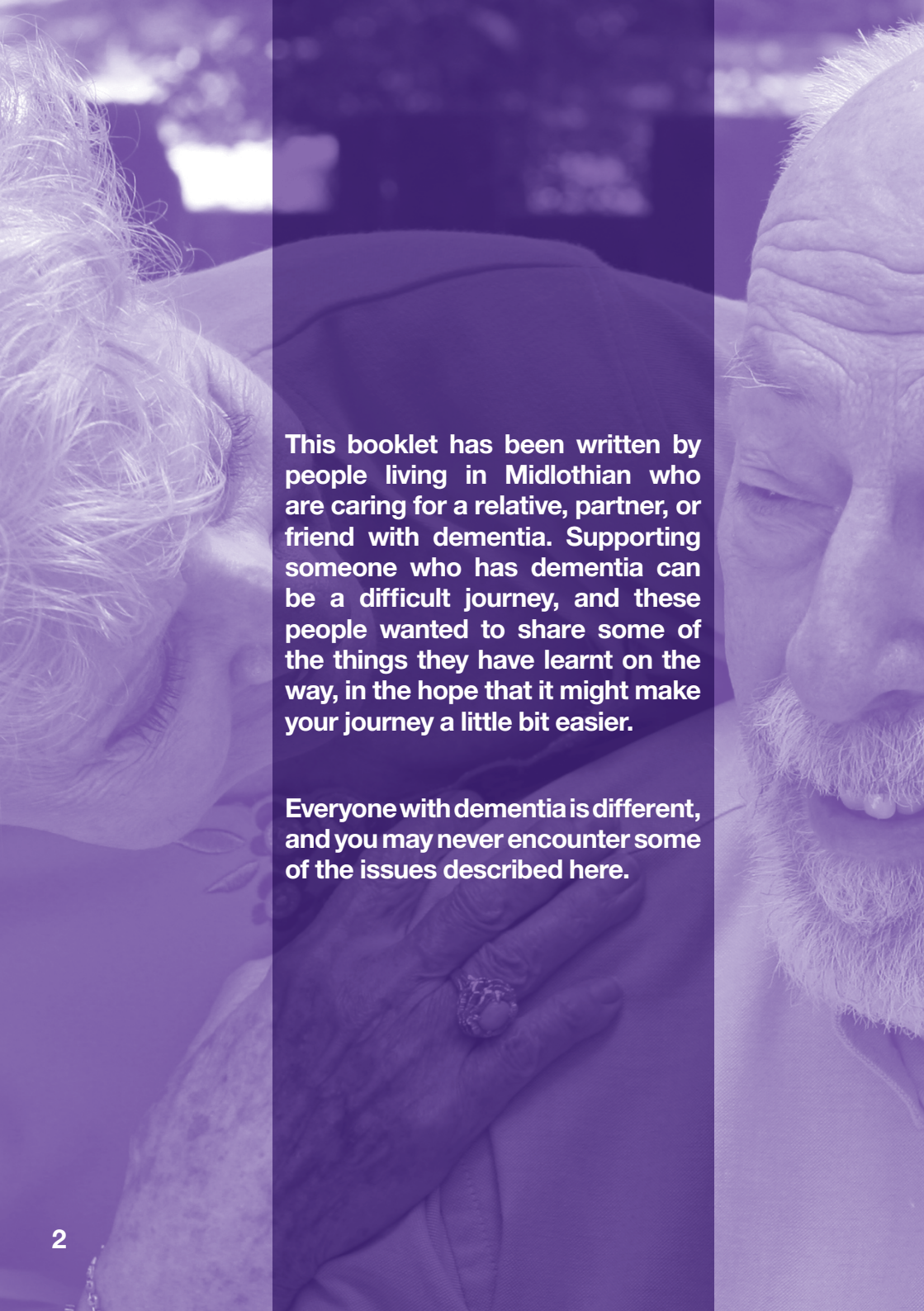




# Hints and tips – when caring for **PEOPLE WITH DEMENTIA**

Written by residents of Midlothian



This booklet has been written by people living in Midlothian who are caring for a relative, partner, or friend with dementia. Supporting someone who has dementia can be a difficult journey, and these people wanted to share some of the things they have learnt on the way, in the hope that it might make your journey a little bit easier.

