

Remember...

The Deaf Dementia Experience in Scotland

... A Toolkit For All







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Foreword



I am delighted to write the foreword for this user-friendly toolkit for Deaf people who use BSL and who are living with dementia, their families, carers, and staff who are supporting them. It is a project that is of great personal interest to me.

I have experienced caring for my late father, Jack, who was Deaf and lived with dementia. I had to fight for a conclusive diagnosis for him after he developed Alzheimer's disease because there is currently no assessment in Scotland tailored for Deaf people who use British Sign Language (BSL).

I attended many hospital appointments with my father. I was faced with the responsibility to ensure that BSL/English interpreters were booked. My father was in hospital for the last six weeks of his life. When I visited him I could see other families having real quality time with their loved ones but when I was there much of my time was taken up in making sure that the appropriate support was in place. Those concerns made me anxious, and my time with my father was overshadowed by this.

I do not want any Deaf person who uses BSL, whether they are the patient, a family member or carer, to **experience unfair treatment**. BSL users deserve **equal access** to information and services in order to have better life outcomes.

This toolkit closely aligns with BDA Scotland's vision of ensuring equality of access and services for Deaf people living with dementia, that is, the fundamental citizenship right to language and culture. This is at the very heart of the **Transforming the Deaf Dementia Experience project**.

Information for Deaf people should be led and created by Deaf people so I would like to personally thank the Stakeholder Group for their invaluable contributions to this toolkit, and, to the Life Changes Trust for their funding and support.

Yours in BSL,

Avril Hepner

Community Development Manager, BDA Scotland



It is a privilege to have been asked to write a short foreword to this excellent toolkit. When someone suspects they have dementia, or is diagnosed with dementia, they and their families look for information, advice and support. When someone who uses BSL has dementia, they face greater barriers in accessing suitable resources.

This toolkit is an extremely positive step towards achieving equality of access to information and services for Deaf people. It is informative, visually attractive and provides helpful reminders, for example, “You have the right to choose your preferred interpreter” and “Don’t forget to ask about support services for YOU, the carer.”

In Scotland we aim for a human rights based approach to service provision, based on legislation, policy and charters such as the ‘Charter of Rights for People with Dementia and their Carers in Scotland’. This toolkit, and the work of BDA Scotland more generally through ‘Transforming the Deaf Dementia Experience’, is an excellent example of what a human rights based approach looks like in practice.

BDA Scotland is to be commended for its deep commitment to partnership working. In developing this resource they have drawn on the expertise of Deaf people living with dementia and carers; they have built solidly on learning from the wider dementia community in Scotland and are contributing back to that community with openness, willing to share their resources.

We are certain that the toolkit will be an extremely popular publication and there will soon be demand for a second edition!

Anna J. Buchanan

Anna Buchanan
CEO, Life Changes Trust



Acknowledgements

BDA Scotland was able to create this toolkit as a result of the support, ideas and contributions from the Stakeholder Group. The group, who gave their time willingly and shared their experiences, included 9 Deaf people who use British Sign Language. Grateful thanks to:

- **Scott Campbell** (Former carer)
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- **Helga McGilp** (Former carer)
- **June Mitchell** (Former carer)
- **Linda M. Richards** (Former carer)

The Dementia Journey

The Dementia Journey is different for everyone. Some start with a diagnosis. Some need to organise care. Some want to find out more information. Some need to make choices and decisions. We hope this toolkit will give tips and advice to support people as they travel on their Deaf Dementia Journey.





Introduction

Deaf people with dementia, their carers and families are **often excluded** from mainstream services, care home activities and medical or professional discussions. This toolkit may be a **useful resource** for all involved in **supporting Deaf people living with dementia**, to help them remember the needs of the **Deaf person who uses British Sign Language (BSL)**, whether they are the patient, the family member or the carer.

That's why this toolkit is called... '**Remember...**'

BDA Scotland would like to thank the **Life Changes Trust** for funding the **Transforming the Deaf Dementia Experience project**, one of the outcomes of which is this toolkit.

Why do we need a toolkit?

Feedback from Deaf people who use **BSL** and their families informs us that Deaf people living with dementia:

- Have a **history of poor access** to information;
- Experience a lack of/limited access to **resources in BSL**, and;
- Encounter services that have **little understanding of the linguistic and cultural needs** of Deaf people.

BDA Scotland wants to transform this experience and help make the **Deaf Dementia Experience** a better one **by producing this toolkit** – a resource people can dip into, refer to, and read at their own pace.

How did BDA Scotland create this toolkit?

A Stakeholder Group was formed to give ideas and develop this toolkit. **Meetings** were held in **BSL and English**, and many **ideas and contributions** from this group have been included in the toolkit. A list of those who were involved can be found in the Acknowledgements section.

What is unique about this toolkit?

The Stakeholder Group agreed we wanted to produce a **Deaf user-friendly** toolkit in **plain English**, and **BSL**, and which included the **personal experiences of families living with dementia**. The group hopes this toolkit will provide you with the information you need as you start your **dementia journey**.

Let's talk about the onset (pre-diagnosis) of dementia

- What is dementia?
- Getting medical advice
- Working with a BSL/English interpreter



Let's talk about the onset (pre-diagnosis) of dementia

Albert's story

“Albert and his brother James were sitting in their living room. James was asleep in the armchair. When Albert went to wake him up, James said “Who are you? What are you doing in my house?” Albert was upset and said “I am your brother”. James replied, “Oh, right, sorry. Yes, you are my brother.” Albert later told James’s daughter, Isabel, what had happened. They realised that they needed to get medical advice.”

What is dementia?

Dementia is a word used to describe a set of symptoms, which are caused when brain cells become damaged and stop working properly. When brain cells do not work well, this can affect how someone thinks, remembers or communicates.



The sign for dementia

In BSL we use a sign at the top of the forehead to show something has been ‘forgotten’, or that something is ‘missing’ from the brain. If you do not know the sign, ask the Deaf person to show you.

Types of dementia

There are different types of dementia. The four most common types of dementia are:

- Alzheimer’s Disease
- Vascular Dementia
- Frontotemporal Dementia
- Dementia with Lewy Bodies

Information about all four of these types of dementia, as well as a general guide about dementia, have been translated into BSL by BDA Scotland, with permission from Alzheimer’s Society.

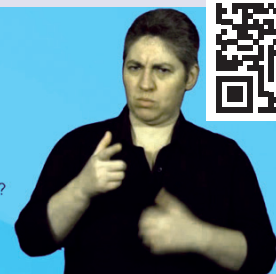
This is the link for the BSL clips (with English text):

<https://bda.org.uk/project/dementia>

- What is Dementia?
- Alzheimer’s Disease
- Vascular Dementia
- Frontotemporal Dementia
- Dementia with Lewy bodies

Contents

- Symptoms
- What causes dementia?
- Who gets dementia?
- How can I tell if I have dementia?
- Diagnosis dementia
- How is dementia treated?



