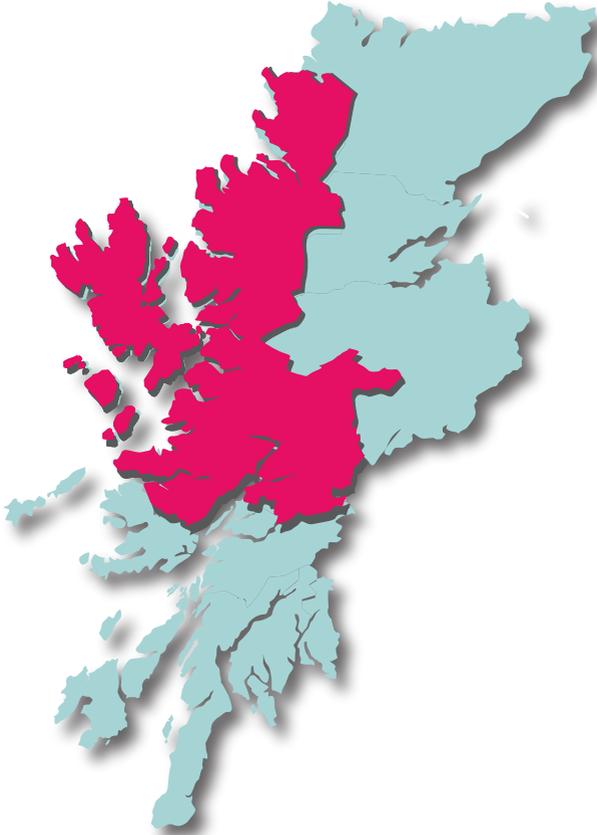




A guide for families living with dementia in West Highland



Making sure no-one goes through dementia on their own

Supported by Argyll & Bute Council,
The Highland Council and NHS Highland
Compiled May 2012



LOTTERY FUNDED

Welcome and how to use this guide

This guide has been produced as a result of many discussions with families and staff who are supporting someone with dementia in the NHS Highland area.

The guide is broken into three sections:

- **Section 1**

Issues and things to think about. This section provides an overview of important issues and identifies where to find out further information.

- **Section 2**

Who's who and what's their role. This outlines the main staff and agencies likely to be involved in supporting the person with dementia and their key roles.

- **Section 3**

Local and national supports and services. This section provides contact details for advice, information and support in your area for you and the person with dementia.

We hope you find this guide a real help to you and your family in living with dementia.

Signatories:



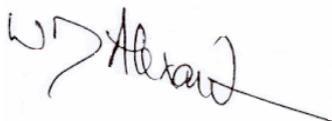
Henry Simmons – Chief Executive,
Alzheimer Scotland



Elaine Mead - Chief Executive,
NHS Highland



Cleland Sneddon - Executive Director,
Community Services, Argyll & Bute Council



Bill Alexander - Director of Health &
Social Care, Highland Council



Alzheimer Scotland

Action on Dementia

Acknowledgements

We are indebted to all the family members who took part in the research for giving their time, suggestions and commitment, which has provided the foundation of the content, design and style of the guide.

The guide has drawn on a number of resources. In particular we would like to thank NHS Health Scotland (www.healthscotland.com) for their permission to refer to the following publications:

- Facing dementia – how to live well with your diagnosis
- Coping with dementia – a practical handbook for carers

Single copies of the above booklets and their accompanying DVDs are available to people with dementia, their partners, families and friends from the Dementia Helpline on 0808 808 3000. Professionals may order from their local Health Promotion Department or email: nhs.healthscotland-publications@nhs.net

Lastly, we would like to thank the Big Lottery Fund for funding the production of this guide.



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SECTION 1:

Issues and things to think about

1a. Dementia – the basic facts

Is it dementia?

Many people worry about cognitive impairment (e.g. reduced concentration, inability to do familiar tasks such as making a cup of tea, memory loss, etc) and fear that it is the start of dementia.

The **GP** is the **first point of contact** who will examine for other causes such as infections, depression, anxiety, tiredness and the side effects of some prescribed medications.

They will then either conduct **memory tests** or refer the person to a **Consultant Psychiatrist** or **Community Psychiatric Nurse** for **assessment**, which may include a **CT or MRI scan**.

What is dementia?

Dementia is a term for a **range of illnesses** that affect the brain and how it functions. There are **many different types** of dementia and they all progressively damage the brain.

Types of dementia

The most common types are **Alzheimer's** disease and **vascular** dementia. Other less common types include: Lewy body dementia; Fronto-temporal dementia (including Pick's disease); Parkinson's related dementia; and Korsakoff's Syndrome.

Common symptoms of dementia

Symptoms can vary from person to person and also depend on the type of dementia. Generally, the key symptom of dementia is:

- serious **memory loss**
- but others include:
- losing track of the **time**
 - getting **lost** in familiar places
 - changes in **behaviour and personality**
 - reduced ability to **reason** clearly and make **decisions**.

All of these can be very distressing for families living with dementia.

Treating dementia

Dementia is a **progressive disease**. Drug treatments can be used which, for some people, can help with symptoms but are **not a cure**. Treatments depend on the type of dementia and whether they interact with any other health issues. Treatments **work best** when they are introduced at the **early to mid stages** of dementia.

In addition, the main other supports that help are social care based (see Section 3 Local and national supports and services).

With the right **help and support**, most people with dementia can go on living at home and enjoy a good quality of life for a long time.

What happens after diagnosis?

- **Post diagnosis** - This is a vital stage. There are many things to consider practically, financially and emotionally. In many areas of NHS Highland you and the person will be supported by a **Link Worker**, who will help you after the diagnosis to come to terms with the condition, identify issues to think about, how best to live with the symptoms and access support services.

Staff, such as your **GP, Community Psychiatric Nurse (CPN), Alzheimer Scotland local service** (in some areas of Highland), **Alzheimer Scotland Dementia Advisor** or **Social Work** services, should also be able to help you or point you towards those who can. (See Section 2 for more detail on the roles and remit of all these staff).

- **Mid stage dementia** - As the disease progresses, you and the person with dementia are likely to need increasing support from social work services or other agencies. This will happen by **getting an assessment** (see Section 1c) or you can purchase support using your own funds or a direct payment (see Section 1f).

- **Latter stages of dementia** - The person you care for may eventually require more care than you are able to give, which may include full time nursing care. It is best that this is a **planned stage** rather than the result of a crisis. This should take into account the wishes of the person.

The NHS Health Scotland booklets 'Coping with dementia' and 'Facing dementia' (see further Information on page 6) give useful explanations of what happens after diagnosis.

1b. After diagnosis - what to do next

Finance/ benefits - You and the person with dementia may be entitled to benefits to help with extra costs or loss of earnings. Here are some to check:

- **Attendance Allowance** is for people aged 65 or over who need help with personal care or require supervision.
- **Disability Living Allowance** is for people under 65 who need help with personal care or require supervision. People with dementia could also be entitled to the mobility component if they require guidance going to unfamiliar places. Neither of these benefits is affected by the person's income or savings.
- **Pension Credit** is for all people over the state pension age for women and provides a guaranteed minimum income.
- **Income Support** may be available if you are under the state pension age for women, are on low income and have caring responsibilities.
- **Carer's Allowance** is for people who provide care for at least 35 hours a week. However, it is complicated, so **get expert advice** before claiming (see Section 3 e - Legal & finance).

Council tax

People with dementia and their carers may get help with this by way of Council tax benefit, discount, disability reduction or exemption.

You can get forms from local council offices but also check on the council website to download.

Council tax exemptions and discounts apply from the **date that the qualifying conditions are met** and not the date of the application. If you've been paying too much you might get a refund but you may have to **ask for it**.

www.alzscot.org/council-tax

Legal issues

While the person is still able to do so, it is **vital** to put in place certain legal powers including:

- **Power of attorney** – is a document giving someone you trust the authority to make decisions about your finances and your welfare when you are no longer able to make these decisions yourself. Although you can draw up the document yourself most people use the services of a solicitor. Power of attorney documents must be registered with the Office of the Public Guardian. (See Further information box)
- **Guardianship/ Intervention Order** - if a power of attorney is not in place or does not give enough powers, and you are no longer able to make decisions, someone might have to apply to court for a **guardianship order** (for financial and/or welfare affairs) or an **intervention order** for a one-off decision or action.

- **Access to Funds** - If you are no longer able to manage your bank account and have not created a financial **power of attorney**, someone can apply to access your account through the **Access to Funds scheme**. Call the **Dementia Helpline** for advice or the **Office of the Public Guardian** for forms. (See **Further information** – Dementia: money & legal matters)

Driving

Once your family member has a diagnosis of dementia, **by law**, they must tell the **DVLA** and their **insurance company**. You can do this on their behalf.