Everyone with dementia is different, and you may never encounter some of the issues described here.

## Working with paid carers

Having paid carers from the council or an agency coming into the home is often a new experience. These are some suggestions which might help make the experience a little smoother, and give you more peace of mind knowing the person you care for is well looked after.

### Communicating how the person should be cared for

- You can try putting together a one page summary of how the person should be cared for. Family carers could complete this jointly with the paid carers. Such a document should be concise, as paid carers have very little time during their visits to read a lot of information, try using bullet points. A template is attached below which may be useful (see Appendix A).
- Another document that you could use is the '**Getting to know me**' document, which is a bit longer but could be used at home or in hospital settings to communicate to professionals what the person likes and how they want to be supported.

To obtain a copy of this document contact **Alzheimer Scotland** on **0808 808 3000** or download it from their website.

### Keeping paid carers informed

Some people put up a notice board or white board in their kitchen to write key bits of information that they would like paid carers to be aware of.



- When leaving notes make sure you include.
  - the date
  - who the note is for.
- Most care organisations have a care plan folder with all the clients' information in the person's home. This includes a visit log which is used to note what they have done on a visit and to communicate with other carers on different shifts. You can also use this to put in messages to paid carers in their file to keep them updated.
- If you're using paper for notes leave them in the same location each time. Rather than using different bits of paper some people prefer a fixed note pad to be used. However if the person with dementia is likely to move/hide it then use the communication log in the paid carers care plan folder.
- Make sure the person with dementia's care planning file is put somewhere that the person with dementia won't move it / tidy it away.
- Tell paid carers if you're **planning to go away** or about any change of key contact.

### Medication

- **Important:** tell paid carers if there have been changes in the person's **medication**. If they have been given a new medication product make sure you remove the old ones. The rules for paid carers administering medication are quite strict so you might want to call the paid carers' office to tell them of any significant changes.
- Dosette boxes – there are new rules for paid carers about medication and they are not allowed to administer it from dosette boxes (the boxes with the days of the week on) if they have been prepared by the person or family. They have to administer it from the original packaging. However if the dosette box has been prepared by pharmacists they can use it. You can ask your pharmacist if they will prepare a dosette box for the person you care for.
- A medication safe may be required to store medication securely if the person is liable to self medicate when they are not able / shouldn't. Safes don't have to be expensive and some large supermarkets stock them. For small amounts of medication something as simple as a petty cash box could be used.





## Secure storage

- A key safe is a secure box fitted to the outside of a home containing a set of keys to enable professionals or relatives to get in if the person is unable to answer the door. Each safe has an individual access code of your choice. You can give the code to anyone you trust who needs to access the property. They can be purchased from hardware stores, or you can ask about the council's telecare service, Midcare.
- If there are issues around money such as the need to prevent the person with dementia having a lot of money on them you may need a safe/lockable box.

## Who's who

- It may be useful for the person with dementia and the paid carers to have named photos of family members or friends readily available in the house. This can help create conversation between paid carers and the person with dementia. Also the paid carers can assist the person if they can't remember their names.
- If you have access to digital photos then photo printing companies such as Boots, can make them into books/albums for you. Text can be inserted under each picture to explain who is in the photo. These books are often more hard wearing than standard photos and can give people a lot of pleasure to look at.



## Meal times

- Does the person have preferred cutlery that they use, which is important for assisting at meal times? Make sure these are known about and easily available for paid staff.
- If the person is supported only at meal times then make sure the paid carers check if the person has any personal care requirements before commencing meal preparation.

## Miscellaneous

- Make sure there is sufficient toilet roll in the house and you have undone it / got it started (if the person finds it difficult to start the roll).

### What to do if things are not working out with paid carers

- If you're not happy with how things are running with the paid carers, the first thing to do is to raise your concerns with the manager in the care organisation.
- If you feel that your issue hasn't been resolved to your satisfaction then the Council has a Quality Assurance Officer who you can contact. The Quality Assurance Officer works with care providers to help maintain standards and will pick up on issues either through inspection or customer feedback on areas for improvement.

**ACCQualityAssuranceOfficers@midlothian.gov.uk**

**Telephone: 0131 271 3900**

## Advice on simple things to help when caring for a person with dementia

Below are some strategies that Midlothian Carers have developed when caring for a person with dementia. Some of these suggestions might work for you, and some of them might not. Everyone with dementia is different, and there can be a lot of trial and error involved in finding out what works for them. Also some of the things that don't work now may work later on as the person with dementia's condition changes.

