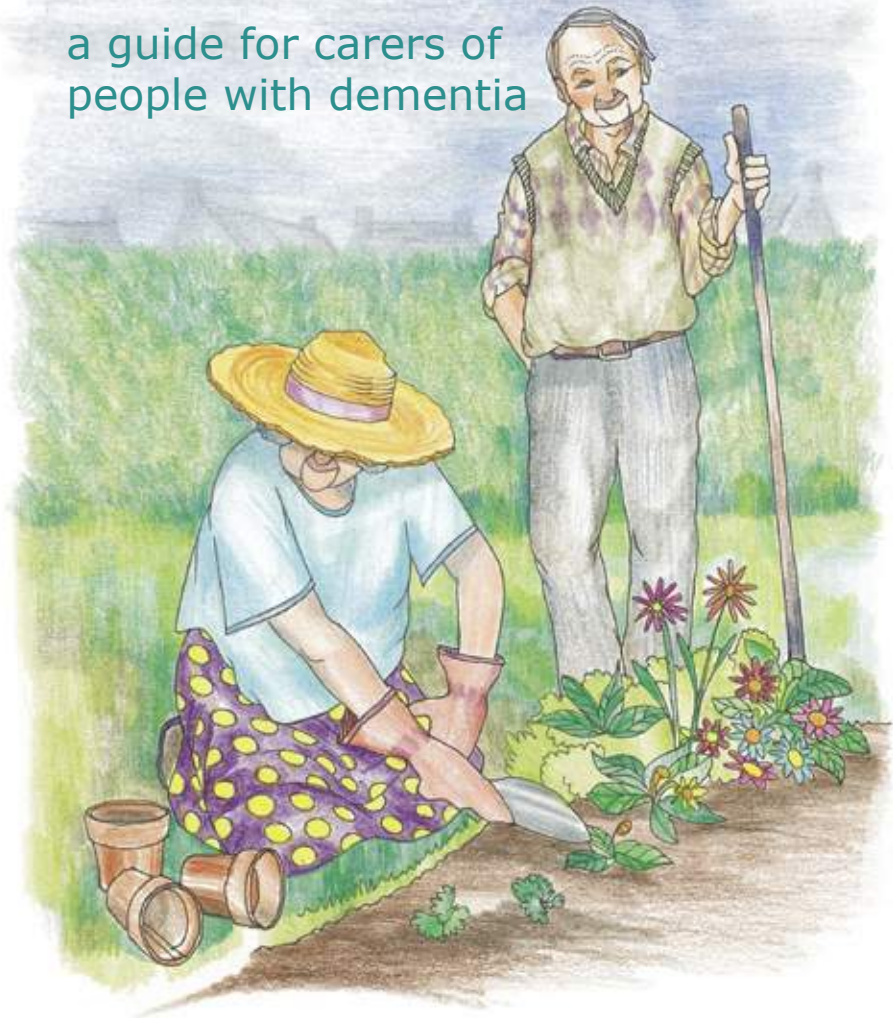




Alzheimer Scotland
Action on Dementia

Activities

a guide for carers of
people with dementia



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Introduction

This booklet is for carers who look after someone who has moderate to severe dementia and need help with planning daily activities. Carers often ask how they can help the person with dementia structure their day by doing different activities.

Keeping someone with dementia busy and engaged will become more difficult as the dementia progresses. However by focusing on what he or she **can** do, even when the illness is quite advanced, you can both enjoy a range of stimulating activities and outings together. How much time you can devote to activities will depend on your personal circumstances. If you work, have other commitments or have a young family to care for you will obviously have less time, but there are still activities you can do as part of the daily routine.

The types of activities that the person you care for will be able to do will depend on his or her degree of dementia and general health. Activities should be appropriate to the person and reflect his or her previous and present interests. Tailor the activities to fit in with the person's preferences and abilities and make sure he or she will be able to cope with them physically. Activities should be positive and enjoyable.

Remember that you do not need to do all these activities with the person you care for by yourself. If you have family and friends nearby ask them to help. Use day care, companion services and short breaks when you need a rest. This is important for your health and will allow you to recharge your batteries, so that you can continue caring. Speak to your social worker or the local Alzheimer Scotland service for more information about possible breaks.

