Sheds for Life
An initiative by Irish Men's Sheds Association

dementia
understand together

THE Alzheimer
SOCIETY OF IRELAND

IRISH MEN'S SHEDS ASSOCIATION
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Your Shed and Dementia

A Manual

Acknowledgments

We, in the **Irish Men's Shed Association (IMSA),** would like to thank everyone involved in developing this manual. This manual was designed to raise awareness of dementia as well as offer advice for Shedders, their families, carers and shed committees on supporting a member with dementia in the shed.

A special thank you to The Australian Men's Sheds Association (AMSA) and Alzheimer's Australia NSW who have been very proactive in the area of dementia and developed a Men's Sheds Dementia Manual. They kindly gave the IMSA permission to adapt their version of the manual that would be representative of Irish Men's Sheds.

This manual would not have been possible without the collaboration of The Alzheimer's Society of Ireland and Dementia: Understand Together Campaign, who collectively recognise the value that Sheds bring to men and the opportunity to involve men with dementia.

And finally, a special thanks to our Shedders who have contributed to this manual. Over the last couple of years, through the IMSA's work in developing the Sheds for Life programme, the topic of dementia has been raised on many occasions by shed members and shed committees as a topic they would like advice and direction on.

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Introduction

Welcome to the IMSA's Dementia Manual, in collaboration with The Alzheimer's Society of Ireland and Dementia: Understand Together Campaign. This manual aims to raise awareness of dementia as well as offering advice for Shedders, their families, carers and shed committees on facilitating a member with dementia in the shed.

Some information about our dementia partners

The Alzheimer Society of Ireland works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers.

Dementia: Understand Together is a public support, awareness, and information campaign lead by the HSE. It is aimed at inspiring people from all sections of society to stand together with the 500,000 Irish people whose families have been affected by dementia.

Additionally, they aim to take on simple actions such as:

- See the person, not the dementia
- Talk about dementia
- Ask how you can help
- Stay in touch
- Support the person to keep up hobbies and interests

What this Manual is about

Until now there has been little specific information available to support men who are in the sheds who have dementia. This manual provides Shedders with the tools to change this and shows how you can effectively work with, and help out, friends who are living with dementia in a way that is respectful and empathetic. It provides practical ideas of how to involve a person with dementia that are easily achievable, and which can make a positive difference.

Many people with dementia continue to do lots of things they enjoy for some time. The shed could offer friendships, support, and routine. However, this does not mean that the shed is right for everyone. Each person with dementia is a unique individual with their own very different experiences of life, their own needs and feelings and their own likes and dislikes. This manual gives advice to shed members, committees and carers, in determining whether the shed is the right place for someone with dementia. This manual aims to improve your knowledge about dementia and encourage conversations around the condition. It is important to see the person and not just the dementia.

How to use this manual?

There is a tool for everyone here and the manual has been designed so that it can be read in sections or as a whole.

Some of the tools on offer are:

- Tools for all shed members– a summary of what dementia is, how to recognise it and simple ways to support men with dementia which can make a big difference. There are also tips on communication, and supporting carers within the shed. Go to pages 4-6 and 13-19

- Tools for men who are interested in joining a shed and have been diagnosed with dementia. Go to pages 7-12.

- Tools for helping the shed committees to make the best decisions for all concerned. Go to pages 20-23.

1. Dementia Information

Men's Health, the Brain and Dementia

What is Dementia?

Dementia is the term that is used to describe a collection of symptoms. Dementia affects thinking, behaviour and the ability to perform everyday tasks enough to interfere with a person's normal, social or working life.

Everybody's experience of living with dementia is different and their support and needs will vary over time.

Ageing, memory changes and dementia

Dementia can happen to anybody. Although the risk of getting dementia increases with age, the majority of older people do not get dementia. Dementia is not a normal part of ageing. However, dementia is more common after the age of 65 years. When people younger than 65 develop dementia, it is called "young-onset dementia".

Memory changes are a common experience of ageing, but these normal memory changes do not interfere with everyday life in a dramatic way. The following table helps to show the difference between memory loss in an older person compared to a person with dementia.

Dementia Compared to Normal Forgetfulness

Description	Person with Dementia	Normal Aging
Events	May forget part or all of an event	Memory may sometimes be vague
Words or names for things or objects	Progressively forgets	Sometimes may forget words or names are on the tip of the tongue
Written & verbal directions	Increasingly unable to follow	Able to follow
Stories on TV, in movies or books	Progressively loses ability to follow	Able to follow
Stored knowledge	Over time loses known information such as historical or political information	Although recall may be slower, information is essentially retained
Everyday skills such as dressing & cooking	Progressively loses capacity to perform tasks	Retains ability, unless physically impaired

It is important to remember there are a number of conditions people might think are dementia but are actually something else.

