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## Introduction

This booklet is for you if you care for someone with dementia. It has been produced with the help and support of many carers across Scotland.

Caring for someone with dementia can be a very intensive, challenging, rewarding and at times stressful experience. Carers of people with dementia often describe the joys as well as the tribulations of caring for a relative or friend with dementia. Whilst grieving for the losses that dementia inevitably brings, carers also often find a strong appreciation of the person and of the familiar activities, memories and social life that they are still able to enjoy together.<sup>1</sup>

However, caring for someone with dementia is even more complex and demanding than caring for someone with physical disabilities.<sup>2</sup> One study found that compared to non-caregivers, carers for people with dementia visited their GPs 50% more and took up to 86% more prescribed medications.<sup>3</sup>

Carers face very different caring challenges at each stage of the illness. Adjusting to the diagnosis and coping with the changes the illness will bring can cause a great deal of stress, but if you are well prepared and know what you may need to provide in the way of care it can help a great deal. Having a good network of family and friends who know how they can help you is also very important.

1 Alzheimer Scotland - Action on Dementia (2003) Signposts to support: Understanding the special needs of carers of people with dementia. Supported by Scottish Executive.

2 Zarit S H, Gaugler J E, Jarrott S E (1999). Useful services for families: research findings and directions. *International Journal of Geriatric Psychiatry* 14, 165-181

3 Katon et al. (1982) Depression and somatization. A review. *Am J. Med.* 72, 127-135

This booklet will provide guidelines which will help you cope with your caring role, and help you understand why it is so important that you look after yourself. When you are caring for someone with dementia it is often very difficult to see why and how you could possibly take any time out for yourself.

*‘It is very hard to accept advice about how to look after myself - even though I know it is important, it is often impossible to see a way to make any changes.’*

Each person is different and each caring situation is unique. Asking for help and finding out what suits you and the person you care for can be very difficult, but there are many ways you can make life easier for both you and the person you care for. Stress affects your health, and much of the information in this booklet explores ways of reducing stress.

If there is any information you need regarding dementia and your caring role please contact the 24 hour freephone Dementia Helpline **0808 808 3000** for advice, information and support.

## About 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 their illness affects them will depend on which areas of the brain are damaged.

One of the main symptoms most people with dementia experience is memory loss, which gets worse as the illness progresses. Often some of the first signs can be the person behaving in a slightly odd manner or out of character. The person may also begin to lose track of time and be unable to work out directions even in places they are familiar with. The ability to reason clearly may decline, leading to problems with decision-making. Dementia can also cause behaviour changes, which can be very distressing for carers. Some people will develop changes in their behaviour such as constant repetition, aggressive behaviour, inappropriate language or loss of inhibitions. Any of these symptoms can be difficult to deal with and can be very distressing for carers.

**But there are ways of coping.**

Dementia can also cause psychological changes. The person may become withdrawn or depressed, seem self-centred, become frustrated by not being able to do things, or lack insight into his or her problems. These changes can affect the relationship between the carer and the person with dementia. There are ways of dealing with these changes and it is important you seek help, so that you will be supported as you care for the person with dementia.

Gradually, over a period of years, the person with dementia will increasingly have to be helped with day-to-day tasks, such as bathing, washing, cleaning teeth, dressing, eating and going to the toilet. This decline in the person's ability to care for him or herself means that the

carer is often ‘on duty’ 24 hours a day, seven days a week. The impact of this intensive caring in physical and emotional terms can be huge and carers need support and services to help them cope.

## Why you should look after yourself

### *‘Looking back I don’t know how I coped’*

Caring for a person with dementia can become a very stressful and exhausting experience, although it must be emphasised that many carers report positive sides to being a carer. Carers say that being able to manage and feeling like they are doing a good job has helped them cope with caring. Understanding the importance of looking after themselves by taking regular breaks, keeping fit, having regular check-ups, accepting help, maintaining their own interests and social lives all help carers to cope with their caring role.