However, if the person wants to **keep driving** this may still be possible especially in the early stages. The person should **ask the GP** if he or she is safe to drive. The GP may make a referral to the Scottish Driving Assessment Centre for this to be checked.

If possible, discuss with the person when driving should stop and also start to explore other ways to travel.

www.alzscot.org/driving

Working out a plan

Although it may be difficult, it is important to **discuss with the person** while they still have the ability to do so, certain aspects of their future. That way everyone knows what the person wants and can try to implement that as far as possible:

- **Advance statement** – this outlines what medical treatment they may or may not want, information on their beliefs and values and who they would like to be consulted about any treatment
- **Living arrangements** – this outlines what they would like to happen if they become unable to live in their own home
- **Making a will** – a will is only valid if made when the person is clearly aware of what they are doing.

Life Story book - a very positive activity to do with the person is to put together a collection of reminders (photos, postcards, tickets and other keepsakes) of important times in their life. This can be helpful when reminiscing and help those involved in their care now, and in the future, know more about the person. See www.knowmewell.com/ for examples of putting together a life story book.

Further information:

- **Dementia – money and legal matters**
www.alzscot.org/moneylegal
- **Coping with dementia – a practical handbook for carers**
www.healthscotland.com
- **Facing dementia – how to live well with your diagnosis**
www.healthscotland.com
- **The Office of the Public Guardian – 01324 678300**
www.publicguardian-scotland.gov.uk

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

1c. Knowing your rights

The rights of people with dementia

The rights of people with dementia are enshrined within the European Convention of Human Rights and form the foundations of the Scottish Government's **Charter of Rights for People with Dementia and their Carers**. The national Dementia Strategy and **Standards of Care for Dementia in Scotland** are there to further improve support. The Standards cover 6 important areas:

Diagnosis: If a person is worried about their memory or has been feeling confused, they are entitled to a timely assessment and diagnosis. They are also entitled to take someone with them to all medical appointments.

Following a diagnosis, you should be:

- offered time and professional support **to talk about how you feel**
- given **information about the illness** and any treatments
- given **information about the supports** available (emotional and practical) to help you live well with your diagnosis.

Dignity and respect: The person has the right to be treated with dignity and respect at all times and to be **free from any kind of discrimination** or harm.

Access to a range of treatments, care and supports:

The person should be given the help they need to stay well and be given the opportunity to be as **involved as possible in all decisions** which affect their life.

If the person needs help to have their voice heard, they should be offered support from an independent advocacy service.

Independent and included in their community: The person should be **supported** to make sure that they have **equal access** to all of the leisure, recreational and cultural activities within and beyond their own local community.

Have carers who are well supported and educated about dementia: The family, partner or friends who care for the person should be **fully supported** in their caring role.

The person has a right to be cared for and supported by paid professional health and social care staff who are **knowledgeable about dementia**.

End of life care that respects your wishes:

The person should have the opportunity to say what will be important to them towards the end of their life, including:

- being **involved in planning and deciding** on how their needs are met using such things as preparing an **advanced statement** or **advanced directive** (see Section 1b – working out a plan)
- towards the end of their life they should be cared for in a way that **respects their wishes and beliefs**.

Your rights as a carer

The Scottish Dementia Strategy sets out that, as a carer, you have the right to:

- receive **information about available services** to help support you in your caring role
- be offered an **assessment of your own needs** in supporting the person you care for
- to have **your views listened to** and **taken into account**
- to be **respected** by professionals as a person in your own right
- to be offered information about dementia and **dementia care training**
- to have **access** to a range of flexible options for **breaks from caring**
- to have the opportunity to meet other carers to **share experiences** and receive **mutual support**.

Your rights to be involved in the care of the person you care for

If the person you care for **can't make a decision** regarding their care without help, you have the right to be involved. This includes **the right to:**

- **express an opinion** about any planned care or treatment, and have your opinion taken into account
- be **present** with the person you care for **at appointments**, unless they state they do not wish this
- be given **written information** about the **care and treatments** the person you care for is receiving
- **disagree** with any decisions made, and to request a **second opinion** with regards to health treatments.

One of the first things a person with dementia should seek to do after a diagnosis is to make a **power of attorney** (see Section 1b – legal issues).

As their **welfare attorney**, your right to be involved in decisions is then legally greater when the person is no longer able to make their own decisions about matters regarding their care and treatment, including:

- Your consent should be sought with regard to any treatments and supports regarding the person you hold welfare attorney for;
- Greater rights regarding challenging any decisions made about the care and treatment of the person you hold welfare power of attorney for.

Complaints & what to do if you are not happy

In the first instance it is usually best to try discuss what you are unhappy about with the service or organisation concerned and seek a solution, if this is appropriate.

If you are still unhappy, you should ask for a copy of their complaints policy and make a formal complaint. If you are still dissatisfied there are a number of organisations that you can complain to. They cover a range of services and issues. (see Section 3-Regulatory and complaints bodies: address list).

If you remain unhappy you may also wish to complain via your local councillor or MSP/MP.

Further information:

- **Caring & Consent: Your right to be involved in decisions about the health care of the adult you care for**
www.hris.org.uk/index.aspx?o=5099
- **Facing Dementia – How to live well with your diagnosis**
www.healthscotland.com
- **Complaints – what to do if you are not happy with a service**
www.alzscot.org/complaints
- **Charter of Rights for People with Dementia and their Carers in Scotland**
www.dementiarights.org/
- **Standards of care for dementia in Scotland – A guide for people with dementia and their carers**
www.alzscot.org/standards

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

1d. Getting an assessment

The person with dementia

Community care assessment – the person with dementia has a right to this. If it is not offered, **contact your local social work services** to ask for one.

A social worker, care manager or other community care professional will visit to talk with you both about what the person's needs are and if any services are needed. If the assessment shows that they need services, a **care plan** will be drawn up stating the details of the '**package of care**'. A copy should be left with the person but if not, do **ask for one**. The care plan can be managed by Social Work or the budget can be directly managed by you and the person with dementia through **Self-Directed Support** (see Section 1f), or a combination of both.

There may be a waiting list for assessments but if you need help right away, ask if they can do an **emergency assessment**.

You can ask for a **re- assessment** at any stage, especially if you feel the person's needs have changed.

The carer

Carer's assessment - if you are providing '**substantial and regular care**', you also have the right to an assessment to look at:

- how you are coping with caring for the person with dementia
- what other services you might need to help you
- how able you are to carry on doing so.

You can ask for a re-assessment at any stage, especially if you feel things have changed for you and/or the person you care for.

Further information

- **Community care and assessment (Information sheet)**
www.alzscot.org/commcare
- **Coping with Dementia – a practical handbook for carers**
www.healthscotland.com
- **Facing Dementia – How to live well with your diagnosis**
www.healthscotland.com

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

For information and a free copy of information sheets and booklets contact:

- Alzheimer Scotland Dementia Helpline (24 hour): 0808 808 3000
 - Alzheimer Scotland Highland: 01463 711707
- Alzheimer Scotland Argyll & Bute: 01436 678050 / 01631 570614

1e. Types of support & how to access them

Medical supports - Drug treatments focus on **treating the symptoms of the disease**. Drug treatments may be prescribed depending on the **type of dementia** and any **other conditions** that the person may suffer from.

In addition to that, health staff may provide support to the person you care for; for example the **Community Psychiatric Nurse (CPN)** and the **Occupational Therapist (OT)**.
(see Section 2 Who's who and what's their role)

Social care supports - There are a number of social care supports that can be provided both to the person with dementia and the carer. Examples include:

- day care
- respite
- home support
- personal care
- telecare.

(see Section 3 Local and national services and supports for more details)

Community supports - There is a range of community supports available across NHS Highland, which can assist greatly in supporting you and the person you care for. Examples include:

- community transport schemes
- lunch clubs
- befriending and social activities
- peer support groups for the person with dementia and the carer
- carer centres.

Remember that **staying active** and involved in the community can greatly help someone with dementia feel **stimulated and motivated**.

(see Section 3 Local and national services and supports for more details)

Types of support someone with dementia could expect at the early stages of dementia:

- medication (if appropriate)
- contact with the CPN or Psychiatrist
- contact with the Alzheimer Scotland Link Worker or Dementia Advisor
- involvement with community-based supports, including peer support
- support from the GP.

Types of support someone with dementia could expect at the mid stages of dementia:

As per 'early stages' and in addition:

- contact with the Occupational Therapist
- contact with community nurses
- contact with community based peer support
- contact with Social Work to assess level of need
- access to support services such as day care, home support and respite.