These include vitamin and hormone deficiencies, depression, dehydration, medication effects and infections. Many of these problems are treatable and so need to be discussed with your doctor.

There is no one symptom which fits everyone, and dementia may have an impact in various different ways in the early stages.

It is important that a medical diagnosis is obtained when symptoms first appear to ensure a person is diagnosed and treated correctly.

If the symptoms are caused by dementia, a timely diagnosis will assist access to any available treatment, support and early interventions.

Different types of dementia

There are over 400 different types of dementia. The four most common types of dementia are:

- **Alzheimer's disease**
- **Lewy body disease**
- **Vascular dementia**
- **Frontotemporal dementia**

It is common for people to have more than one type of dementia.

Alzheimer's disease is caused by flaws in the brain (plaques and tangles) that stop communication between nerve cells and cause them to die.

Vascular dementia is a cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke or series of mini strokes.

Lewy body disease is characterised by the presence of Lewy bodies inside nerve cells. These abnormalities occur in specific areas of the brain and cause changes in movement, thinking and behaviour.

Frontotemporal dementia involves progressive damage to the frontal and/or temporal lobes of the brain. Symptoms often begin when people are in their 50s and 60s and sometimes earlier.

Common early symptoms of dementia

Although symptoms of dementia are different for different people, common early symptoms include:

- **Increasing confusion**
- **Reduced concentration**
- **Personality or behaviour changes**
- **Apathy and withdrawal or depression**
- **Loss of ability to do everyday tasks**

For more information about the different types of dementia you can call the Alzheimer Society of Ireland's National Helpline on 1800 341 341 or visit the website: www.alzheimer.ie

2. Sheds and men with dementia

The relevance of dementia to Men's Sheds

The number of people with dementia in Ireland is expected to more than double from 64,142 today to 150,131 in 2045. It is therefore probable that the Men's Shed you are involved in may encounter dementia, through either a member or a spouse being diagnosed at some stage.

There may also be men with early stage dementia or carers of spouses or partners with dementia interested in participating in their local Men's Shed as a meaningful social activity.

More than half of people who have dementia have the early stage or mild form. People with early stage dementia do not generally need assistance with daily activities. Depending on their interests and skills, many can meaningfully contribute to the activities of Men's Sheds.

For people with dementia, doing something meaningful and being engaged socially has been shown to increase their quality of life and sense of self-worth. There is now also some evidence that involvement in meaningful activities that include social engagement can potentially slow down the progression of dementia.

Sheds and men with dementia

Men's Sheds are a safe and friendly environment where men can work on meaningful projects at their own pace in their own time, in the company of other men. A major objective of Men's Sheds is to advance the wellness and health of their male members by reducing their social isolation and increasing their social engagement.

Men with early stage dementia are welcomed by Men's Sheds across Ireland. Many men with early stage dementia who are members of Men's Sheds are active participants in Shed activities. As one Shed member says, "They're just like us!" Men's Sheds can provide a place for doing something meaningful and social.

> **"A friend brought me to the local men's shed, and to say I haven't looked back is an understatement. The shed has given me a new lease of life. I'm there every day.**
>
> - Men's Shed Member

What things do you need to consider before you join a Men's Shed?

1. Work out which Men's Shed is right for you.

There are more than 450 Men's Sheds in Ireland, so it is likely that there are several close to where you live. Each Shed is different. Some are small (around 3-10 participants), some are large (more than 40 participants).

Each Men's Shed offers different activities from woodworking and metalcraft to card games and gardening and everything in between. So how do you decide which shed is the right one for you?

Find out what Men's Sheds are in your local area. The IMSA website has a Shed finder for helping you find your local Sheds.

Call or email your local sheds to see what their main activities are.

Arrange a visit to some local Sheds that have activities that match the things that you are interested in being involved in.

You may want to take a friend or relative for the first few visits to the Shed to see if you feel comfortable there and make new friends at the Shed.

