

“True enjoyment comes from activity of the mind and activity of the body, the two are ever united.”

- Wilhelm von Humboldt



Your parkrun and dementia manual

2024

 Vhi
presents
parkrun

dementia
under stand together



Introduction

Welcome to 'Your parkrun and dementia manual'.

To lead a fulfilling life in an increasingly fast-paced world, it is important to look after your health and wellbeing. Research has shown that physical activity is not only good for your physical health, but also your brain health. Regular activity in mid-life, and possibly in later life, may reduce the risk of developing dementia by improving the health of your cardiovascular system (your heart and blood vessels). It boosts your brainpower, and exercising with other people is a great way to make friends.

Activities like parkrun are good for everyone's mental and emotional wellbeing - as well as our physical fitness. That includes people with dementia, their families and supporters. Everyone is welcome to pull on those runners, come along to the local park and enjoy better health the parkrun way.

Thank you to **parkrun Ireland** for collaborating in the creation and development of this manual.

Together, we aim to highlight the physical and social benefits that parkrun provides for everyone.

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Who's who?

Dementia: Understand Together is a national public awareness and stigma reduction campaign. It aims to inspire people from all sections of society to stand together with more than 500,000 Irish people whose families have been affected by dementia. It is one of six key priorities of the Irish National Dementia Strategy. The campaign is led by the Health Service Executive (HSE) in partnership with the Alzheimer Society of Ireland, Age Friendly Ireland, Age and Opportunity, Healthy Ireland and the Dementia Services Information and Development Centre. The campaign is supported by many national organisations across Ireland and thousands of community champions who are leading the way in creating communities that welcome and include those living with dementia and their families.

parkrun began in the Republic of Ireland with the first running of Malahide parkrun in 2012. parkrun's mission is to create a happier, healthier planet. It is a free, community event where you can walk, jog, run, volunteer or spectate. The parkrun itself is 5km in length and takes place every Saturday at 9.30am. parkrun is positive, welcoming and inclusive, there is no time limit, and thanks to the presence of a 'tail walker' volunteer at every event, no one finishes last. Everyone is welcome to come along.



What's in the manual?

We'll be highlighting the benefits of physical activity, give you facts on dementia, and show how parkrunners can work with, and support family members and friends who are living with dementia. We'll show you how parkrun can help people with dementia to carry on doing things they enjoy by offering friendship, support and routine. We're offering ideas for parkrun event directors (EDs) and volunteers on how to reach out to people with dementia, their families and supporters.

However, this does not mean that parkrun is right for everyone. Each person with dementia is a unique individual with their own experiences, needs and feelings, and likes and dislikes. If you are thinking of joining parkrun, this manual can help you decide whether it is the right activity for you. We will also suggest other ways you can get involved with parkrun, such as through volunteering or spectating.

“It is important to see the person
and not the dementia.”



Section 1 - Benefits of physical activity

Regular physical activity has many benefits for your health - from strengthening muscles and bones to improving the cardiovascular system (your heart and blood vessels). The advantages of activity for your mind and brain are just as important. Many studies have shown that doing regular physical activity can improve cognitive brain skills such as memory, attention, planning and organising.

Helping your brain

How does this work? Regular activity helps create new brain cells. It does this by releasing certain chemicals that help brain cells to grow. This is known as neurogenesis, and takes place especially in the part of the brain responsible for learning and memory. This means that activity helps to keep your mind sharp and can lessen the effects of ageing on the brain.

Physical activity may benefit your brain by:

- improving blood flow to your brain
- reducing inflammation
- lowering levels of stress hormones

I “What’s good for the heart is good for the brain.”

The following factors can protect you from heart disease:

- regular activity
- a diet containing fruit and vegetables
- staying at a healthy weight
- not smoking

How much activity do you need? Just 2 hours and 30 minutes of moderate activity spread across the week will improve your bone and heart health, brain power and mental health. The more time you spend being physically active, the greater the health benefits. But even small increases can improve your health and quality of life.

