



THE ALZHEIMER
SOCIETY *of* IRELAND



I have dementia... First steps after diagnosis



A photograph of an older woman and an older man standing outdoors in front of a large, classical-style building with many windows. The woman, on the left, has short blonde hair, wears glasses, a black jacket, a pearl necklace, and a black dress with large green polka dots. The man, on the right, has white hair and is wearing a dark suit jacket over a white shirt. They are both holding a large, light blue speech bubble-shaped sign that contains the text "I have dementia, I have a voice". The man is also holding a wooden walking stick. The ground is paved with light-colored stones.

**I have dementia,
I have a voice**

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Message from the Chair of the Working Group

When I was first diagnosed with Alzheimer's I felt I was left to cope on my own. No information was given to me and I didn't know who I could talk to. It was a difficult time for me and for my family. When I met other people with dementia who are members of the Irish Dementia Working Group, we

realised that many people do not get the information they need when they are diagnosed. We want to ensure that no-one goes through dementia alone.

The Working Group partnered with The Alzheimer Society of Ireland to develop this booklet. We shared our experiences since dementia entered our lives. We shared the tips and strategies that work for us.

We hope this booklet gives you the information you need to deal with those initial weeks, months and years after your diagnosis. We hope you will see that it is possible to live your life with dementia, that you can adapt to the changes that come and that you can still enjoy what life has to offer.

I would like to thank all the members of the Working Group for their time, commitment and courage in sharing their story. I hope you find this booklet helps you.

Helen Rochford Brennan

Chairperson of the Irish Dementia Working Group



First printed in 2014 by The Alzheimer Society of Ireland.
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About this booklet:

This booklet is for people who have been diagnosed with Alzheimer's or another cause of dementia. People with dementia helped to write this booklet. They are members of the Irish Dementia Working Group. Throughout the booklet, they share their experiences and talk about how they live their lives with dementia.

This booklet contains:

- 👁 information about dementia,
- 👁 practical tips to help you to live well, and
- 👁 details of where you can go to find out about supports and services.

People with dementia helped to write this booklet. They share their experiences and talk about how they live their life with dementia.

Acknowledgements

The Alzheimer Society of Ireland would like to thank all the members of the Irish Dementia Working Group for their expert input, time and commitment to this project.

We would also like to thank Matthew Gibb, Senior Social Worker and member of the ASI Medical and Scientific Panel for his helpful contribution to the project.

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There are over
48,000 people with
dementia in Ireland.



What is dementia?

Dementia is the name for a range of conditions that cause damage to the brain. This damage can affect memory, thinking, language and the ability to carry out everyday tasks.

There are many conditions which cause dementia. Alzheimer's is the most common cause. Vascular dementia, Lewy body dementia and Fronto-temporal dementia are other causes.

Sometimes a person may experience a mix of two dementias and this is called mixed dementia. Some people may be diagnosed with dementia and it may not be possible to confirm if it is Alzheimer's or another cause of dementia.



How will dementia affect me?

Each person's experience with dementia is unique.

Your experience with dementia can be influenced by:

- the cause of your dementia,
- other health conditions you may have, and
- supports and services that may be available to you.

While it is not possible to say exactly how dementia will affect you, some common symptoms include:

- **changes to your memory:** you may find it hard to remember recent things but find it easy to remember things from your past. You may also repeat yourself, for example you may tell a person the same story a number of times.
- **changes to how you communicate:** you may find you are searching for words to express yourself and you may lose track of a conversation.
- **changes in mood:** you may feel low in mood or feel less confident in yourself. There may be times when you feel sad, angry and frustrated. You may find it hard to express how you are feeling.
- **changes in completing daily tasks:** you may find it hard to plan or to concentrate at times and so find it difficult to do some things you used to.

There are lots of things you can do to help with these symptoms.

People with dementia can continue to do many of the things they always did as well as take up new hobbies and interests. For tips to help you see page 9.

See page 9 for
tips to help your
symptoms.





How does dementia progress?

It is not possible to say exactly how long a person will live with dementia or exactly how dementia will progress. Everyone is different.

For most people changes happen gradually. Many people with dementia continue to do lots of the things they always did and maintain their independence for many years.

