syndrome type 2. In the test battery, all tests are presented tactually. Functional vision and hearing are thus not necessary in order to complete the tests. The task may be introduced orally or in writing with adequate regard to the communication demanded of each participant. Therefore, it is important that the test, in accordance with needs, is carried out in quiet surroundings with good lighting and with the necessary assistive devices at hand to ensure optimal communication between examiner and examinee. Thus, it is necessary that the examiner has knowledge about how the examinee best communicates.

The tactile test battery consists of seven different tests. All seven tests take place in a box that has an opening that allows the examinee to place his dominant hand within the box. The examiner, who sits opposite to the test person, guides the hand of the person through an opening in the reverse side of the box, enabling him to explore the stimulus characteristics of the test material placed in the box. Instructions are given orally or in tactile or written spelling. In some tests, the person has to respond verbally, in other situations by manual performance. The fact that the tests are carried out in a box, eliminates the possibility of using any remaining vision in solving the task (see figure 1).

The tests represent the most important cognitive functions that normally are part of a neuropsychological dementia examination, e.g. learning and recall, perceptual identification, naming, clock reading, and processing speed (see figure 2).

At this moment the tactile test battery is undergoing a final validation process. Hopefully, the result will show that the test battery is useful as a supplement to existing tests in the mental state examination for dementia in people with acquired deaf-blindness.

**Figure 1**

*The test is carried out inside the box and eliminates the use of any remaining vision.*



**Figure 2**

*The tactile version of: Clock Reading test, Form Board and Spatial Memory test.*



Photo: Trine Skov Uldall

## LITERATURE AND RELEVANT LINKS

- Socialstyrelsen (The National Board of Social Services):  
[www.servicestyrelsen.dk/handicap/erhvervet-dovblindhed](http://www.servicestyrelsen.dk/handicap/erhvervet-dovblindhed)  
here you can read more on acquired deafblindness in the elderly and you can download or order free publications and articles.  
You can also find information on:
  - Vision disability:  
[www.servicestyrelsen.dk/handicap/synshandicap](http://www.servicestyrelsen.dk/handicap/synshandicap)
  - Hearing disability:  
[www.servicestyrelsen.dk/handicap/synshandicap](http://www.servicestyrelsen.dk/handicap/synshandicap)
  - Dementia:  
<http://www.servicestyrelsen.dk/aeldre/demens>
- Nationalt Videnscenter for Demens (Danish Dementia Research Centre): <http://www.videnscenterfordemens.dk/>
- "1+1=3 – En artikelsamling om ældre med kombineret høre- og synsnedsættelse" Videnscenter for døvblindblevne (The Information Center for Acquired Deafblindness), 2010
- "Håndbog om demens, til pleje og omsorgspersonale på ældreområdet, undervisere og frivillige", Servicestyrelsen (The National Board of Social Services) 2008
- "Håndbog om demens, til myndighedsniveau: Ledere, politikere og forvaltningsmedarbejdere."

## Communicating beyond speech

Dementia is an umbrella term covering a number of conditions that lead to a progressive and irreversible loss of cognitive functions. There is no single pattern or symptoms of deterioration throughout the illness making it a very difficult condition to deal with. Alzheimer's disease (AD) is the most common cause of dementia accounting for approximately 42 per cent of cases, with vascular dementia and mixed vascular and AD accounting for a further 24 and 22 per cent, respectively<sup>1</sup>.

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Age is the biggest risk factor for developing dementia and, as life expectancy continues to grow, the number of people with dementia worldwide is predicted to rise from 25 million in 2000 to 63 million by 2030, and 114 million by 2050<sup>2</sup>. In the UK, figures for 2009 put the cost of caring for the estimated 822,000 people currently living with dementia at £23bn per annum, £3bn higher than the combined care costs of cancer (£12bn) and heart disease (£8bn)<sup>3</sup>.

One particularly challenging aspect of dementia is the effect it has on communication. This is problematic both for people with a dementia diagnosis and with those who care for them<sup>4</sup>. As dementia progresses, people become increasingly less able to communicate through speech, which has a negative impact both on their relationships with others and their ability to participate in the social world. As dementia severity increases, many people reach a point where speech is no longer an effective means of communication. As such, the attempts of people with dementia to communicate with caregivers are increasingly ignored or judged incomprehensible<sup>5</sup>. This may be due to caregivers' 'intuitive dependence on language as a sign of emotional connection'<sup>6</sup>, such that they believe that when someone can no longer speak, they can no longer communicate.

