



Making the most of your post-diagnostic support

Information for you, and those who care for you, if you are newly diagnosed with dementia.

Making sure nobody faces dementia alone.

Contents



Why do you need this information? **page 01**



How to use this information **page 02**



What is dementia post-diagnostic support and why is it important? **page 03**



How do you get post-diagnostic support? **page 06**



What you can expect from high quality post-diagnostic support **page 07**



What to do if your post-diagnostic support is not meeting your expectations **page 17**



Additional information and resources **page 18**



Why do you need this information?

This information explains what to expect from dementia post-diagnostic support in Scotland. If you, or the person you care for, have been newly diagnosed with dementia then you are entitled to receive this support. Many people don't know about this support or what to expect from it which is why we have produced this information for you.

The word carer refers to unpaid carers and will include anyone who might be supporting you such as a spouse, family member, friend or neighbour.

For the purpose of this leaflet, we refer to post-diagnostic support for people living with dementia as the service is primarily for them. The information in the guide is however applicable to carers to let them know about the support the person they are caring for is entitled to, and the extent to which a post-diagnostic support worker can support carers.



How to use this information

You can use the information in this document to help you:

- understand what high-quality post-diagnostic support should look and feel like
- decide if you want post-diagnostic support
- ask your local Health and Social Care Partnership contact for post-diagnostic support if you haven't already been offered it
- plan your post-diagnostic support and consider what you would like to prioritise
- recognise if the service you receive is doing what it should be doing or if it could be better.



What is dementia post-diagnostic support and why is it important?

Dementia post-diagnostic support is a specific service that people with dementia in Scotland are entitled to following their diagnosis. This support is delivered by a post-diagnostic support worker, often called a Dementia Link Worker, who is allocated to you for at least one year.

Not all workers who deliver post-diagnostic support are called Dementia Link Workers. Your support could be delivered by a worker with a different job title such as a Community Mental Health Nurse or a Health and Social Care Worker. Sometimes support can be shared between a couple of workers.

There is no charge or age restrictions for the service.

Following your diagnosis, and with your consent, a worker will visit you to speak to you about your diagnosis, find out what matters to you and what kind of support is best for you.

Some people may feel that they don't need, or want, post-diagnostic support at this time, but it is important to take it up at a time when you can really make the most of it. The worker can help you adjust to your diagnosis to live as well and as independently as possible. They may suggest other services to you and help to arrange referrals to these. They can also give your carer advice and support such as directing them to carer organisations in their local area.

It is the worker's role to help you with the following five areas guided by what you want when you feel ready:

- Help you to understand your illness and manage your symptoms
- Support you to stay connected to your community
- Help you to meet others who are coping with the same sort of challenges as you are
- Help you to plan for your future decision-making
- Support you to plan for your future care by helping you develop a personal plan which captures what matters most to you.



These five areas were identified by Alzheimer Scotland in 2011 and are known as the 5 Pillars Model of post-diagnostic support.

Here's what people with dementia and their carers have said when they have received high quality post-diagnostic support:



How do you access post-diagnostic support?

If you have been newly diagnosed with dementia you may be referred directly for post-diagnostic support by the professional who gave you your diagnosis or by a member of the team where you received your diagnosis.

If this hasn't happened, then it is your right to contact them to ask why. Alternatively, ask a health and social care professional (such as your GP, Community Mental Health Nurse or health and social care professional) to refer you.

If services other than post-diagnostic support are considered to be more appropriate for you then you will be advised of this.



What you can expect from high quality post-diagnostic support

The following sections provide the detail of how post-diagnostic support should be delivered. They are based on what people with dementia said made a difference to them.

Each section has a tick list at the side. You might not need all of the support mentioned so you can use this tick list to prioritise what you need and this can guide the worker.

You can also use the tick list to record whether the support you are receiving resembles what is being described in the list.

✓ You experience post-diagnostic support at the right time

■ Post-diagnostic support is offered, planned and delivered at a pace, order and time which reflects your needs and strengths.

■ You can access post-diagnostic support irrespective of your age, race, sexuality, disability, background and where you live.

■ Information about the service is provided in a language and format that is easy for you to understand.

■ If your needs would be better met by another available service, then you are referred to it.

■ You are given contact details to access the service should you wish to do this at a later date, either for the first time or to come back in to the service.

■ You are told about the different professionals who can support you and, if appropriate, are asked for your consent to being referred to them.



-
- You are given practical suggestions about activities to improve your wellbeing; including simple memory aids, technology and adaptations to your home.
-
- You are given information on driving and assisted travel options if this is relevant to you.
-
- You are referred to other professionals if more help is needed for you to remain independent for as long as possible.

Your notes on your post-diagnostic support:

✓ You know more about your dementia and can begin to adjust to your diagnosis

- You are given information on the type of dementia that is relevant to you.
-
- You are supported to find ways of coping and adapting to having dementia.
-
- You are given information on how to meet with others in a similar situation for support, if you wish.

Your notes on your post-diagnostic support:



What to do if your post-diagnostic support is not meeting your expectations

If your post-diagnostic support doesn't resemble what's in this information then speak to the worker as soon as possible.

Let them know about your concerns to see if they can do something about this. If this doesn't help, ask to speak to the worker's manager or the lead person for post-diagnostic support in your area and discuss your concerns with them.

If you are still dissatisfied then you should ask your Health and Social Care Partnership for their complaints procedure.

Add local contact information here:



Additional information and resources

Accessing post-diagnostic support

Find more information and literature on accessing post-diagnostic support on the Alzheimer Scotland website.

www.alzscot.org

Online post-diagnostic support resource

NHS Lanarkshire's mental health and learning disability service developed an online dementia post-diagnostic support tool for carers, patients and health practitioners. The online tool was developed to enhance the post-diagnostic support already provided in Lanarkshire. It is full of information to support people through their journey with dementia by providing practical advice and guidance and was developed in partnership with a number of agencies including Alzheimer Scotland. Whilst it highlights the local

support and resources available in Lanarkshire, much of the information in the tool is useful to anyone who needs post-diagnostic support.

Access the tool here:

<https://bit.ly/2kyYpWs>

You are welcome to email comments or feedback on any aspect of this information to:

hcis.focusondementia@nhs.net
or info@alzscot.org

Focus on Dementia and Alzheimer Scotland collaborated on the development of this information.

Focus on Dementia is a national improvement team based within Healthcare Improvement Scotland's Improvement Hub (ihub).

Alzheimer Scotland is the leading dementia charity in Scotland. With fundraised income we are able to offer support through our 24 hour Freephone Dementia Helpline, Dementia Resource Centres, Dementia Advisors, Community Activity Organisers, Volunteer Coordinators, invest in research, campaign for equal rights and much more to help people live well and make sure nobody faces dementia alone.

We would like to thank members of the Scottish Dementia Working Group, the National Dementia Carers Action Network and other individuals living with dementia for their help in developing this information.

You can read and download this document from Alzheimer Scotland's website **www.alzscot.org**

To order paper copies contact **info@alzscot.org**



**Alzheimer
Scotland**

Action on Dementia

160 Dundee Street
Edinburgh EH11 1DQ

0131 243 1453

www.alzscot.org

24 HOUR
Dementia
Helpline
Freephone 0808 808 3000
Email helpline@alzscot.org



Healthcare
Improvement
Scotland

ihub

Edinburgh Office

Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB

0131 623 4300

Glasgow Office

Delta House
50 West Nile Street
Glasgow G1 2NP

0141 225 6999

ihub.scot/focus-on-dementia