One of the problems often described by carers is that either their GP referred the person with dementia too late for services or they themselves left it too late before asking for help. This can result in a crisis situation where carers feel they can't cope even when the services are put in place to help them.

The secret to successful caring is to seek help **before** a crisis situation occurs. Know your own limits and don't feel guilty about asking for help, **sooner rather than later!**

You can get information on practical services such as home help, day care and breaks from caring from the social work department. You can get information and support from the Dementia Helpline and through local dementia services. Contact your GP who should be able to help and can refer you on to other support services.

## Diagnosis

*'Until you get a diagnosis you don't know where to go for help'*

Before a diagnosis is made it is often very difficult for all concerned, as they do not understand what is happening. Family and friends will be puzzled, worried and perhaps rather frustrated with the behaviour of the person with dementia and not know what to do about it. Not knowing what is wrong can be very stressful.

*'I didn't know whether I should go to a marriage guidance counsellor or to the doctor for help when my husband first started to develop dementia. I didn't know what was wrong'.*

Once a diagnosis is made there can be a period of shock until the carer and the person with dementia come to terms with the diagnosis. Everyone copes in different ways. Try to make sure you talk about the diagnosis with friends, family and your GP. Once you know what is wrong you can then find out as much as possible about the illness.

Many carers have said how frustrating it can be at the beginning before they find out who can help them and what information is available. Understanding the illness and knowing what services are available will take away some of the uncertainties.



## Getting information

*‘I did a lot of reading in the early stages. Some books were more helpful than others, but this gave me more insight into things.’*

Carers who are well informed can help make life better for both themselves and the person with dementia.

Understanding what kind of care the person with dementia will need and how this will affect you and the person you are caring for will enable you to plan ahead. Many carers have said that the initial shock of learning the diagnosis and adjusting to the situation was made worse by lack of information and support from professionals.

*‘Keep asking for information and help - eventually you should be able to find someone who will explain what is going on.’*

Find out what services are available from the social work department and work out which ones would suit you and the person you care for. To start planning what help you need try to think about:

- what problems are difficult to deal with, both for you and the person you care for
- what you want to know
- what you and the person with dementia need in terms of practical help and emotional support.

Keep talking to your GP and family and friends about any problems you are having. Often family and friends are scared and feel unable to deal with the situation if they do not understand what is going on. Usually once you explain what is happening it will help them understand and they will be able to offer support.

If you need further contacts or information call the 24 hour freephone Dementia Helpline **0808 808 3000**.

## Emotional impact

As you adjust to the situation after diagnosis you will feel a wide range of emotions, some of which may be difficult to cope with. Fear, grief, anger, guilt and despair are some of the emotions you might feel.

**These feelings are all normal.** Keep in touch with friends and family and discuss what is going on. If you are finding it hard to cope ask your GP to refer you to a counsellor or contact the Dementia Helpline for support.

## Grief

Grief is a natural response to a loss. You may grieve as the person you are caring for loses their memory and changes from how they used to be. Many carers say this is an ongoing process as the dementia progresses. Speaking to other carers can be very helpful, as they are aware of what you are going through and can support you through



the hard times. Contact the Dementia Helpline to talk, or for information on carers' groups in your area.

## Anger

You may at times feel angry at the person because they have changed, they are behaving strangely or they can't do things they used to be able to do. This is a normal reaction. You may also feel angry at the situation or at yourself. For instance you might feel resentful that you have to care for the person, or frustrated that you are not coping as well as you feel you should. There are many different ways of coping with anger. Over time you will find out what works best for you. Talk to friends, family, your GP and other carers to find out how they have coped with these feelings.

There are training courses available for family carers, which can help you understand what is happening to the person you are caring for and help you deal with the problems you are having. Contact the Dementia Helpline for more information, or your local Alzheimer Scotland service.