The national recommendations for physical activity for adults over 18, including people with a disability, are:

- doing moderate-intensity aerobic physical activity for between 2 hours and 30 minutes and 5 hours during a week;
or doing vigorous-intensity aerobic physical activity for between 1 hour and 15 minutes to 2 hours and 30 minutes during a week
- doing extra muscle-strengthening activities for the whole body at moderate or high intensity on 2 days or more a week - for example, carrying heavy shopping, doing yoga, digging the garden, or pushing a wheelchair
- for people over 65, including those with a disability: doing a variety of additional activities on 3 days a week or more to improve balance and strength and help prevent falls - for example, sideways walking, step-ups or standing on one leg

What are moderate or vigorous aerobic physical activities?

Moderate aerobic activities include:

- brisk walking
- slow dancing
- riding a bike
- mowing the lawn
- sweeping the floor

The activity should increase your pulse rate and make you breathe faster and feel warmer.

Vigorous aerobic activities include:

- running
- swimming
- cycling uphill
- walking upstairs
- playing football

The activity should make you breathe hard and fast.

One of the simplest ways to be more active is to get out for a walk as many times as possible during the week and go to parkrun on Saturday to meet your friends.

Section 2 - Information about dementia

What is dementia?

The term 'dementia' covers a range of symptoms. Dementia can interfere with your normal social or working life as it can affect your thinking, behaviour and the ability to do everyday tasks.

There are many different types of dementia, and you may have more than one type at the same time.

The most common types of dementia are:

- **Alzheimer's disease** - Alzheimer's disease happens when certain proteins in the brain build up as plaques and tangles. These stop nerve cells sending signals to each other, and cause them to die.
- **Vascular dementia** - Vascular dementia is caused by reduced blood flow in the brain. This damages brain cells. It can be caused by narrowing of the small blood vessels deep inside the brain through general wear and tear and lifestyle choices such as smoking, alcohol and poor diet. It can also be caused by a single stroke or a series of mini strokes.
- **Lewy body dementia** - Lewy body dementia is caused by clumps of abnormal protein forming inside brain cells. They occur in specific areas of the brain and affect movement, thinking and behaviour.
- **Frontotemporal dementia** - Frontotemporal dementia involves damage to the front or sides (or both) of the brain - the frontal and temporal lobes. Symptoms often begin when people are in their 50s or 60s or sometimes earlier.

Symptoms of dementia

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

Common symptoms include:

- memory problems
 - confusion
 - finding it difficult to concentrate
 - personality or behaviour changes
 - apathy, withdrawal or depression
 - becoming unable to do everyday tasks
-

Who is at risk?

Dementia can happen to anybody. The risk of getting dementia increases with age, and it is more common after the age of 65. However, dementia is not a normal part of ageing, and the majority of older people do not have it. When people under 65 develop dementia, it is called young-onset dementia.

It is estimated there are over 64,000 people living with dementia in Ireland. Each year more than 11,000 people in Ireland develop the disease - that's about 30 people a day. All are living with a worsening condition that damages their nerve cells and deeply affects their lives and the lives of people who care for them.

Most people with dementia live in the community, and want to continue doing so. We can all help to ensure they can carry on with social and physical activities to support their health and wellbeing.

Simple ways to support people with dementia

Here are six simple things we can all do to support people with dementia and their families:

- see the person, not the dementia
- talk about dementia
- ask how you can help
- stay in touch
- encourage the person to keep up hobbies and interests
- if you provide a space or a service, make sure it is easy to use



Section 3 - parkrun and dementia

What does the rise in cases of dementia mean for parkrun?

The number of people with dementia in Ireland is expected to more than double from over 64,000 today to over 150,000 by 2045. This means that your parkrun is likely to involve people living with dementia, whether they are taking part or supporting someone with dementia.

People with dementia are welcomed by parkrun across Ireland. Many people with dementia, and their families or supporters, already take part.

People who are diagnosed early in the disease process are often extremely able and do not require any kind of support to participate. As the condition progresses their support levels may change.

How does parkrun help people with dementia?

