

Respect, support and value the person living with dementia.



## Respect, support and value the person living with dementia.

A person with dementia is a unique individual and a valuable human being. As dementia progresses, people can feel vulnerable and need support. Understanding what it is like to live with dementia can help you support them. This factsheet offers suggestions on how to help a person living with dementia to live well. Dementia also affects people in different ways. Their experience of living with dementia daily will be affected by:

- their life history
- their environment
- their relationships
- their daily routines and activities

When you are supporting a person living with dementia, it is helpful to think about how all these factors may impact them. There is no specific way of supporting a person living with dementia. You can try to adjust your support to what you know about the person's individual wishes and preferences.

A dementia diagnosis can trigger emotions such as grief, shock, disbelief, anger, fear, and loss. Some people may struggle to deal with a diagnosis because they may feel anxious about the future. They may not understand what their symptoms mean, or they may be worried about the impact of dementia on those around them. For others, there is a degree of relief, because they now understand what is happening.

## What to do if the person does not acknowledge that they have dementia?

When a dementia diagnosis is made, it can be very difficult for that person to accept their diagnosis. They may not be aware of any issue and may feel that nothing is wrong. Sometimes a person does not want to accept a diagnosis because they are afraid and are in denial. Allow them time to come to terms with the diagnosis and let them talk about it when they are ready. Sometimes it can be helpful not to use the word dementia, and use softer terminology to acknowledge how the person is feeling without scaring them.

There are ways to help someone even if they do not want to accept their diagnosis. For example, you could contact the Alzheimer Society of Ireland's national helpline to see what services and supports are available to help a person come to terms with their diagnosis.

You could also request some of our factsheets such as Practical Tips for living well with Dementia, and Practical steps to support your independence. Focus on what they can do rather than what they can't do

- Allow the person living with dementia to talk about their diagnosis and acknowledge how they feel.
- Let them know that you are there for them.
- Always try to see things from their perspective.

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- Give them time to handle their emotions.
- While it can be valuable to think ahead and make plans, try to also concentrate on the time that you have here and now.

#### You may need to remind others that:

- Family, friends, and professionals may need to adjust how they communicate and interact with a person living with dementia. See our Communication factsheet for tips and strategies.
- People living with dementia often remember the past far more clearly than the recent present and are often happy to talk about their memories.

#### Background information

The more background information you can gather and share about the person's past, as well as their present situation, the easier it will be for others to see them as a whole person, rather than simply as someone living with dementia

Use a diary or create a life story book. The person living with dementia may be able to help. These can be used to record important details from a person's past daily routines, likes and dislikes, names etc and once completed will always be there as a guide for whoever is caring for your loved one or filling in for you while you have a break. See our Information for Families
 Life story book at home factsheet or you can purchase a life story book from our website or by contacting our National Helpline on 1800 341 341.

Contact the Alzheimer National Helpline for free confidential help and support.

The Helpline is open Monday to Friday 10am to 5pm and Saturday 10am to 4pm. Freephone **1800 341 341**.

Email: helpline@alzheimer.ie or visit live chat via www.alzheimer.ie

## A person living with dementia is still an adult

It is important that everyone continues to treat the person as an adult, with respect regardless of the stage of dementia they are in.

- Be kind and reassuring without talking down to the person living with dementia or as though they are a child.
- Never talk over the head of a person living with dementia or across them as though they are not there.
- Do not talk about the person living with dementia in front of them unless they are included in the conversation.
- Avoid scolding or criticising the person as this will make them feel small.
- Look for the meaning behind what they may be trying to communicate even if it does not seem to make sense.

#### Feeling valued

The person living with dementia needs to feel respected and valued for who they are now, as well as for who they were in the past. It helps if those caring:

- are flexible and tolerant
- can make time to listen and to chat & enjoy being with the person
- can show affection as appropriate
- Focus on what they can do rather than what they can't do.

#### Feeling useful

We all need to feel useful and needed. Helping with simple tasks around the home or in the garden, if you have one, is a good way of enabling people living with dementia to practise everyday skills and feel useful at the same time.

Suggestions for chores in the home include:

dusting

clearing tables

polishing

drying dishes

hanging clothes

sorting cutlery

folding clothes

Work in the garden might include digging, watering, raking or sweeping leaves.

Look and see whether you can also help them maintain skills related to past interests. If the person enjoyed cooking, they may be able to advise you on a recipe or help with a particular dish. Or if they were good at carpentry, they may get satisfaction from sawing a piece of wood, for example. (You could contact your local men's shed to see if they are looking for new members. Contact details are at the back of the document.)

