



Alzheimer Scotland  
Action on Dementia

# Don't make the journey alone

A message from fellow travellers



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Alzheimer's - vascular - Lewy body - frontal lobe - Picks

Alzheimer Scotland – Action on Dementia produces a range of information giving details about the condition you have been diagnosed with, medication available, current research, money advice, getting practical help and much more. They can also put you in touch with a local project that may be able to help or answer your questions. To get this information, or just to talk to someone about how you're feeling...

Contact the free 24-hour Helpline: 0808 808 3000  
or use the Internet address: [www.alzscot.org](http://www.alzscot.org)



Photographs by James

## A positive message for you

*Like you, the authors of this booklet were diagnosed with one of the conditions commonly referred to as dementia. We were diagnosed over two years ago but can still remember those first shattering feelings – shock, disbelief, fear, shame, feeling cut off... and feeling very alone. Your brain feels numb and you can't take it all in.*

*But take heart... these first terrible feelings really do pass. We know – we've been there and really do understand your concerns. We want to share our experiences to reassure you that you can adapt. There is life after diagnosis. It's not the same life you had before, it's a different life. Hopefully one day you will feel able to embrace the change.*

Pat, James and Ian

We would like to thank Jenny Douglas, Having our Say, First Hand Service and Marilyn Dunbar, Glasgow Younger Persons Support Service. We would also like to thank all those who contributed with the many valuable comments.

## Some personal thoughts from the three of us

- ▶ Same person? – no, I’m a better person, I now have a greater understanding of impairments. **Ian**



- ▶ Being diagnosed with Alzheimer’s disease is not the end of the world, whilst appreciating that things have changed, there’s still a whole world to enjoy. **Pat**

- ▶ Dementia is not a major part of your life, just part of it. I don’t waken up with my first thought being “I have dementia!” I plan ahead and wake up thinking of the activities I have arranged to do that day. **James**

## About the Condition

### Tell me again – what exactly is it I’ve got?

- ▶ You might have been given a specific diagnosis, such as Alzheimer, vascular, Lewy body or a similar condition. All of these are types of progressive conditions affecting the brain. They can affect your memory, your thinking and how you cope with everyday life. The precise effects will depend on how and where your brain has become damaged. Sometimes things are not clear enough for your doctor to give you a precise diagnosis for your specific condition.

### How long do I have?

- ▶ No-one can tell you really accurately. You need to keep things in perspective. All of these conditions get progressively worse, but change for most is usually gradual. And yes... it can lead to death, but you are just as likely to die from other causes. Try and make sure you enjoy the life in between.

*The best person to help you cope with your new life is yourself. It is your attitude that is going to be really important.*

## Can medication help, is there a cure?

- ▶ Medication can help some people. However, the new drugs do not provide a cure; they have a delaying effect. Beware media reports of new magic drugs - they usually refer to promising research. It takes years to test a product and license it for use. In short, there is no cure at present, but research is ongoing.

## Does age matter?

- ▶ No, what ever your age you should expect good quality services, medication and the help you need.



*It may take some time to accept your diagnosis. The length of time varies from person to person. The information here is an introduction only. When you are ready to learn more, read any of the publications mentioned at the end of this booklet, or find someone to read it with you.*

## The positive changes

### What we have gained

- Life does change but offers new positive things despite the illness. I have time to learn new skills.
- I now give myself more time, I don't let myself get so worried about things
- You get to know yourself and what works for you.
- I now concentrate on the things I do well.
- I use my time fully now, I don't waste a minute.
- I'm less embarrassed and less inhibited, I'd have never spoken in public before my diagnosis but I do so now.
- My creative side has blossomed and I compose music and write poetry. I am more adventurous as well.
- I can use the computer now, something previously beyond me.
- Writing this booklet has been a new experience for me. I feel able to help others come to terms with their illness.
- I can spend more time with my grandchildren
- Whilst not wishing this diagnosis, I have made new friends through it.

*Don't look at yesterday - you can't go back*

## Things that can change

### Family relationships



Things can be tough for everyone at times. It sometimes feels that people are not tolerant or forget the real difficulties. Make sure people you care about are well informed

about your illness - talking about things can help. Deep down, your family still appreciate you for who you are. You all need time to adjust.

### Friendships

Do tell other people, especially any special friends. You may lose contact with some friends but make others.

### Sharing responsibility

Your role may change. It is hard if you have to depend more on others. Try to do as much for yourself as you can, but ask for help if you need it.