## Embarrassment

The person you are caring for may behave in an embarrassing way as the dementia progresses. Loss of inhibitions can lead to the person using inappropriate language and behaviour. Try to remember this is not to do with who the person is, but it is the illness affecting them. Explain to other members of the family and friends what is going on, so they also understand what is happening.

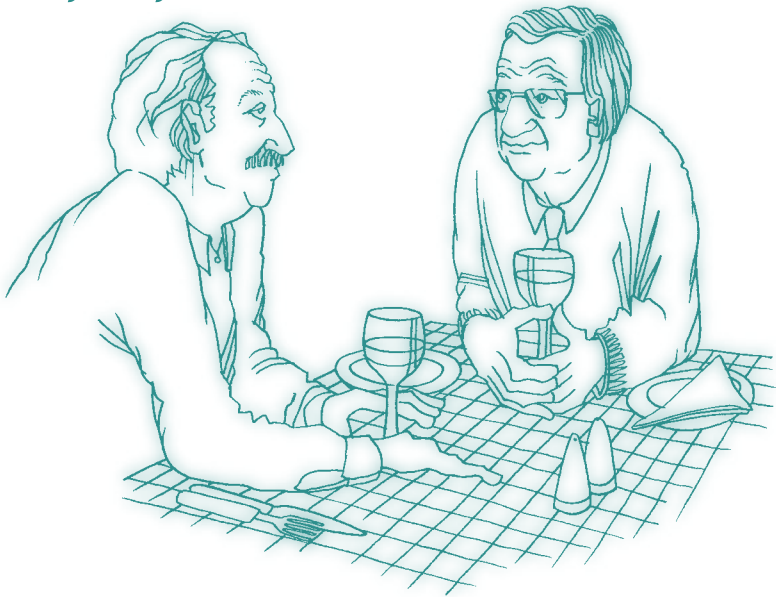
## Loneliness

*'Keep up friendships - don't lose contact'.*

Carers often report feeling lonely and isolated. One of the reasons is that as the dementia progresses the person you are caring for will not be able to offer the same sort of companionship. You may also find you no

longer see friends as often. Perhaps they cannot cope with the situation or do not understand what dementia is. Talk to them and explain the effect of the illness. If you feel you no longer have time for outside commitments, remember that keeping in touch with other people is very important if you are to cope with the situation yourself. Being able to talk to others and enjoy contact with your family and friends is vital.

*'It is important to have someone to talk to. Friends all too often stay away.'*



## Looking after yourself

In order to look after the person with dementia and yourself you need to plan how you are going to stay physically and emotionally healthy. These are some suggestions which other carers have found helpful. A frequent comment from carers is how to overcome feelings of guilt when they do things for themselves. Understanding how important this time is both for you and the person with dementia will help. Although you may feel guilty going out and leaving the person with a friend or family member or using a care service, in the long run this may well

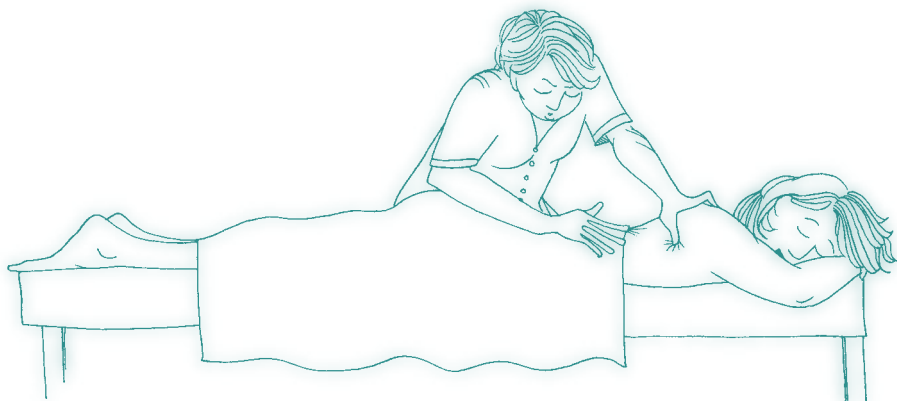
prevent a crisis occurring. Remember that looking after yourself, physically and emotionally, will help you to care for the person with dementia for as long as you choose to.