Try not to worry if such tasks are not done very well. What matters is that the person living with dementia is active, involved and still using their abilities.

- It is more important that the person feels they are helpful and of value.
- Be very tactful if you do have to redo a chore.
   Make sure that the person is not aware of this fact.
- Remember to thank them for helping.
   Compliments, praise and encouragement are so important to make them feel valued and useful.

#### Feeling Safe

The less anxious and stressed the person living with dementia feels, the more likely they are to be able to use their skills to the best of their advantage. A relaxed, uncritical atmosphere is therefore important.

- Familiar surroundings and a regular routine are reassuring for people living with dementia.
- Too many conflicting sounds or too many people can be confusing. Turn off the radio or TV or take the person to a quiet place if they need to concentrate on a task.

- The person may be upset or embarrassed by their changing abilities or clumsiness and will need plenty of reassurance.
- Although you need to be tactful and encouraging, sometimes you just have to laugh together when things go wrong.

#### Repetitive behaviour

It is very common for a person living with dementia to become fixated with something. This can range from counting money, cleaning, locking doors. This can be because the person living with dementia is trying to have a sense of purpose and they don't feel in control. They develop these coping strategies that can be labeled as obsessive.

For more information on behaviour and ways to help, you can request our **Behaviour** factsheets by calling our **National Helpline on 1800 341 341** 

## Changes in emotions / expressing feelings

As dementia progresses, a person may react differently to certain experiences. This is because dementia affects the thinking and reasoning part of the brain and memory. For example, they may have sudden mood changes or appear more irritable. They may appear apathetic and not interested in things, particularly if they are not sure of their environment.

People living with dementia are likely to be sad or upset at times. They have the right to expect those caring for them to try and understand how they feel and to make time to offer support rather than ignoring them or jollying them along.

In the earlier stages, people may want to talk about their anxieties and the problems they are experiencing. It is important that others do not brush these worries aside, however painful they may be, but listen and show that you are there for them and will be there for them.



#### Depression and anxiety

Depression and anxiety are common, particularly in the early stages of dementia when people are more likely to be aware that something is wrong.

- If the person can talk about what is troubling them, listen, and show you understand their feelings rather than brushing them aside or distracting them. Offer affection and support.
- If you feel that the person is particularly depressed or anxious, ask the GP for advice. It is often easier to deal with such problems at an early stage. The GP may make a referral to a psychiatrist.



#### Identity

Having dementia means a person may have do some things differently but they are still the same person. You have an important role in helping them to be themselves.

Our sense of who we are is closely connected to the name or names we are known by. It is important to make sure that others address the person living with dementia in a way they recognise and prefer. Not everyone is happy for other people to call them by their first name or by the name used by friends and family. Some may prefer younger people or those who do not know them well to use a courtesy title such as 'Mr' or 'Mrs'. The person living with dementia may not remember your name. When you meet them, it is a good idea to use your name and theirs. It reassures the person you know them, and they know you.

Make sure that anyone caring for the person living with dementia has appropriate details about any relevant cultural or religious customs or beliefs so that these can be respected.

These may be anything from diet/clothing/use of jewellery/ ways of undressing/doing hair.

Some forms of touch which are taken for granted in some cultures are considered disrespectful in others. You may need to explain any religious observances such as prayer and festivals as well as other traditions to those providing care from a different culture.

If the person you're supporting identifies as LGBTQ+, they may face other challenges living with dementia, for example, revealing their sexual orientation or gender identity. They may need specific support that takes this into account.

For information and advice, you can call the LGBT Ireland National Helpline on 1800 929 539

#### Respecting privacy

Try to make sure that the person's right to privacy is respected.

- Suggest that people knock on their bedroom door before entering, for example.
- If the person needs help with intimate activities such as washing or going to the toilet, this should be done in a sensitive way. Make sure that the bathroom door is kept closed if other people are around.

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#### Offering choice

It is important that the person living with dementia should be informed and wherever possible, consulted about matters which concern them. They should also be given every opportunity to make appropriate choices.

- Even if you are unsure how much the person can understand, always explain what you are doing and why. You may then be able to judge their reaction from their expression or body language.
- Although too many choices can be confusing, you can continue to offer choice by phrasing questions that only need a 'yes' or 'no' answer such as 'Would you like to wear your blue jumper today?'