While there is no cure for dementia, there are treatments and medications that can help some people and there are supports and services that can help you to live well.

For more information about dementia you can:

- 🕒 speak with your doctor,
- 🕒 contact our National Helpline at **1800 341 341**, and
- 🕒 visit **www.alzheimer.ie**

Reacting to your diagnosis

Hearing your doctor tell you that you have dementia is hard. It is normal to feel a range of strong emotions including:

👁 shock

👁 denial

👁 anger

👁 sadness

👁 frustration

👁 fear

👁 relief

It takes time to absorb and adjust to this diagnosis. It takes time for you and your family to understand dementia and the changes that it can bring.

It is important to talk to someone about how you are feeling. If you feel anxious, down and low in mood talk to your doctor.

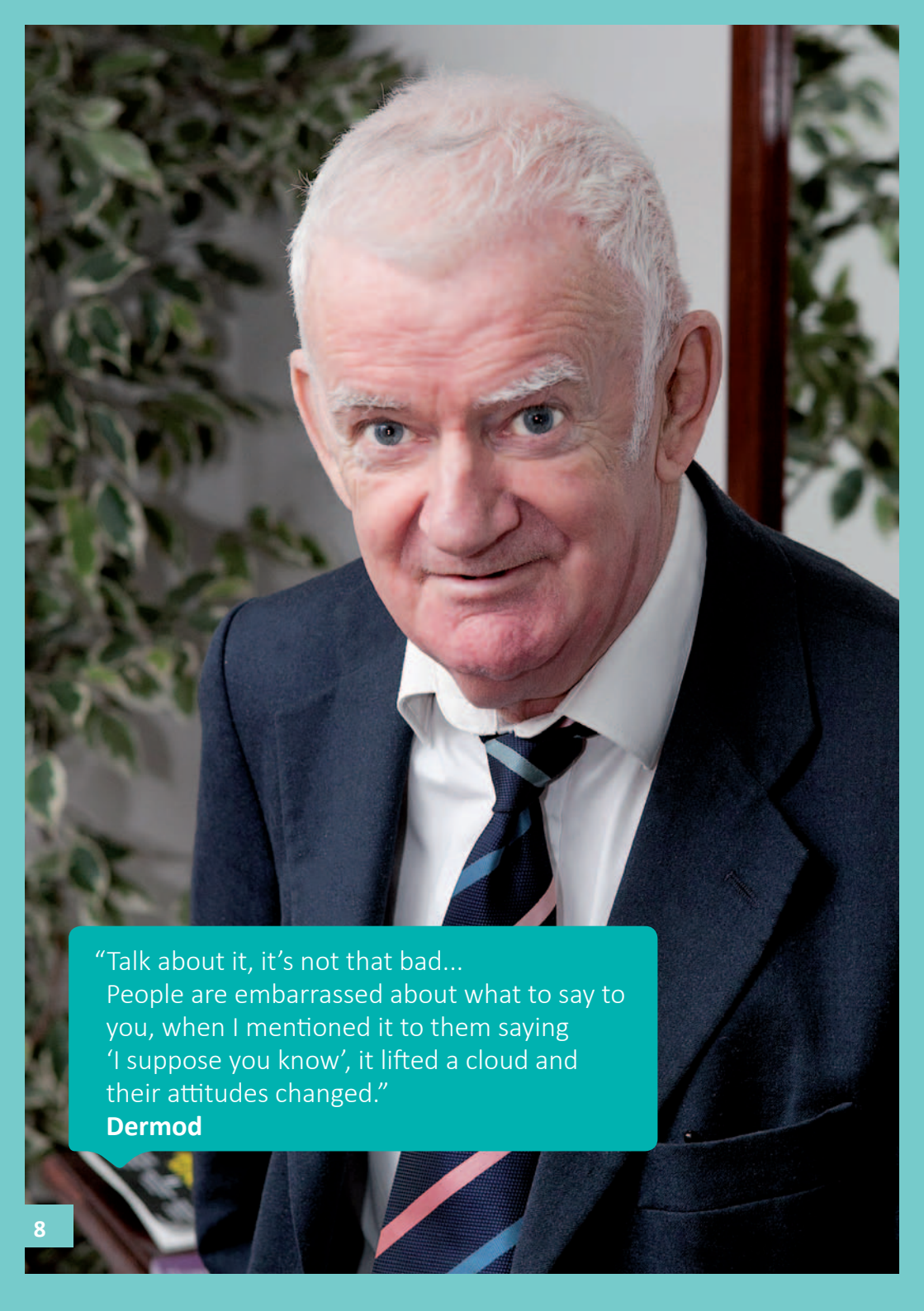
The following pages may help you to think about what you can do to live well with dementia.