Finding sheds close to where you live

1. Go to IMSA website - Shed Finder Page **https://menssheds.ie/shed_county/all-provinces**
2. Select your province or county
3. You will see the details of Sheds within your area

> **"I have personal experience with a member with dementia, who we all fell in love with and part of the reason we fell in love with him I suppose was for all sorts of reasons but there was a caring attitude. When you see somebody else that could be you and could be you an awful lot sooner than you think.**
>
> – Men's shed member and Shed Support Volunteer

2. Talk to the Shed about your level of ability.

Health and safety at the Sheds is a key consideration so it is important to be frank about the extent of your abilities. There may be some things that are unsafe for you to do and there may be some areas of the Shed you may need to avoid for your own safety. Men attending Men's Sheds need to have a level of independence and if they are not independent, need a carer.

Things to consider and talk to your spouse, family or carer about before you participate

- **What activities will be safe and what activities will be unsafe for you to participate in?**
- **What is the best time of day to participate? (Is there a time, e.g. the morning where you feel more like going out and being social?)**
- **Is it a good idea to bring along a carer?**
- **What does the carer need to know when they come to the Shed with you?**
- **What are the carer's responsibilities when they are at the Shed supporting you as a shed member?**

> **We all gravitated towards him because he was a musician. He brings music to the shed which has transformed it. It's a universal language. We can all share it. So, he's brought a lot of enjoyment.**
>
> – Men's shed member and Shed Support Volunteer

Have a plan for yourself and the Shed for when your dementia gets worse

It is helpful to have a plan for what to do when your dementia progresses and discuss this with your spouse or partner or carer and the Shed. This may mean bringing a carer to the Shed with you. It may mean changing the activities you do at the Shed or going to the Shed for shorter periods or at a different time. Members are encouraged to let their Shed colleagues know how they can help overcome situations that might be becoming difficult to manage. This might be a railing or modified workbench and additional labelling in areas.

It is important that you or your carer advise the Shed member in charge of operations of any changes in ability, if this change may have an effect on your safety or the safety of others at the shed.

There will come a time when you may not feel comfortable attending the Shed alone or with a carer. It is helpful to have a plan for this up front. You may want to discuss what kinds of things you may do to keep in contact with the Shed when you are no longer able to attend the Shed and participate independently. For example, find out if you can call in with your spouse or partner or carer for a cuppa.

3. Useful contacts

Organisation	Website	Email	Phone
Irish Men's Shed Association	www.menssheds.ie	info@menssheds.ie	01 891 6150
Alzheimer Society of Ireland	www.alzheimer.ie	helpline@alzheimer.ie	1800 341 341
Family Carers Ireland	www.familycarers.ie	info@familycarers.ie	1800 24 07 24

“

The shed saved my life and that's the truth of it. I wouldn't be here otherwise.

– Men's shed member

3. Supporting members with early stage dementia

Be a friend – supporting men

After a diagnosis of dementia many people experience loss of friends and reduced social contact which can leave them feeling isolated. Maintaining social connections and meaning in life through existing and new friendships and meaningful activities can make a big difference to the quality of life and happiness of a person with early stage dementia.

There are lots of ways you can support members who have dementia by helping them feel comfortable and safe participating in the group. Although a person with dementia may sometimes appear not to understand what is being said, they retain the same feelings and emotions as everyone else, so things like tone and body language are important.

Ways to support members with dementia

Help ensure time is as structured and predictable as possible.	Break down instructions. Focus on one thing at a time.
Day planners and checklists can be helpful.	Encourage joining in and having a sense of belonging in the group.
Encourage freedom of movement through a safe environment.	Learn more about dementia so you can understand more about what the men are experiencing.
Understand that men's ability may fluctuate from day to day.	Do not force men to join in or to do anything.
Initiate conversation.	Give all more time to participate and complete tasks.

Be a friend – Even saying "hello" and "goodbye" can make a big difference.

Communication Tips

Communication is as important for people with dementia, as it is for anyone else. Our attitudes and approach are vital to assisting people with dementia to communicate. Communication and social interactions of people with dementia can improve (it is a misconception they cannot) when communication is encouraged.

Any way you can find to help members with dementia communicate and connect socially will make a big difference to their day and quality of life. People with dementia retain their feelings and emotions even though they may not always understand what is being said, so it is important to help them maintain their dignity and self-esteem. It is helpful to remember all of us rely more on body language and tone of voice than on words to communicate with one another.

You can learn more about dementia and how to support members with dementia by contacting the Alzheimer's Society's National Helpline on 1800 341 341

General Approach

- Smile.
- Stay Calm.
- Establish eye contact.
- Use touch where appropriate; (e.g. a handshake, a pat on the shoulder).
- Speak slowly, calmly and clearly.
- Talk in a quiet place where possible.
- Sit face-to-face where possible.
- Use a calm tone which conveys warmth.
- Use their name so they know you are speaking to them.