### Daily living tasks

- If the person is not sure about what things are, then using visual aids may help. For example, if the person isn't sure about what is in their tea cup and are perhaps wary of what it contains, put a tea pot next to it as a reminder that it is tea. The person may associate the object with a task or another object, which may help to remind them.



“I had problems getting the gentleman I was supporting to shave. His wife told me that when he looks in the mirror he sees his friend. By using his reflection/friend as a way of engaging with the task he perked up when he saw him and was then happy enough to shave himself.”

- As dementia progresses it can sometime affect the person's enthusiasm for eating. This will differ from person to person. Some helpful suggestions include: Make sure they have adequate time for eating; tell them what meal it is and what they will be eating; try not to worry about any untidiness around eating. Sometimes eating together can help as well, as seeing other people eating can help remind the person what they are doing.

### Medication & health

- Sometimes people with dementia develop difficulties in swallowing medication or perhaps administering traditional tablets has become a challenge. You can ask your GP about ways to make this easier e.g. some medications are available as a liquid, which the person may be able to take more easily.

- Often health professionals require specimens, which the person with dementia may have difficulty understanding what is required or, they may not be able to do it for themselves. Putting a container e.g. an ice cream tub, in the bowl of toilet may make this easier.



### Reminiscence

- Although dementia can often affect the memory, this tends to be the short term memory rather than the long term memory. Reminiscence activities often focus on discussion of past activities, events and experiences. People with dementia often enjoy reminiscence activities and this can help them to engage.

- Reminiscence Kits are available from museums and libraries to help people to remember times gone by and may assist in triggering conversations. The mining museum, for example, has reminiscence boxes people can use.
- You can make a reminiscence box yourself. Seek out objects, things that smell e.g. a favourite soap, pictures from a time that they remember and were fond of. Involve the person in putting it together.
- A life story book is a collection of reminders of important times in the person's life, such as photographs, tickets, postcards and so on. Making a life story book is an opportunity for the person to talk about their life. The book can then be very useful for you and family members to reminisce with the person at later stages of dementia. It is also highly useful for staff who are supporting the person as it will give them a good insight into the person's personality and background. See Appendix B for an example of a life story book.
- Music, photographs, poems and discussion of past events are ideal ways of reminiscing with the person with dementia.

## Stimulation & motivation

- There are a number of things that you can do to support, assist and stimulate the person with dementia. The main thing is to encourage the person to continue to be involved in activities that interest them and support them to do as much as they are able to.
- Think about what the person used to enjoy doing and help them to keep doing these activities. The right activities can help the person to maintain their abilities, confidence and independence.
- Remember, that the person's abilities may have changed and they might need support to be active. For example:
  - Avoiding distractions e.g. background noise or a cluttered work space
  - Giving prompts for the person that they can understand – might be simple instructions, demonstrating an action or working together on the activity.
  - Making an activity simpler e.g. measuring the ingredients before so the person just has to pour them into the mixing bowl to make a cake.

As long as the person is safe during the activity and enjoying it there is no right or wrong way – the experience of doing the activity is more important than the end result.



- Encourage friends and family to be involved with activities as it is beneficial for the person to stay involved in family and community life as much as possible.



### Responding to signs of distress or changes in behaviour

Not everyone with dementia will experience these changes, but if they do occur some behaviour changes can be especially difficult for carers. For example:

- Sometimes someone may do things which are embarrassing to you (e.g. swear when they never did before, be sexually inappropriate, be rude to visitors, or start to undress in public). Again, try to

stay calm and matter-of-fact. Gently distract them or take them to another room.

- Sometimes the person may become angry, upset or aggressive. Often this is a response to something that has happened around the person or is their way of telling you they need something or that something isn't right. For example
    - Is the person hungry, thirsty, needing the toilet, too hot or too cold?
    - Is the person physically unwell (e.g. has an infection) or in pain/discomfort? If there is a sudden change in the person's behaviour you should speak to your doctor to check for any physical health problems which could be causing the change.
    - Is the person feeling frustrated? What could be causing this? E.g. difficulty finding the right word, remembering something or understanding what is happening.
    - Is the person feeling anxious or worried about something?
    - Does the person feel overwhelmed or are they bored?
- Try to keep calm and de-fuse the situation, it is often not productive to argue with the person when they are upset. If you notice changes in the person's behaviour it is important that you get support and advice in how to deal with these changes. You can phone the Alzheimer Scotland helpline 24 hours a day for general advice (0808 808 3000) or ask your health professional.