Some thoughts from people diagnosed with dementia...

“In the weeks and months after a diagnosis you might feel isolated and low but it gets better.”

“That first year, I call it my bereavement year ...now I feel it is very important to be visible so people can see you get out... I don't want sympathy I can still do loads of things.”

“When I was first diagnosed, Lewy body dementia meant nothing to me. I was very surprised. I feel more positive now.”

A portrait of an older man with white hair and blue eyes, wearing a dark suit, white shirt, and a striped tie. He is looking directly at the camera with a slight smile. The background is blurred, showing green foliage and a wooden frame.

“Talk about it, it’s not that bad...
People are embarrassed about what to say to
you, when I mentioned it to them saying
‘I suppose you know’, it lifted a cloud and
their attitudes changed.”

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What can I do ?

There is no one way to live well with dementia. It may take some time to figure out what will work for you and what you want to do.

People with dementia who are members of the Irish Dementia Working Group share the following six steps they use to help them to live well.

1. Talk to people about dementia

“Let people know you have it. For years Alzheimer’s was never spoken about. All my neighbours know. I tell everyone.”

“Best to get it off your chest and not be hiding it and get a normal conversation going.”

Talking about your diagnosis may feel like a daunting step but talking to your family and friends is very important. When you feel ready, you can decide how to do this.

By talking about your diagnosis you can:

- 👁 explain how dementia affects you,
- 👁 explain what helps you to manage symptoms,
- 👁 reassure people that you are still the same person,
- 👁 highlight that you can still keep doing the things you want to do, and
- 👁 invite people to do things with you.

Your doctor can help you to tell your family about your diagnosis. You can also call the **National Helpline at 1800 341 341** to talk things through.

2. Keep active

“We can all walk, it’s a simple thing I do everyday and when I come back from my walks I feel very good. I feel a sense of achievement and well being, it’s very gratifying.”

“I feel the way I got on I’m very lucky in many ways. I think I’m always trying to improve things in the house and the garden. I’m always looking to make things better. I sometimes make things worse (laughs) but I keep trying.”

“I walk to the shop every day. This helps me get some exercise, buy some groceries and meet other people.”

Keeping active is important. You can continue to do things you enjoy or you can try something new. At times you may need help, or you might need to make some changes to help yourself.