Independence

Maintaining independence for as long as possible is very important. Often carers feel they have to protect the person with dementia from

all dangers and this can lead to the person becoming fully dependent on them too soon.

Activities

Activities do not need to be structured or complicated. In fact some of the best ways of helping the person with dementia remain active and stimulated are to keep him or her involved in the day-to-day tasks in and around the home. If the person is occupied for part of the day, he or she should gain a sense of satisfaction and achievement, which is important for everyone. This in turn will make your life much easier as the person is less likely to display challenging behaviours which can be hard to deal with, such as becoming lethargic, frustrated or angry.

Keep activities non-competitive so that the person with dementia does not feel a sense of failure if he or she cannot cope. Also make sure you factor in quiet time, as people with dementia become tired very quickly. Often activities are best planned for the morning when the person is more likely to have energy for them. Quieter activities are often better in the afternoons and early evening, when some people with dementia feel restless.

About dementia

What is dementia?

Dementia is the gradual and progressive loss of the powers of the brain. The most common cause is Alzheimer's disease. Other types of dementia are vascular dementias (including multi infarct dementia), alcohol-related dementias, Lewy body dementia and Pick's disease. These diseases damage and kill the brain cells, which is what causes the symptoms associated with dementia. Every person with dementia is different. How the illness affects someone will depend on which areas of the brain are damaged.

One of the main symptoms most people with dementia experience is memory loss, which becomes worse as the illness progresses. The person may also begin to lose track of time and be unable to work out directions even in familiar places. The ability to reason clearly may decline, leading to problems with decision-making. Dementia can also cause behaviour changes, which can be distressing for carers. **There are ways of coping.** Ask for help from family, friends, your doctor or call the 24 hour freephone Dementia Helpline **0808 808 3000** for advice, information and support.

Communication

Mild to moderate dementia

When the person has a mild to moderate degree of dementia you may find that he or she can't find the right words or names of things and may become more repetitive. Be patient and, if necessary, try to help to find the right words without interrupting the person.

“I know I can't always find the right words. Sometimes I just use the word that pops into my head, just to keep the conversation going, but I know it's the wrong one.”

Being able to communicate effectively will help the person with dementia maintain his or her independence. If you are aware of what difficulties the person has with communicating you can help to overcome them. You can also talk to staff from shops, cafes, the local post office and so on, so that they know what problems the person may have. The issue of keeping the diagnosis of dementia private may be important for some carers and people with dementia. This is an area which needs to be given careful consideration. The wishes of the person with dementia should always be taken into account.

“My mother didn’t want to go shopping anymore as she couldn’t explain that she can’t cope with money. Once the shopkeeper knew that my mother couldn’t count out the money, he helped her with that and she has been able to go shopping by herself without worrying about money.”

Later on

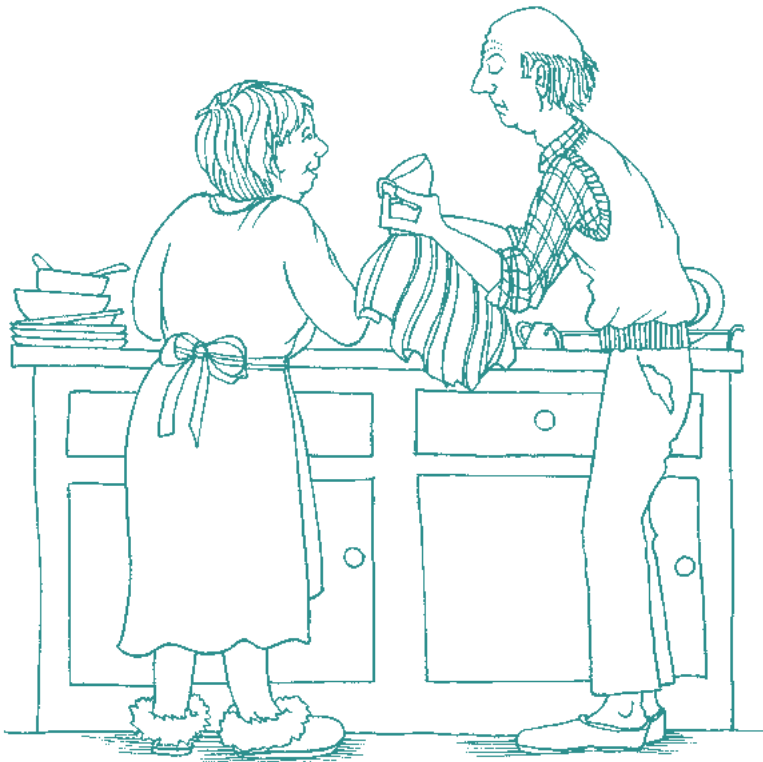
Communication with someone who has a moderate to severe degree of dementia can be difficult. If you are patient and he or she knows you are listening and you keep eye contact, it will help concentration and the person will be more able to focus and respond. Think about behaviour as communication. If you observe the person closely and watch out for body language you can often work out what he or she is trying to express.