Types of support someone with dementia could expect at the latter stages of dementia:

As per '**mid stages**', with increasing involvement of staff to assess the care required for the person with dementia and for you as the carer.

Support will increasingly focus on ensuring a plan is in place for **future care** and any **palliative care** needs for the person with dementia. Support should also increase for you as the carer, as it can be a very traumatic time.

Accessing care:

The majority of health care can be accessed via your **GP** or the **CPN**. The majority of social care is accessed via **Social Work**. **Community supports** are generally freely available.

Further information:

- **Coping with dementia – a practical handbook for carers**
www.healthscotland.com

1f Self-directed support (SDS)

To qualify for self-directed support the person must have been assessed by a social worker or other professional and a care plan agreed. They then have **the right** to access that budget although it has to be spent on meeting their assessed need as set out in their care plan.

What is Self-directed support?

- Self-directed support is not the name of a particular type of service but a **way in which individuals can work with social work**, other organisations and paid workers to put together a package of care which suits their needs and the way they want to live their lives.
- It is for people who would like **more flexibility, choice and control** over their care so that they can live at home more independently.
- It allows them to choose how their support is provided by giving them as much control as possible over the **individual budget** spent on their support.

If the person is already receiving support services and you are interested in this route of support, contact the local social work department.

(See Further information – Taking charge: a short guide to self-directed support for people with dementia and their carers)

How does SDS work?

The person's individual (or personal) budget can operate in several ways:

- it can be taken as a **Direct Payment** (a cash payment)
- it can be allocated to a provider the individual chooses. This is sometimes called an **individual service fund** where the council, or funder, holds the budget but the person is in charge of how it is spent
- the council arranges services for the individual
- the individual can choose a mix of these options.

A record must be kept of how the money is being spent.

Examples of how the budget can be used

SDS is intended to be focussed upon the wishes and needs of the person to allow them to organise their care in ways that suit them. The budget might be used:

- to get support for the person to live in their own home, such as help with cooking and cleaning
- to provide a short break (respite)
- to buy equipment or make temporary adaptations
- to buy a service that helps to reduce the work load of their carer (i.e. **you**) e.g. a laundry service
- to employ a **personal assistant (PA)** who can help the person to get out and about, so they can see friends, attend local activities, go swimming, etc.

Can I, as the carer, access and manage the individual budget?

If the person has appointed someone as welfare and financial power of attorney (see under 1.2 Legal issues), the attorney can manage an individual budget on their behalf.

Where the illness has progressed too far for the person to appoint an attorney, you, as the carer, or another interested party can apply to the **sheriff court** to be appointed **welfare and financial guardian**. The powers requested by the guardian could include the specific power to manage direct payments and self-directed support.

Further information:

- **Taking charge – a short guide to self-directed support for people with dementia and their carers**
www.alzscot.org/takingcharge
- **Dementia – Money and Legal Matters**
www.alzscot.org/moneylegal
- **Scottish Government’s Self-directed support website**
www.selfdirectedsupportscotland.org.uk

If you have any difficulty accessing this information online, contact Alzheimer Scotland’s Dementia Helpline on 0808 808 3000

1g. Supporting the person with dementia

There are a number of things that you can do to **support, assist** and **stimulate** the person with dementia. The main thing is to **encourage the person** to carry on with **existing interests** and activities and to maintain as **high a level of independence** as possible.

Stimulation & motivation

- People with dementia need interesting and enjoyable things to do. Think about what the person used to enjoy doing and help them to keep doing these. The **right activities** can help the person to maintain their **abilities, confidence and independence**.
- Remember, activities need to be **suitable** for the individual, and take account of each stage of their dementia. Talk to your **Occupational Therapist** for suggestions.
- **Encourage friends and family** to be involved with activities as it is beneficial for the person to stay involved in family and community life as much as possible.

Evidence indicates that **mental stimulation** can be a very effective way of the person **maintaining abilities, independence and enjoyment of life**.

Reminiscence

Although dementia can often affect the memory, this tends to be the **short term memory** rather than the **long term**.

- Reminiscence activities often focus on discussion of **past activities, events and experiences**.
- It can often allow the person with dementia to be **highly engaged**.
- **Music, photographs, poems** and discussion of past events are ideal ways of reminiscing with the person with dementia.

Developing a life story book

A life story book is a **collection of reminders of important times** in the person's life, such as **photographs, tickets, postcards** and so on. Making a life story book is an opportunity for the person to **talk about their life**.

The book can then be very useful for you and family members to reminisce with the person at **later stages of dementia**.

It is also **highly useful for staff** who are supporting the person as it will give them a **good insight** into the person's personality and background.

See www.knowmewell.com for examples of putting together a life story book.

Nutrition

As dementia progresses it can affect the person's **enthusiasm for eating**. This will differ from person to person. Hints and things to consider include:

- see that the person gets a **balanced diet** and enough **fluid**
- allow adequate **time** for eating
- **say** what meal it is and what they will be eating
- make sure **dentures fit well**
- be **patient** with untidiness
- **ask** the doctor or nurse **for advice**.

Further information:

- **Coping with dementia – a practical handbook for carers**
www.healthscotland.com
- **Facing Dementia – How to live well with your diagnosis**
www.healthscotland.com

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

1h. Coping with the illness

Behaviour

Dementia not only affects a person's memory but may also affect their **mood and behaviour**. The first thing to remember is **not to take it personally**, but to recognise that how the person behaves may relate to how they are feeling. Some examples are below:

Walking - If the person is walking a lot (some people call this 'wandering') it could be because they feel the **need to exercise**, or they are **bored**, are **looking for something** or **feel lost**.

Consider if it's really a problem if they walk. For example, if you're worried about them walking alone outdoors perhaps someone can go for walks with them.

Following you - if the person is following you around needing constant attention, perhaps they are **feeling insecure**.

Give them plenty of reassurance – but make sure **you get a break too**.

Repetition - If the person repeats the same thing over and over again, remember they don't mean to annoy you, they just **don't remember your response**.

Try other ways of reminding them such as a **notebook or noticeboard**.

Some behaviour changes can be especially difficult for carers. For example:

- someone may become **uncharacteristically aggressive** from time to time. Try to **keep calm** and de-fuse the situation or distract the person. Try to work out if **something triggered it** – perhaps the person was taken by surprise by something which frightened them, or perhaps they are frustrated. **Seek some help**.
- sometimes someone may do things which are **embarrassing** to you (eg swear when they never did before, be sexually inappropriate, be rude to visitors, or start to undress in public). Again, try to **stay calm** and matter-of-fact. Gently distract them or take them to another room.

Coping with behavioural challenges

Many carers find the changes in the person's behaviour very difficult to cope with but there is help out there.

The **community psychiatric nurse (CPN)**, **psychiatrist**, **Alzheimer Scotland Link Worker** or **occupational therapist (OT)** will have experience of helping with behavioural difficulties caused by dementia.

For specific problems, you and the person may be referred to a **clinical psychologist**, if there is one in your area, who will be able to offer specialist help. Your **GP** may also be able to help, and can refer you to other supports and agencies.

There are also a variety of booklets/ leaflets with possible solutions and strategies to help you.
(see Further information at end of section).

Communication

Dementia slows people down in their ability to take things in and make sense of what they hear. This can be very frustrating for both the person and their carer. However, there are a few simple things, which may help:

- Make sure any **dentures, hearing aids** are in good working order and **glasses** are the correct prescription.
- **Speak clearly, simply and slowly**, putting across one point at a time and making sure the person can see your face.
- Use questions that ask for a **simple answer** – avoid ones that require the person to use their memory too much (eg. what did you do yesterday?).
- Talk about things that are **familiar to the person**.
- Use **touch** (if appropriate) and **gesture** - gestures, body language (how we use our hands, eyes and posture), touch and tone of voice are often understood right through to the late stages of the illness.
- Use **facial expressions** to make yourself understood.
- Make sure that you have their **attention** by gently touching their arm and saying their name.
- Use **short, simple sentences** and say exactly what you mean.
- Use **simple questions** which ask for a **simple answer**.
- Try not to **confuse or embarrass** the person by correcting them bluntly.
- Use the **names** of the people you are talking about instead of 'he' or 'she'. It will remind the person who you are talking about.
- Use **pictorial or visual aids** to support verbal communication.

Above all, try to **be patient** and allow plenty of time for the person to take in and reply to what you say

The above is based on 'Communicating with someone who has dementia: 12 helpful hints' by N Thomson, Good Morning Project Ltd via the Glasgow North Dementia Forum - www.goodmorning.org.uk/dementia_forum/Nicky.Thomson-12hints-SCOTLAND.pdf

Health concerns

Here are some of the main health concerns to be aware of which can arise for the person with dementia, especially in later stages of dementia.