## Health

Make sure you look after your own health. If you notice any changes in yourself such as loss of appetite, being unable to sleep, feeling depressed or any other worrying symptoms contact your doctor. You have to stay healthy if you are to continue caring. It is a very demanding and intensive job caring for someone with dementia and you deserve to be looked after too.

## Relaxation techniques

*'I manage to take time out for one hour a week to have an aromatherapy massage. While this is not a lot of time I really enjoy it as it is so relaxing.'*



Relaxation techniques can help you look after your own well-being. For instance aromatherapy, therapeutic massage, reflexology and reiki are all popular ways of relaxing and great ways to take some time for yourself. Some carers' groups have managed to get funding to provide an opportunity for carers to try alternative therapies. Ask your local group if they could organise a similar activity.

## Exercise

Try to fit in some time for exercise. Exercise is very important and will help to keep you healthy and give you some time for yourself. Try your local sports or swimming centre - there are often classes, in everything from step aerobics to the gentler Tai Chi and yoga. If you are over 50 there are often reduced prices.

If you don't have the time for classes, or there is no-one to stay with the person, going for a walk, gardening or any physical activity will also help keep you fit.

## Sleep

Try to get enough rest. If you are disturbed at night, try to sleep when you can. Take advantage when your relative sleeps and get some rest yourself. It's always tempting to get all the things done you would otherwise be unable to do. But it is more important that you are well rested.

Lack of sleep will not only make you tired and so make it harder to cope, but it can also lead to depression and affect your physical health. If you are unable to get enough sleep because you need to look after the person with dementia at night, seek help. See the section on 'Getting help' for more information on community care services, which may be able to help you. In some areas there are overnight services, or short respite breaks might allow you to 'recharge your batteries'. There are also private services which provide care overnight, although these are expensive.



*‘I’m very lucky because now I get help some nights so that I can sleep properly and continue caring during the day. It means I’ll be able to care at home for longer.’*

## **Problem solving and behaviour**

Caring for someone with dementia can be full of ups and downs. Some useful advice from other carers for easier caring to reduce the stress includes:

- remember that repeated questions are not meant to annoy you
  - try to understand why the person is asking the questions and either distract or reassure them
- face the person, speak clearly and use simple sentences
- be patient and allow extra time
- let the person know that you understand how frustrating it is for them
- always allow plenty of time for eating, dressing, bathing etc.
- encourage independence by not doing too much for the person
- alter clothing to make dressing and toileting easier - Velcro and elasticised waists often help
- speak to your GP and a continence adviser or nurse if you need help with continence problems.

There are many other ways in which you can help the person and yourself. A useful book which gives advice and tips is called *Coping with Dementia: A Handbook for Carers* produced by NHS Health Scotland. Contact the Dementia Helpline for a free copy or to talk over a problem.

## **Routines**

*‘I try to keep to a routine and don’t make changes unless I have to.’*

Find a routine which suits you and the person with dementia. Often this will create a more stable and peaceful environment, and the person with dementia will be less agitated and unsure of what is happening. Use reminders, lists and pictures around the house to help the person remember parts of the daily routine. Anything which makes the daily routine run more smoothly will help you cope.

## Being positive

As much as you can try to focus on the good things and try and not think about all the things the person can no longer do. Be positive and enjoy the activities you can still do together. Try to ensure the person can remain as independent as possible for as long as possible. This will be good for the person and help you too.