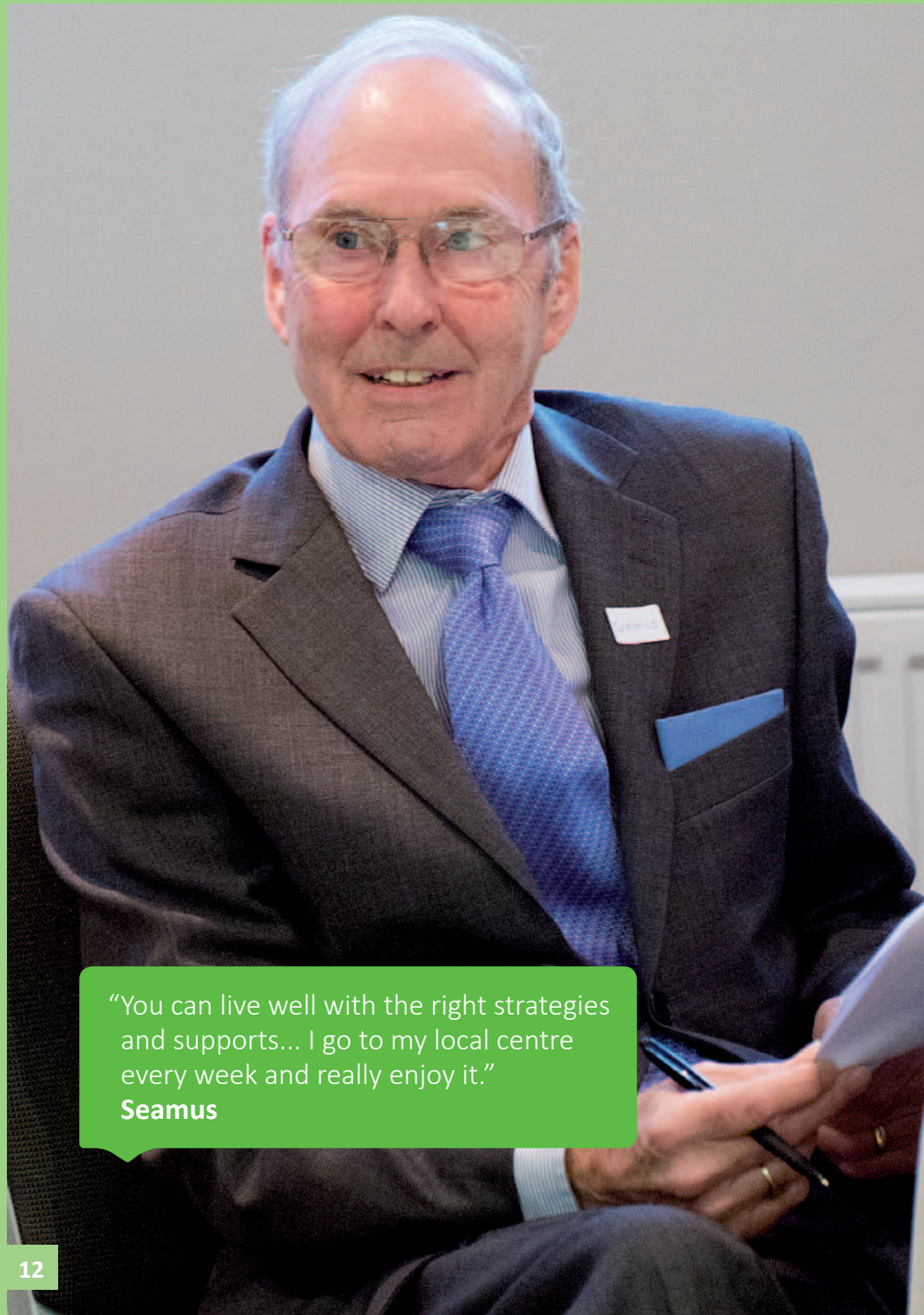
You can contribute to your local clubs and groups. More and more towns and counties in Ireland are becoming Dementia Friendly Communities. That means people in shops, cafes, hotels, clubs and groups value your contribution and want you to remain involved in what they do.

Contact 1800 341 341 to find about projects in your area.



"I was a very active citizen and then (after my diagnosis) there was a huge void in my life... self isolation, a withdrawal period. Once I started coming here (Irish Dementia Working Group) it helped me to be more active in the community."

Helen



"You can live well with the right strategies and supports... I go to my local centre every week and really enjoy it."

Seamus

3. Connect with services and supports

“I consider myself lucky. I’ve more of a sense of the whole scene (since going to an Alzheimer Cafe) I can talk to people with the same problems as me.”

“If you meet people in the same situation you’re mixing with people who understand, you can relax and say what you like. You feel you are not on your own. I got my confidence back.”

In many parts of Ireland, there are supports and services that can help. The Alzheimer Society of Ireland provide the following:

- 🕒 Dementia Advisors in a number of counties who can meet with you and talk to you about your needs.
- 🕒 Alzheimer Cafes and social clubs.
- 🕒 Home care services and day and respite centres in your community.
- 🕒 Cognitive Stimulation Therapy for people with early and moderate dementia.