People with dementia or family members who are caring for a person with dementia may consider taking part or volunteering in their local parkrun as a good physical or social activity.

Doing things with others and taking part in worthwhile activities can improve the quality of life of people living with dementia. It may also slow the development of dementia.

parkrun is a safe and friendly way to get regular activity. Whether walking, jogging or running - anyone can join in. You can also volunteer for various roles. As a volunteer, you can work at your own pace and in your own time. What's more, you will have the company of other parkrunners, because one of the main purposes of parkrun is to help people feel less isolated and more part of a group.





Section 4 - Living with dementia and thinking of joining parkrun

If you are living with dementia and are considering joining a parkrun, but are unsure whether parkrun is right for you, you can always come along to a parkrun of your choice and speak to our many volunteers.

There are more than 110 parkruns in Ireland, so there are probably several close to where you live. Every parkrun offers a 5km walk, jog or run, but otherwise they are all different. Some may have 20-30 participants and others have over 100. If large crowds make you nervous, a smaller parkrun may suit you better. Some parkruns are flat and some are hilly, so choose one that fits your ability. Some have a local café nearby so that you can meet up with other participants each week afterwards for a tea or coffee and a chat.

Decide which parkrun is right for you

- To see a list of all the parkruns in Ireland, what they offer and get a contact email for each one, visit www.parkrun.ie/events
- Try out some local parkruns that look suitable for you.
- You may want to take a friend or family member for the first few visits to a parkrun to make sure you will feel comfortable there.
- If you don't feel ready for a 5km run, jog or walk at your local parkrun, think about volunteering instead.

Talk to your local parkrun about your level of ability

Health and safety is a key consideration at every parkrun. So it is important to be clear about your level of ability. There may be days when you don't feel able to complete a 5km run or walk. Or you may feel it is unsafe to try because the course is too difficult or the weather is bad. On those days you can get just as much benefit by acting as a volunteer. The event director at the parkrun will support you in whatever job you want to volunteer for on the day.

Things to think about before you take part

- Can you get to your local parkrun before 9.30am on a Saturday morning?
- Is it safe for you to do the parkrun on a particular Saturday - for example, due to weather conditions?
- If you need support to take part in a parkrun, is your supporter free for at least 2 hours on a Saturday morning? (We say two hours to allow time for a tea or coffee after the parkrun).
- Does your supporter know what parkrun is about and is familiar with the location you have selected?
- Has your supporter signed up to take part in parkrun along with you?
- Is your supporter able to run or walk the 5km parkrun with you if you need them to?

We understand that sometimes you may feel differently or your needs may change as a result of your dementia.

You can talk to your parkrun event director and your carer or supporter about plans you can put in place so you can still be involved, this could include:

- bringing someone to the parkrun with you
- only completing part of the 5km course
- becoming a parkrun volunteer instead of a runner or walker
- meeting parkrunners at a café even if you have not been able to walk or run



Section 5 - Supporting fellow parkrunners with dementia

A diagnosis of dementia may leave people feeling isolated, with fewer connections and a less active social life. Keeping up with social activities can make a big difference to a person's happiness and quality of life.

Every parkrun has its own culture and identity. There are many ways to help parkrunners with dementia feel a part of the parkrun - from including them in parkrun banter to giving them a key role as a volunteer. At one parkrun for example, the parkrunner's partner regularly bakes biscuits and cakes, which the person with dementia shares out after the parkrun.

As a parkrun participant there are lots of ways you can help parkrunners with dementia to feel welcome and safe at parkrun:

- treat everyone with dignity and respect
 - be a friend, even saying "hello" and "goodbye" can make a big difference
 - encourage people to join in and feel they belong at parkrun
 - start conversations
 - understand that a person's ability may vary from day to day
 - learn more about dementia so you can better understand what life is like for the person you are supporting
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Communication tips

Connecting with others makes a big difference to the day and quality of life of people living with dementia. Your attitude and approach are key to assisting people with dementia to communicate.