## Taking time out

*‘I like to go for a drive - sometimes I go on my own, other times we go together.’*

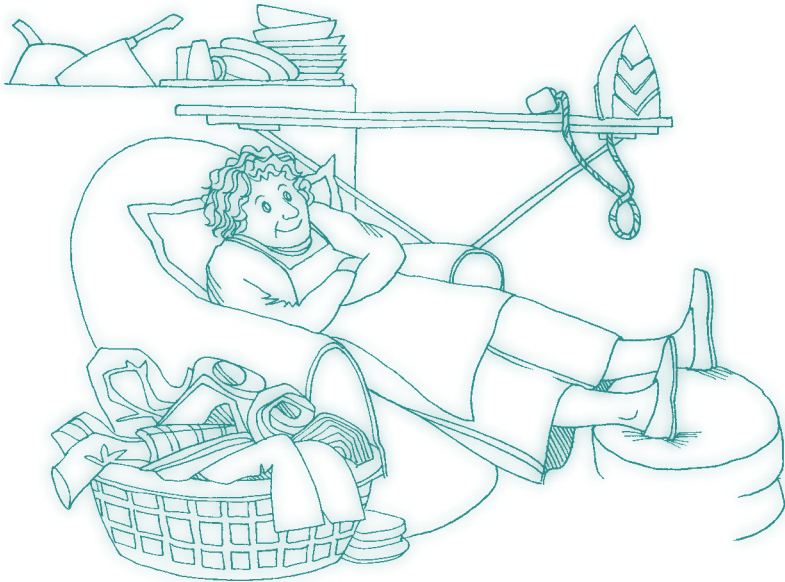
Just taking time out for ten minutes can often help. Go for a walk round the block or do ten minutes gardening, or go somewhere private in the house and read a book. If you feel you have had some time to recharge, dealing with the next part of the routine or a difficult task can be much easier.



## Prioritise tasks

*'Don't bother with housework. It's not important - and can be frustrating if the person you care for is very untidy!'*

Prioritise all the tasks you have to do in the day and decide which ones are important and which ones can wait. Ask someone to help out with the ironing, shopping or cleaning. Often family and friends would be only too happy to find out what they can do to help.



## Getting help

### Dementia Helpline

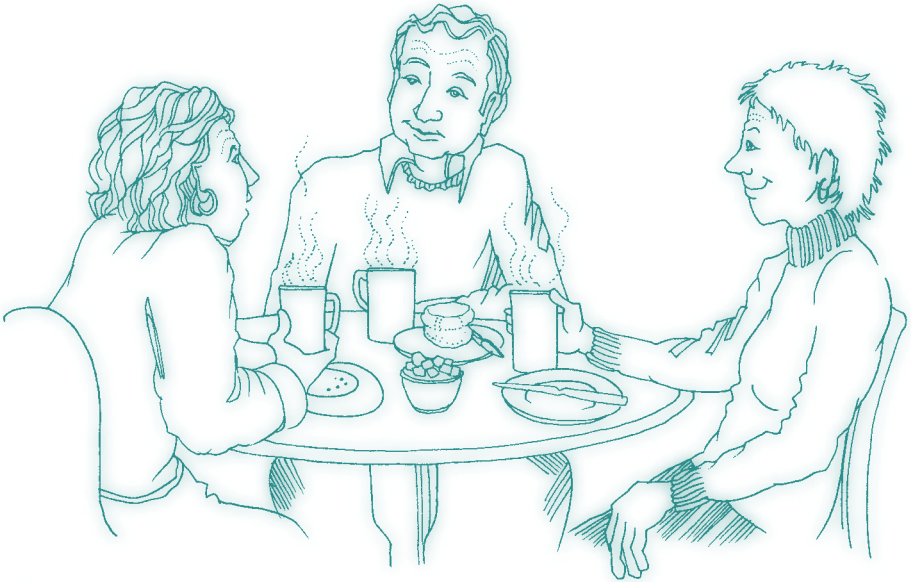
The Dementia Helpline, 0808 808 3000, is a free, confidential 24 hour service offering information and a listening ear. You don't even have to give your name if you prefer not to. Call at any time to talk things over or to find out about any aspect of dementia, how to cope with caring and finding help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

## Community care services

*‘Regular respite has saved my life.’*

If you need services like home help, respite and day care for the person with dementia, contact the social work department and ask for a community care assessment. This will allow the social services to work out what services would be best for you and the person you care for. Keep in touch with the social worker, who can offer advice and information about all services in your area. It may take a while to find a solution you are happy with and the person you care for likes. If you need further advice and information on services in your area contact the helpline.