Find out what is available in your area by calling our free and confidential helpline at **1800 341 341** or visit **www.alzheimer.ie**

There are also a number of dementia projects running in different locations in Ireland. These project all focus on living well with dementia and include a dementia choir, walking groups, exercise classes and much more. You can find out about these projects by calling our free and confidential **helpline at 1800 341 341.**

4. Tips to manage day-to-day

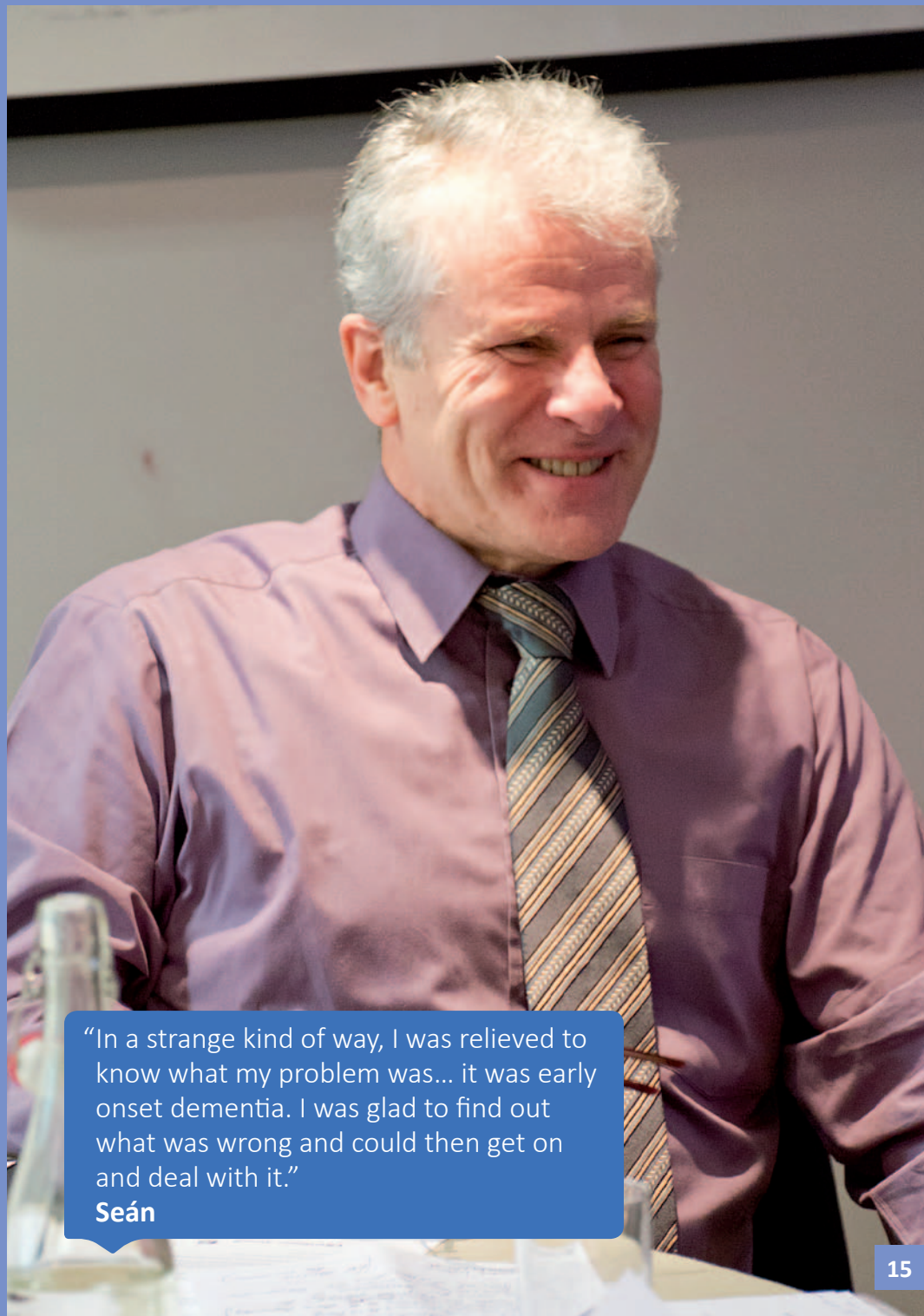
There are positive steps you can take to help yourself with day-to-day life. For most people with dementia, changes happen gradually. You will have time to adjust and to find out what works for you.