Increased confusion

If the person suddenly becomes very confused, this can be a sign that something physical is wrong – check with the GP immediately.

Dehydration

It is important the person drinks **plenty of fluids** to keep their body hydrated, avoid constipation and avoid making them exhausted and more confused. Try to encourage them to drink plenty of fluids such as soup, water and fruit juice in addition to any tea and coffee they drink. Remember caffeine will contribute to dehydration and may also disrupt sleep.

Incontinence/ Urinary Tract Infections (UTI)

Incontinence may be due to forgetting the way to the toilet, how to recognise it or not recognising the feeling of a full bladder. It may also be due to a **UTI**, which can also increase confusion considerably but usually responds to antibiotics.

www.alzscot.org/continence

Constipation and faecal impaction

This can be caused by a lack of **fibre** in the types of **food**, lack of **fluids** and lack of **exercise** or reduced mobility. It can also be a side effect of some types of **drugs** or combinations of drugs. It can lead to a worsening of the person's confusion, as well as symptoms of irritability or aggression, which can be mistaken for part of their ongoing dementia.

www.alzscot.org/constipation

Malnourishment

People with dementia may have poor appetite, be not very interested in eating, confused about whether or not they have eaten, or become 'messy' in their eating. Poor diet can lead to malnourishment or constipation.

There are various things you can do to help:

- make forks and spoons easier to grasp by wrapping the handles to make them thicker
- have the main meal in the middle of the day (better for digestion and sleeping)
- use snacks and finger foods
- allow plenty of time for meals.

Further information:

- **Understanding and dealing with challenging behaviour**
www.alzscot.org/behaviour
- **Communicating with the person with dementia**
www.alzscot.org/communicating
- **Healthy living with dementia** www.alzscot.org/healthy
- **Coping With Dementia – a practical handbook for carers**
www.healthscotland.com
- **Facing Dementia – How to live well with your diagnosis**
www.healthscotland.com

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

1i. Hospitals & dementia

Being admitted to hospital can be a traumatic experience for the person with dementia and their family. This is often due to the **unfamiliar surroundings** which can cause confusion and distress to the person. Families can also feel **excluded** from the care and treatment being provided.

Reasons for admission

The person may be admitted to hospital for a range of reasons but these will likely relate to either of the following:

- General admission for a **medical condition** not related to their dementia
- Admission to hospital for **assessment** relating to their dementia
- Admission to hospital relating to concerns over **behaviour** of the person and regarding **safety** of themselves or others under the **Mental Health Act (Scotland) 2003**.

Transport

Most hospitals offer a non-emergency **patient transport service (PTS)** to help those who are medically unfit to travel and have no alternative means of transport. **Contact the hospital** directly to discuss. In some areas, **volunteer car schemes** can help those who have difficulties using public transport (see Section 3g - Hospital transport)

Reimbursement

If you have to use your own transport or organise privately, make sure to **contact your GP** or the **hospital** to discuss procedures for **claiming back expenses** incurred. Criteria do apply (see Further information - 'NHS Highland: A Guide to Highland & Islands Travel Scheme').

Being involved

Remember, if the person you care for can't make a decision regarding their care without help, you have the **right to be involved and informed**. (see Section 1c - Knowing your rights).

If you have **power of attorney** make sure staff are informed of this.

Make sure staff know the person has dementia

If the person is admitted to hospital for something not connected to their dementia, **don't assume** staff will know they have dementia, or what their needs are. It is useful to provide a list detailing:

- how they like to be addressed, e.g., by their first name or more formally
- what the person is capable of
- what they need assistance with
- things that interest them
- things they do not like or that upset them.

This means staff should be more aware and take this into account to **ensure the patient's comfort**.

Welfare benefits

If the person's length of stay in hospital is greater than **28 days**, it may be necessary to inform any agencies where the person is getting a **welfare benefit or rent assistance**. Ask the Hospital **Social Worker** for further details.

Hospital discharge

Where the person's stay in hospital has been for longer than a day admission, they should always have a **thorough assessment** of their ongoing **health and social care needs** (often called a **Single Shared Assessment**). If they need support, a plan should be made before they are discharged.

Ask to speak to the doctor in charge of the person's care or the **hospital social worker** if you have any concerns.

Further information:

- **NHS continuing healthcare and hospital discharge arrangements (Age Scotland factsheet 37s)**
www.ageuk.org.uk/scotland/
- **NHS Highland – A Guide to Highland & Islands Travel Scheme**
<http://tinyurl.com/highlandtravel> (Argyll & Bute)
www.nhshighland.scot.nhs.uk/services/documents/travel%20costs.doc (Highland)

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

1j. Choosing a dentist, optician or podiatrist (chiropodist)

It is important to make sure that the person continues to receive regular services from a dentist, optician and podiatrist (chiropodist).

It's important for the person with dementia that....

- they have **regular dental check ups** to make sure there are no problems with their teeth, gums or dentures, as this can give problems with eating and drinking.
- they have their **eyesight checked regularly**; any problems with this can make it harder for them to recognise people and objects
- they have any problems with their feet checked out by their doctor or a podiatrist (also known as a chiropodist) as **healthy feet are important** in keeping them active and mobile.

It will help both the person you care for and the professional if you:

- make the professional **aware** of the person's dementia
- talk about how to make the visit a **positive experience**.

However, there may come a time when it is not possible for the person to go to the clinic and so:

- ask if your **dentist** will do **home visits**. If not, check with your local health board or the Community Dental Service for those who do.
- check with your **optician** and **podiatrist** about **home visits**. If they don't do them then ask them or your local health board who does.

1k. Thinking about long-stay (residential) care

Some people are able to stay at home throughout their illness, but it can become very difficult to meet their needs even with help and many people with dementia are likely to need to move into long term care in the later stages of the illness.

Making the decision

There may come a time when it is no longer possible for you to care for the person with dementia at home.

There may be various reasons for this:

- their condition may have recently worsened
- they may now need a team of people to care for them
- perhaps your own health has changed.

You may already have discussed future living arrangements with the person (see 1b - Working out a plan) but remember that things change and it may now be in **the person's best interests** to move into a care home, even if that isn't what they would have chosen to do.

You're not on your own

This can be a difficult and painful time but you don't have to make the decision on your own:

- the **social worker, GP, CPN** or **staff at services the person uses** can help you
- try to involve **the person** themselves as much as you can
- involve other **family members** too if you can, but remember, if they disagree, you, as the carer, know the person and situation best
- it may help to **talk to other carers** who have also had to make the decision about long term care.

Arranging long term care

- Ask for a **community care assessment** for the person with dementia. It will ensure they get the right kind of care plus it is essential in order to get the free personal or nursing care allowance towards the care home fees.
- A **carer's assessment** will let you and the professionals involved in the person's care look at how you are coping and how able you are to go on caring (See Section 1d - Getting an assessment).
- Check with the **Care Inspectorate** or your local **social work** office for a list of care homes in your area and inspection reports (see Section 3c - Support for the person with dementia).
- Visit care homes and ask questions about the care they might be able to provide for the person before you make your choice.

Above all, **take care of yourself** – this can be a very difficult time for you and you may feel guilty or think others will disapprove. It may help to talk to friends, professionals or other carers about how you feel. The **Dementia Helpline** is also there **24 hours a day**.

Even though the care home will have the responsibility for the day to day physical care needs of the person, you can still continue to be involved in their life as much as you want to.

Further information:

- **A positive choice – choosing long-stay care for a person with dementia – making the decision** - www.alzscot.org/positive
- **Coping with dementia – a practical handbook for carers** www.healthscotland.com
- **Letting go without giving up: continuing to care for the person with dementia** - www.alzscot.org/lettinggo
- **Facing Dementia – How to live well with your diagnosis** www.healthscotland.com

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

11. Tips for coping and caring

The following includes **tips from family carers** and are intended to help you in your role of supporting a person with dementia.

Looking after YOU - too often the people that are supporting someone forget about their **own needs** and the need for them to **look after themselves**, physically and emotionally. Caring is **stressful** and can affect your health so it is important to remember this.

'It is OK to get frustrated now and again'. Try keep patient – if you feel things are getting on top of you. Try to get some space to regain your composure.

'Get plenty of sleep'. Your body needs to rest so grab every opportunity.

'It's OK to say 'what about me''. Give yourself a break when you can, and try not to let caring take over your life completely.

'Try and see it from the humorous side.'
'What the heck if you have broken something or left something. Laugh it off, that's a much better way of dealing with things'.