*‘Use short breaks to meet up with friends and keep up with hobbies.’*





Use the time you have to yourself from day care, home care or short/ respite breaks for something you want to do, not always things you have to do. Catching up on housework, shopping etc. may be necessary some of the time, but make sure you meet friends for coffee, carry on with hobbies or just go out for a walk so you have quality time to yourself.

## Carers' assessments

If you are 'providing a substantial amount of care on a regular basis' you have a right to a carer's assessment, separate from the assessment for the person you care for. Contact the social work department for details. A carer's assessment does not guarantee services, but carers' needs have to be taken into account when the social work department assesses what services might be needed for the person with dementia. The aim is to help the person with dementia and the carer, and to ensure that the carer's health is not affected, so that they can carry on caring for as long as they wish. An assessment will ensure that you are listened to and consulted about the care provided for the person with dementia.

## Taking a break

*'I feel guilty just thinking about using respite care.'*

Guilt about taking a break of few days or a couple of weeks is very common. It may take time to find a suitable care home or someone to be at home with your relative while you are away. But if you can, it will help you rest, relax and recharge your batteries. Talk to the social work department about local respite services. If you are considering a care home for a



respite break, go and speak to staff and look around. Discuss what care your relative would receive. It is important that you are happy with the quality of care your relative will be receiving.

Many carers have said that the person with dementia will often take a long time to settle down once they return home. Be prepared for this and work out ways in which it might be easier to settle the person back into the usual routines.

## Holidays

Taking a holiday by yourself or with a friend can be of great benefit. Contact the Dementia Helpline for an information sheet on holidays. If you can't face leaving the person with dementia behind, look into breaks you can have together where you can be relieved of some of the responsibilities of caring while still being with the person.

## Legal and money matters

It will make life easier if you and the person with dementia deal with planning ahead for financial and legal matters as early on as possible, when the person with dementia can still make decisions for him or herself. Encourage the person to set up powers of attorney as soon as possible so that he or she can choose who should take decisions on finances or personal welfare in the future if he or she becomes unable to do it. The person should also think about a will and may wish to write an advance directive or 'living will' about future medical care.

Later in the illness there are ways of helping someone even if he or she did not set up powers of attorney.

See the Alzheimer Scotland publication *Money and Legal Matters* for more information. See [www.alzscot.org](http://www.alzscot.org) or call the Dementia Helpline for a free copy.

Make sure you have applied for all the benefits you and the person with dementia are entitled to. Ask for advice from the Citizens Advice Bureau, social work department, the Welfare Rights Office or call the Dementia Helpline for advice.

## How other people can help

### Accept help

*‘Accept all the help that is offered and let people know exactly how they can help you.’*

Try to work out ways in which friends can help. Often people do want to help, but do not know how. Maybe they can bring a meal once a week to save you cooking, or sit with the person with dementia for an hour to give you a break.

For example, one carer finds it difficult to collect bulky continence pads every month, so she has asked a friend to pick them up, and the friend is delighted to feel useful.

### Carers’ groups

*‘The most important thing I did was join a carers’ group.’*

Many carers find carers’ groups very supportive. Meeting with other carers is a good way of discussing problems and sharing practical information too. Carers can unburden themselves knowing that they are in a safe environment where other people understand what they are going through. Some groups also invite special guest speakers to provide information on specific subjects.

*‘When at home you are alone - at the carers’ group people understand and listen.’*

## Carer education and training

Carer education and training courses cover a variety of topics for carers and respond to what carers say they want to know. Some of the courses offered may include: what is dementia, coping with challenging behaviour, promoting continence, legal issues and dementia and satisfactions and caring. Carer education 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 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 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.