People with dementia recommend the following practical tips:

- Write things down
- Give yourself time
- Be patient with yourself
- Try to keep a routine
- Use a diary
- Keep important things in the same place
- Use technology to help you
- Ask your family and friends to help you
- Get to know your good times of day
- Eat healthily and keep hydrated
- Exercise (pick an activity that you enjoy)
- Make time to relax and rest
- Enjoy life and enjoy the good moments
- Laugh as a sense of humour is important

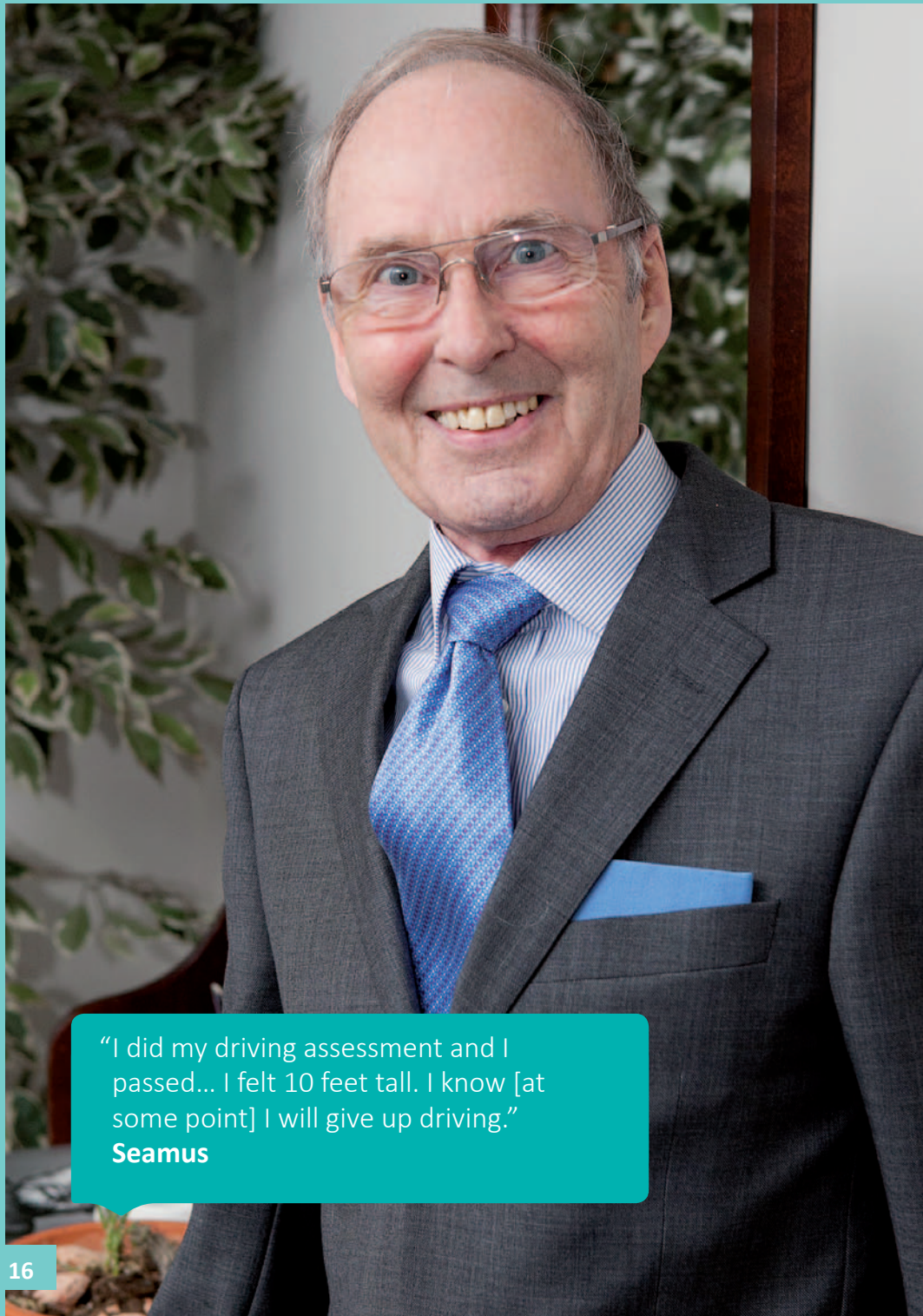
For more information about living well day-to-day, please see our factsheet [Practical tips for living well with dementia](#). You can order copies by calling **1800 341 341** or read this factsheet online at www.alzheimer.ie

“You are still the same person; you need to take things day by day.”



