Keeping active and involved

Living with dementia series

Alzheimer’s Society
United Against Dementia
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Living with dementia: Keeping active and involved

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Why is it important to stay active and involved?

When you have dementia, it’s important to try to keep doing things that you enjoy. You’re still the same person, and you can still be active and feel involved – you just might have to do things a bit differently.

After a diagnosis of dementia, you may be worried about the future or feel less confident. You may not want to go out or take part in the things that you usually do. However, staying active and involved will help you to live well with dementia. You are still valued by others and have a lot to give to your family, friends and community.

Staying active and involved is important because it keeps you in touch, or reconnects you, with other people, and so can stop you feeling lonely. Having people to talk to and spend time with can help you feel supported and understood. It is also reassuring to know that there are people you can reach out to for help when you need to.

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For more information visit alzheimers.org.uk
Why is it important to stay active and involved?

Staying active can also help you:

- feel more positive, and less anxious or depressed
- raise your self-esteem and increase your confidence in your abilities
- maintain your physical, mental and social skills
- express your feelings and connect with others
- share your experiences with other people who are affected by dementia.

This booklet gives you tips on how to keep doing the activities you enjoy. It also suggests some activities that you can try at home or out in the community.

Whatever you choose to do, the most important thing is that it makes you feel good.

‘Singing is great because you feel so much better if you do it, even if you don’t feel like it.’

Person living with dementia

For more help and advice call our Dementia Connect support line on 0333 150 3456
Practical tips

Living with dementia doesn’t mean you have to stop doing what you do now. However, you may need to make small changes to make things easier, safer or more comfortable for you. This section has some tips to help if you feel worried about doing something or if it feels difficult. These tips may also be useful when starting any new activities.

One step at a time

Even tasks that seem simple, like having a bath, can be quite a complex process. Try to break the task down into smaller parts. For example, bathing involves:

- running the water
- making sure the water is the right temperature
- having a clean towel in the bathroom
- getting clean clothes or nightwear ready to change into.

It can help to keep a list of these steps. Think about each step and how you will do it. Can somebody help you with some of them?
Keep things simple

Simplifying your routine or daily tasks will make them easier to manage. Sometimes just a small change can make a big difference, for instance setting up direct debits so that your bills are paid automatically.

There may also be equipment and technology that can help you. For example, putting your tablets into boxes that are labelled with days or times (dosette boxes) can make it much easier to organise your medication. Your GP or pharmacist can help to arrange this.

Pick a good time and give yourself more time

You will enjoy something more if you do it when you feel well. Think about what time of day you’re at your best and try to do activities at that time. Stop if you feel tired or ill. Give yourself longer if you need to, rather than feeling rushed.

Reduce distractions

It may be easier to focus and enjoy an activity if you can give it your full attention. Try to reduce clutter and background noise (for example, switch off the TV) or go somewhere quieter if it helps you concentrate.
Eyesight and hearing

Look after your eyesight and hearing so that you can keep doing your day-to-day tasks and enjoying your favourite activities. If you wear glasses, make sure they are the right kind, that they fit well, and that they are clean. If you wear a hearing aid, make sure that it is working properly.

It is important to get regular sight tests and hearing check-ups. These may be free for you. Speak to your GP for more information.

Speak to a professional

If certain tasks get difficult, for example getting dressed, cooking or shopping, then you may want to speak with a professional. An occupational therapist can assess what’s making these things difficult – for example problems with moving, mobility or your memory. They will recommend ways for you to stay independent for longer. They can also advise on assistive technology or equipment that can make tasks easier for you.

Speak to your GP, adult social services, or another health or social care professional to arrange an assessment. The Royal College of Occupational Therapists can also help you find an independent occupational therapist (who will charge a fee) in your area – see page 26 for details.
Your local authority adult social services department will also have an independent living team who can advise you.

For more about this see factsheet 437, Using technology to help with everyday life or booklet 819, Making your home dementia friendly.

Don’t be hard on yourself

You may find that you can’t do things as well as you did before, or that they take much longer. You may feel frustrated or upset by this. Try to be kind to yourself. Take things at your own pace and try to accept that some of your abilities have changed.

You may need support to do some things. It can be hard to get used to this, but it’s important to keep doing what you enjoy, even if it’s with a little help. Some days will be better than others – just as they are for everyone else.
You can get involved in a number of routine and leisure activities in and around the home. These are just a few ideas. Some will be familiar and there may be others that you have not tried before.