Communication is an important aspect of activities. Often a person who may not have spoken for some time will suddenly remember a past event or person and talk animatedly about the memory. This sudden return of a memory can be triggered by seeing a photograph or hearing a particular piece of music. Remember that the person you care for is still the same person he or she has always been, even though he or she has dementia. Finding ways to help the person communicate will ensure that he or she retains long-term memories and will help you feel that he or she is still there with you.

About activities

Encouraging independence

Routine and continuity are important in activities. It is especially useful to encourage daily activities such as getting dressed and washed; buttering bread; washing up; polishing furniture and folding clothes - even if they are done over and over again. It is important that the person is happy to do the tasks and activities. Being allowed to carry on with everyday activities for as long as possible will not only help the person hold on to these skills and encourage independence, but will allow him or her to feel able to contribute and know that the help is valued. This sense of purpose and wellbeing should also help to ensure the person is less agitated and anxious.



Why are activities so important?

Participating in activities can help to prevent frustration, boredom and challenging behaviours. Activities can:

- help the person maintain independence in and around the home
- help maintain skills
- improve self esteem
- improve the quality of life for the person with dementia - and you will also benefit
- often compensate for lost abilities
- allow the person to express his or her feelings, through art, music, singing and dance
- bring pleasure to both of you as you share these moments together
- provide social contact through social activities and outings, keeping both of you in touch with family and friends.

How to plan activities

Keeping to a routine is very important: planning activities which can be part of a regular routine will help you structure the day. If the person you care for has always gone down to the local shop for the paper, the chances are he or she will be able to carry on collecting the paper until quite late on in the illness. Safety issues are of course important; crossing roads alone will become unsafe as the illness progresses.

Try to plan activities for the person with dementia which you enjoy too. Don't be afraid to say no to activities if you really can't face doing a particular thing. The best thing to do is to suggest another activity: 'Why not come and help me sort through these photos', or 'Let's go for a walk'.

Have a variety of activities organised that the person with dementia can do each day, e.g. a memory box, looking at photos, looking

through a life history book; clothes and napkins ready for folding; dusting; knitting or other activities which are enjoyed. If a certain task does not appeal one day you will always have another activity to suggest instead.

- Plan tasks and activities which you can do together and also plan activities the person with dementia can do by him or herself. This allows you some time to yourself.
- Think about what the person has enjoyed doing in the past and plan activities which will involve things he or she can remember.
- It is usually better not to do anything which involves learning new tasks and skills - stick to what they already know. However, some new tasks can be learned.

“My father learned how to play ‘Solitaire’ using a mouse on the computer in 10 minutes. He loved it!”

- Make sure the person will be safe, by providing an environment which will allow him or her to enjoy the activity without you worrying about safety.

Things to keep in mind

Prompting

In order to help the person through a task you may have to help with all the different stages of the process. For example, for vacuuming, you might need to remind the person where the vacuum cleaner is kept, where to plug it in and how to switch it on. If you don't help with all of these stages each time, the person will no longer vacuum. While this may seem like a lot of work for you, it will be of great benefit to the person you care for. Retaining skills and providing a way in which he or she can be useful will allow the person to experience a sense of satisfaction in helping with each task.

Time

Remember that many people with dementia have problems concentrating. The person you care for may be unable to do certain

tasks for any length of time. Plan for this by having a variety of activities he or she can do.