Be open - talk to the whole family and friends about the illness. **Don't hide the fact** that the person has dementia. That can often lead to more stress for you.

Try where possible to **share caring** with other members of the family and friends.

'Be prepared to explain to people that your loved one has got a problem with memory or whatever and **work out a strategy** for dealing with that and telling people'.

Struggling? - don't downplay with agencies when you are finding it difficult to cope. **Agencies need to know** just how hard things might be for you and the person so they can prioritise and organise support.

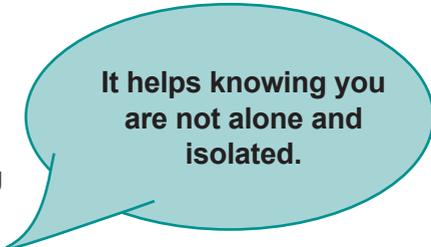
'it's OK to ask the questions',
and its **OK** to ask for help from services – be prepared to fight for your case – and have someone to support you in this if you feel you need to'.

Be prepared – planning in advance can reduce some of the anxieties and worry, especially in an emergency.

- The **Message in a Bottle** scheme holds emergency information in a place that staff know where to find it (the fridge) when it is needed, such as emergency admission to hospital (see further information – local Alzheimer Scotland contacts; or your local carer centre – see Section 3 for details)
- Think about and write down the sort of information that will help hospital or care staff to know how best to care for the person, such as what name they like to be called by, things that may worry or upset them, any hearing or eyesight difficulties, eating and drinking abilities and preferences.

Don't be alone - try and talk to other people who have had similar experience and pick up tips from them - or talk to someone that will understand and **just LISTEN** to you!

Remember **younger family members** may require information and support (see Further information – Understanding dementia: a guide for young people)



It helps knowing you are not alone and isolated.

Join a **carers' support group** if there is one in your area.

Call the **24-hour Dementia Helpline** free on 0808 808 3000 if you need to talk to someone.

Further information:

- **Coping with dementia – a practical guide for carers**
www.healthscotland.com
- **Understanding dementia – a guide for young people**
www.healthscotland.com

If you have any difficulty accessing this information online, contact Alzheimer Scotland's Dementia Helpline on 0808 808 3000

SECTION 2:

Who's who and what's their role?

Although service delivery can vary across NHS Highland, within this people generally see a similar range of staff.

The GP:

The family doctor or general practitioner can be a very good source of **help and information**. They can help make sure the person with dementia stays as physically healthy as possible. They can **put you in touch with other health professionals** such as community nurses, physiotherapists, health visitors and hospital services.

The Psychiatrist:

Psychiatrists are doctors who specialise in mental health, including dementia and will likely be responsible for **confirming a formal diagnosis** and assessing **suitable medication**.

The Community Psychiatric Nurse (CPN):

The CPN can give **emotional support** and **practical advice** to help both carers and people with dementia throughout the illness. They offer information about the illness and on practical ways of coping. They can help with changes in the person's behaviour, and they can also monitor treatments.

At **any stage** you can ask your GP to arrange for a CPN to visit.

Dementia Advisor:

Across NHS Highland, Alzheimer Scotland employs Dementia Advisors to help families living with dementia.

Your local Dementia Advisor is there to **answer your questions** and **put you in touch** with other people who can help. You might be referred to them by your GP when your family member has been diagnosed – if not, ask your GP to give you their details.

Dementia Link Worker:

In many areas of Highland you and the person should be supported by an **Alzheimer Scotland Link Worker** who will help you after the diagnosis to:

- **come to terms** with the condition and learn how to cope with the symptoms
- **keep connected** to your community
- **find support** from other people living with dementia
- support the person with the diagnosis to put **legal arrangements** in place for the future
- support the person to **plan ahead** for their future.

Ask your **GP** for their details or to make a referral.

Local Alzheimer Scotland Service/Dementia Resource Centre:

For people with dementia, their families and carers, professionals and members of the public. These are a resource for advice, information, training, support services, local involvement and representation of people with dementia and carers.

The Social Worker, Care Manager & Community Care Assistant:

This will often be the person who visits and **assesses** the needs of the person with dementia and of the carer and helps you **access services** both within the social work department and elsewhere.

At any stage you can ask for a re-assessment from Social Work for **yourself** or **the person you care** for.

The Occupational Therapist (OT):

The OT helps people to continue doing as much as they can in their daily lives, for example with social and practical activities. An OT can visit the person at home to assess risks and suggest ways to **improve safety, maintain independence** and encourage **well-being**. OTs can be employed by Social Work and also by the Health Board.

The Community / District / Practice Nurse:

The community nurse can visit to **assess and advise** on the nursing needs of the person with dementia, such as **bathing or incontinence**.

Ask the **GP** or contact the community nursing service directly. In most areas they are based at the Health Centre or GP surgery.

Clinical Psychologist:

A clinical psychologist can work with people with dementia to help them learn ways of overcoming **difficulties** or **coping better**. He or she may be able to help with **behavioural changes**, such as aggression, 'wandering' and self-care problems.

The clinical psychologist can help carers deal with stress and feelings such as grief. Clinical psychologists are usually based in hospitals.

Ask the **GP** or a **dementia team member** if you would like to see a clinical psychologist.

Re-ablement teams:

These teams are a part of community care services with a focus on supporting people to continue living safely at home. They work intensively with people needing short-term support to regain their independence at home.

This approach may be helpful for some people with dementia but not for others, and there is work going on in Scotland to look at how best a re-ablement approach might be used for people with dementia.

a) Carer Support

Advocacy

Provides support to people

- to help them to think through and solve their issues
- when plans and decisions about them are being made in meetings, reviews or interviews.

Carer advice, information & support

Provides a safe and supportive environment for family carers to:

- talk openly about their fears, anxieties
- help them cope and reduce stress.

In addition, agencies that focus on supporting carers often provide a wide range of support groups and leisure activities.

Information on support available for young carers.

Local

Highland Carers Advocacy

Tel: 01463 723569

Email: carersadvocacy@hccf.org.uk

Alzheimer Scotland Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Connecting Carers

Tel: 01463 723560

Email: carers@hccf.org.uk

National

Scottish Independent Advocacy Alliance

Tel: 0131 260 5380

Email: enquiry@siaa.org.uk

Web: www.siaa.org.uk/

Carers Scotland Advice Line

Tel: 0808 808 7777

Web: www.carersuk.org/scotland

The Princess Royal Trust for Carers

Tel: 0141 221 5066

Email: info@carers.org

Web: www.carers.org/

Alzheimer Scotland Dementia Helpline

Tel: 0808 808 3000

Email: helpline@alzscot.org

Web: www.alzscot.org

a) Carer Support

Counselling

A counsellor, or therapist, helps you understand the causes of your problems and learn how to manage them.

See your GP

and ask for a referral.

National

COSCA (Counselling & Psychotherapy in Scotland)

Tel: 01786 475140

Email: info@cosca.org.uk

Web: www.cosca.org.uk

Bereavement counselling

Counselling support for people following the death of a loved one.

See your GP

who can make a referral.

Cruse Bereavement Care

For up-to-date local information

Tel: 0845 600 2227

COSCA (Counselling & Psychotherapy in Scotland)

Tel: 01786 475140

Email: info@cosca.org.uk

Web: www.cosca.org.uk

Cruse Bereavement Care Scotland

Tel: 0845 600 2227

Email: info@crusescotland.org.uk

Web: www.crusescotland.org.uk

a) Carer Support

Dementia advice, information & support

Explains types of dementia and their effects, support available, how to help people with dementia and other services available.

Local

Alzheimer Scotland Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

National

Alzheimer Scotland

Dementia Helpline

Tel: 0808 808 3000

Email: helpline@alzscot.org

Web: www.alzscot.org

a) Carer Support

Stress management and relaxation

Provides the family carer with

- skills to manage stress from the strain of coping
- strategies to remain calm in situations of high pressure
- ways to avoid the health problems that can come with long term stress.

Local

See your GP

who can make a referral.

Connecting Carers

Tel: 01463 723573

Email: carers@hccf.org.uk

National

Helplines

Alzheimer Scotland

Dementia Helpline

Tel: 0808 808 3000

Email: helpline@alzscot.org

Web: www.alzscot.org

Samaritans

Tel: 0845 790 9090

Email: jo@samaritans.org

Web: www.samaritans.org

Breathing Space Scotland

Tel: 0800 838 587

Email:

info@breathingspacescotland.co.uk

Web:

www.breathingspacescotland.co.uk

b) Support for the person with dementia

Advocacy

Provides support to people

- to help them to think through and solve their issues
- when plans and decisions about them are being made in meetings, reviews or interviews.