“In a strange kind of way, I was relieved to know what my problem was... it was early onset dementia. I was glad to find out what was wrong and could then get on and deal with it.”

Seán



"I did my driving assessment and I passed... I felt 10 feet tall. I know [at some point] I will give up driving."

Seamus

5. Driving and dementia

A diagnosis of dementia does not automatically mean have to stop driving. Over time, dementia does affect our ability to drive. Some people choose to stop driving themselves. Others would like to continue to drive. If you want to drive after your diagnosis, you need to:

- inform your insurance company that you have been diagnosed. (You will not be insured if you do not do this. Your insurance company can tell you the steps you need to take in order to continue to drive.)
- inform your Driving Licence Authority that you have been diagnosed. You can find your local centre on www.ndls.ie.
- successfully complete an 'on-road' driving assessment. This assessment is not like the learner driving test. It usually involves an assessor accompanying you as you drive in your local area to assess your ability to drive safely. This assessment may need to be repeated at agreed intervals, usually every six months.

"I give myself more time and I plan my route carefully... I drive the roads I know and that works for me at the moment."

For more information:

- read our factsheet Driving and dementia. You can order copies by calling **1800 341 341** or read online at www.alzheimer.ie,
- talk to your doctor.

6. Plan for the future

At any time planning for the future can feel overwhelming. When you are dealing with your diagnosis of dementia, it may feel like the last thing you want to do. But making decisions early is important.

Planning for the future includes:

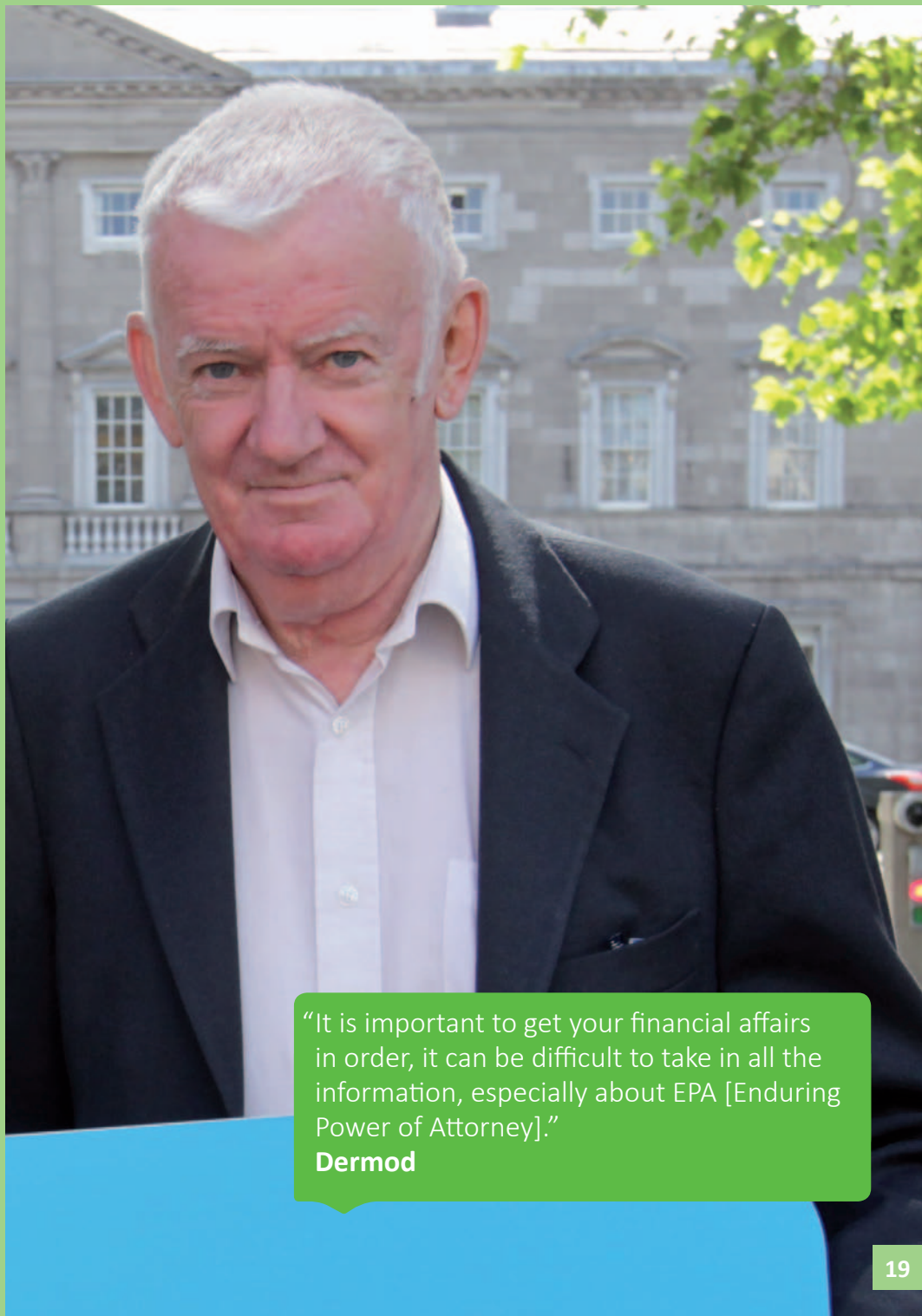
- 🕒 sorting out your financial affairs, savings, income and debt,
- 🕒 talking to a solicitor about your will and your legal affairs, and
- 🕒 talking to your family and doctors about your wishes and preferences.