All activities are likely to take a bit longer to do than before. Try to be patient and allow more time than you would normally. For example, getting dressed can be a long process; however if you adapt to this and let the person do as much as he or she can, step-by-step, he or she will be able to dress him or herself and will retain these skills.

Support

Try not to be critical of how the person does things. The main aim of activities is to help the person with dementia achieve what he or she is capable of and be stimulated and happy. A perfectly clean kitchen or a well-made bed is not the goal. It is important that the person gains a sense of achievement and satisfaction.

Do not over stimulate as this may make the person anxious and agitated. Plan quieter activities for when he or she is tired, anxious or likely to become disturbed by loud noises, busy places etc. If you enjoy going out for a coffee or to a restaurant together choose quieter times when you can relax and enjoy the experience.

Adapt

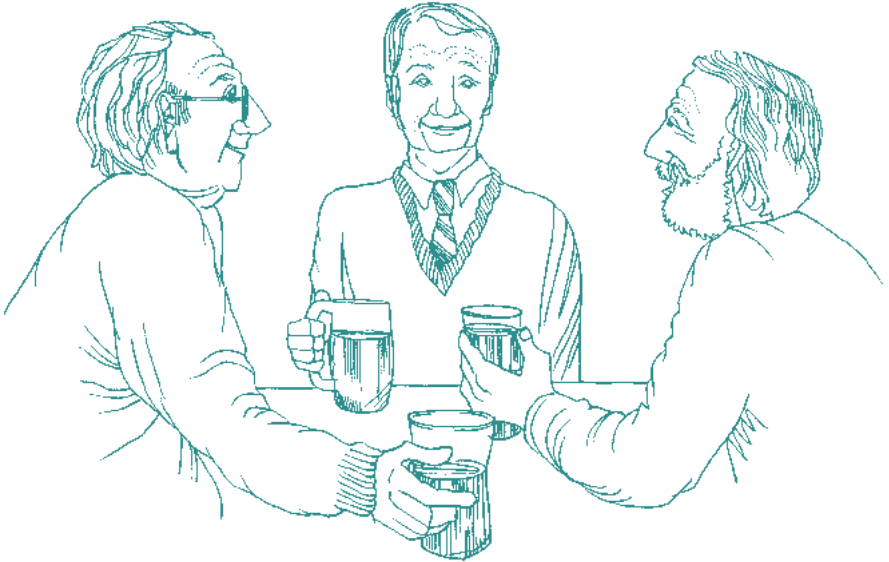
Remember that the person with dementia will gradually lose the ability to do some tasks as the illness progresses, but will retain other skills. Each person will lose different skills depending on which part of the brain the dementia affects. Try to be aware of these changes and adapt activities accordingly. This will reduce the amount of distress and anxiety he or she feels as the dementia progresses.

Always remember the person you care for is still who he or she always was, it is just the ability to do things which changes.

If the person becomes frustrated or angry, because he or she cannot cope, make sure you work out what help he or she needs or change the activity.

Community

Help the person stay involved in community activities. For example, the person may have been used to going to the local church, synagogue or mosque or to local clubs. Make sure that he or she can continue to go if he or she wants to, as it is important to keep in touch with friends and maintain a normal routine. This will ensure the person with dementia remains a part of the community.



Explain to people the person may come into contact with that he or she has dementia (as long as he or she is happy with disclosing this information). You can outline what difficulties he or she may have and let them know how they can help. Give friends a copy of the booklet *I'll get by with a little help from my friends*, available from the Dementia Helpline, to help them understand why their friendship is important and what they can do.

Some suggestions for activities

Carers throughout Scotland have provided many suggestions for activities, which might work for you too. Some of them are outlined below. Why not try them and see if the person you care for enjoys them?

In the home

If you can involve the person you care for in everyday household activities this will help him or her retain useful skills. Usually he or she will be happy to help, as long as you give guidance to help him or her through the tasks one step at a time.

It is usually a good idea to suggest activities by saying something like 'Could you give me a hand with the dusting', or 'Would you mind folding these clothes for me?' By allowing the person with dementia to feel useful and included in the day-to-day activities you will provide an important sense of self-fulfilment. Most people like to feel useful and needed.