Local

Advocacy Highland

Tel: 01463 233460

Email: info@advocacy-highland.org.uk

National

Scottish Independent Advocacy Alliance

Tel: 0131 260 5380

Email: enquiry@siaa.org.uk

Web: www.siaa.org.uk/

Befriending

Offers supportive, reliable relationships to help people keep active and involved within their community and reduce isolation.

Contact any of the organisations opposite for further information:

Befrienders Highland - Distance Befriending

Tel: 01463 235675

Email: info@befriendershighland.org.uk

Contact the Elderly

Tel: 01479 817007

Email:

alileen.reed@contact-the-elderly.org.uk

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Befriending Network Scotland

Tel: 0131 225 6156

Email: info@befriending.co.uk

Web: www.befriending.co.uk

b) Support for the person with dementia

Day care & home support

Supports the person with dementia by providing activities and stimulation either in a day care centre or by a paid carer / support worker coming to the person's home.

These supports aim to enable people with dementia

- to retain their skills
- maintain their lifestyle
- live positively with dementia for as long as possible.

Contact any of the organisations opposite for details of providers:

Local

Highland Health & Social Care Partnership (Social Work Services)
Tel: 01349 886606

**Alzheimer Scotland
Skye & Lochalsh Services**
Tel: 01478 613450
Email: Skypeservices@alzscot.org

**Dementia Advisor North Highland
- Ross-shire, Skye & Lochalsh
(Alzheimer Scotland)**
Tel: 07584 328776

**Dementia Advisor South Highland
- Lochaber (Alzheimer Scotland)**
Tel: 01463 516004
(Please always dial complete with code)

Care Inspectorate
Tel: 01463 227630/ 0845 600 9527
Email: enquiries@careinspectorate.com

National

Care Inspectorate
Tel: 0845 600 9527
Email: enquiries@careinspectorate.com
Web: www.scswis.com

b) Support for the person with dementia

Local

Home care

Essential care for people with dementia such as:

- washing & bathing
- basic continence care
- meal preparation
- basic housework
- shopping
- budgeting.

Contact any of the organisations opposite for details of providers:

National

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

Alzheimer Scotland

Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland

- Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Care Inspectorate

Tel: 01463 227630/ 0845 600 9527

Email: enquiries@careinspectorate.com

Care Inspectorate

Tel: 0845 600 9527

Email:

enquiries@careinspectorate.com

Web: www.scswis.com

Meal providers

Prepared meals delivered to the home.

Contact any of the organisations opposite for details of providers:

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

b) Support for the person with dementia

Local

Medical loan of aids & equipment

Provides short term loan of wheelchairs to locals and visitors in the area for a small fee or donation.

Also may provide other equipment, e.g. commodes.

British Red Cross
Tel: 01463 231620

See your GP - who can advise.

National

Pet fostering

Short term emergency care service for pet owners who temporarily can't care for their pet because of accident or illness.

Please ensure the pet is fully vaccinated in case you need this service.

Contact any of the organisations opposite for details of providers:

Munlochy Animal Aid

Tel: 07740 237728
Email: See website
Web: www.munlochyanimalaid.com

Pet Fostering Service Scotland

Tel: 0844 811 9909
Web: www.pfss.org.uk

b) Support for the person with dementia

Pet re-homing & adoption

Re-homes pets that can no longer be looked after by their owner. Also can advise on other options.

Please ensure the pet is fully vaccinated in case you need this service, although some organisations will do so (may ask for a small donation towards this).

Contact any of the organisations opposite for details of providers:

Residential care homes

To find out;

- which care homes are in the area
- things to consider when choosing a care home.

Contact any of the organisations opposite for details of providers:

Local

Munlochy Animal Aid

Tel: 07740 237728

Email: See website

Web:

www.munlochyanimalaid.com

SSPCA (Highlands & Islands)

Tel: 03000 999 999

National

Bluecross

Tel: 0300 777 1897

Email: info@bluecross.org.uk

Web: www.bluecross.org.uk

SSPCA

Tel: 03000 999 999

Web: www.scottishspca.org/rehoming/centres

Highland Health & Social Care Partnership

(Social Work Services) Tel: 01349 886606

Alzheimer Scotland Skye & Lochalsh

Services Tel: 01478 613450

Email: Skyseservices@alzscot.org

Dementia Advisor

North Highland - Ross-shire, Skye &

Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland -

Lochaber (Alzheimer Scotland)

Tel: 01463 516004. (Always dial complete with code)

Care Inspectorate

Tel: 01463 227630/ 0845 600 9527

Email: enquiries@careinspectorate.com

Care Inspectorate

Tel: 0845 600 9527

Email:

enquiries@careinspectorate.com

Web: www.scswis.com

b) Support for the person with dementia

Local

National

Social activities

A wide range of activities are available.

- Some of these are for people with dementia.
- Others are for anyone, such as lunch clubs and groups for older people. Often the person with dementia may be able to use these, depending on the support they may require, and what stage their dementia is at. Check if they are suitable.

What is on offer can change so, for the latest details, contact any of the organisations opposite:

Alzheimer Scotland Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh

(Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Skye Old People's Welfare

Tel: 01478 612921

Email: info@slcvo.org.uk

b) Support for the person with dementia

Telecare

Telecare equipment helps people be independent and keep safe in their homes.

Here are some examples

- a full alarm service in the home
- door sensors to signal if someone with dementia has gone outside
- flood sensors for bathrooms.

Local

Highland Health & Social Care Partnership (Social Work Services)
Tel: 01349 886606

**Alzheimer Scotland
Skye & Lochalsh Services**

Tel: 01478 613450
Email: Skyseservices@alzscot.org

**Dementia Advisor North Highland
- Ross-shire, Skye & Lochalsh
(Alzheimer Scotland)**
Tel: 07584 328776

**Dementia Advisor South Highland
- Lochaber (Alzheimer Scotland)**
Tel: 01463 516004
(Please always dial complete with code)

National

c) Respite

Respite is where the family carer can get a break from the potential strain of caring for someone with dementia. Respite comes in a number of different forms:

Home Based Respite

A care attendant or support worker comes into your home to support the person with dementia. This allows you some free time to get on with whatever you choose.

Normally this is for a few hours but may also include overnight stays, which allow you to go away from the house.

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

Alzheimer Scotland

Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Care Inspectorate

Tel: 01463 227630/ 0845 600 9527

Email: enquiries@careinspectorate.com

Crossroads Caring Scotland

Tel: 0141 226 3793

Email: [see website](http://www.crossroads-scotland.co.uk)

Web: www.crossroads-scotland.co.uk

Care Inspectorate

Tel: 0845 600 9527

Email:

enquiries@careinspectorate.com

Web: www.scswis.com

c) Respite

Respite is where the family carer can get a break from the potential strain of caring for someone with dementia. Respite comes in a number of different forms:

Short break respite

Provides support in organising holidays for the person with dementia. The holiday can be with the family carer or without them.

It can include help with organising paid carer support for the person with dementia so that you get a break from caring while also enjoying your time together.

Alzheimer Scotland Dementia Resource Centre

Tel: 01463 711707
Email: Highlanddrc@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004
(Please always dial complete with code)

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

Shared Care Scotland

Email: office@sharedcarescotland.com
Web: www.sharedcarescotland.org.uk

c) Respite

Respite is where the family carer can get a break from the potential strain of caring for someone with dementia. Respite comes in a number of different forms:

Short term residential respite

The person with dementia goes into residential care for a short time (usually one week) to allow you to get a break from caring.

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

Care Inspectorate

Tel: 01463 227630/ 0845 600 9527

Email:

enquiries@careinspectorate.com

Alzheimer Scotland Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Care Inspectorate

Tel: 0845 600 9527

Email:

enquiries@careinspectorate.com

Web: www.scswis.com

d) Legal & financial

Benefits advice

Ensure you are claiming the correct benefits and receiving all you are entitled to.

- Carers Allowance
- Attendance Allowance or Disability Living Allowance
- Pension Credit or Income Supportor any others.

Local

The Highland Council Money Advice & Benefits Maximisation

Tel: 0800 090 1004

Citizens Advice Bureau:

Skye & Lochalsh CAB

Tel: 01478 612032

(Contact for details of outreach service in Kyle)

Ross & Cromarty CAB (Dingwall)

Tel: 01349 864850

Lochaber CAB

Tel: 01397 705311

(Contact for details of outreach in Kinlochleven and Mallaig)

Alzheimer Scotland

Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland

- Ross-shire, Skye & Lochalsh

(Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland

- Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

National

Alzheimer Scotland

Dementia Helpline

Tel: 0808 808 3000

Email: helpline@alzscot.org

Web: www.alzscot.org

Department for Work & Pensions

Tel: 0800 882 200

Email:

Customer-Services@dwp.gsi.gov.uk

Web: www.dwp.gov.uk/directgov/

d) Legal & financial

Debt advice

Free confidential, independent advice on how to deal with debt problems.