## ADVANCED DEMENTIA

Alongside loss of speech, people with advanced dementia commonly experience loss of mobility and loss of control over the most basic activities of daily life. As a consequence they may spend a lot of time in bed in their rooms, alone and apart from other people. In this situation, people with advanced dementia face huge difficulties expressing themselves to caregivers, who, in turn, may feel awkward or uncomfortable, faced with these people's profound needs. Consequently, those in the most advanced stages of dementia may only see or be in the presence of another person when that individual comes in to carry out essential care tasks, such as giving them food or assisting with personal hygiene<sup>7</sup>. This can lead to those with advanced dementia becoming almost completely excluded from the social world, which has a major impact on their experience of self and 'personhood'<sup>8,9</sup>.

## PERSONHOOD

Personhood is a socially constructed phenomenon whereby interaction with one or more people affirms an individual's existence as a human being. As such, personhood is 'co-created' through co-operation with one or more other individuals, in much the same way as cognitive and communication skills develop in infants through interaction with parents<sup>10</sup>. Personhood is maintained by relationships that encourage effective and supportive communication<sup>11</sup>.

Although speech-based interactions eventually become impossible for people with very advanced dementia, this does not mean that they have lost the urge or ability to communicate<sup>12-14</sup>. Kitwood<sup>8</sup> argued that: 'In the course of dementia a person will try to use whatever resources he or she still has available. If some of the more sophisticated means of interaction [such as speech] have dwindled away, it may be necessary to fall back on ways that are more basic and more deeply learned'. Fundamental communication skills that are learned in infancy, such as the ability to make facial expressions, gestures, sounds, laughter and purposeful movement, are the sorts of 'resources' Kitwood referred to. Even in the advanced stages of dementia, people may retain some or all of their fundamental communication skills, which could be used to provide the basis for communication<sup>12-14</sup>.

Improving interpersonal communication in the care environment has the potential to improve not only the quality of life of people with advanced dementia, but also the job

It is necessary to work with the communication skills they still possess, essentially to 'learn their language'.

satisfaction and enjoyment of care staff<sup>15</sup>. A critical element in achieving this is facilitating the co-creation of personhood by enabling caregivers to make meaningful connections with people with advanced dementia. Although there has been little research into this area, the evidence suggests that maintaining the communicative status of people with advanced dementia requires the most effort on the part of others. The challenge is how to facilitate communication with people with advanced dementia who can no longer speak, and may only make sounds or repeat isolated words or movements. Of course, it is not possible for people with advanced dementia to re-learn how to use speech. Therefore, in order to communicate with people with dementia at advanced stages, it is necessary to work with the communication skills they still possess, essentially to 'learn their language'.

### INTENSIVE INTERACTION

Intensive Interaction (II) is a method for learning the language of people with severe communication difficulties<sup>16</sup>. II developed in the 1980s as an approach to communicating with children with severe and profound learning disabilities who do not have speech. Based on work on the fundamentals of communication, II focuses on behaviours such as turn-taking, facial expressions communicating emotions, sounds and eye gaze. In II, the behaviour of people with severe communication difficulties is viewed as intentionally communicative, and their partner attempts to learn and respond to this.

II commences with the caregiver or communication partner becoming familiar with the person they want to communicate with, including the types of interactions and behaviour in which the person might engage. This initial contact is then developed into a set of spontaneous activities based on the behaviour of the person who is without speech<sup>17</sup>. For example, a sound or action they make, such as a repeated movement, will be reflected back by their partner, either directly or with some variation in the rhythm. The person with speech follows the behaviour of the person without and tries to create a connection between them. The connection is usually evident when the person without speech pays attention to the other person, either by making eye contact or a movement or sound and pausing, as if to see what will happen. From this initial to and fro, a 'dialogue' is slowly built up over time. By responding in ways that are familiar and meaningful to a person without speech, i.e. initially imitating and then developing non-verbal communications into a shared 'language', it is

possible to build and sustain close relationships (Caldwell, 2005).

In II, the caregiver responds contingently to the person without speech's behaviours to continuously co-create and expand the interactions between them. By responding in ways that are familiar and meaningful to a person without speech, i.e. initially imitating and then developing non-verbal communications into a shared 'language', it is possible to build and sustain close relationships (Caldwell, 2005). The caregiver also supports the person without speech to take a more active role in communication. Such benefits and positive effects on communication are clearly desirable for those with advanced dementia. II, which takes the nonverbal fundamentals of communication as the basis of interactions, thus appears to have great potential for improving communications between people with advanced dementia and those who care for them.

### **INTENSIVE INTERACTION FOR ADVANCED DEMENTIA – ADAPTIVE INTERACTION**

To investigate the usefulness of the II approach to facilitating communication and consequently supporting personhood in people with advanced dementia, we first conducted a single case study<sup>14</sup>. In this we set out to explore the communication repertoire of Edie, an 81-year old woman with advanced dementia who had lived in a nursing home for over five years. This involved spending time in the care home to piece together a picture of (I) the communication that took place between caregivers and Edie, (II) the opportunities for communication that occurred during any given day, and (III) Edie's repertoire of communication skills. The study revealed that Edie spent most of her time alone in her room, with caregivers going in for very short periods only to carry out specific care tasks, such as providing meals. Communication that took place was brief and consisted largely of questions such as, 'Have you seen the weather today?' or 'Did you eat your breakfast?' to which Edie was unable to respond with speech.