If the person wants to do certain activities over and over again, as long as they are not dangerous or likely to harm anyone, let him or her carry on if you can bear it. As long as the person is happy and content with what he or she is doing there is no harm in repetition.

Housework

Doing housework may not be to everyone's liking, but often it can be an enjoyable activity as these types of skills are often retained until later in the illness. Polishing, dusting, tidying stacks of magazines, sweeping, making the bed, folding clothes are all activities which can often still be done successfully.

Be sensitive to the person's wishes. If he or she has never liked housework, he or she may be unwilling to take part in these tasks now!

Try reminiscing at the same time - recalling how things were done in the old days can make tasks more meaningful and enjoyable.

Music and dance

Listening to music, singing and dancing are other activities which can be enjoyed at home right through to the later stages of dementia. Carers have suggested obtaining a 'walkman' with headphones (as long as the person with dementia can tolerate them). Listening to familiar music can be of great comfort.



Many people with moderate to severe dementia can still sing favourite songs from their childhood and younger days. If the person used to play the piano or another instrument this will often be another skill he or she retains.

“I couldn’t believe it when he sat down at the piano and could play many of the pieces he used to play. It was wonderful.”

If the person with dementia finds it hard to communicate during the later stages of dementia you will often find that he or she can express his or her emotions through the music.

Record favourite pieces of music and play them when he or she is restless or upset. This will often calm the person. Carers have suggested playing the music in the bathroom can help the person relax, especially if bathing is not enjoyed by the person you care for. Singing can also be good when you are helping the person with intimate care tasks, such as washing or dressing. It can help to calm and distract the person. It can also help the person feel secure - especially useful for people who don’t understand why they need help.

Massage

Try giving a hand massage or manicure. This is easy to do at home and can provide a great deal of pleasure and relaxation, as there is social as well as physical contact. This is often particularly appreciated later in the illness when verbal communication is limited.



Reading

Reading can become difficult for someone with dementia as his or her concentration and mental ability to read decreases as the illness progresses. If the person would still like to read papers, magazines and books you can help by reading aloud and helping him or her go through the paper.

“I often point out articles of interest and read and talk about what is in the article. It makes it easier for her to concentrate and understand the article.”

Reading to the person will allow him or her to keep up with the latest news and follow interests. Family and friends can also help with this activity.

Audio books are useful as the person can relax and listen to the book on tape. There are a huge variety of these tapes available from the libraries and bookshops. In many areas there is a talking newspaper service, which can keep the person up to date with local events and news.

Keep books with pictures of particular interest around the house which the person with dementia can look at during quiet moments.

Watching TV

Many carers say that quiz programmes, old films and programmes about the person’s special interests can be enjoyed by both the person with dementia and the carer.

Try taping the programme and watching it in parts. This allows the person with dementia to take a break and you can also discuss what is happening in the programme.

“I have found it very useful to discuss the programme before it comes on TV. This way we can talk about the film or

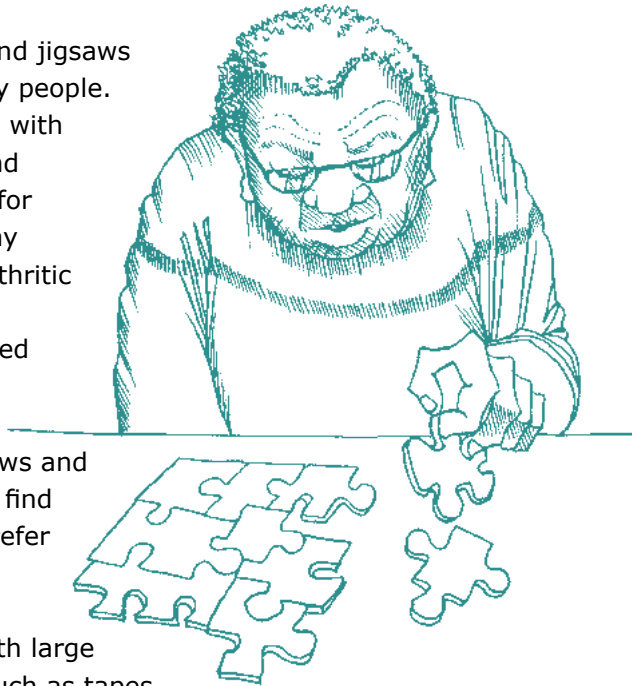
documentary and it is easier for the person I care for to understand the programme more quickly.”