Listening Hints

- Allow plenty of time for what you have said to be understood. Silence can give time to think.
- Do not jump in if a person is still thinking of a word. Allow them to formulate their sentence.
- Prompt where appropriate.
- Listen and take what is being said seriously, even if the person's reality may be different. For example, they say "It is a cold day" when it is actually a really hot day. Do not correct them, just acknowledge, and say "Could be...".
- Show you are listening by your body language, paraphrasing what they have said and by asking questions.

Language Hints

- Keep sentences short.
- Only focus on one instruction or idea at a time.
- Use nouns and names. For example, say "Can you pass the hammer?" instead of "Can you pass that?"
- Use gestures. for example e.g. point to objects or demonstrate actions, wave when you say hello and goodbye.
- Limiting choices for response will make it easier to respond. For example, "Do you, want a scone or a sandwich?" instead of "What would you like to eat?".
- Say things to orient men to where they are, such as what time of day it is and what is happening. For example, it is nearly lunch time here at the shed.

Easy ways to include men with dementia

Every Men's Shed has its own unique culture and identity. There are numerous ways to help Shedders with dementia feel a part of the Shed group, from including them in the Shed banter to ensuring they have a key role in the Shed.

Some Shed member's wives regularly bake biscuits and cakes that the members proudly bring to the Shed for a shared morning tea. Giving the shed member the opportunity to get involved in projects or tasks will create a sense of belonging. Even a simple gesture of saying ''hello'' and ''goodbye'' to men at the shed makes a major difference to all men feeling included.

> **“I thought that this man would benefit greatly and we benefit greatly too. He’s a bonus, he’s a plus, he’s teaching us. We are benefiting from his presence in the same way that he is benefiting.**
>
> – Men’s shed member and Shed Support Volunteer

When it is time to say goodbye

There will inevitably be a time when members with dementia will no longer be comfortable or be able to participate in the Shed on a regular basis. The best way to help is to stay interested and in touch with the member and let them know how much they are valued as a friend.

Below are some ways you could continue to support members with dementia when they are no longer regularly attending the Shed.

- **Invite them to the Shed for a cuppa every now and then.**
- **Phone them or call in to see how they are doing.**
- **Invite them to special events (e.g. Christmas party).**
- **Write them a letter to thank them for their contribution to the shed.**
- **Continue to send them your Shed's newsletter or Shed information.**
- **Ask them, their carer, their spouse or partner what might be useful ways to continue to support them.**

> **"If we had not gotten to know his wife we would have missed a trick you know, that fact that us knowing her and she knowing us. We had a huge relationship with her and her daughter. It paints another side of his life, it helps us in regards to him, in understanding him and understanding his life. This is what goes on behind the scenes.**
>
> – Men's shed member and Shed Support Volunteer

4. Looking out for men who are carers

Supporting a shedder who is caring for a family member or friend

Shed members and men wanting to become members may be the carer of someone who has dementia or another condition that requires supportive care either at home or in a residential facility. Caring can be emotionally and physically demanding. Carers need support so they can look after themselves as well. Carers may have difficulties in accepting what is happening to the person they are caring for and coping with the changes they are experiencing in their own life. They may be dealing with many different feelings such as guilt, grief, loss and anger. Men can find the task of caring even more challenging as they may not have the emotional support network of women and may need extra help.

How to help someone who is a carer

- Be willing to listen - Listening is one of most important things you can do for a carer.
- Find out what sort of assistance they may need.
- Help them locate assistance within the community.

Listening to carers

- There is no proper or right thing to say to a carer.
- Be willing to listen.
- Ask them "Are you okay?" or "How is your wife/partner?" and then listen. It can really help them to give them the chance to talk things through.
- It is also important to remember they may not want to talk about their 'caring role' and may prefer to have time out from talking about it at the Shed.
- Listen carefully, rather than jumping in with suggestions. You may find the support they need is not what you had expected.
- It can be tempting to offer practical solutions, but often people just need a chance to say how they feel.
- Try to be supportive and accepting, and not judgmental.
- Listen for issues such as carer stress or loneliness.
- Be open to helping them locate assistance in the community.