### Thinking about when to tell people things to minimise distress

- Some people find that when they tell the person with dementia about something which is going to happen in the future (e.g. we are going away next weekend), this can make them anxious or distressed. Sometimes people find it is easier for the person not to tell them things too far in advance (e.g. wait until the morning of the event to tell them, so they do not have too much time to worry about it and become anxious).

“I used to feel that I had to tell my mum what was going happen well in advance and give her plenty of notice. In fact this just used to work her up and make being in the house after I told her very difficult. Also not long after I’d told her she didn’t remember anyway. I then learnt that I had to be more considered about what I told her. I hated it at first, I felt I was being dishonest and even disloyal but actually I would tell all carers that you shouldn’t feel bad about this.”



### Self recognition

- Some people may stop recognising their own reflection as the person they remember is a younger version of themselves. They may feel unsure or even distressed about seeing their own reflection.
- If someone thinks there is someone else in the house then check to see if there are mirrors in the house. The person may not recognise themselves in the mirror and think that someone else is in their house. You can take down all the mirrors or cover them up. Also, if it is dark outside, it may be best to draw the curtains so the person cannot see themselves reflected in the windows.

### Pick your battles – whose problem is it?

- Sometimes your concerns or even embarrassment about the person's actions are yours and not the person with dementia. If the person is happy then ask yourself, do you really need to worry about it?

"I was on holiday when my wife ran up to someone she thought she knew. I was very embarrassed and worried about how the person would react. Previously I would have tried to drag my wife away worried about the inconvenience to the other person, which would have upset her. However the person was understanding and was kind enough to spend time talking with my wife. When I thought about it, I realised that I didn't need to worry, my wife was having a really nice time, so I could relax while they spent time chatting."

"My husband started sleeping in his clothes and not wanting to change into his pyjamas. I really struggled trying to get him to change for bed when I realised that it probably wasn't worth the battle. He happily changed his clothes every day, so what did it matter if the clothes he slept in weren't 'night wear' in the traditional sense."

## SUPPORT FOR YOU AS AN UNPAID CARER

It's important that carers look after themselves too. It may be helpful to seek some support, or making sure you have some time to yourself, or even just being able to talk to someone who understands. There are a number of local and national organisations that can help you:

### VOCAL

Midlothian Carers Centre run by VOCAL offers carers' training, counseling, access to short breaks, expert advice, advocacy and one to one support.

30/1 Hardengreen Estate, Dalhousie Road, Dalkeith, EH22 3NX

Tel: **0131 663 6869** Email: **midlothian@vocal.org.uk**

### Alzheimer Scotland

Alzheimer Scotland in Midlothian provide a range of services, support and information for people with dementia and their carers, including a Dementia Cafe twice a month which has a carers' support group and various social activities for people with dementia.

3 Edinburgh Road, Dalkieth, EH22 1LA

Tel: **0131 654 1114**

The 24 hour Dementia Helpline is a freephone Scottish service for people with dementia, carers and anyone concerned about dementia. The Dementia Helpline is confidential, and you don't even have to give your name if you prefer not to. They also provide free information packs to people with dementia and their carers.

Freephone **0808 808 3000**

### Single Dementia Service

The Midlothian Dementia Service provides a single point of access for people with dementia and their carers to services and support including Dementia diagnosis, support after you are diagnosed, help with your care needs at home and support to carers.

Bonnyrigg Health Centre

109-111 High Street, Bonnyrigg, EH19 2ET

Tel: **0131 271 3900**

# APPENDICES

# APPENDIX A

## A one page summary of how the person should be cared for

Complete the template below. For each section thinking about the following areas:

- What the person can do for themselves
- What you need to prompt
- What you need to do for the person.

Keep the information brief and concise so paid carers can refer quickly to this information.