People with dementia have feelings like anyone else, even though they may not always understand what is being said. It is important to uphold everyone's dignity and self-esteem in the way we treat each other.

Use body language

It is helpful to remember that we all rely more on body language and tone of voice than on words to communicate with one another. It is important to:

- smile
- be calm
- establish eye contact
- use touch where appropriate (for example, a handshake or a pat on the shoulder)
- talk in a quiet place where possible
- sit or stand face to face where possible
- introduce yourself if the person does not know you: "Hi, my name is..."
- use their name so they know you are speaking to them
- if the person is struggling to follow what you are saying try speaking more slowly and clearly

Tips on listening

Allow plenty of time for the person to understand what you have said. Silence can give time to think.

- Do not jump in if a person is still thinking of a word. Let them work out their sentence.
 - Prompt only when it is appropriate.
 - Listen carefully and take seriously what is being said, even if they seem to be experiencing a different reality.
 - Show you are listening by asking questions, by paraphrasing to confirm what they have said; and through your body language.
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Tips on speaking plainly

- Keep sentences short.
- Focus on one instruction or idea at a time.
- Use nouns and names to specify what you mean. For example, say “Can you pass me the finish token?” instead of “Can you pass that?”.
- Use gestures. For example, point to objects, demonstrate actions, wave when you say hello and goodbye.
- Make it easier to respond by limiting the choices. For example, ask “Do you want to walk the course today or volunteer with me at the finish line?” instead of “What would you like to do today?”.
- Say things to make sure a person knows clearly where they are, the time of day and what is happening. For example, “It is nearly 9.30am and almost time to start the parkrun.”



When it is time to say goodbye to parkrun

There may come a time when a parkrunner with dementia will no longer be comfortable at parkrun or able to take part regularly. But they may have found new friends at parkrun. If you are one of these friends, don't let dementia end the friendship. The best way to help is to stay in touch with your friend after they leave parkrun, and let them know how much you value their friendship.

Here are some ways you could continue to support your friend with dementia when they are no longer regularly attending parkrun:

- invite them to the parkrun café for a cuppa
- phone them or call in to see how they are getting on
- invite them to special events (such as Christmas parkruns or anniversaries)
- write them a letter to thank them for helping out at parkrun
- introduce them to the parkrun Facebook page
- if they are unable to use the internet, print out the newsletter for them
- ask them, their family or supporters how you might continue to support them

parkrun benefits health and wellbeing through increased physical activity, skill development, friendships and socialisation, mutual support and personal empowerment.



Section 6 - Looking out for carers

Caring can be hard - emotionally and physically. Carers may need support so they can look after themselves as well. They may face a range of difficulties. For example, they may find it hard to accept what is happening to the person they are caring for and to cope with the changes this brings to their own life. They may have a mix of feelings, such as guilt, grief, loss or anger. Also, carers can easily become cut off from their own friends and social life. Participating in parkrun could be a joyful activity for them.

How to support someone who is a carer

- Be willing to listen. Listening is one of the most important things you can do for a carer.
 - Ask “are you okay?” or “how is your husband/wife/partner?” and then let them tell you. Giving them the chance to talk things through can help.
 - Remember they may not want to talk about their caring role and may prefer to have time out at parkrun from thinking about it.
 - 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.
 - Don’t expect to know exactly what to say to a carer, as there is no magic solution.
 - Try to be supportive and accepting, and not judgemental.
 - Look out for signs of stress or loneliness in the carer.
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Section 7 - Information for the parkrun core team

Every parkrun is organised under the guidance of parkrun Ireland, but each is unique in various ways - for example, some may have steep hills, some may have a 5km loop while others make up the 5km route in multiple laps.