Taking steps towards diagnosis

“ I remember it was my sister who first told me that she thought my wife had dementia. My first question was how did she know, and she said she'd noticed a change in my wife's voice. I started to have my own suspicions after she kept putting the kettle on without any water in it. Twice, we had to get a new kettle. **Sandy** ”

A proper assessment needs to be done to make the right diagnosis. Often, it is family, neighbours or friends who start to notice there may be changes in someone's behaviour, for example, they might do something they have never done before.

Someone who may have dementia may find it **difficult** to:

- Remember what day it is
- Remember recent events
- Plan or organise things like meals, shopping, or activities
- Make decisions or solve problems
- Remember the word or sign for something
- Judge distances or depth
- Keep their balance – they may fall over
- Put things in the right place
- Remember where they are – they may get lost or confused
- Sit and watch TV for a long time
- Distinguish between colours

There may be **changes to behaviour** such as becoming:

- Confused
- Frustrated or irritable
- Anxious or upset
- Sad
- Withdrawn
- Less empathic

Remember: It is very important to make an appointment to see a doctor and get a proper diagnosis (reason for the memory loss).

Some of these symptoms may be evidence of dementia but they could be happening because of something else, such as an infection or depression. It is best to write down the symptoms, things you or others have noticed, and make an appointment to see a doctor.



Let's talk about the onset (pre-diagnosis) of dementia

Getting medical advice



At the doctor's

When you go to see the doctor together, the doctor may ask you, the carer, to explain your concerns. **The doctor may ask the person with dementia for permission to carry on with you, the carer.**

The doctor may ask:

- What's changed?
- Is the person behaving in a different way?
- Are they more forgetful?
- What they are doing differently or what do they forget?
- What medication is the person taking at the moment?

The doctor may do a simple test. This is a memory assessment called a **mini mental state examination (MMSE)**.

The carer is usually not involved in this test however, the carer has the right to express their concern if s/he spots that the person is struggling with the questions.

“ I had to fight for a diagnosis for my dad, Jack, after he developed Alzheimer's. There is currently no assessment for Deaf people. I demanded access to a specifically tailored BSL assessment. Until then, although it looked like my dad was responding to the tests, my suspicion was that he was mirroring or copying what the interpreter was signing, which gave a false picture as to how well he understood. **Avril** ”

It is important for professionals to be aware that some questions may be difficult for a Deaf person to understand because of cultural differences. Please do ask for advice from BSL/English interpreters, local Deaf organisations as well as family members/carers about the best way to phrase questions. For example:

Question: What season is it at the moment?

Rephrase: Is it summer or winter now?

Question: Who is the Prime Minister?

Rephrase: Who lives at number 10 Downing Street?

The doctor may ask the person:

- The date
- An historical date (for example, when was World War II?)
- To identify pictures
- To spell a simple word
- To remember a simple address and repeat it back a few minutes later
- Who the Prime Minister is
- The name of the monarch (Queen/King)
- When is your birthday?

Why does the doctor ask these questions?

The answers give information to the doctor about the different parts of the person's brain, and whether they are working well. By the way, doctor doesn't ask all these questions – just some of them.

What happens next?

The doctor may refer the person to a specialist, based in a memory clinic, to do more tests.

This is because the doctor wants the person to see experts who specialise in memory problems, for example: a nurse, doctor or psychologist. At the memory clinic, the medical staff can do a full assessment, including different tests to make sure the memory issues are not being caused by an infection or other illness.

Remember: It may be dementia or it may be something else, for example, an infection or depression. That's why it's important to see a doctor and get a proper diagnosis – to find out why the person is having memory loss.

What is a memory clinic?

Memory clinics are specialist centres where they can carry out more tests. The staff there have more time to do a full memory assessment with the person to find out the reason for their memory issues. They do different tests to find out more about what might be happening.

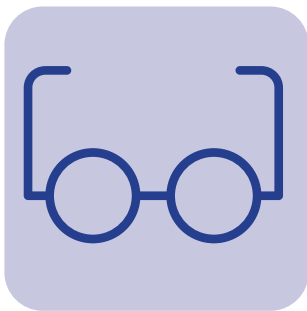


Let's talk about the onset (pre-diagnosis) of dementia

Getting ready to go to the memory clinic

A nurse, doctor or psychologist will see the person. It is better if you, as the carer, can go with them. This is because the doctor may want to ask you more about any of the memory issues the person is having, and about how their behaviour is different from before.

Don't forget to take the person's:



Glasses



Hearing aids



List of medicines



GP details

The appointment usually lasts about an hour. Ask for a longer appointment and ask them to book a BSL/English interpreter.

Remember: Ask the doctor to tell the memory clinic to arrange a longer appointment (more time) and to book a BSL/English interpreter for the appointment.

What else happens at the memory clinic?

The memory clinic may also do a blood test and there may be brain scans such as a CT or MRI scan.

If you are not sure about what happens in a CT or MRI scan, **please ask.**

At the end of the visit, the person or their family will be told the details of the test results. The memory clinic will send details of the test results to the doctor. The clinic may ask the person to come back in a few months for more follow-up tests.

If the person is diagnosed with dementia, they may be given medicine to take. It depends on the type of dementia they have.

Remember: Don't forget to ask about support services for YOU, the carer.

Support networks

Information and advice will be given about how to access support networks. These support networks are usually for hearing people so it is important to ask about support services for Deaf people.

Working with a BSL/English interpreter

Who needs a BSL/English interpreter?

Any meeting between Deaf and hearing people involves two languages, BSL and English. A BSL/English interpreter needs to be booked so that everyone understands each other. Communication is everyone's responsibility.

The majority of Deaf people are born to hearing parents. This means there are many Deaf people who are caring for their ageing hearing parent; they still need access to healthcare information in BSL. Whoever needs to use BSL (the person with dementia, or the family member or carer who is Deaf) must have a BSL/English interpreter so they are included in the meeting.

If you are a Deaf carer, it is important you also understand what is happening or being discussed. Would it be useful for you, or the Deaf person who has dementia, to have a Deaf co-worker as well as a BSL/English interpreter? For example, would it be helpful to have a Deaf advocate, Deaf Relay Interpreter, a buddy or other person to help with communication? It is important that the person with dementia fully understands the discussions.

Interpreters may be booked through the NHS Board, the doctor's surgery, the hospital or the memory clinic. If there is an interpreter, Deaf advocate, Deaf Relay interpreter, a buddy, or other person that you or the person with dementia **like to use**, ask the medical centre to book this person.

