



run by people with dementia

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24 HOUR Alzheimer Scotland Action on Dementia
Dementia Helpline
 Freephone 0808 808 3000
 Email helpline@alzscot.org

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Post Diagnostic Resource

Scottish Dementia Working Group



“Please don’t label me, I am more than my dementia.”

Acknowledgements

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The hints and tips in this leaflet were formed and discussed through a subgroup with members from the SDWG, however you may also have hints and tips about what you found useful when receiving a diagnosis of dementia. Please get in touch and share your ideas with us at

ScottishDementiaWorkingGroup@alzscot.org

Introduction

The SDWG have developed this peer to peer resource for people who have been recently diagnosed with dementia. Members of the SDWG hope this document highlights that people are still very capable and can live well with dementia. Four themes were established from a conversation which began with the question:

What is one thing you wish you had been told from somebody with dementia after being diagnosed?

This led to a wide discussion, however the following key themes were identified:

1. How to find acceptance and positivity
2. Stay engaged in things that matter to you
3. Having support from others can be vital to living well with dementia
4. Get informed!

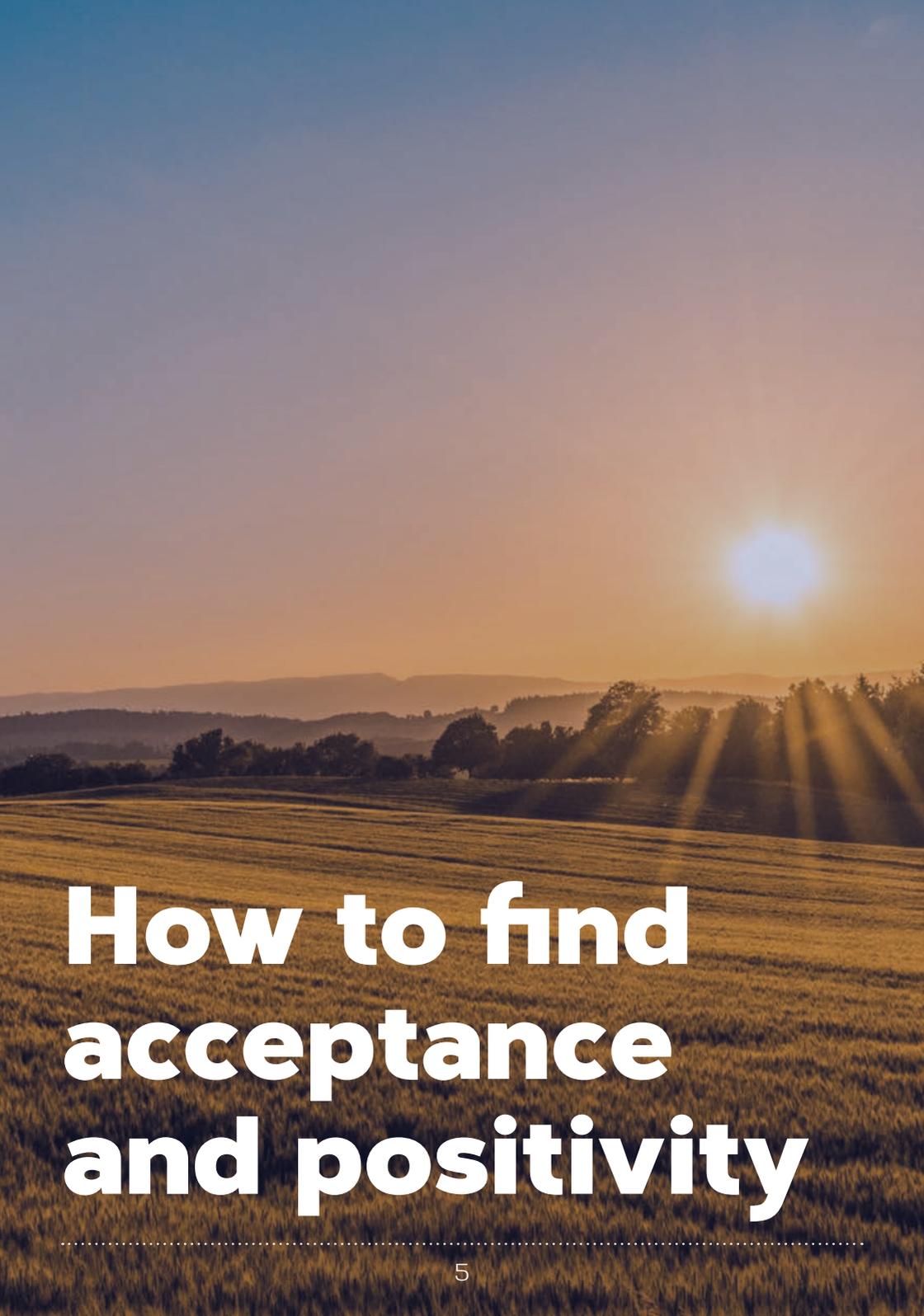
The SDWG believe that the first thing you should be given when diagnosed with dementia is hope and our aim is to have this resource available to assist in achieving that.