For more information about planning for the future:

- 🕒 read our booklet 'I have dementia... how do I plan for the future?',
- 🕒 speak to your solicitor or doctor,
- 🕒 call our **National Helpline at 1800 341 341**, and
- 🕒 visit **www.alzheimer.ie**

"I'd prefer it sorted out... the trouble and expense it causes [is huge] if you don't do it..."

"It's good to have things sorted out."



“It is important to get your financial affairs in order, it can be difficult to take in all the information, especially about EPA [Enduring Power of Attorney].”

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For more information:

Useful publications



I have dementia...
I Have Rights



I have dementia...
**How do I plan
for the future**



**Practical tips for
living well with
dementia**



**Driving and
dementia**

You can order free copies by calling **1800 341 341**
or emailing **helpline@alzheimer.ie**

Disclaimer

The Alzheimer Society of Ireland has taken great care to ensure the accuracy of the information contained in this booklet. We are not liable for any inaccuracies, errors, omissions or misleading information.

If you would like to comment on this booklet, please contact Samantha Taylor, Information and Helpline Manager at **01 207 3800** and **staylor@alzheimer.ie**

Most photographs feature people with dementia who are members of the Irish Dementia Working Group. Some feature models.

Useful contacts

The Alzheimer Society of Ireland's National Helpline

This service provides information about dementia and about supports and services in your local area.

Freefone 1800 341 341 or

Email helpline@alzheimer.ie

Visit www.alzheimer.ie

The Irish Dementia Working Group

The Working Group is an advocacy group, led by people with dementia.

Freefone 1800 341 341

Visit www.alzheimer.ie

The Dementia Advocacy & Support Network International (DASNI)

This network provides an online support network for people with dementia.

Website www.dasninternational.org

The Frontotemporal disease Support Group

This is an online support group for people with Fronto-temporal dementia (including Pick's disease), Primary Progressive Aphasia and alcohol related dementia.

Website www.ftdsg.org

Citizen's Information Service

This service provides information about grants and income supports.

Locall 0761 074000

Website www.citizensinformation.ie

The Alzheimer Society of Ireland

National Helpline: 1800 341 341

Email: helpline@alzheimer.ie

Website: www.alzheimer.ie