Remember: You have the right to choose your preferred interpreter.



Let's talk about the onset (pre-diagnosis) of dementia

“ I attended a lot of hospital appointments with my dad. It was a lot of work and responsibility to make sure BSL/English interpreters were booked. My dad was in hospital for the last six weeks of his life. When I visited him I could see other families having real quality time with their loved ones but when I was there much of my time was taken up in making sure that there was a doctor coming, that a BSL/English interpreter had been booked, and so on. My time with my dad was overshadowed by these concerns. I was always anxious, making sure the appropriate support was in place. *Avril* ”

Who pays for the interpreter?

For medical appointments, the interpreter's fees are paid by the local NHS Board. Most interpreters are freelancers, who charge a fee for their professional services. Interpreting services must be requested and/or booked through the NHS before the meeting.

Care Homes should provide interpreters at care review meetings and the Care Home or Social Services should pay the interpreter's fees.

The **Useful information** section has more information about BSL/English interpreters

Preparing for the meeting

Think about your needs and the needs of the person with dementia before any meeting.

Checklist:

- ✓ Is there a BSL/English interpreter you prefer or are comfortable with?
- ✓ Do you need a Deaf Relay interpreter?
- ✓ If the person who has dementia is Deaf, do they need a Deaf advocate?
- ✓ Would you like the same BSL/English interpreter/Deaf Relay interpreter/Deaf advocate at the next meeting?
- ✓ Remember, it is okay to say if you are nervous or uncomfortable during the meeting.
- ✓ Make notes of things you want to ask in the meeting.



Arranging the meeting

The person arranging the meeting needs to:

Before the meeting:

- ✓ Give plenty of notice for the meeting.
- ✓ Allow at least double the usual time required.
- ✓ Ask if there is a BSL/English interpreter the Deaf person/Deaf carer prefers or is comfortable with.
- ✓ Book a BSL/English interpreter.
- ✓ Book a Deaf Relay interpreter and/or Deaf advocate if requested.
- ✓ Is one BSL/English interpreter enough? How many Deaf people are attending?
- ✓ Do you need an advocate or buddy for the Deaf person who has dementia?
- ✓ Book a large, warm, quiet room with good lighting.
- ✓ Put the chairs in a circle so that everyone can see each other.
- ✓ Send a letter with the names/roles of those who are attending, and explain what will happen in the meeting.



At the meeting:

- ✓ Make sure the BSL/English interpreter is sitting opposite the Deaf person/people.
- ✓ Keep introductions short and clear.
- ✓ Draw a plan with everyone's names and where they are sitting.
- ✓ Have regular breaks and make refreshments available.
- ✓ Keep the discussions short.
- ✓ When asking questions, or changing the subject, remember it is helpful to give the topic first.
- ✓ Check that everybody is following what is going on.
- ✓ Have recaps of each point and a summary at the end.
- ✓ BSL/English interpreters know both languages and both cultures. Work with them; use their skills and assistance to ensure a good meeting for all.





Let's talk about the onset (pre-diagnosis) of dementia

After the meeting:



- ✓ Check if anything needs to be done in a different way next time.
- ✓ Send notes (or a BSL video) of the meeting for the Deaf person/family/carer to read later. Ask the family for their preference.
- ✓ If everyone is happy, try and book the same interpreter for follow-up meetings. Continuity is very important and can save repeating information. It is also important for the person with dementia, as they may be anxious about meeting new people.

Notes from the meeting should be written in plain English. Bullet points are good.

There may be a request for the information to be given in BSL.

How this is done should be agreed at the meeting and followed through by whoever is the lead person.



Let's talk about a diagnosis of dementia and what to do

- Sensitive conversations
- Telling family and friends
- Who to inform?
- Referral to Social Services
- Power of Attorney and making a Will



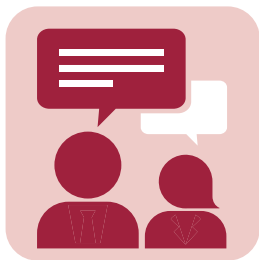
Let's talk about a diagnosis of dementia and what to do

“ My dad's use of sign language was not different, but the way his every day behaviour was different. He loved football, but started to be really distracted halfway through a match. This really was not like him at all. As a Deaf family, it was important that my suspicions about changes in my dad were confirmed. **Avril** ”

You may be wondering what to do after you have received your diagnosis. You can carry on living at home. This may include having some support. You can continue doing the things that you enjoy. You can continue working and you can continue going to the Deaf Club and meeting your friends there. You may carry on with your social activities, or you may choose to do new things.

You and your family may not know what dementia is. You may all need to find out more information about dementia and what to do next.

Sensitive conversations



When dementia has been diagnosed and confirmed, it is very important to start thinking, talking and making plans. These may be difficult and upsetting conversations, which

will need people to be patient, sensitive and understanding.

Remember: Telling family and friends, or dealing with things you did not expect, may be upsetting and difficult. Make sure you look after yourself and keep well.

Dementia means the person's memory and actions will be affected. So it is important to start planning and writing down what the person's wishes are while they are still able to make decisions. There are many things to think about at different times and with different people. Some things are practical and easy to do. Some things need more thought and support from others.

Some conversations are good to have, to tell people and get support. Some conversations are more difficult or may mean a change in the person's life, for example, whether the person is allowed to continue driving. It is important to be open and honest. Try and get as much information from the doctor or memory clinic about the type of dementia which has been diagnosed. If you are asked questions and you do not know the answer, say so. You can find out later, or ask them to help you find out. Make notes before you meet your friends and family to help you remember and explain.

Telling family and friends



Telling family and friends about a diagnosis of dementia:

There is no right time to tell your friends or family members about your diagnosis of dementia. You can do it in stages. Why not practise what you would like to say? Think about what support you would like from them, now, and later.

It is not easy to tell people about a diagnosis of dementia. Make sure you have the information you need, are clear what you want to say, and have no distractions (no television or other things going on). People will react in different ways. They may be shocked, ask lots of questions or want to know how to support you.

Sometimes a person living with dementia does not want to tell anyone about the diagnosis. This is okay. They can tell people in their own time.