Games

Dominoes, card games and jigsaws are also enjoyed by many people.

There are special jigsaws with larger pieces available and specially designed cards for those whose eyesight may be failing or who have arthritic fingers. Try out games you know they have played and enjoyed in the past.

Although some people will enjoy children’s jigsaws and games, many people will find them too childish, and prefer more appropriate ones.



One source of jigsaws with large pieces and other items such as tapes and CDs with radio tunes and voices from the 40’s and 50’s, which can stimulate memories and encourage discussions, is ROMPA. Contact them on 0800 0562323 or look on their website, www.rompa.com. Jigsaws from ROMPA are approximately £15 and tapes are £17.

Reminiscence

Remembering our early childhood experiences is usually an enjoyable activity, and to some people with dementia it can be the only way that they can make contact with their own identity. People with dementia often forget recent events; however when you talk about the past or look at photos you will often find that these trigger detailed distant memories.

The person will often show great delight in being able to share these memories and talk about old times. It is best if you do not 'test' the person's memory when looking at old objects and photos, as this can make the person feel frustrated or anxious if he or she can't remember certain people or events.

How to help the person remember

On some days the person will remember many events from looking at photos. He or she may remember who the people are in the photo or where the photo was taken, but on other days the photos will not trigger any memories. You can help by labelling photos to identify who and where the people are. Often a few hints will bring the memories flooding back.



Do take time to talk about past events, as these memories may be the only ones remaining to the person and are therefore precious. This can be an enjoyable experience for both of you, especially if you are reminiscing about the times you have enjoyed together. It can strengthen the bond between you and remind you of all the good times.

The senses

Smell, touch, taste, sight, sounds, photos, music and movement can all be part of reminiscing. You can just have an informal chat or you

could prepare a set of objects, photos and music. Often smells like lavender or smells from work or holidays will bring back very vivid memories and can start a long discussion about past times. Music is also a very powerful way of evoking memories.

Family and friends

Often friends and relatives enjoy these types of reminiscence activities and are willing to bring photos and objects with them. This is a great way of involving visitors in stimulating activities.

Sometimes it can be a bit stressful for visitors if they are unsure of how they should act or what they can do with the person with dementia. You can help by preparing them in advance, especially with tips on communication. Social contact is very important and you should encourage as many visitors as possible, as long as the person with dementia enjoys them.



One carer got friends and relatives to tape anecdotes onto a cassette for the person with dementia to listen to. The tapes can be enjoyed together, as a chance to reminisce, or the person can listen alone.

You may find that the person enjoys visits from grandchildren or friends' children. Children are usually very happy to communicate in any way they can with people. They may enjoy playing games the person with dementia remembers from his or her childhood.

Memory boxes

Putting together a memory box is a good way of stimulating and drawing out memories. Put favourite objects, old photos, and items from the person's work in the box to be examined. If the person is agitated, looking at the objects may calm him or her down. During quiet moments, when the person is tired or you don't want to go out somewhere, looking at the photos and objects can be a very relaxing way of being together.

Life story book

In the same way as the memory box you can also put together a life story book. You could combine photos with notes about his or her:

- mother and father, sisters and brothers
- children
- work
- places he or she has visited or lived in
- favourite holidays
- friends
- hobbies
- favourite foods, least favourite foods
- colours
- favourite films, music
- likes and dislikes
- politics.

Photos, post cards, scraps of material from old clothes or bedcovers and other memorabilia can be added to the story book. This can

be a very enjoyable activity for both of you. As the person's illness progresses it will become more important that the memories are all written down and recorded so that others can help the person recall those important times.

If the person does have to go into a care home this book can be taken and shown to the staff. It will provide them with a very valuable history and background of the person's life, which will help them to get to know him or her.

Creative activities

Writing

You may find that the person you care for enjoys writing if he or she has mild dementia. Perhaps you could suggest he or she writes about school days, past holidays and family meetings, so that grandchildren will be able to read about his or her past. These stories could be made into a book with photos and old postcards. Even later on, writing post-cards and birthday cards can be a way for the person to keep in touch with friends and family.