**Cooking, household tasks and gardening**

You can keep – or start – cooking, as long as it is safe for you. If it becomes difficult, there are some small changes that can make things easier.

For example, you can:

- ask someone to help you in the kitchen
- try recipes that have fewer steps or ingredients
- use pre-prepared ingredients such as ready-made sauces or chopped vegetables.
Many jobs round the home also provide a good form of gentle exercise and can help you to keep physically active. These include:

- doing housework – for example, washing up, folding clothes or dusting
- gardening – for example, gently weeding the garden, maintaining houseplants, or growing herbs or flowers in window boxes.

You can ask someone to do these tasks with you if this makes them more enjoyable or easier.

“I made a homemade lasagne for tea – with a bit of prompting from my partner. I know it’s not a big deal for most but it is for me.”

Person living with dementia
Hobbies and pastimes

There are many creative activities and crafts that you can still enjoy or try out at home. These include:

- painting
- playing an instrument
- knitting
- writing.

Continuing any hobbies and interests like this can help you to maintain your skills and self-confidence after your diagnosis.

Music and singing can be very powerful ways to relive memories, and music is also used as a form of therapy. Music therapy is enjoyable and can improve your mental wellbeing. For more information on finding a qualified music therapist in your area, see page 24 for details of the British Association for Music Therapy.

Tips

It can be helpful to put out the things you need before starting a task so that you have a visual prompt – for example, tools for gardening or ingredients for cooking.
Keeping active and involved at home

Any activity that exercises your mind is also good for you. For example, you might enjoy:

- reading
- board games
- crossword puzzles
- online games or apps.

If games and puzzles get difficult, you can try games made specifically for people with dementia, such as jigsaws with larger pieces, and a range of touchscreen apps. See ‘Other useful organisations’ on page 24 for more information.

If you like to read but are finding it difficult, you can try switching to audio versions of books, newspapers and magazines. A friend or family member might also be able to help, and you might also find a local poetry or reading group where members read aloud.
Keeping in touch using technology

Coronavirus made it more difficult to visit friends and family in person, and there are other reasons why sometimes this isn’t possible. However, there are many ways to keep in touch with people virtually from your home. Devices such as laptops, tablets and smartphones offer many great ways to communicate with other people.

You can use them to:

- send emails and different types of instant messages (such as text, video, pictures and sound clips)
- make video calls, such as on Skype and Zoom
- share and connect with people on social media, such as Twitter, Facebook and Instagram
- join online communities, such as Talking Point
- play online games with others.

Touchscreen technology – such as tablets and smartphones – can be easier to use than desktop computers. If you’re not sure about how to use these devices, a friend or family member might be able to help you.
Culture

Watching videos, films and TV shows, or listening to music or podcasts, can be enjoyable ways to explore your personal interests. They can also help you to remember things that you have enjoyed in the past. For example, you can:

- watch films or television shows – old and new
- listen to your favourite songs or find new ones
- find video clips on YouTube of places that you have visited or hobbies you enjoy
- find podcasts about subjects, places and pastimes that you like
- read short stories and articles that interest you.

‘My father lives with me and he can Skype my sister. The extra visual dimension adds a lot for him.’

Daughter of a person living with dementia

For more help and advice call our Dementia Connect support line on 0333 150 3456
Smart devices and virtual assistants such as Amazon Alexa, Google Assistant or Apple Siri can also help you to stay active and involved at home. You can use your voice to give commands and ask questions. For example, you can tell them to:

- play music or a particular radio station
- check the weather or the news
- remind you to take medication or go to an appointment.

If you have or would like a device but are not sure how to set it up, try asking a friend or family member to help you.
Going out

Being outside can benefit your health in many ways, including lowering stress, increasing your mood and improving your overall wellbeing. Outside activities range from walking in nature to shopping or attending community events. It’s important to choose what you enjoy and there is lots of support available to help you to do this.

You may feel less confident about going out after your diagnosis. However, there are things that can help you feel prepared and supported. For example:

- Ask a family member or friend to go with you.

- Take time to think about anything you need to do beforehand or prepare – for example do you need to book tickets in advance, will you need to take food or drink with you, and is there anything you need to bring from home to help you feel safe and comfortable?

- Plan how you’ll get to and from your destination – it can be useful to make a note of bus routes and train times, as well as stations where you will need to get on or off public transport. If you are driving, try to find out where you can park.