If support is needed, there are some things you and your family and friends could do. For example, you might want to:

- Tell your family about any Care Plan which may have been agreed with Social Services
- Ask your family to help you design and use a new visual diary with pictures for appointments, events, meetings, and outings. You might like to use a whiteboard for this
- Ask friends to become your buddy and travel with you on the bus to the football or to the Deaf Club
- Plan independent living – including driving and travelling around
- Give the Deaf Club or groups you attend a note of who to contact
- Agree on a circle of support
- Agree on communication support
- Have a named carer and/or Carer Service (use photos to show who the people are)
- Use visual stickers to show what is behind doors, in the drawers and in the cupboards
- Use bright and contrasting colours to show differences
- Ask family or friends to help make your house safer. Think about using bright lights, removing rugs, kitchen safety, using colourful plates to see the food easier, and getting alerting equipment or personal alarms from Social Services, Telecare or others



Let's talk about a diagnosis of dementia and what to do

- Explain your personal preferences around hygiene and self-care: for example, bath or shower, wet shave or electric shaver
- Plan for someone to be with you when you cook a meal
- Stay at work and plan how to tell your employer and work colleagues
- Make plans for the future
- Apply for a Blue Badge, which allows you to park your car nearer to where you are going. You and your carer must be in the car when the Blue Badge is being used. See BSL link about Blue Badges: www.facebook.com/BritishDeafAssociation/videos/2035712936491017

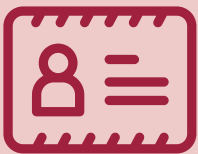
Remember: Alzheimer Scotland, Social Services and medical teams can give you more information. You do not have to deal with matters on your own. You are not alone.



Be aware that a person with dementia may also have visual difficulties. Check for any loose flooring, remove rugs, improve lighting and use bright and contrasting colours.

Who to inform?

There are two organisations the person with dementia or carer might need to inform: the DVLA and their employer.



1. DVLA

A diagnosis of dementia does not necessarily mean you have to stop driving. The doctor will tell you if you need to stop. However, the DVLA must be informed. If you do not tell them, they can fine you. The doctor may inform DVLA about your dementia. This is because dementia affects the ability to judge distances or to read and understand road signs. This means it may become unsafe for you to drive.



2. Employer

If you are diagnosed with dementia under the age of 65 and are still working, you may need to inform your employer. It is better to check your workplace handbook. In some places, the employer must be told. In others, it does not matter but you may want to tell them anyway, so they can help with any reasonable adjustments in the workplace. Carers can ask their employer for support too. Carers have the right to ask for unpaid leave and to request flexible working hours. Check with your employer, the staff handbook, or ask HR.

Referral to Social Services

Medical staff may ask Social Services to get involved in supporting someone with dementia, or you can ask them to come yourself.

A Social Worker can:

- Arrange a community care assessment for the person with dementia, and one for the carer
- Check you are claiming the right benefits (for example, Attendance Allowance and Direct Payments). Ask your Social Worker to find out what you are eligible for
- Tell you about Council Tax exemptions (if the person with dementia is living alone)
- Get the right equipment to use at home to keep safe
- Give information about respite breaks for the person with dementia as well as for the carer
- Tell you about support groups and services which might be useful

Care Plan

After a community care assessment, a Care Plan will be drawn up. This will cover the kind of things the person with dementia likes to do and their needs. As part of the Care Plan, Social Services can explain about the support that may be available which can make living with dementia a bit easier.

Checklist:

- ✓ Help with washing and dressing
- ✓ Meals on wheels or delivery of ready meals
- ✓ Shopping, cooking and cleaning
- ✓ Reminders to take medicine
- ✓ Managing money and paying bills
- ✓ Equipment for the home to stay safe
- ✓ Enjoying a social life



The Care Plan may include information about private care agencies. Some people will not qualify for free care or benefits but you can ask for a review if the person's financial situation changes.



Let's talk about a diagnosis of dementia and what to do

Power of Attorney and making a Will

One of the first things to do is to meet with a solicitor to discuss:

- Power of Attorney
- Making a Will
- Trusts
- Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000



Power of Attorney:

A Power of Attorney (PoA) is a legal document, which allows someone to make decisions on behalf of the person with dementia. There can be one or more PoAs in place. The person who has PoA needs to follow the wishes of the person with dementia, or to act for them, in their best interests. The person named as having PoA can be a member of the family or a close friend. It is a good idea to ask first if they are happy to do this, explain the role and check that they agree before their name goes onto the document. The PoA is a legal document, which can only be done by a solicitor. At the same time, the solicitor may ask if you have made a Will and may also give other advice, for example, about guardianship.

Any legal business with a solicitor has to be paid for. Therefore, you will need to pay their costs for putting a PoA in place, drawing up a Will, and so on. You can ask what these costs are before you meet with the solicitor. The solicitor should not charge you for any interpreting costs. Make sure you are clear about who is responsible for booking and paying for the interpreter before you meet the solicitor.

What does a Power of Attorney (PoA) do?

The person who is given PoA may manage bank accounts, pay bills, collect benefits/pensions and deal with anything to do with the person's house, such as organising repairs. A person with PoA may also make decisions about medical care, welfare, using care homes and daily routines. The PoA stops when the person passes away.

Remember:
Always ask your solicitor to explain anything you do not understand.

A PoA can only be done when a person has capacity. This is because they must be able to say what they want to happen in the future about their welfare and financial affairs.



Making a Will

A Will sets out what a person wants to happen to their estate when they die. An estate is what the person owns – maybe they have a house, jewellery, pictures, furniture, clothes, tools, car, or things linked with their hobbies such as golf clubs or cameras.

A Will covers all these things:

- What will happen to the person's belongings – who will get them?
- Who will get any money, and how much?
- What kind of funeral does the person want?
- Does the person want a burial or to be cremated?
- Where does the person wish to be buried or cremated?

All of these things need to be talked about and arranged with a solicitor.

If dementia has been diagnosed, the medical team and Social Services will ask if there is a PoA and a Will in place.

Remember: Planning ahead will give peace of mind. It means the person's wishes have been discussed and recorded.

You do not have to wait until you are older or have been diagnosed with dementia to arrange a PoA or make a Will.

You can arrange a PoA or make a Will at any time. Try to do it earlier, then you will know everything has been arranged.

If you don't have a PoA or a Will, it may be difficult and complicated to follow your wishes.

Let's talk about living well with dementia

- What may change?
- All About Me
- Making plans for the future
- End of life care options
- Support for carers



Let's talk about living well with dementia

Two important matters to talk about are:

- Staying at home
- Care Home options

Can the person with dementia stay at home or do they need to go into a care home?

Firstly, it is important to realise there are other options. This is why having a Social Worker will help. They can do a community care assessment to look at all parts of a person's life and their needs so that the right support can be put in place.

A person with dementia may be able to stay at home with a little support, they may be able to stay at home with lots of support, or they may need to go into a care home. A decision can be made after the assessment.

Before the Social Worker visits, it is a good idea to make notes about your life, including your daily routine.