Art

Producing artwork is often exciting and interesting. Even if the person has not painted a picture since his or her school days, being creative with paints and other craft materials can be very enjoyable and satisfying. Remember that the end results do not have to look like 'works of art'.

Depending on the person's interests and what he or she enjoys doing there are many different types of projects you could enjoy together. Painting on plant pots or wooden photo frames, or even small pieces of furniture like wooden stools can be very satisfying and produce some great results. Look around art shops for ideas. There are kits available for sand art, painting by numbers and collage kits. Art galleries and exhibitions are also likely to be a source of interest and a subject for discussion. For most people it's best to use adult materials because items obviously meant for children can offend.

Restoring furniture

Carers have also suggested buying old pieces of furniture to restore. Sanding and polishing can be very relaxing and the person with dementia is often absorbed for long periods of time if he or she enjoys this type of work. However, beware of paint strippers as they can burn the skin; electrical sanders should also be avoided.

“I can't believe how much time my husband spends on restoring pieces of furniture. He loves doing it and seems to find it very satisfying.”

Knitting, sewing and embroidery

If the person you care for has always knitted or done embroidery or tapestry you may find he or she retains these skills for a long time. You might have to encourage him or her to start and be prepared to help with each stage, but it is worth persevering. The end result can give a wonderful sense of satisfaction.

Gardening

Gardening is another favourite activity enjoyed by many people. Gardening provides a change of scene and will also ensure you both get some fresh air and exercise. It may be a good idea for the person to have his or her own patch of garden to dig and plant in. Weeding, trimming lawn edges, sweeping paths and general tidying in the garden can all be tasks many people with dementia can cope with. However, make sure he or she doesn't use electrical equipment or potentially dangerous tools.

Try to plan the garden so that there are lots of different varieties of plants, with bright colours and interesting scents - for example, lavender and rosemary. These can be stimulating and enjoyable for people with dementia even late on in the illness.

“My husband enjoys gardening so much I haven't the heart to stop him. He sometimes makes rather a mess, but I think it's worth it for the pleasure it gives him.”

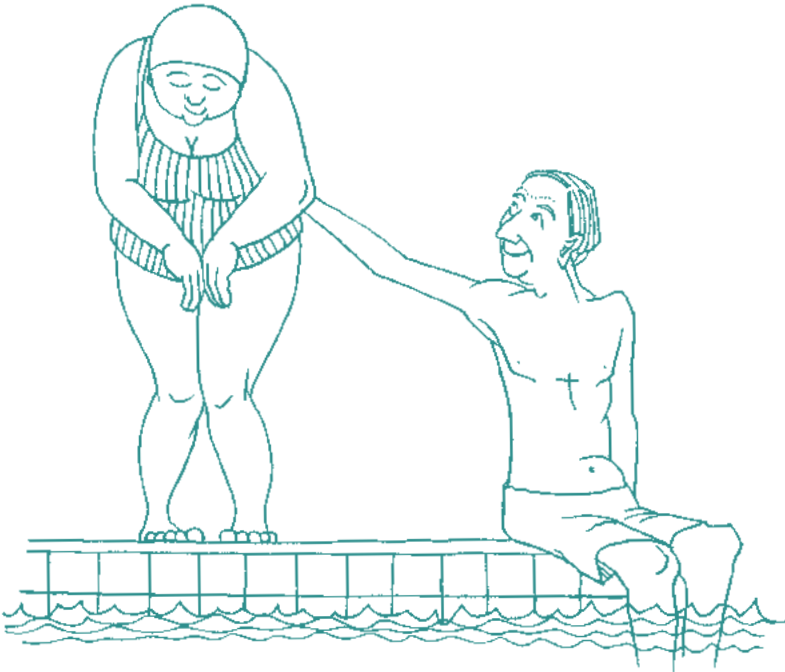
If you do not have access to a garden, indoor gardening, such as planting bulbs and herbs in pots can an enjoyable activity too.



Going out and about

Exercise and sports

Getting out for some exercise and a change of scene will help both of you. Try to incorporate a daily walk in your routine. It doesn't have to be far - it could just be down to the local newsagent. If the person you care for has always enjoyed longer walks, keep this up and try to vary the route and location.



