

Dementia and Self-Management

Peer to Peer Resource



Written and researched by
people living with dementia

Scottish Dementia Alumni: David, Agnes, Nancy and James



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Introduction

Why we carried out this project

This booklet was written and researched by the Scottish Dementia Alumni, a group of people who have each been living with different diagnoses of dementia for over ten years. We are experienced campaigners who have actively fought for the rights of people living with dementia for over a decade. We are people who have had to learn how to manage our own lives during the unspecified timescale of the dementia journey. In that time, between us we have gained a Churchill Fellowship Award, two MBE's, a BEM, an Honorary Doctorate from Strathclyde University, written books and booklets and been referenced in other publications. We received grants from the Life Changes Trust and the DEEP Network which enabled us to produce this booklet and the accompanying video.

We had often heard professionals, service providers and policy makers using the term 'self-management' when talking about the lives of people living with dementia, but we did not know what was meant by the term. After first receiving our diagnosis, many of us had been left largely alone for a number of years, in effect to self-manage our lives and condition.

But we were unable to get a clear definition or guidance from official or medical sources of what ‘self-management’ was, so we were keen to find out what the term means to people living with forms of dementia in different circumstances and how the idea affects their everyday lives.

Some say that self-management means having control over how you live, others express different views. We hope that this booklet is a strong example of how those of us living with dementia in all its forms can take control of the debate around issues which affect our ability to continue to live fulfilling lives.

The contributions to this booklet came directly from people with a diagnosis of different types of dementia. We learned that dementia is only a word that covers many personal, family and clinical contexts, but once again we found that when given the time and support, people with lived experience of their condition are very able to contribute and offer insight.

This is inspiring and can positively change social, medical and personal perceptions of ‘dementia’, and gives hope.

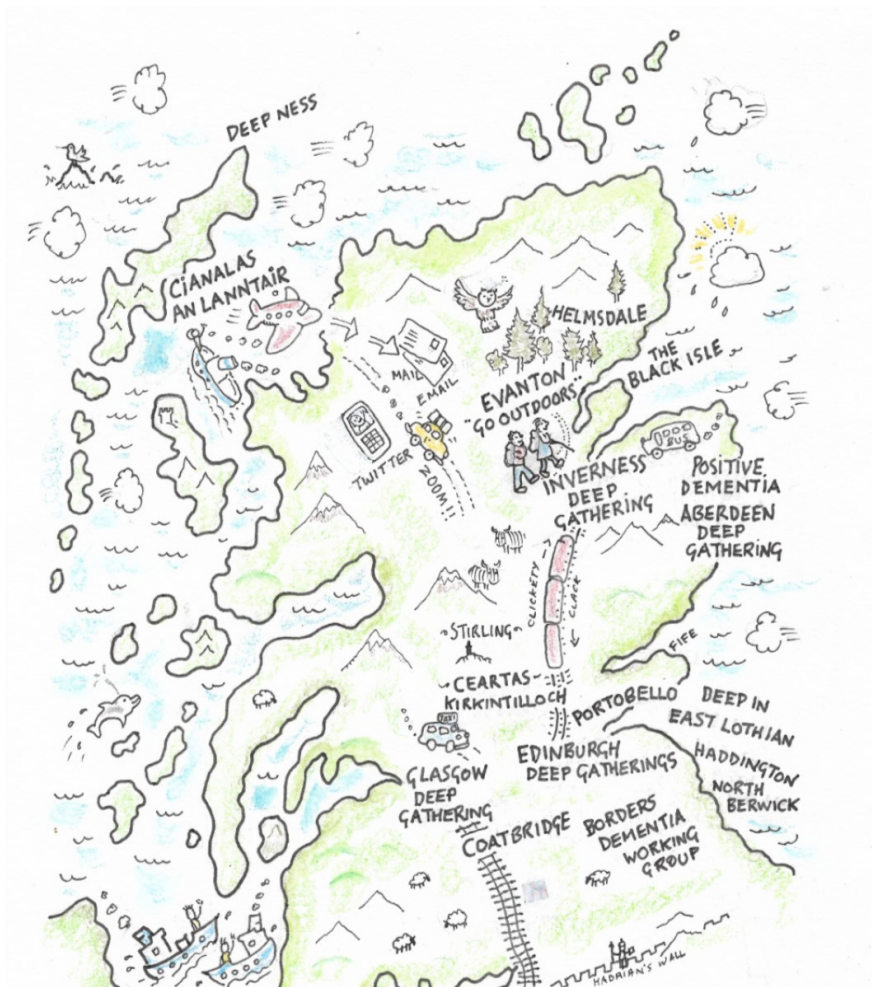
During our initial research we found the ‘Self-Management Strategy for Long Term Conditions in Scotland’. This was part of the ‘Gaun Yersel’ document published in 2008 by what is now the Health and Social Care Alliance Scotland.