The use of pictures can support a person living with dementia to make choices for example - pictures of food choices at dinner.

#### Communication

Communication with the person will become more challenging as their dementia progresses. There are many ways to help someone to communicate. For more information see our factsheet on **Communication**. You can request this from our Helpline by calling 1800 341 341

## Independence and maintaining skills

Try to support the person to do things as independently as possible. When someone is struggling with a task, you may feel like you want to complete the task for them. For someone living with dementia, this can result in a loss of skills and feelings of frustration.

If the person doesn't want to ask for help, or refuses offers of support, this can be upsetting and frustrating for you. Remember that they may be finding it hard to adjust to needing support.

- Try to help the person to do things for themselves rather than taking over. It may mean tasks take longer but it can help them to retain their skills.
- When offering help, involve the person living with dementia as much as possible. This may mean doing things in the way they prefer (if it's practical and safe to do so).
- To promote independence, make sure the items required for the task are in the person line of vision. Ensure there is adequate lighting.
- If the person wears aids such as glasses, hearing aids or false teeth, ensure these are in place before they start an activity.
- Think of ways you can adapt activities so that the person can continue to do them independently. For example, you could pre-set their favourite radio station so they can enjoy it without having to tune the radio themselves. You can purchase easy to use remote controls for the TV. Putting pictures on wardrobes of clothing can assist the person when dressing. Pictures on doors can help identify the bedroom or bathroom and promote independence.
- Don't assume that the person can't understand what is happening or is unable to participate. Allow plenty of time for them to respond. Focus on one task at a time.
- O Give plenty of praise and encouragement.
- It is important that the person living with dementia does not feel that they are being supervised or criticised in any way. The tone of voice can imply criticism as well as the actual words.
- Ask other people (especially professionals) to speak directly with the person living with dementia first, and then if they need to, with you.
- An occupational therapist can advise on aids and adaptations and other ways to help the person living with dementia to retain their independence for as long as possible. For advice on where you can get these aids, contact the National Helpline on 1800 341 341 or email helpline@alzheimer.ie. You can contact an occupational therapist through the public health nurse, the local health centre, your GP or your local hospital.



Memory resource technology rooms give the opportunity to see how assistive technology can promote independence. Contact details can be found by going to https://alzheimer.ie/service/ memory-technology/ or by contacting the Alzheimer Society of Ireland National Helpline on 1800 341 341.

If you are caring for someone living with dementia, you will want to ensure that they remain as fit and healthy as possible. The better the person feels, the more enjoyment they are likely to get from life and the easier it will be for both of you to manage. It is helpful if you can prevent health problems from occurring or at least catch them at an early stage. Do not hesitate to contact the GP or other professionals for advice. Here are some suggestions that you may find useful.

#### Check-ups

Regular check-ups are important if there are concerns, such as high blood pressure, diabetes or issues with eyes, ears, and teeth. It is also a good idea to get all aspects of physical health checked as soon as possible while they are still able to give information about themselves and more able to adjust to any changes such as glasses, hearing aids or dentures. Often health issues can be dismissed as symptoms of dementia.

#### Medication

In general, the fewer drugs the person must take, the better.

- Check with the GP to make sure that the person is not taking any unnecessary drugs. People sometimes continue with repeat prescriptions longer than is needed.
- You may also want to check that they are taking the lowest possible effective dose of any drug that they need.
- Some drugs or a combination may increase a person's confusion or have other side-effects. Always let the GP know immediately if this occurs.

- Blister packs can be used to make it easier for the person living with dementia to take their medication.
- If memory problems are more severe, you may have to supervise their medication in case they overlook a dose or take an extra dose by mistake. Lock medicines away as an extra precaution.
- It can be helpful to keep a diary of different medication they are on and any side effects that happen because of them.

#### Feet

Healthy feet are essential if the person living with dementia is to remain mobile and active.

- Check that their shoes fit well. Backless slippers should never be worn.
- Keep feet clean and dry. Toenails should be cut short. (If there is a diagnosis of diabetes, toenails should only be cut by a chiropodist)
- If any part of the foot becomes swollen, painful or there is a noticeable change of colour to the skin, contact the GP as soon as possible.
- If there are problems such as corns or ingrown toenails, for example, consult a chiropodist.



#### Exercise

Regular exercise is vital for the health of someone living with dementia. It enables them to remain mobile and independent for as long as possible. Improves circulation and help to prevent stiffness and muscle wasting. Improves sleep quality and helps to reduce anxiety, depression and stress.