These findings were used to construct what we termed a 'standard interaction', comprising a set of questions, similar to those reported above. The second author (MPE) spent 10 minutes with Edie, working through the baseline questions and allowing 30 seconds after each for Edie to respond. Subsequently, MPE conducted a second 10-minute session with Edie, using the principles of II in an attempt to learn Edie's language and engage in a dialogue with her.

Based on this approach, we found that Edie had a rich

communication repertoire, comprising sound, movement, directed eye gaze, and facial expressions<sup>14</sup>. She also engaged in turn-taking and initiation, signalling her willingness to communicate and engage with another person through her nonverbal behaviour. These findings illuminate the collaborative nature of personhood even in the most advanced stages of dementia, and the continued importance of social interaction for all human beings.

These findings suggested that an approach to communication based on II has something to offer people with advanced dementia who can no longer speak. However, the severe memory problems seen in this population mean that no assumptions can be made about building up a repertoire of communication from session to session. Instead, communication partners must approach each interaction with people with advanced dementia as a unique encounter, and adapt their behaviour anew each time. We therefore termed this approach 'Adaptive Interaction' (AI) to reflect its variation from typical II.

### GROUP OF CASE STUDIES

To build on the findings of the case study with Edie, we carried out a second study with five older people. The average age of the group was 82.6 years; all had very advanced dementia and lived in a nursing home. The main aim was to continue our exploration of the effectiveness of AI as a means of learning the language of people with advanced dementia. We were particularly keen to explore similarities and differences between the communication repertoires of the five individuals. A second aspect of the research was to make a start on examining the role of the communication partner, i.e. the person with speech, typically a caregiver, in co-creating a shared language with a nonverbal person with advanced dementia. This is especially important for enabling care staff and families to maintain relationships with people who have advanced dementia.

As in the case study, we used the 'standard interaction' questions for comparison with AI. These standard interaction sessions were carried out to provide baseline data, akin to that which might occur between people with advanced dementia and caregivers whilst assisting with activities of daily living. AI was used to explore the potential for engaging people with very advanced dementia in a shared activity, and whether this provided an opportunity for affirming their personhood.

As in the case study, the findings showed that each of the five participants had a repertoire of nonverbal behaviours that could be used as the basis of communication and social interaction. These included sounds, movements, directed eye gaze and facial expressions. There were some similarities between the five participants, in that they all responded to their communication partner in some way, as well as demonstrating an urge to communicate and to retain their identity as a social being. The one behaviour that all five people with advanced dementia demonstrated was eye contact with their communication partner. Four of the five people made speech sounds, four of the five smiled and three pointed during the AI session. Additionally, each person had a clear and distinct repertoire of communication behaviours comprising a unique combination of movements, gaze, facial expressions and sounds. Thus the study provided further evidence for the collaborative nature of personhood and the importance of social interaction, even in the most advanced stages of dementia.

The results suggest that in the absence of speech, even those with very severe dementia are able to use nonverbal communication to engage in dyadic exchanges with a communication partner. The findings support those reported from the use of II with other populations, including adults and children with severe and profound learning disabilities<sup>17</sup> and autistic spectrum disorder<sup>16</sup>, which demonstrate that speech is not a necessary requirement for people to demonstrate their continued existence. AI provides a mechanism for those with very severe dementia and no functional speech to demonstrate awareness of themselves as social beings in relation to another person. Finally, the study highlights the necessity for interaction partners to be responsive and adaptive to the needs of nonverbal people with dementia. Providing a supportive and facilitative communication environment can enable people, even in the most advanced stages of dementia, to demonstrate their continued personhood through social interactions with another human being.

## CONCLUSIONS

Adaptive Interaction (AI), a system of tailored, intensive interaction that focuses on learning the language of people who are nonverbal, appears to have potential as a tool for promoting and supporting communication between people with advanced dementia and those who care for them. Our research reveals that people with advanced dementia retain



nonverbal behaviours, involving sounds, body movements, and eye gaze, as well as other fundamental communicative abilities, such as turn-taking, which can be used as the basis of social interactions<sup>17,18</sup>. The ability and desire of people with dementia to communicate also indicates the continued existence of self-awareness, and the potential for co-creating personhood through social interaction with others<sup>19</sup>.

Our research shows that AI can reveal a rich communication repertoire in people with advanced dementia, and may open up opportunities for communication. It is notoriously difficult to communicate with individuals at this stage of the illness. However, by learning the language of people with advanced dementia, there is clear potential for caregivers to make contact and engage in a 'dialogue' – just one that does not involve speech.

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