Some people enjoy swimming throughout the course of their illness. Ask at the swimming pool when the quieter times are, as lots of noise and activity can make the person anxious. Many pools can also provide assistance so that you can help the person in and out of the pool.

If the person you care for likes watching sports, he or she may enjoy trips to watch favourite sports.

“My husband always loved watching sports and now I try and make sure we go down to the bowling green once a week. Even if we only stay half an hour, it’s an outing we both enjoy.”

Going out for a coffee or a meal

If you both like going out try to make this part of your routine. If you can, find a quiet café where you can both relax.

Museums

Going to a museum and looking at objects which the person can relate to and which are part of his or her past can be very enjoyable. Watch out for exhibitions which may be of special interest.

Theatre and cinema

If you both like going to the theatre or cinema it is a good idea to keep going for as long as possible.

Going for a drive

Taking the person you care for out for a drive will often calm him or her down. Driving round areas remembered childhood, or where the person worked will often stimulate memories and you can talk about past times.

“My wife used to love visiting gardens and RSPB nature reserves even when the dementia was at an advanced stage.”

Public transport

If you don’t have access to a car perhaps you could organise family or friends to help out occasionally or look into other options which would allow you to get out and about. Most people with dementia will be able to get free local bus travel at off-peak times. The Scottish Executive says that every local council must provide free off-peak bus travel to people who are over 60 or are disabled.

- If the person is 60 or over he or she will definitely qualify.

- If the person is under 60, he or she might qualify - some local authorities include people with dementia and some don't - check with your local council.

Ask your local council about how to get a bus pass.

Some councils provide more than just free off-peak bus travel. In some areas you will be able to travel on local trains or ferries too. In the future, the Scottish Executive plan to extend the scheme to include off-peak bus travel across Scotland as well as local buses.

Taxi card schemes

Ask your local council if it has a taxi transport scheme. Many councils provide cheaper taxi travel or a certain number of free or cheap taxi journeys a month to disabled people, including people with dementia.

Who can help

Family and friends

Ask family and friends to come round and visit. Make sure they know what to expect and perhaps suggest they bring a favourite game or help the person do some cooking or gardening while they visit. Often visitors welcome a chance to do something active and positive. Looking through old photos, reading the paper or watching a favourite TV programme with the person are other suggestions from carers. Give friends a copy of the booklet *I'll get by with a little help from my friends*, available from the Dementia Helpline, to help them understand why their friendship is important and what they can do.

Dementia Helpline

The Dementia Helpline, **0808 808 3000**, is a free, confidential 24 hour service offering information and a listening ear. You don't even have to give your name if you prefer not to. Call at any time to talk things over or to find out about any aspect of dementia, how to cope with caring and finding help locally. They can also send you a free information pack on caring for someone with dementia.

Courses for carers

Carer courses cover a variety of topics and respond to what carers say they want to know. Carer courses can help carers come to terms with the condition. The courses offer advice and information on practical skills, as well as encouraging alternative ways of thinking not only about what dementia means, but also about what it means to you to be a carer. Going on a course is a good way of getting in touch with other carers who know what it is like from first-hand experience and also to share your experiences and expertise if you wish.

“The course was greatly beneficial, not just for the information received, but for the insights it provided in listening to other carers talk about their problems.”

Contact the Dementia Helpline or your local Alzheimer Scotland service for more information.

Conclusion

Keep the person involved. Activities don't only pass the time, but also help the person retain important skills and provide enjoyment and social contact. Involve other people as much as possible. This will also help you cope.

Don't feel you have to fill every minute of the day! Quiet times are important too - including sleep.

Don't forget to look after yourself too. Alzheimer Scotland has produced a booklet for carers, *Looking after yourself*. Contact the Dementia Helpline on 0808 808 3000 for a free copy.

Acknowledgements

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www.alzscot.org

This booklet is for carers of people with dementia who would like help with planning daily activities at home. You can enjoy a range of stimulating activities and outings together by focusing on what the person with dementia *can* do. The booklet will help you to plan appropriate, positive and enjoyable activities which reflect the person's interests, preferences and abilities.

This information is available in large print on our website www.alzscot.org or from the Dementia Helpline.

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