#### Mobility

The more mobile the person remains, the better for their health. Look for ways of helping the person to remain mobile.

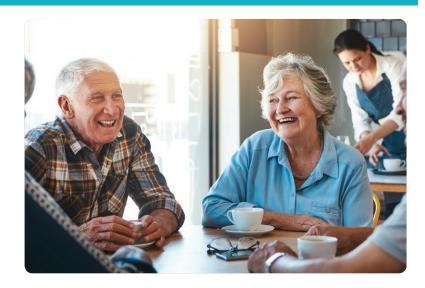
When mobilising, where possible try to encourage the person living with dementia to wear a good pair of shoes. Ideally ones with laces. There are elastic laces available which don't have to be tied every time. They stretch and retract as the person is putting the shoe on and taking it off.

If they become unsteady on their feet, seek advice from a physiotherapist who can advise on walking aids to help them to move more safely. They will probably spend quite a lot of time sitting, so a firm comfortable chair is important. It should be one with arms that is easy for them to sit down in and get up from. If the person requires support to move, seek advice from an occupational therapist or physiotherapist to prevent injury to yourself and the person living with dementia.

#### Social Skills

Meeting people and getting out and about can enable people to maintain their social skills and help counteract the apathy and withdrawal that are common in dementia. People living with dementia will usually need one-to-one attention on outings or at social gatherings.

- Explain the situation to friends and neighbours so that they will understand any slight changes and encourage them to drop in for a chat. Maintain relationships in the community by walks in the local park, going to a local football match where it is not too busy or noisy.
- Encourage the person to go to a social club, alzheimer café or a day centre. There are also several dementia friendly community projects around Ireland which focus on helping people to stay connected with their community. Call our Helpline or visit www.alzheimer.ie.



- Encourage the person living with dementia to continue to go out and about. Depending on what they enjoy, this might be a visit to the shops, for example, or visit to the local garden centre or to hear music in the park. Encourage the person to take pride in their appearance so they feel more confident.
- If the person enjoys going out for a drink or a meal, try to continue this. A word with the manager of the restaurant/coffee shop can often smooth the way if there are likely to be minor embarrassments.
- If the person was always shy, they may not feel comfortable in a busy community centre or shop. A walk with just the two of you can be just as beneficial to them.

Local community centres or gyms often have gentle exercise classes that may be suitable for them to attend.

Maintain relationships in the community by walks in the local park, going to a local football match where it is not too busy or noisy.



**Alzheimer National Helpline** 

1800 341 341

#### Other useful publications

- Moving and Handling
- Communication
- Practial steps to support your independence
- Engaging activities at home
- Practial tips for living well with dementia
- Understanding change
- Information for Families- Life story book at home
- Assisting with Personal Care

#### Useful contacts

#### The Alzheimer Society of Ireland

Contact the Alzheimer National Helpline Monday to Friday, 10am to 5pm Saturday, 10am to 4pm Freephone 1800 341 341.

Email: helpline@alzheimer.ie
Visit / Live Chat www.alzheimer.ie

#### **HSE**

The Health Service Executive (HSE) To find out where your local HSE Health Centre is or to ask about services that may be available in your area including occupational therapy and physiotherapy;

Call: 1800 700 700 Visit: www.hse.ie

### Irish Association for Counselling & Psychotherapy

To find a counsellor or psychotherapist in your area

Call: 01 230 35 36 Website: www.iacp.ie

#### **Alone**

Alone is a national organisation that enables older people to age at home as well as providing befriending services, advocacy and support.

Call: 0818 222 024

#### **HSE Social Prescribing Service**

Social Prescribing is a free HSE service which helps to link you with sources of support and social activities within your community. These include physical activity, men's shed, arts and crafts, musical groups.

#### For more information visit

https://allirelandsocialprescribing.ie/

Email: helpline@alzheimer.ie

#### Men's Shed

A Men's Shed is a dedicated, friendly and welcoming meeting place where men can come together. It's a place where men can share their skills and knowledge with others, learn new skills or redevelop old skills. Becoming a member of a Men's Shed provides a safe and busy environment where you can relax and enjoy yourself. Also, importantly, there's no pressure. Men can just come and have a chat and a cuppa if that's all they're looking for.

Website: https://menssheds.ie/

Phone: 01 891 6150

#### **Citizens Information**

Citizens information can provide legal and financial advice and information on entitlements and grants that you may be entitled to.

Website: www.citizensinformation.ie

**Phone:** 0818 074 000

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