The Strategy said: '(Self-Management) is a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition. The role of health and social care providers is to support the person's journey towards living well in the presence or absence of symptoms.'

This definition of self-management spoke to us above others. When 'Gaun Yersel' was published in 2008 it was probably widely assumed in general society that people living with a dementia diagnosis did not have the capacity to contribute to policy or to 'self-manage' their lives, a common enough assumption in those days, and one we have worked to improve on.

We sought views from different sections of the community and we asked the same questions of all who took part in our research. Some respondents live alone, some with a family or care partners, some use support groups or services, while others do not. In Scotland we spoke to people through our personal contacts, and we visited groups in the DEEP Network and others across Scotland.

Where we went



Where we went

- Stornoway
- Helmsdale
- Inverness
- Stirling
- Coatbridge
- Edinburgh
- Haddington
- Evanton
- The Black Isle
- Aberdeen
- Glasgow
- Moffat
- Portobello
- North Berwick
- Kirkintilloch

Who we spoke with

- Individuals living with dementia
- Borders Dementia Working Group

- Cíanalas An Lanntair
- Positive Dementia
- DEEP gatherings
- Ceartas Advocacy

What we asked:

We asked people with dementia the following questions:

- Do you live alone?
- How long have you lived with a diagnosis of dementia?
- Do you know what type of dementia you live with?
- Have you heard the term ‘self-management’ of dementia?
- What does this mean to you?
- Do you get advice from any professionals to help you to self-manage?
- Do you self-manage?
- What helps you to self-manage?
- Who helps you to self-manage?
- Do you feel in control of your life and your dementia care?

What this booklet is for:

- Giving peer-to-peer support to others living with dementia and to inform them about what self-management means
- Helping people living with dementia to self-manage their journey and be in the driving seat
- To be useful and helpful for anyone interested in supporting people living with dementia to live fulfilling lives 'in the presence or absence of symptoms'
- To inform about how people living with dementia self-manage, where to find help to self-manage and how to ask for that help
- To campaign for support to enable self-management
- To bridge the gaps between policy, theory and practice about living with dementia
- To give people hope

What people said:

What does the term “self-management” mean to you?

“I should do more for myself but I make a mess of everything I touch”

“You get on with it and ask for help when you need it”

“To get on with your life and look after yourself”

“Support to stay independent to carry on living”

“I remember that I am a gardener who happens to have dementia”



“I haven’t a clue, I haven’t heard of it”

“I don’t really know, I don’t understand it”

“To keep doing what I use to do”

“I am in control of my life and my dementia”

“I think it means doing your own banking and taking care of yourself”



These responses show that people who live with dementia can have insight into their cognition and limitations. These insights can help people to self-manage.

Do you get help from any professionals to self-manage?

“Doctors don’t seem to have knowledge”

“I get help with medical things but they don’t know about self-management”

“There was a six-week course but it lost its funding”

“Not from any professionals that I know”

“No. My GP is good but he never mentions self-management”



“The Alzheimer Society. I now have a funeral plan and have organised Power of Attorney”

“I get help from the staff at the Art Centre and the staff at my sheltered housing”

Do you self-manage?

“No, not really, not without the help of my daughter”

“Only if I get help, support or knowledge”

“I hope so, I try”



“I can if I am aware of my limitations”

“I manage by myself; I have always managed that way”

“My family helps”

What would this support look like?

People who live with a dementia have a desire to self-manage, but need support to do so.

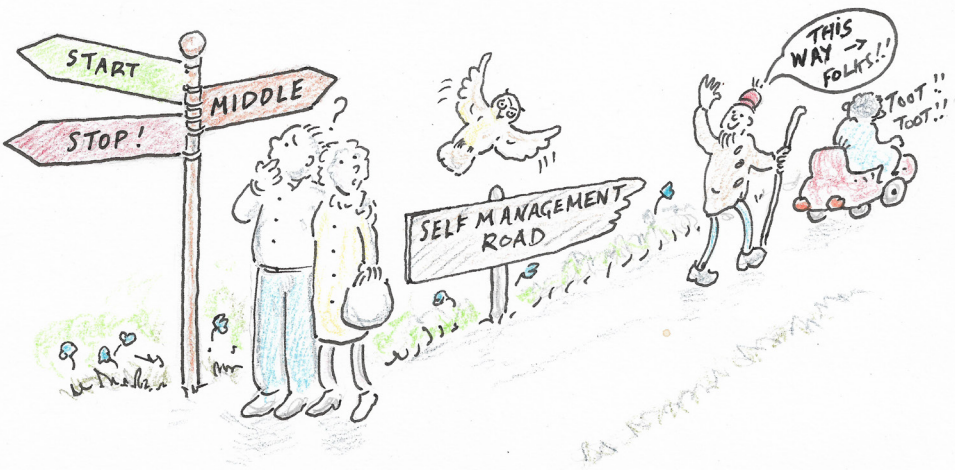
“Self-Directed Support Funding would help us to choose the right support – support to remain independent and to live a normal life.”