What is one thing you wish you had been told from somebody with dementia after being diagnosed?



“
...you are the same person as before your illness...
”



How to find acceptance and positivity

Everyone's path to acceptance is different

Give yourself time to process your diagnosis. Some people may take longer than others, and that's okay. Often having a good support network or knowing that someone is there to check in on you can help you through the process.

Don't stop believing in your strengths and abilities now that you have a diagnosis

Some people and their families think that being diagnosed means you "can't do anything anymore". However, you may find that you feel more confident, therefore become more involved, when you receive a formal diagnosis due to better support and understanding of how the illness will affect you.

Don't give up hope for the future

Although you may not be the same, this may be an opportunity to try new hobbies or groups. Trying new things can add value and purpose to life after a diagnosis. People sometimes feel they live a better life now compared to when they were first diagnosed.





**Stay engaged
in things that
matter to you**

Hobbies

Don't withdraw from your hobbies – they can be vital to keeping you connected with your community and can provide you with purpose in a time of difficulty.

Being active

Try to keep active (i.e. walking) as moving and getting out of the house not only benefits you physically but can also benefit your mental health.

Let others help you stay engaged

Sometimes you need others to encourage you to get out there and get involved with things again. Allow opportunities for your family and friends to schedule things for you and get their support in keeping you engaged in your community, important hobbies and social outings.





Having support from others can be vital to living well with dementia

Support from family and friends can be key but can also come with its own challenges

A dementia diagnosis can turn someone's world upside down and it's at this time that friendship is valued the most. Alzheimer Scotland's Friendship and Dementia leaflet provides hints and tips on how to provide support to people with dementia, at all stages of the illness.

www.alzscot.org/friendship

Your friends and family may be unsure of how to act around you after they find out about your diagnosis due to the stigma surrounding the illness or for fear of doing something wrong. They may need reassurance to know that what they are doing is okay. Letting them know that you are the same person as before your illness and having an open stream of communication can be of comfort to them as well.

Accept the offer of help

It's ok to accept help. Your friends and family will want to support you, so don't be afraid to ask for assistance if you need it. This could be asking someone for a lift if you no longer have a driving license or want some company while shopping.

Encourage your friends and family to also get informed

Encourage your friends and family to also get informed about dementia through resources such as Dementia Friends or the Alzheimer Scotland Dementia Resource Centres so that they have a better understanding of some of things you are experiencing and how they can support you.

We can all play our part in being a good friend. Why not find out more about becoming a Dementia Friend? It's a free interactive and informative training course that will provide you with an understanding of how to interact with people living with dementia. Find out more at:

www.dementiafriendsscotland.org

Carer's Card

It may also be useful for family and friends to carry a carer's card to let others know that they care for a person with dementia in case of emergency or if they should become ill. Find out more at:

www.alzscot.org/carercard

You may find it useful to reach out to other people with dementia

Simply speaking to someone who knows what you are going through and can relate to you can be a very positive experience after recently being diagnosed. A good starting point can be Alzheimer Scotland day centres, the SDWG or other more informal dementia organisations. Alzheimer Scotland's 24 hour Freephone Dementia Helpline, Dementia Advisors and Link Workers can help you with what activities and groups are available in the area, along with helping you match what group might be right for your interests.