### Personal care

### Meal preparation

### Medication

### Other information




# APPENDIX B

## Making a Life-Story Book

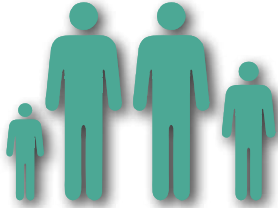
### Some suggestions on what you might want to include

The purpose of a Life-Story Book is to help people get to know the person as well as possible. The book can be made up by anybody who knows the person well. The more they can contribute themselves, the better.

- Get a small photo album (6" x 4" or 8" x 5")
- It is good to begin with a photo of the person; one which they are happy with. Perhaps one from when they were younger.

	<p>This is me</p> <p>I like to be called</p>
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- Put photos of family, pets and places of interest e.g. holidays, places where the person has lived, favourite places to visit, in the album.
- On the opposite page explain who / what is in the photo e.g. husband / partner / wife, daughter/son. Describe the occasion when the photo was taken.

	<p><b>This is my family</b></p> <p>My Husband ...</p> <p>My Children</p> <p>My grandchildren...</p> <p>My sister</p> <p>My Pet.... My Partner</p>
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- List things that your family member does e.g. favourite TV programmes, radio stations they listen to, what music they listen to, crosswords, jigsaws, bingo, card games etc.

<p><b>Likes</b></p> <p>I like a good joke and I love talking</p> <p>I love shopping</p> <p>I enjoy listening to music</p>	<p>I play Scrabble and cards</p> <p>I like reading books and magazines</p> <p>I like watching TV. My favourite</p>
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- List what activities the person does or did in a normal week e.g. Monday shopping, Saturday play golf.

<b>My Week</b> Monday: I get my hair done Tuesday: I go on the bus to town Wednesday: Rest Thursday: Visit my friend	Friday: Warm water swimming Saturday: Lunch club Sunday: Rest
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- Make a list of favourite foods and foods disliked. Include preferred ways of preparing and serving

<b>Foods</b> Breakfast Snacks Lunch	Dinner Puddings Drinks
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- Make a list of spiritual or cultural needs

<b>My beliefs</b> I like to pray / meditate I don't eat ... for religious reasons My culture forbids....	These are the days I like to celebrate.  What I do
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- Make a list of proud moments or achievements

<b>I am proud of:</b> I came first in the cross-country at school when I was 15. I have knitted more than 60 jumpers.	I grew the best onions in my village  I did my job for 40 years without single day off sick
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**Anything can be included in the life-story book that helps the person with dementia tell you about themselves.**

## COMMUNICATING CLEARLY

We are happy to translate on request and provide information and publications in other formats, including Braille, tape or large print.

如有需要我們樂意提供翻譯本，和其他版本的資訊與刊物，包括盲人點字、錄音帶或大字體。

Zapewnimy tłumaczenie na żądanie oraz dostarczymy informacje i publikacje w innych formatach, w tym Braillem, na kasecie magnetofonowej lub dużym drukiem.

ਅਸੀਂ ਮੰਗ ਕਰਨ ਤੇ ਖੁਸ਼ੀ ਨਾਲ ਅਨੁਵਾਦ ਅਤੇ ਜਾਣਕਾਰੀ ਤੇ ਹੋਰ ਰੂਪਾਂ ਵਿੱਚ ਪ੍ਰਕਾਸ਼ਨ ਪ੍ਰਦਾਨ ਕਰਾਂਗੇ, ਜਿਵੇਂ ਵਿੱਚ ਬਰੇਲ, ਟੇਪ ਜਾਂ ਵੱਡੀ ਛਪਾਈ ਸਾਮਲ ਹਨ।

Körler için kabartma yazılar, kaset ve büyük nüshalar da dahil olmak üzere, istenilen bilgileri sağlamak ve tercüme etmekten memnuniyet duyuyoruz.

اگر آپ چاہیں تو ہم خوشی سے آپ کو ترجمہ فراہم کر سکتے ہیں اور معلومات اور دستاویزات دیگر شکلوں میں مثلاً بریل (دیکھنا افراد کے لیے) بھرے ہوئے حروف کی لکھائی (میں ٹیپ پر یا بڑے حروف کی لکھائی میں فراہم کر سکتے ہیں۔

Contact 0131 270 7500 or email: [enquiries@midlothian.gov.uk](mailto:enquiries@midlothian.gov.uk)