Local

The Highland Council Money Advice & Benefits Maximisation

Tel: 0800 090 1004

Citizens Advice Bureau Skye & Lochalsh CAB

Tel: 01478 612032

(Contact for details of outreach service in Kyle)

Ross & Cromarty CAB (Dingwall)

Tel: 01349 864850

Lochaber CAB

Tel: 01397 705311

National

National Debtline

Tel: 0808 808 4000

Email: see website

Web: www.nationaldebtline.co.uk/scotland/index.php

d) Legal & financial

Self-directed support & direct payments

A method for people assessed by social work as needing support which allows you to plan and organise care in ways that best suit the person and yourself.

Local

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

Alzheimer Scotland

Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland

- Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland

- Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

National

Self Directed Support in Scotland
www.selfdirectedsupportscotland.org.uk

Scottish Personal Assistant Employers Network

Tel: 01698 250280

Email: info@spaen.co.uk

Web: www.spaen.co.uk

HM Revenue & Customs

Tel: 0845 607 0143

Web: www.hmrc.gov.uk/employers/new-emp-telephone.htm

e) Training

Dementia awareness training

Provides knowledge and skills to family carers to help them cope with caring for someone with dementia e.g:

- facts about dementia
- legal & financial issues
- communication
- coping with challenging behaviour.

Carer training

Training to support carers in their caring roles e.g.

- moving & handling
- stress management
- First Aid
- healthy eating.

Local

Alzheimer Scotland Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland

- Ross-shire, Skye & Lochalsh

(Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland

- Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Connecting Carers

Tel: 01463 723573

Email: carers@hccf.org.uk

Alzheimer Scotland Skye & Lochalsh

Services Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland

- Ross-shire, Skye & Lochalsh

(Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland

- Lochaber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

National

Dementia Services Development Centre

Tel: 01786 467740

Email: see website

Web: www.dementia.stir.ac.uk

On Line Dementia Training

Social Care Institute for Excellence

Email: see website

Web:

www.scie.org.uk/publications/elearning/dementia/index.asp

f) Health

If you have a health issue you are concerned about contact the services opposite:

Local

See your GP

NHS 24

Tel: 0845 424 2424 (out of hours)

National

NHS 24

Tel: 0845 424 2424

Web: www.nhs24.com/

g) Housing

Housing adaptations & support

Provides aids to living at home such as:

- grab rails for baths and toilets
- walk in baths
- stair rails
- seating aids.

Local

See your GP

Highland Health & Social Care Partnership (Social Work Services)

Tel: 01349 886606

Alzheimer Scotland

Skye & Lochalsh Services

Tel: 01478 613450

Email: Skypeservices@alzscot.org

Dementia Advisor North Highland - Ross-shire, Skye & Lochalsh (Alzheimer Scotland)

Tel: 07584 328776

Dementia Advisor South Highland - Locharber (Alzheimer Scotland)

Tel: 01463 516004

(Please always dial complete with code)

Locharber Handyperson Services

Tel: 01397 706333

Tel: Email: info@lcr.org.uk

National

Directgov. website

Web: www.direct.gov.uk/en/DisabledPeople/index.htm

g) Housing

Small repairs service

Range of services for home owners and private sector tenants who are over 60 and/or disabled.

Examples include

- replacement of lightbulbs
- rewiring plugs
- installation of peepholes/ key-safes
- installation of security chains
- minor repairs
- flat pack assembly.

For Housing Association tenants contact your local housing officer.

Home fire safety

Free fire safety visits and checks to reduce the risk of fire in your house.

Local

**Care & Repair -
The Highland Council Service Point**
Tel: 01349 886606

**Handy Person Services -
Care Lochaber**
Tel: 01397 700311
Email: administrator@carelochaber.org

Lochaber Care & Repair
Tel: 01397 706444
Email: info@lcr.org.uk

**Handy Person Services - Skye &
Lochalish**
Tel: 01478 612035

**Ross and Cromarty Handyperson
Service (ILM Highland)**
Tel: 01349 884774
Email: ilm@ilmhighland.co.uk

**Highland & Islands Fire & Rescue
Service Community Risk
Management Department**
Tel: 01463 227000
Email: kevin.dingwall@hifrs.org
or andrew.johnstone@hifrs.org

**Highland & Islands Fire & Rescue
Service**
Tel: 08000 12 13 12
Email: see website
Web: <http://www.hifb.org/>

National

g) Housing

Local

Sheltered housing

- Purpose built housing for elderly
- Upkeep & services managed for you
- Emergency alarm system
- Usually communal facilities
- Warden services may be available.

The Highland Council Service Centre
Tel: 01349 886606

Care Inspectorate

Tel: 01463 227630/ 0845 600 9527
Email: enquiries@careinspectorate.com

National

h) Transport

Local

Blue badge scheme

Operates throughout the UK.

- for people with severe mobility problems either as drivers or passengers
- allows you to park close to where you need to go.

The Highland Council Service Centre
Tel: 01349 886606

National

Blue Badge Scheme Scotland

Web:

www.transportscotland.gov.uk/road/blue-badge-scheme

Shopmobility

Lends manual and powered wheelchairs, and powered scooters to people with limited mobility so they can shop, visit leisure and commercial facilities.

Check with the national organisation if there is a scheme where you want to shop.

Lochaber Shopmobility

Tel: 01397 700051

Email:

shopmobility1@madasafish.com

The Highland Council Service Centre

Tel: 01349 886606

National Federation of Shopmobility

Tel: 0844 414 1850

Email: info@shopmobilityuk.org

Web: www.shopmobilityuk.org

h) Transport

Community transport

Transport for people who would otherwise be unable to make important local journeys.

Local

Lochaber Community Car Scheme

Tel: 01397 701222
Email: carscheme@carelochaber.org

Mallaig & District Community Transport

Association Tel: 01687 450263
Email: info@mdcta.co.uk

Morvern on the Move Community Transport Association

Tel: 01967 421665
Email: morvermonthemove@aol.com

Lochaber Action on Disability

Tel: 01397 701171
Email: enquiries@lad.org.uk

Skye Old people's Welfare

Tel: 01478 612921
Email: chrisanne@sicvo.org.uk
(Transport for pensioners and those with disabilities on Skye and Raasay)

South West Ross Community Car Scheme

Tel: 01445 791335

Dial-a-Bus - Provides a bus service which operates on demand within a defined area and time period

Subsidised Taxis

Alternatives to bus services and operate on demand within defined time periods in certain remote areas where bus services would not be feasible. Tel: 01349 886606

National

h) Transport

Transport to hospital appointments

Takes patients to and from their pre-arranged hospital appointments, or for their admission and discharge to hospital.

Patients can claim back **travel expenses**. The distance from the patients home or place of residence to the hospital must total at least 30 miles, unless the journey to hospital includes a ferry journey.

Ask your GP or see following:
www.nhshighland.scot.nhs.uk/services/documents/travel%20costs.doc

Queries about patient travel and entitlement can also be made by phoning 01463 704902.

Local

Scottish Ambulance Service Patient Transport Service

In some areas the request for transport is made by doctors and consultants. In other parts patients contact one of the SAS Area Service Offices directly to request this. **Details will come with your appointment card.**

Eligibility criteria based upon access to either own or public transport may apply. Web: www.scottishambulance.com/WhatWeDo/pts.aspx

Red Cross

Tel: 01463 231620

Or contact your local hospital/GP direct

Belford Hospital, Fort William

Tel: 01397 702481

Dr MacKinnon Memorial Hospital / Broadford Hospital

Tel: 01471 822491 (switchboard)

Portree Community Hospital

Tel: 01478 613200

Raigmore Hospital, Inverness

Tel: 01463 704000

National

Scottish Ambulance Service Patient Transport Service

Web:
www.scottishambulance.com/WhatWeDo/pts.aspx

i) Other useful resources

Publisher

How to get hold of

Health & Social Care Services Directory

(local & national services)

High Life Highland

An interactive website for community information about clubs, organisations, societies and social care providers across the Highlands.