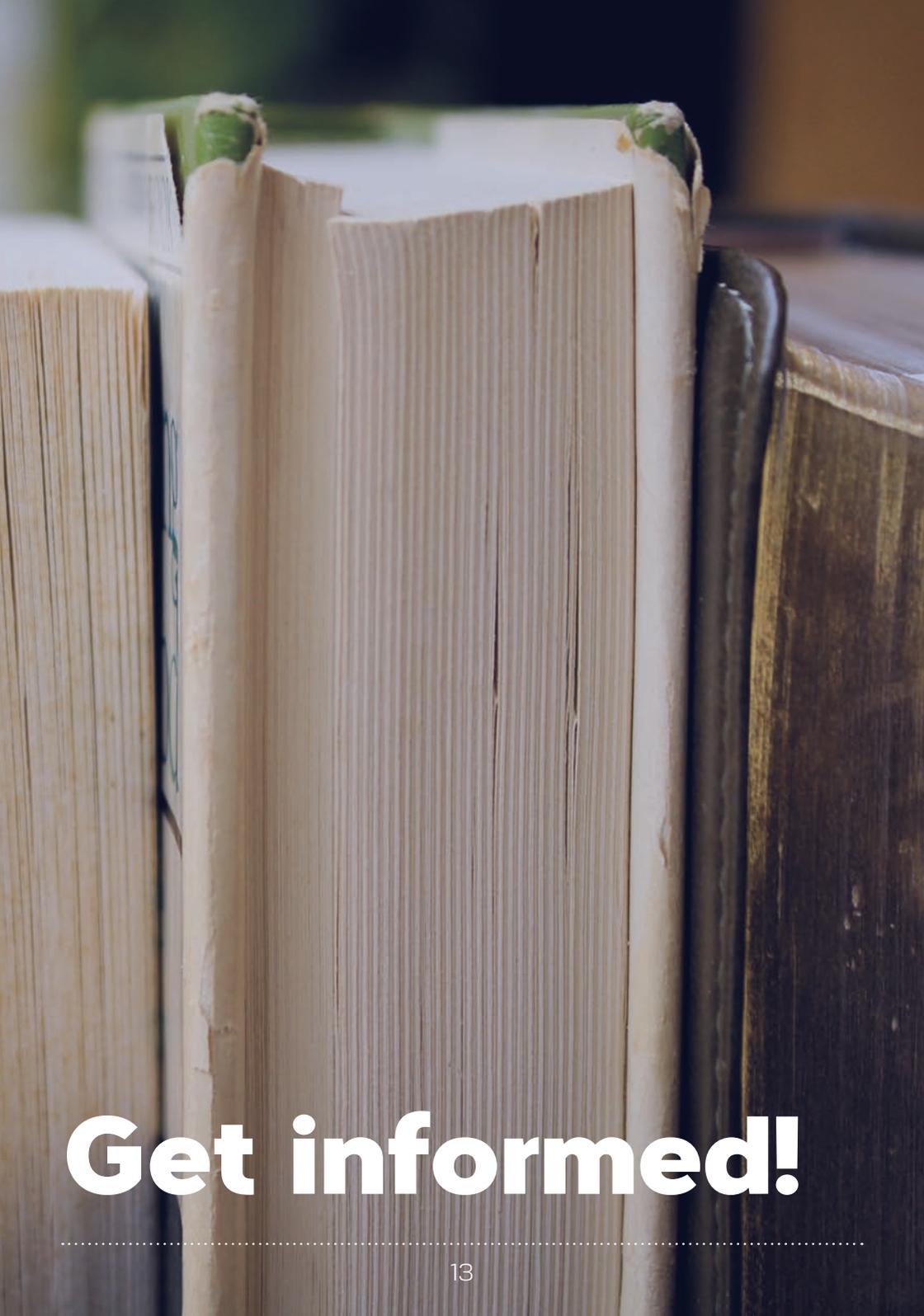
Being a member of the SDWG can be an extremely valuable role following diagnosis

Being an advocate and campaigning for the rights of those living with dementia can give a sense of structure, routine and purpose as well as supplement some of the roles a person may have withdrawn from following diagnosis (i.e. work).