What helps you to self-manage?

“Friends in the same boat as me”

“My family”

“Getting Self-Directed Support (SDS) funding helps me to self-manage”



“Speaking to people outside my family”

“Keeping fit”

“Going to Church, my social clubs, my lunch club, helping to run things”

“My own character, my background and training in my work from the past”

“Three days a week down at the Men’s Shed”

“I use technology and I am developing new technology”

“Getting out and about, I can still drive”



“Meeting others with dementia and chatting”

“Walking the dog, riding my push bike, keeping fit helps the brain”

“Meeting others”

“Colouring books and gardening”

“Looking after my grandchildren and pets. Keeping fit”

“Joining a design course, designing a pattern for a dress, I have never done that before”

“Keeping to my routine, going to the gym and the library”

“Not going out of my comfort zone”



“Knowing more about dementia”

“Keeping active, swimming”

**“Sharing laughter, fun and
humour”**

“Getting up in the morning”

Who helps you to self- manage?

“My family”

“Meeting others with a diagnosis”

“My wife and my daughter”

“People at Church”

“My Community Psychiatric Nurse”

“The clinic”

“My personal assistant”

Conclusion

“Dementia doesn’t define us. We are still people and we need to be treated with respect”

What people living with dementia have told us about self-management supports the importance of everyday things. The late psychologist Tom Kitwood talked about this as far back as the 1990’s. Central to his “Flower of Emotional Needs” is Love.



Self-management when living with a diagnosis of dementia involved all parts of this flower of needs. This is the same for all people, and when one has a long-term condition such as dementia one can still lead a fulfilling life when all involved act together.

“(Self-Management) is a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition. The role of health and social care providers is to support the person’s journey towards living well in the presence or absence of symptoms”

Gaun Yersel, 2008.

Love from our families and friends, our community and peer support and enjoying social opportunities all help us to fulfil our needs and to self-manage our lives.

Having an occupation, campaigning and making connections with others who are “in the same boat” give us a sense of purpose and attachment and achievement. All this helps to create, above all, hope.

As the Scottish Dementia Alumni, we have been part of the DEEP Network's regular "Gatherings" in Scotland, together with many others. These gatherings have involved people living with dementia developing priorities, based on lived experiences and these priorities have helped stimulate us to produce this booklet.

We hope this booklet helps all who are interested to see that self-management of life with dementia is possible, with the love, help and support of family, friends and professionals. It would not be possible without putting the person with dementia, and their experiences, at the core, so that we can lead our normal lives in our community. That is our human right.

Acknowledgements

The Scottish Dementia Alumni want to thank and acknowledge all those who helped us to produce this booklet.

We are grateful for the great help and support of the Life Changes Trust, Innovations in Dementia, the DEEP Network and the Scottish Health and Social Care Alliance for their generosity and hospitality.

We acknowledge the Alliance's 'Gaun Yersel' publication of 2008, from which we quote the paragraph which first stimulated our curiosity.

Above all we want to thank the many people who live with dementia who contributed so generously at gatherings, by post, email and in their own homes to this project.

The illustrations were kindly provided for us by Paul Thomas.

You can watch our accompanying video, for which we thank and acknowledge all the above and Cormorant Films, and find more excellent and inspiring information and materials by visiting the Life Changes Trust website at www.lifechangestrust.org.uk and the DEEP Network website at www.dementiavoices.org.uk

The Scottish Dementia Alumni are contactable via the DEEP Network website.

Helpful Resources

Websites:

- DEEPness Dementia Radio
<https://bit.ly/38rSvub>
- ALISS (A local information system in Scotland for finding help and support close to you)
<https://www.aliss.org/>

- Self-Directed Support Scotland
<https://bit.ly/2LLFQsf>
- Scottish Independent Advocacy Alliance
<https://www.siaa.org.uk/us/>
- Age Scotland: Dementia
<https://bit.ly/36tpBYX>
- Alzheimer Scotland
<https://www.alzscot.org/>

Peer-to-Peer Resources:

The following resources can be accessed on the Life Changes Trust's Peer-to-Peer Resources webpage: <https://bit.ly/2PaN23d>

- MILAN Senior Welfare Organisation: Urdu/Punjabi dementia awareness video
- British Deaf Association (BDA) Scotland: BSL videos for deaf people on different types of dementia and diagnosis
- Dr James McKillop MBE: Driving and Dementia booklet
- Outside the Box 'Food Buddies' and Agnes Houston MBE: Taste, Smell and Dementia Resource
- Agnes Houston MBE: Dementia & Sensory Challenges Booklet



If you would like hard copies of the Dementia and Self-Management booklet or any of the booklets above, please contact the Life Changes Trust:

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