Skye & Lochalsh Council for Voluntary Organisations

The Highland Council

Web: www.slcv.org.uk/health

Web: www.high-societies.org/contact.html

j) West Highland local address list

Name	Address	Contact details
Alzheimer Scotland Inverness (Regional Office)	Dementia Resource Centre Unit 2, Strothers Lane, Inverness, IV1 1LR	Tel: 01463 711707 Email: highlandrc@alzscot.org
Alzheimer Scotland Skye & Lochalsh Services	Tigh Na Drochaid Bridge Road Portree, Isle of Skye, IV51 9ER	Tel: 01478 613450 Email: SkyeServices@Alzscot.org
Advocacy Highland	Albyn House, 3rd Floor (Suites 23/24), 37a Union Street, Inverness, IV1 1QA	Tel: 01463 233460 Email: info@advocacy-highland.org.uk Web: www.advocacy-highland.org.uk
Befrienders Highland (Distance Befriending Service)	19 Church Street, Inverness, IV1 1DY	Tel: 01463 233460 Email: info@advocacy-highland.org.uk Web: www.advocacy-highland.org.uk
British Red Cross	Forbes House, 36 Huntly Street , Inverness, IV3 5PR	Tel: 01463 231 620
Care Inspectorate	First Floor, Castle House, Fairways Business Park, Inverness, IV2 6AA	Tel: 01463 227630 0845 600 9527 Email: enquiries@careinspectorate.com

j) West Highland local address list

Name	Address	Contact details
Citizens Advice Bureau	Kyle Health Centre, Main Street, Kyle of Lochalish, IV40 8AE	Tel: 01478 612032
<ul style="list-style-type: none"> Skye & Lochalish CAB (Contact for details of outreach service in Kyle) 	Kyle Health Centre, Main Street, Kyle of Lochalish, IV40 8AE	Tel: 01478 612032
<ul style="list-style-type: none"> Ross & Cromarty CAB (Dingwall) 	4 Church Street, Dingwall, IV15 9SB	Tel: 01349 864850
<ul style="list-style-type: none"> Lochaber CAB (Contact for details of outreach in Kinlochleven and Mallaig) 	Dudley Road, Fort William, PH33 6JB	Tel: 01397 705311
Connecting Carers	Highland House, 20 Longman Road Inverness, IV1 1RY	Tel: 01463 723573 Email: carers@hccf.org.uk Web: www.hccf.org.uk/connectingcarers
Handy Person Services Care Lochaber	An Drochaid, Claggan, Fort William, PH33 6PH	Tel: 01397 700311 Email: administrator@carelochaber.org Web: www.carelochaber.org
Highland Carers Advocacy	Highland House, 20 Longman Road, Inverness, IV1 1RY	Tel: 01463 723569 Email: carersadvocacy@hccf.org.uk Web: www.hccf.org.uk/carersadvocacy
The Highland Council Service Centre		Tel: 01349 886606 Email: customer.service@highland.gov.uk Website: www.highland.gov.uk

j) West Highland local address list

Name	Address	Contact details
Highland Health & Social Care Partnership (Social Work services)	Contact the main Social Work Services number for details of your local office	Tel: 01349 886606
Highland & Islands Fire & Rescue Service - Community Risk Management Department	16 Harbour Road, Inverness, IV1 1TB	Tel: 01463 227000 Email: kevin.dingwall@hifrs.org or andrew.johnstone@hifrs.org Web: www.hifb.org
Local Hospitals West Highland Area		
● Belford Hospital	Belford Road, Fort William, PH33 6BS	Tel: 01397 702481
● Dr MacKinnon Memorial Hospital / Broadford Hospital	High Road, Broadford, Isle of Skye, IV49 9AA	Tel: 01471 822491 (switchboard)
● Portree Community Hospital	Fancyhill, Portree, Isle of Skye, IV51 9BZ	Tel: 01478 613200
● Raigmore Hospital	Old Perth Road, Inverness, Inverness-shire, IV2 3UJ	Tel: 01463 704000

j) West Highland local address list

Name	Address	Contact details
Lochaber Action on Disability	Caol Shopping Centre, Glenloy St, Caol, Fort William, PH33 7DB	Tel: 01397 701171 Email: enquiries@lad.org.uk Web: www.lad.org.uk
Lochaber Community Car Scheme	An Drochaid, Claggan, Fort William, PH33 6PH	Tel: 01397 701222 Email: carscheme@carelochaber.org Web: www.carelochaber.org
Lochaber Shopmobility	The Portacabin, Travel Centre, Fort William, Inverness-shire, PH33 6EN	Tel: 01397 700051 Email: shopmobility1@madasafish.com Web: www.shopmobilitylachaber.org.uk
Munlochy Animal Aid	Woodend, North Kessock, Inverness, Inverness-shire, IV1 3XD	Tel: 01463 811722 Mb: 07740 237728 Web: www.munlochyanimalaid.com
Skye Citizen's Advice Bureau	The Green, Portree, Isle of Skye, IV51 9BT	Tel: 01478 612032 Email: adviser@skyecab.casonline.org.uk Web: www.adviceguide.org.uk
Skye Old People's Welfare	Tigh Lisigarry, Bridge Road, Portree, Isle of Skye, IV51 9ER	Tel: 01478 612921 Email: christanne@slcvo.org.uk Web: www.slcvo.org.uk/skye-old-peoples-welfare.htm
SSPCA	5 Inshes, Inverness, IV2 5BA	Tel: 03000 999 999

k) Regulatory and complaints bodies – address list

Agencies that ensure standards of care and who you can complain to if you are unhappy with any care setting or support service.

Name	Address	Contact details
Citizens Advice Bureau Patient Advice and Support Service (PASS) - helps people make complaints about the NHS	103 Academy Street Inverness IV1 1LX	Tel: 0844 499 4111 Email: enquiries@invernesscab.casonline.org.uk Web: www.cas.org.uk/
The Care Inspectorate: can investigate complaints against registered social care providers.	Compass House 11 Riverside Drive Dundee DD1 4NY	Tel: 0845 600 9527 Email: enquiries@careinspectorate.com Web: www.scswis.org
Healthcare Improvement Scotland: deals with complaints about independent health care providers.	Delta House, 50 West Nile Street, Glasgow, G1 2NP	Tel: 0141 225 6999 Email: comments.his@nhs.net Web: www.healthcareimprovementscotland.org/home.aspx
Local authority: can investigate complaints about a service it provides or arranges for you.	The Highland Council	Tel: 01349 886606 Web: www.highland.gov.uk

k) Regulatory and complaints bodies – address list

Name	Address	Contact details
<p>Mental Welfare Commission for Scotland: safeguards the rights and welfare of people with dementia and others and can investigate when you do not receive the right care.</p>	<p>Thistle House 91 Haymarket Terrace, Edinburgh, EH12 5HE</p>	<p>Tel: 0800 389 6809 Email: enquiries@mwcscot.org.uk Web: www.mwcscot.org.uk</p>
<p>Office of the Public Guardian (OPG): can investigate concerns where the property or financial affairs of an adult with incapacity seem to be at risk.</p>	<p>Hadrian House, Callendar Business Park, Callendar Road, Falkirk, FK1 1XR</p>	<p>Tel: 01324 678300 Email: opg@scotcourts.gov.uk Web: www.publicguardian-scotland.gov.uk/</p>
<p>Scottish Public Service Ombudsman (SPSO): considers complaints about organisations providing public services in Scotland, including local authorities and the NHS.</p>	<p>4 Melville Street, Edinburgh, EH3 7NS</p>	<p>Tel: 0800 377 7330 Email: see website Web: www.spsso.org.uk/contact-us</p>

Emergency Contacts

Fire, Police, Ambulance Tel: 999

NHS 24 Tel: 08454 242424

**Highland Health & Social Care Partnership
- Social Work Services**

8am – 6pm, Mon – Fri

and 9am - 12 midday Sat **Tel: 01349 886606**

Out of Hours

& Public Holidays..... **Tel: 0845 601 4813**



Dementia Alzheimer Scotland
Action on Dementia

Helpline **24**
HOUR

Freephone **0808 808 3000**
Email: helpline@alzscot.org

Important

To prevent misuse, the **Dementia Helpline does not accept calls where the caller's number has been withheld**. If you normally withhold your number, please enter 1470 before dialling the helpline number.

This does not affect the caller's right to confidentiality under the terms of the Helpline's policy.

VIPs

Very Important Points

It is vital that someone has explained and discussed the following topics with you and the person you care for:

- Dementia types and what to expect
- Power of attorney & other legal issues
- Driving and dementia
- Income maximisation (benefits and pensions)
- Council tax rebate or exemption
- Available supports in your area
- Self-directed support

If someone hasn't spoken to you about any or all of these, contact:

Alzheimer Scotland Highland: 01463 711707

**Alzheimer Scotland Dementia Helpline (24 hour):
0808 808 3000**