Your notes may include:

- ✓ What time you like to get up and go to bed
- ✓ Bath/shower preferences
- ✓ Dressing yourself
- ✓ What you do each day
- ✓ Shopping, preparing food and eating
- ✓ Cleaning
- ✓ Using a washing machine
- ✓ Activities and hobbies
- ✓ Memberships of clubs
- ✓ Family and friends
- ✓ Any medicines you are taking
- ✓ Driving and travelling



Don't worry. You do not have to remember everything. The Social Worker will help by asking questions about your life so that an effective Care Plan can be agreed and the right support is arranged. Your Social Worker may be able to help if you need additional equipment to support you at home.



Let's talk about living well with dementia

What may change?

“ Sometimes, Betty would get very angry and I would spend a lot of time reassuring her. One time, I was trying to find out why she was so reluctant to go to the dentist. The issue with the dentist was with the rubber gloves they would wear. She did not like the sensation and could not stand balloons for the same reason; she was terrified of balloons. *June* ”



What is a carer?

Anyone can be a carer for a Deaf person living with dementia. Most carers are unpaid. If you are in a role of a carer you have the right to an assessment to support your needs. You can ask a Social Worker to do this.

This section is mainly for the family member(s) who are caring for the Deaf person living with dementia. The carer is most likely to see the changes in a person who has dementia. They will need to make sure the Care Plan is reviewed and any changes or new needs are assessed by the Social Worker or other professional.

Can someone with dementia get better?

Sadly, dementia is a disease which gets worse. There is no cure. Medicine may help slow down the dementia.

As the dementia develops, someone with dementia may:

- Show a change in their personality
- Repeat questions over and over
- Pace or walk about in the room
- Have broken sleep
- Experience difficulties with their vision
- And/or, their other symptoms may get worse

Adjusting to your new role as carer

- Make sure you get support
- Check with your Social Worker about getting financial support, including benefits, and ask about respite options
- Stay positive
- Find out options for support at home or other care arrangements, such as a befriender scheme, or local Deaf services. Ensure they have had access to dementia training
- Plan ahead
- Take some time out for yourself – you deserve a break, a treat, time with friends or to follow your hobbies

Health reviews and check-ups of the person with dementia

- The dementia may develop slowly or quickly. In part, this depends whether they received an early or late diagnosis
- Note any changes in their health and get a doctor's advice

“Everyone is different, I suppose. I would say that the hardest thing about a Deaf person having dementia is that it can be really, really hard work to communicate with them if you don't sign. Betty used to be really difficult when staff wanted to give her a bath and wash her hair. Betty would flat out refuse, and they'd look to me for help. I used to try, but I hated having to do it, as I wanted to be more than a carer or someone to use for communication. I tried my best. *June*”

Remember: Inform health professionals about any changes which you, as the carer, see in the person living with dementia. If possible, try and include the person with dementia in these discussions.

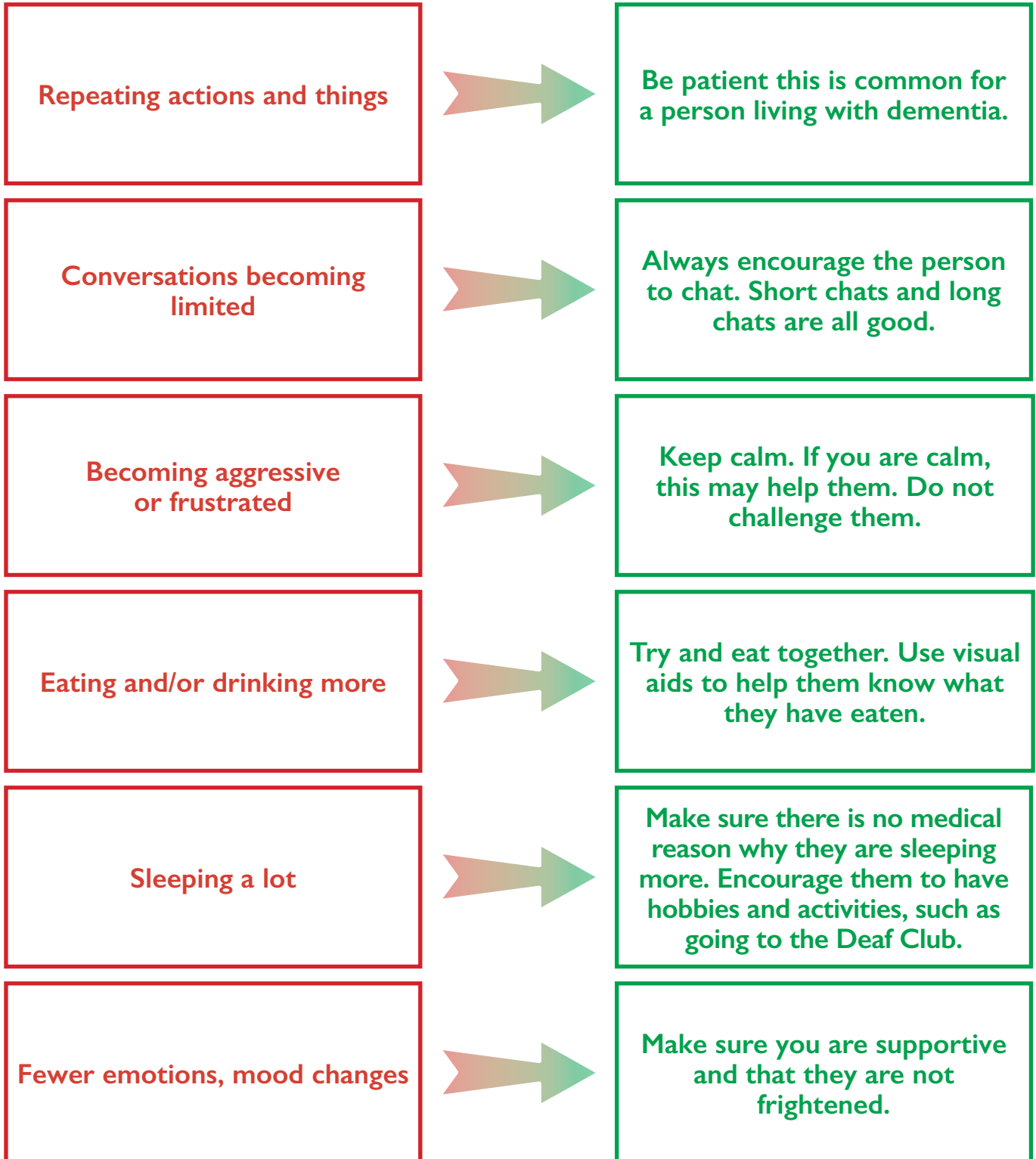


Let's talk about living well with dementia

The person with dementia may not be aware of the changes that are happening to them or may find them upsetting. Here are some coping strategies you might find useful:

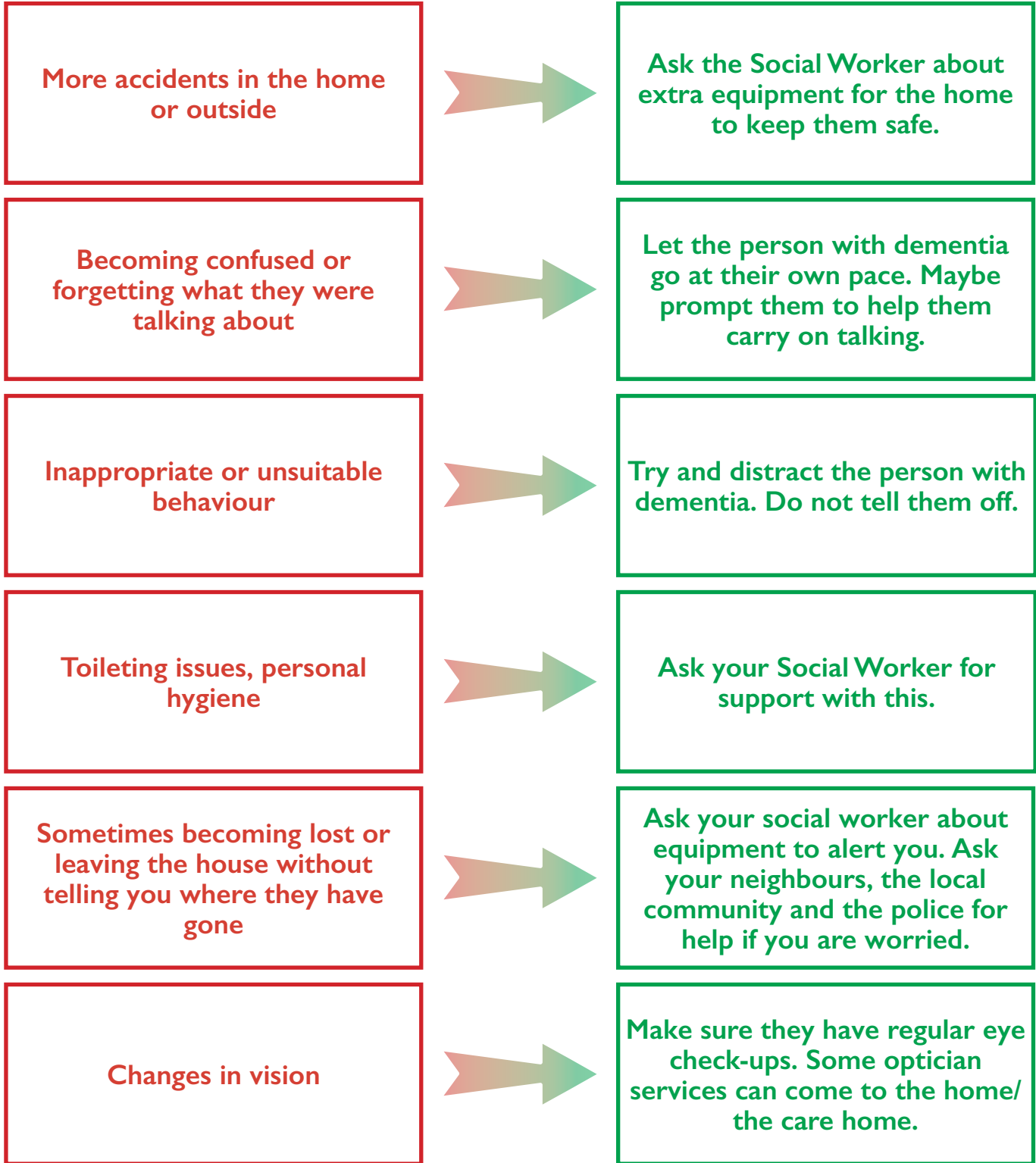
Changes

What you can do



Changes

What you can do





Let's talk about living well with dementia

All About Me



All About Me is a personal form that is yours whether you receive support at home and/or move into a care/nursing home. It tells people about the person with dementia and what they like to do. Also, what they dislike, for example, they may not like mushrooms. The person with dementia/carers/family members may want to do this. No-one needs to wait until they need more care or go into a care home. They can do this anytime. It could be fun to compare what people like/don't like or how their tastes have changed over the years. Here are some of the things which can go on the form:

Communication – BSL, written English, hearing aids?	What are your favourite newspaper(s) and/or magazine(s)?
Food – likes/dislikes/allergies?	Hobbies?
Favourite TV programmes?	Clubs and other memberships?
Bath or shower?	Medicines?

Making plans for the future

Sandy's story

Sandy's wife lived with dementia for over twelve years. This included nine years in a care home. Sandy never stopped caring for his wife all this time – even while she was in the care home. This was because Sandy felt the four walls of the care home were like a prison for her, because she had no communication with anyone; there was no one who could talk with her. The staff could not sign. Sandy wished that the staff at the care home staff could sign, or, at least, have some basic knowledge about how to communicate with his wife. This would have reduced the isolation and anxiety for both of them.

This section is about planning for the future.

At this point, you may have already agreed with your family member what their choices are and you may have written this down in a Will.

Remember: There may be Deaf care support staff who use BSL in your area. Ask.

Have you thought about the following?

- Does the person want to stay at home?
- If the person has to move to a care or nursing home, have you chosen a care or nursing home together?
- Do you have Deaf care support in place, or do you know where to get it if you need it?
- Do you have access to a Deaf buddy or BSL volunteer?

Transition to a care home or nursing home

I offered to meet up with Betty on a voluntary basis, so that she had some interaction in BSL. Her family members – also Deaf – attended a review meeting at the care home where they asked I be allowed to visit and support Betty. The care home refused, saying they already had all the staff they needed. I pointed out to them that their staff could not sign and therefore could not communicate with Betty. *June*



Let's talk about living well with dementia

Care home/Nursing home requirements:

- Is the person's room accessible? Does it have a flashing fire alarm? Does it have a flashing doorbell? Is the room well lit?
- If there is a television, are there subtitles?
- Are there suitable activities for Deaf people? (For example, musical events may not be suitable)
- Are interpreters booked for meetings or events within the care/nursing home?
- Do you have access to any support groups that use BSL?

Remember: Cater for all. Activities in care homes for people with dementia are often music-related. Deaf people respond very well to visual stimulus such as photographs and movies.

End of life care options

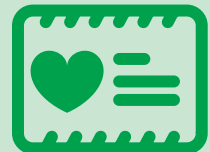
DNR

If your family member has any other life-limiting illnesses, they may need to move into a hospice.

Do you know your family member's wishes for, Do Not Resuscitate (DNR), and, their organs?