- Find out what services are available at the destination – for example, whether they have seating, a café or toilets.

For more help and advice call our Dementia Connect support line on 0333 150 3456
Consider what time of day to go out – you might find quieter (off-peak) times are more comfortable for you to travel and visit places.

Find out what support is available and make a note of any phone numbers you might need.

It may be helpful to look up a map or images of the venue online first so that you are familiar with the space.

Use helpcards – these are small cards that show people that you have some difficulties and how they can help you. You can also record emergency contact details on them. You can order helpcards at alzheimers.org.uk/helpcards or by calling 0300 303 5933.

You could also speak with your GP about ‘social prescribing’. This is a way for health professionals to refer people to community-based support and activities.
Days out

There are many fun ways to spend a day out and about. These include going to:

- the shops
- cinemas and theatres
- museums and concert halls
- public gardens
- sports events
- National Trust venues
- restaurants, cafes and pubs
- see family or friends.

It may also be helpful to know that lots of places are becoming ‘dementia friendly’. This means that their staff and volunteers have had dementia awareness training so they should be more understanding and supportive. Dementia friendly venues may also be designed in a way that makes it easier for people with dementia to attend and use them, for example by using signs and having a clear layout.

Some of these venues organise events or activities specifically for people living with dementia, such as theatre performances or film screenings, and exhibitions or tours.

For more help and advice call our Dementia Connect support line on 0333 150 3456
Groups, communities and clubs

A lot of places run activity groups that bring people with dementia together. Popular groups can include singing (for example, Singing for the Brain), making music or art classes. Other activities include drama, dance, reading, writing or poetry.

It’s important to find something that has meaning for you and that you enjoy. This could be a faith or community group, rather than a creative activity. If you already attend a group like this, a diagnosis of dementia does not mean you’ll have to stop. Consider speaking with the group about any adjustments they could make to help you, if you feel comfortable doing this.

You may not want to get involved in a group activity. But if you do, a group can create a sense of togetherness and belonging.

You can find ideas for activities through some of the organisations listed in ‘Other useful organisations’ on pages 24–27. To find out what is happening in your area, search online at alzheimers.org.uk/dementiadirectory or call Alzheimer’s Society on 0333 150 3456, or get in touch with your local library, community centre or place of worship.
Sports, leisure and exercise

Exercise is great for your physical and emotional wellbeing. You may find it easier, safer or more fun to do it with other people rather than alone.

Physical activity includes walking, cycling, swimming, dancing or gentle exercise (such as tai chi or yoga). Or you could do sports such as golf, football, tennis, basketball or cricket.

Ask at your local leisure centre about classes that might be right for you. Many centres run specific sessions for older people or those with dementia. This includes adapted activities such as walking football.

If you’ve not exercised much before and want to start, it’s a good idea to talk to your GP, or community nurse, first. They can suggest ways for you to build up gradually and safely.

For more information see factsheet 529, Physical activity and exercise.

“We have a tandem I bought as we’re both members of a local cycling club... it now means my wife can get out and ride along with them.’

Husband of a person living with dementia
Travelling and taking a break

Travelling and going on holiday can be a great way to relax, have fun and have new experiences. It is still possible to travel and go on holiday after a diagnosis of dementia. However, it’s important to plan ahead.

When choosing where to go, you may find it easier to go to familiar places. Think about all aspects of the trip and how easy or difficult you will find them. For example, long-distance travel can be very tiring.

Before you travel, you should make sure you are insured against any problems that may arise, such as sickness or lost items. Your travel insurance policy will also need to cover any medical conditions that you have – this includes dementia. It is possible to travel alone but, as with many activities, it is easier if you have someone with you. Whatever you choose to do, make sure you:

- take the time to prepare
- keep lists – for instance, things to pack
- write down travel and accommodation details, such as your flight times or hotel address
- bring any documents you need, for example insurance documents, your passport, and any visas.
If you are travelling alone, also make sure you:

- let a family member or close friend know the details of where you are going. You could arrange to ‘check in’ with them when to get to key places such as stations, hotels or places of interest

- carry a list of emergency contact phone numbers in case you need advice or support in a hurry.
Getting involved through Alzheimer’s Society

Alzheimer’s Society offers many opportunities for you to keep active and involved. This includes volunteering your time in different ways. These activities can give you the chance to meet other people, share your experiences, learn new skills and make a difference. Here are some examples of what you can do.