### Doing the things I was good at

There are some losses that will always hurt. However, you will find you can still do many of the things you used to as well as learn new things!

### Loss of confidence

This is not surprising considering what you have been through. However, you can rebuild it through time.

### Driving and public transport

You don't automatically lose your driving licence, some people carry on driving for some time. Make sure you tell the relevant authorities. Please be responsible if you are having difficulties. If you haven't used public transport for some time, consider becoming familiar with it as early as possible and ask about any local concessionary travel schemes.

### Work

You may have already given up work. If not, and you can, try to keep going - your employer may help. If you are worried about money, check you are claiming the benefits you are entitled to.

### Not being able to handle money

Not everyone will be affected. If you are, you need to think about getting help to manage some of your affairs from someone you trust. Try to work out together a level of involvement and independence that suits your capabilities. You could feel anything from relief to resentment with this loss. There are special arrangements you can make and some practical suggestions further on in this leaflet.



## So how can you help yourself?

▶ There is no one right way to do things, what is right for one is not right for another. You must develop your own best way.

These are some thoughts to get you started.

At all times keep a sense of humour. It's no laughing matter having dementia, but you could soon be laughing again.

If you really want to do something, try – I went on holiday to America!

Be positive; you might not do things exactly how you used to but you can still do them.

Look after yourself – healthy body – health mind. What you eat is really important.

Give yourself a wee bit of time to settle down after getting the diagnosis.

Get the most out of your consultant and others.

- you may need to be assertive or take someone with you.
- Prepare before the appointment. Be clear what you want from the consultation.
- Ask the questions you want answers to, no matter how trivial they seem.
- Take along a written list with you and ask the person to write the answers down so you can refer back.

You can increase your confidence when out and about.

- Carry a Help Card – it tells people that you have dementia and describes the help you need. Available from Alzheimer Scotland.
- Keep a £10 note in your wallet/purse for emergencies.
- If coins are difficult to work out quickly, keep a bag of those you need regularly, e.g. when concessionary fares were 40p, I kept a bag of 20p coins

There are lots of things that can help your memory.

- Write things down in diaries, calendars, white boards, post it notes. Make a list of things you need to do and tick them off when you have done them.
- Keep special places to put important things (with a reminder somewhere of your special place).
- Organise reminder calls, pre-set your phone with contact numbers keyed in. Also do this with your mobile in case you get into difficulty when you are out.

If people talk to you and you can't remember who they are, keep the conversation going to give your brain time to think, they may give you a clue that helps!

Enjoy the present and when you are ready, think about the future. You may want to make some legal or financial plans now. There are booklets to help, some of these are listed on the back page.

What I do when things get me down

- Go for a walk
- Give myself more time
- Have a blether
- Eat a bar of chocolate

*Dementia* is the term commonly used to refer to all the different conditions that cause the changes you are experiencing. The authors of this booklet dislike the word *dementia*. We feel it is negative and makes people look at us in a negative way. Your problems are linked to the specific damage to your brain caused by the particular condition you have been diagnosed with. So, until someone comes up with a better name, we have tried to turn the word dementia into something positive.

**D** - don't give up on life

**E** - enjoy life, even with the restrictions

**M** - make use of every minute

**E** - eat sensibly

**N** - now is the time to do what you've always wanted to

**T** - try to cope by yourself but be prepared to ask for assistance

**I** - insight, learn more about your illness and how to live with it

**A** - act normally, it can be hard for others to spot. Ask for assistance only when you must.

## Finding out more and getting help

Remember to ask your consultant for information about your condition as well. You may also be allocated a Community Psychiatric Nurse (CPN) who can help.

Other free publications you can read are:

- Facing Dementia - useful information for people with dementia
- Dementia Money and legal matters – a guide
- Eating for health

These are all available from Alzheimer Scotland – Action on Dementia - call the dementia helpline on 0808 808 3000.

Dementia Services Development Centre has a range of material for sale and a lending library which you or your carer can use. Tel: 01786 4677040, E-mail: [www.stir.ac.uk/dsdc](http://www.stir.ac.uk/dsdc)

If you have any comments or would to contribute your own ideas to future editions of this booklet contact Kate Fearnley, Information Manager, Alzheimer Scotland - Action on Dementia, 22 Drumsheugh Gardens, Edinburgh EH3 7RN.



*We are travelling from an old life to a new. If you can think in a positive way and get the help and support you need, the journey can be brighter and less frightening. Remember you do not travel alone.*

Pat, James and Ian