DNR means if the person is dying, they do not wish to be revived or brought back to life. Do you know if the family member wishes to donate their organs? Have they registered their wishes – to opt in or opt out – on the Organ Donor Register?

Do you know your family member's wishes for their funeral? Do they wish to be buried or cremated? Which interpreter would you like to have at the funeral?



You can discuss all of these matters with your solicitor, your family and your Social Worker.

Support for carers

- Do you need access to bereavement counselling?
- Do you have friends/family that you can talk to?
- Are there any local support groups you can go to?
- Can you go to your local Deaf Club and see your friends there?
- Do you have access to a Deaf organisation that can support you?
- You might want to talk about your experiences with others who are going through a similar experience.

When your family member passes away, you will be given a death certificate and a unique reference number. Use this unique reference number to inform all the important departments and organisations (for example, benefits, pensions, tax, DVLA, local council). The 'Tell Us Once' service means you only need to fill out this form once and all the key organisations will be informed.

You can go to <https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once>



You may not have been happy. You may wish to complain:

Making a complaint

If you are not happy about the service you are getting, ask to see the manager or person responsible for the service. Discuss your complaint with them. If you are still not satisfied, then ask for details of their formal complaints procedure.

Health and Social Care Standards

<http://hub.careinspectorate.com/knowledge/policy-and-legislation/policy-portals/new-health-and-social-care-standards>



Promoting Excellence: A framework for all health and Social Services staff working with people with dementia, their families and carers

www.gov.scot/publications/promoting-excellence-framework-health-social-services-staff-working-people-dementia-families-carers



Useful information

- Deaf people and British Sign Language
- Communication tips
- Useful resources



Useful information

This information and resources section is for everybody involved in working with, or caring for, Deaf people with dementia and their carers.

Deaf people and British Sign Language



Fast facts about Deaf people

See: <https://bda.org.uk/fast-facts-about-the-deaf-community>

Deaf with a capital 'D'

The word Deaf – with a capital 'D' – describes someone who both uses British Sign Language, and, identifies as culturally Deaf. Capitals are also used when referring to terms such as the Deaf community, Deaf culture, and Deaf identity.

British Sign Language (BSL)

BSL is the sign language used by Deaf people in the UK. BSL is a visual gestural language with its own grammar and syntax. BSL is Britain's fourth indigenous language. BSL was legally recognised by the UK Government in March 2003.

See: 'What is British Sign Language?' – <https://bda.org.uk/help-resources>

BSL (Scotland) Act 2015

There are an estimated 13,000 Deaf people who use British Sign Language (BSL) in Scotland, and 125,000 in the UK, making it the third most used indigenous language in Scotland after English (Scottish Census, 2011). The BSL (Scotland) Act came into force on 23rd October 2015. The Act required all public bodies such as local authorities, health boards, and other public authorities, to meet the needs of Deaf people who use BSL in accordance with the local plans for those bodies (which themselves are drawn from the National Plan.) These plans have been drawn up in consultation with Deaf BSL users and set out a series of responsibilities and actions concerning Deaf people's access to services and information via BSL.



Useful information

Deaf education

Historically, there have been a wide range of schooling opportunities for Deaf people. Some schools advocated for the use of listening and speaking and BSL was removed as the method of instructing Deaf pupils, whereas other Deaf schools fully promoted the use of BSL. The Deaf person with dementia may sometimes revert to using the language they used most as a child which, in some cases, may be spoken English.

Lip-reading

Some Deaf people living with dementia may not use BSL anymore and may only rely on spoken communication.

Some Deaf people may be able to use speech. This does not mean that they understand your speech. Remember, only 30% of the English language is lip-readable. Some of the alphabet is invisible on the lips. Some sounds are 'silent'. Some words look the same on the lips, for example, 'mat', 'pat', 'bat'.

Remember: Just because a Deaf person may be able to speak does not mean they understand you.

Lip-reading relies on the Deaf person knowing the word/s in the first place, which is difficult if you have never heard or learned it.

Deaf culture

Culture is a way of life. Many specific and unique features in the way Deaf people live their lives are what make up Deaf culture. These features include language, values, traditions, norms and identity.

Deaf culture, like BSL, is recognised in the United Nations Convention on the Rights of Persons with Disabilities, (Article 30, paragraph 4). This states that, 'Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.' For more information, visit the World Federation of the Deaf (WFD) page: www.wfdeaf.org

BSL and Deaf culture

Language, community and culture are interrelated. Deaf culture goes hand in hand with BSL.

BSL and Deaf culture are not exclusive to Deaf people. Hearing people who have learned BSL or who are from families which use BSL also know and understand the norms of Deaf culture – our way of doing things – such as getting attention and eye contact.

Deaf community

The Deaf community is a vibrant society where Deaf people are traditionally drawn together through sharing news, experiences, activities and sporting events. Such events are part of Deaf culture. Membership of the Deaf community is more than often a lifelong experience for many Deaf people.

Members of the Deaf community are more likely to see the onset of dementia in someone that they know well, as they will notice changes in routine or behaviour – such as arriving late, not being able to count out money, and forgetting time, conversations or recent events.

The Deaf community is where the Deaf person with dementia needs to continue their presence, to attend Deaf events and be with their friends. Their friends and the Deaf community's activities and events should remain a part of the Deaf person's life for as long as possible and all efforts should be taken to enable this to happen.

Deaf identity

When a Deaf person says they have a 'Deaf identity', they are saying they are proud to be Deaf, of using British Sign Language, that they appreciate the history and values of the Deaf community and value being a part of it.



Communication tips



Expressive faces

Expressive faces or, to give the correct linguistic term, non-manual features, are a vital part of BSL. The nature and range of these facial expressions are far greater than those used by hearing people and can, if wrongly used, lead to misunderstandings.

Hearing people may commonly have been taught to not wave their hands or point, to keep “a stiff upper lip” and remain poker faced. This can make it difficult for Deaf people to follow them or to gauge their emotions.

Being at the right distance

Everyone included in the conversation should be at the same eye level – and at the right distance – not too close or too far away.

Eye contact

Communication can start once eye contact has been established. This is an example of where the cultural norms between Deaf and hearing people differ. When hearing people talk to each other, the listener may look away while the speaker is talking to them. For Deaf people, eye contact is always made at the start of the conversation. The person signing may look occasionally away from the person watching, but as they are signing they will use their eyes in conjunction with the signs they make. They will look back often to the person they are signing to as a way of checking they are following.

Deaf people will apply this rule even if the person they are signing to cannot sign or is using an interpreter. The person watching must engage in eye contact. Looking away is a breach of this norm and is considered rude.