Helpful contact suggestions for assistance for carers

Type of Assistance	Operation Name	Contact Information
Confidential information and support service for people with dementia and carers	Alzheimer Society of Ireland	National Helpline 1800 341 341
Information about caring roles, carer services and entitlements	Family Carers Ireland	National Careline 1800 24 07 24
Information about a range of community care programmes and services available to help people stay in their homes	Health Service Executive	HSE Live 1850 24 1850

5. Information for the Shed Committee team

This section outlines some practical considerations which Shed Committees might like to consider with regard to supporting a man with dementia in the shed.

Two situations you may encounter are:

1. A person with dementia who is interested in becoming a member of your Shed.
2. A fellow Shed member who has a diagnosis of dementia.

Things to consider if a person with early stage dementia is interested in joining the shed.

It is worth remembering that men with early stage dementia can be valuable members of your shed. Most sheds are set up for independent participation and socialisation by members. It is up to each Shed to make the rules and set the boundaries of its membership that is appropriate to the capacity and circumstance of each individual Shed and its members.

Key questions you may want to consider for interested members

- Are their interests a good match to the activities available at your Shed?
- Will their level of ability enable them to participate safely? Are there areas or activities that will have to be restricted?
- Are any modifications required to the Shed for safe participation? (Note: this consideration is no different from considerations for any other prospective Shed member with a disability).
- Do they have access to a carer who can accompany them to the Shed if required?
- Are there next of kin contact details and set times for the member to come to the shed?
- Is there a clear understanding that the Shed needs to be notified and communicated with if there are any changes in the member's ability that may have an impact on their safety or the safety of others at the Shed?
- Do they need any assistance to overcome situations in the Shed that might be difficult to manage? (e.g. hazard paint on steps or anti slip tape on edges)

Completion of membership processes

Once the Shed and the prospective member agree the Shed is a good match for their interests and abilities and they will be able to participate safely (and whether they need a carer to attend with them or not), completion of the membership formalities can get underway. You may want to suggest the new member attends the first few sessions with a relative or friend until they feel comfortable at the Shed and new friendships are formed.

Supporting a fellow shedder with dementia

If the condition of any member changes and this has safety implications, it is important to consider ways in which the member can be supported to stay in the shed safely. For example there may be a need to change their role in the shed, decrease the number of hours they spend there or for their carer to accompany them. The shed may also need to be modified. This should all be worked out with the member, and his spouse, family or carer.

If the decision is made for the member to exit the shed, it is suggested that an exit plan is formed with the member, spouse, family or carer. This could include short social visits to the Shed in the lead up to the exit and phone calls or visits to the home by fellow Shedders after their exit to ease the transition and reduce the impact of the loss of social connection.

How to ensure the shed is as safe as possible

People with dementia may be experiencing increasing difficulties in their physical and social environments. As dementia can affect the cognitive, sensory and physical abilities of a person, there are specific issues to keep in mind to ensure a safe shed environment for all.

Things that could help the environment:

- Clear labelling – don't write words in all caps as it's harder to read.
- Be clear about "out of bounds" areas.
- Give simple instructions.
- Avoid clutter and obstacles.
- Focus on one thing at a time.
- Match any activity to the person's abilities.
- Ensure good lighting.
- Look out for each other.
- Provide supervision.
- Reduce noise levels if possible.
- Involving a person's carer in the shed.
- If a member needs to bring a carer to assist their participation at the Shed, there are a few things they need to know.

What carers should know

- They are principally at the shed to help the member they are caring for to participate.
- Their role is to help the member they are caring for to participate.
- They are the sole carer of the member at the Shed.
- The carer is not at the shed as a member themselves. However, membership may be required. For example carers may need to become members for insurance purposes.
- Paid carers should have existing insurance that covers them for attendance at the shed.

Useful contact information

Type of information	Organisation	Website	Phone
About dementia & supports/services for carers & people with dementia	Alzheimer Society of Ireland	www.alzheimer.ie	1800 341 341
About dementia inclusive communities, training & awareness	Dementia: Understand Together	www. understandtogether. ie/get-involved	
About Men's Shed's	Irish Men's Shed Association	www.menssheds.ie	01 891 6150
About caring roles, carer services & entitlements	Family Carers Ireland	www.familycarers.ie	1800 24 07 24
About community care programs and services	Health Service Executive (HSE)	www.hse.ie	1850 24 1850
About brain health	Alzheimer Society of Ireland	www.alzheimer.ie	1800 341 341

01 891 6150
info@menssheds.ie
www.mensshed.ie
Irish Men's Sheds Association,
Irish Farm Centre, Bluebell, Dublin 12
Charity No: 20078591