Have your say with Dementia Voice
Dementia Voice is our programme for including people with dementia in our work. You can review our publications, help us recruit staff, give your feedback on our services, and much more. For more information, go to alzheimers.org.uk/dementiavoice

Make your community more dementia friendly
Join or create a local community group to raise awareness of dementia and encourage more people, groups and organisations to support people with dementia better. To find out more email dementiafriendlycomm@alzheimers.org.uk
Taking part in research
Register with Join Dementia Research to be part of a local dementia study – for example, testing a new dementia service or treatment. You can sign up at www.joindementiaresearch.nihr.ac.uk or by calling Alzheimer’s Society on 0333 150 3456. Or you can join Alzheimer’s Society Research Network where you can help us pick research projects to fund. For more information email research@alzheimers.org.uk or call 020 7423 3656.

Stay connected with our magazine
Keep in touch by reading Dementia together magazine in print or online, or listening to the CD version or podcast. Here you’ll find real-life stories from people affected by dementia, activity ideas and tips for living well. You can subscribe at alzheimers.org.uk/magazine

Get involved in fundraising events
Contact your local fundraising team to find out what’s happening in your area. You can take part or help out at a range of events from marathons and memory walks to carol concerts and quizzes. For more information visit alzheimers.org.uk/getinvolved
Other useful organisations

AcTo Dementia
www.actodementia.com

AcTo Dementia is a website that gives independent recommendations and advice on touchscreen apps designed for people living with dementia.

Arts 4 Dementia
020 3633 9954
info@arts4dementia.org.uk
www.arts4dementia.org.uk

Arts 4 Dementia is a charity that works with arts organisations to give workshops on subjects such as art, drama, dance and music.

British Association for Music Therapy (BAMT)
020 7837 6100
info@bamt.org
www.bamt.org

BAMT is the professional body for music therapy in the UK. Their website includes information and details of local therapists.
Other useful organisations

Creative Dementia Arts Network
07801 509993
info@creativedementia.org

Creative Dementia Arts Network promotes the health and wellbeing of people with dementia through creative arts.

Dementia Adventure
01245 237548
info@dementiaadventure.co.uk
www.dementiaadventure.co.uk

Dementia Adventure is a charity that runs small-group short breaks and holidays for people living with dementia and their partners, family, friends or carers.

Extend
01582 832760 (9.30am–2.30pm Monday–Thursday)
admin@extend.org.uk
www.extend.org.uk

Extend provides gentle exercise classes to music for older people and for anyone of any age with a disability.

Keep Fit Association (KFA)
01403 266000
kfa@emduk.org
www.keepfit.org.uk

KFA offers people the opportunity to exercise together for fun. It offers a range of classes across the UK, including classes specifically for people over 50.

For more help and advice call our Dementia Connect support line on 0333 150 3456
Royal College of Occupational Therapists (RCOT)
020 3141 4600
hello@rcot.co.uk
www.rcot.co.uk

RCOT is a professional body that has details of independent occupational therapists in each area.

Thrive
0118 988 5688
info@thrive.org.uk
www.thrive.org.uk

Thrive uses gardening to bring about positive changes in the lives of people with health conditions including dementia. They run gardening programmes at regional centres and also in the community.

Walk4Life
www.walk4life.info

Walk4Life offers information about walking, and details of walks and walking groups in your area.

Walking for Health
www.walkingforhealth.org.uk

Walking for Health is England's largest network of health walks with over 350 active schemes, helping people to lead a more active lifestyle.
Other useful organisations

**Water Wellbeing Programme**
01509 640700
health@swimming.org

The Water Wellbeing Programme is run by Swim England to create a network of swimming pools that are dementia-friendly and generally easier for people with long-term health conditions to use. Get in touch with Swim England to find out if any pools in your area are part of the programme.
Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Linda Nazarko, Nurse Consultant Physical Health Care at West London Mental Health NHS Trust

This booklet has also been reviewed by people affected by dementia.

To give feedback on this publication, or for a list of sources, please email publications@alzheimers.org.uk

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Alzheimer’s Society is the UK’s leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

If you have any concerns about Alzheimer’s disease or any other form of dementia, visit alzheimers.org.uk or call our Dementia Connect support line on 0333 150 3456. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on 0330 333 0804 or go to alzheimers.org.uk/donate