Pointing

Pointing is part of both BSL and Deaf culture. Pointing with the forefinger identifies people or objects and places them in space and time – including when they are not in sight. Pointing is not considered culturally rude by Deaf people and its use is a recognised linguistic feature of BSL.

Getting attention

While hearing people tend to call out a name or make a noise to secure someone's attention, Deaf people may give an outstretched wave, ask someone to tap the Deaf person on the shoulder or do it themselves. There are also various other ways to gain attention – depending on the space, other forms of attracting attention may include flashing the lights quickly or creating vibrations by stamping on the floor or banging on a table. These different, practical ways of getting attention are part of the social norms within the Deaf community. For Deaf people, communication cannot begin until eye contact is established.

Group gatherings

Being able to see each other is important. Deaf people prefer circular layouts so everyone can see one another.

Staggered rows of seating and good lighting are vital too and it is usual for Deaf people who gather together to sign away with little regard for time.

Remember: Just because the Deaf person nods their head does not mean they have understood. Always check what they are nodding their head to, by asking them, repeating information or showing them visually.



Useful information

Useful resources

Here are some links to organisations, information and resources you may find useful.

Deaf people and British Sign Language

British Deaf Association (BDA)

www.bda.org.uk

British Sign Language (Scotland) Act 2015

www.bslscotlandact2015.scot

Deaf people and dementia

BDA's dedicated website on dementia

www.bda.org.uk/dementia

Dementia and Carers organisations

Alzheimer Scotland

www.alzscot.org

Alzheimer's Research

<https://www.alzheimersresearchuk.org>

Alzheimer's Society

www.alzheimers.org.uk

Carers Trust Scotland

www.carers.org/country/carers-trust-scotland

Dementia UK

www.dementiauk.org

tide – together in dementia everyday

www.tide.uk.net

Diagnosis of Deaf people with dementia and information for professionals

National Cognitive Disorders Clinic for Deaf patients

<https://www.ucl.ac.uk/dcal/clinical>

University of Manchester

www.manchester.ac.uk/deafwithdementia

Legal matters

Tell Us Once

www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once

What to do when someone dies: step by step

www.gov.uk/when-someone-dies

Life stories and resources for families

Dementia Explained for Young Kids, Juniors and Teens

<https://kids.alzheimersresearchuk.org>

Insights on Living with Dementia with English subtitles (Glorious Opportunity)

www.vimeo.com/58247379

Life Story Book Template (Dementia UK)

www.dementiauk.org/for-professionals/free-resources

Share – The Deaf Visual Archive

www.bda.org.uk/heritage



Useful information

Living independently at home with dementia

Blue Badge

www.facebook.com/BritishDeafAssociation/videos/2035712936491017

Community App (Purple Alert and Dementia Circle – part of Alzheimer Scotland)

www.purplealert.org.uk

(An app to raise an alert, report sightings or get updates about people with dementia who go missing.)

Early Stage Dementia: A carers guide to creating a dementia friendly home

www.ageuk.org.uk/globalassets/age-scotland/documents/ia---factsheets/dementia/dem-11-a-carers-guide-to-creating-a-dementia-friendly-home

Getting to Know Me document

www.alzscot.org/assets/0002/7225/Getting_to_know_me_form_-_editable.pdf

Helpcard (Alzheimer Scotland)

www.alzscot.org/assets/0001/8501/Helpcard.pdf

Helpcard (Alzheimer's Society – UK)

www.alzheimers.org.uk/get-support/publications-and-factsheets/helpcards

Symptoms of walking about

www.alzheimers.org.uk/get-support/daily-living/making-decisions-walking-about

Telecare Choice

www.telecarechoice.co.uk

University of Stirling

www.dementia.stir.ac.uk/design/virtual-environments/virtual-care-home

NHS Health Scotland

NHS Health Scotland – Living well with dementia

www.healthscotland.com/topics/stages/healthy-ageing/dementia/living-well-with-dementia.aspx

Organ Donation Scotland

Organ Donation Scotland

www.organdonationscotland.org/more-information-your-choices-explained

Sign Language Interpreters

The National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD)

www.nrcpd.org.uk

The Scottish Register of Language Professionals with the Deaf Community (SRLPDC)

www.sasli.org.uk

Toolkit Partners

British Deaf Association (BDA) Scotland

www.bda.org.uk/glasgow-office

Life Changes Trust

www.lifechangestrust.org.uk



The British Deaf Association – BDA

The BDA stands for **Deaf Equality, Access and Freedom of choice**

Vision

Our vision is Deaf people fully participating and contributing as equal and valued citizens in wider society.

Mission

Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- Improving the quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL.

Values

The BDA is a Deaf people's organisation representing a diverse, vibrant and ever-changing community of Deaf people. Our activities, promotions, and partnerships with other organisations aim to empower our community towards full participation and contribution as equal and valued citizens in the wider society. We also aim to act as guardians of BSL.

1. **Protecting our Deaf culture and Identity** – we value Deaf peoples' sense of Deaf culture and identity derived from belonging to a cultural and linguistic group, sharing similar beliefs and experiences with a sense of belonging.
2. **Asserting our linguistic rights** – we value the use of BSL as a human right. As such, BSL must be preserved, protected and promoted because we also value the right of Deaf people to use their first or preferred language.
3. **Fostering our community** – we value Deaf people with diverse perspectives, experiences and abilities. We are committed to equality and the elimination of all forms of discrimination with a special focus on those affecting Deaf people and their language.

4. **Achieving equality in legal, civil and human rights** – we value universal human rights such as the right to receive education and access to information in sign language, and freedom from political restrictions on our opportunities to become full citizens.
5. **Developing our alliance** – we value those who support us and are our allies because they share our vision and mission, and support our BSL community.

About BDA

Founded in 1890, the British Deaf Association (BDA) is a national Deaf-led organisation that works directly with Deaf people who use British Sign Language (BSL). Our work concentrates on campaigning for equal rights on a national level and working at a local level empowering Deaf people to achieve access to their local public services. This is carried out through projects delivering individual and community advocacy. We also work to ensure BSL is included by public bodies by delivering a public commitment through signing the BSL Charter.

Our Board of Trustees are all Deaf (we use the capitalised 'D' to denote the fact that we have a separate language and culture), and, 80% of our staff are Deaf.

Many Deaf people who use BSL lack access to education, health services, employment and other public services. Our work is designed to empower Deaf people and to improve access to general information and public services. We seek to achieve this by working with Deaf people at the local level through setting up forums to lobby public bodies and supporting Deaf people individually.

This is in line with the overall BDA objectives, which are: **D**eaf **E**quality, **A**ccess and **F**reedom of choice

For a list of signatories to our BSL Charter, FAQs, and other information, including what the BDA can do for your organisation, please look at our website: www.bda.org.uk



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