“parkrun Ireland is striving to be welcoming and inclusive to people living with dementia and their supporters”

As part of the core parkrun team, you need to ensure your parkrun is as safe as possible for everybody. Bear in mind that people with dementia may have increased challenges with their surroundings and social life. As dementia can affect their thinking, sensory and physical abilities, you should consider the following range of measures to support them:

- check that labels and signposts are clear
- avoid clutter and obstacles
- give simple instructions - keep the pre-run briefing simple and easy to understand
- focus on one thing at a time
- match any activity to the person's abilities
- ask parkrunners to look out for each other
- provide supervision
- reduce noise levels if possible
- involve a person's supporter at parkrun

For the parkrun core team if someone with dementia enquires about taking part:

- does your parkrun match the person's interests
 - will their level of ability enable them to take part safely
 - are there areas or activities they will need to avoid
 - is someone accompanying them to the parkrun if needed?
 - is public parking available close to the parkrun
 - are public toilets available close to the parkrun
-

Getting started

When you and the new member have agreed that your parkrun is a good match for their ability and that they can take part safely, they can get started. You could suggest they come along to the first few sessions with a relative or friend until they feel comfortable at the parkrun and form new friendships.

Help ensure the activity follows a set pattern every week. It helps to:

- focus on one thing at a time
- break down the instructions into small steps
- don't force anyone to join in or to do anything they are not comfortable with
- give people plenty of time to take part and complete tasks

If the person with dementia is supported by a carer let the carer know that:

- parkrun encourages carers to also register for parkrun, which is free, although this isn't compulsory. Everyone, both participants and volunteers, are insured when taking part in parkrun
- the carer's main role at parkrun is to help the person with dementia to take part as a volunteer or to complete a 5km walk or run
- the carer has sole responsibility for the person at parkrun

Supporting a fellow parkrunner with dementia when their ability to take part changes

Dementia is a progressive condition and a fellow parkrunner's abilities may change. As this could affect their safety, you should consider ways to support them at parkrun. For example, they may need to:

- change from running to walking
 - do a shorter route distance
 - have someone accompany them on the walk or run
 - become a volunteer instead of a participant
 - choose a different volunteering role
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What if they have to give up parkrun?

If it is decided that a person with dementia should stop going to a parkrun, consider agreeing an exit plan with the person, family or supporter. This could include:

- making shorter visits to the parkrun before leaving entirely - such as just going to the café
- asking fellow parkrunners to phone or visit the person at home to make up for not meeting in person at parkrun
- encourage parkrunners to stay in touch with the family member or supporter and ask if there is something they can do



“Working in general practice, you see for yourself the effects of inactivity and social isolation. parkrun provides a wonderful opportunity for everyone to get activity and social involvement in a welcoming and friendly environment. Having first-hand experience of parkrun makes it easier to encourage a person to attend. Multiple studies have shown the benefits of regular activity in improving health and longevity for the population as a whole, and parkrun is a wonderful free resource that can help all of us achieve our activity targets.”

- Dr Deborah Ryan, Meath Faculty of the Irish College of General Practitioners

Useful contact information

The Alzheimer Society of Ireland

Information about dementia and supports/services for carers and people with dementia

Call the national helpline for free on 1800 341 341

www.alzheimer.ie

Dementia Services Information and Development Centre

Information on dementia, training and education, and research

Email: dsidc@stjames.ie

Tel: 01 416 2035

www.dementia.ie

Dementia: Understand Together

Information about dementia inclusive communities, training and resources

Email: understandtogether@hse.ie

www.understandtogether.ie/get-involved/

Family Carers Ireland

Information about caring roles, carer support services and entitlements

National Freephone careline 1800 24 0724

www.familycarers.ie

Health Service Executive (HSE)

Information about community care programmes and services

HSE information line 1850 24 1850

www.hse.ie

parkrun Ireland

Information about parkrun

www.parkrun.ie

Additional resources

- Be active guidelines - <https://www2.hse.ie/living-well/exercise/active-for-your-lifestyle/>
 - Eating well guidelines - <https://www2.hse.ie/living-well/healthy-eating/>
 - Mental health - visit www.yourmentalhealth.ie for ways to look after your mental health
 - Quit smoking - visit www.quit.ie or call the QUITline on 1800 201 203
 - Ask about Alcohol - visit www.askaboutalcohol.ie or call the HSE Alcohol Helpline on 1800 459 459
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Notes