The process of becoming a member has been tailored to provide an open and inviting atmosphere that is welcoming to everyone living with dementia. You can find out more about the SDWG here:

www.sdwg.org.uk





Get informed!

Know about your illness

Having an awareness of some of the challenges associated with the illness can assist you in your daily life. For example, physical spaces in the community can be challenging for some people due to differences in depth perception. This may mean that you are more conscious about your safety when using stairs and doorways or look to install some adaptations such as a handrail. These would all be informed decisions that you could make as you learn more about your dementia.

Some individuals find it empowering and comforting to take charge of their own future and begin to get their affairs in order (such as Power of Attorney). Keep in mind that too much information all at the same time can become overwhelming. This should be done at a pace that works for you, and you can choose whether you would like someone to assist you with this process.

Know that sometimes, it isn't the illness

Let yourself be human. Know that “symptoms of dementia” happen to everyone sometimes, such as walking into a room and forgetting why you intended to go in there. Don't be too hard on yourself for forgetting and making mistakes as it can happen to anyone.

Know the resources available to you

Alzheimer Scotland has a range of resources available to individuals at every stage of the dementia journey. A good place to start can be finding your nearest Alzheimer Scotland Dementia Resource Centre for accessible information and support. Find your nearest Centre here:

www.alzscot.org/drc

Joining new groups in your community that meet regularly,

whether they are for people with dementia or not, can be a useful resource. Some examples include walking groups, recreational clubs, leisure clubs and lunch clubs.

Lastly, fire safety and healthy home checks can ensure that your home is as safe as possible and that precautions are taken to minimise any risks.

The Scottish Fire and Rescue Service offer free home fire safety visits. Find out more at:

bit.ly/oldsafe

Know how to access your communities

Being able to access the community is a vital part of staying engaged in the things that matter to you. Knowing the bus schedules, taxi cards and blue badge options available can help you, if you are no longer driving, reach the things that are important to you.

For those still driving, this Alzheimer Scotland resource, Driving and Dementia, can help:

www.alzscot.org/driving

Further, many tips for accessing and staying safe in the community can be found in the SDWG Top Tips Leaflet:

bit.ly/demtip

Know that you are entitled to immediate support

Having a professional to assist you when you are recently diagnosed is important. Scotland's Third National Dementia Strategy (2017-2020) includes a focus on high quality Post-Diagnostic Support (PDS) which entitles every person with a new diagnosis of dementia to one year of PDS from a Dementia Link Worker or a similar named person. To access this specific support, you can ask for your doctor to refer you for PDS, or you can search Alzheimer Scotland's website to

find a Dementia Link Worker or other form of PDS in your area.

For more information on PDS, visit:

www.alzscot.org/recentlydiagnosed

If you would like to read more about Scotland's National Dementia Strategy, visit:

www.alzscot.org/nationalstrategy



Useful documents and publications

The Scottish Dementia Working Group have published a top tips document for “Living well with Dementia”. This includes several useful hints and tips for living well with dementia that were tried and tested by members of the group. Information regarding the Scottish Dementia Working Group can be found at www.sdwg.org.uk including other publications by the group.



Alzheimer Scotland provide a card for people with dementia. This can be used to help others understand what they can do to help. This is available from Alzheimer Scotland offices.



You can find out more information on any aspect of dementia by phoning the Alzheimer Scotland free 24 hour helpline on 0808 808 3000, or visit www.alzscot.org for more information.

Summary of resources included in this leaflet

Dementia Friends:
www.dementiafriendsscotland.org

Carer's Card:
www.alzscot.org/carercard

SDWG:
www.sdwg.org.uk

Alzheimer Scotland Dementia Resource Centres for accessible information and support:
www.alzscot.org/drc

Scottish Fire and Rescue Service:
bit.ly/oldsafe

Driving and Dementia:
www.alzscot.org/driving

SDWG top tips:
bit.ly/demtip

Alzheimer Scotland's "Recently Diagnosed" Information:
www.alzscot.org/recentlydiagnosed

Scotland's National Dementia Strategy (2017-2020):
www.alzscot.org/nationalstrategy