

Today **1** in **90** Scots have dementia



In 2031 it will be **1** in **50**



*Let's make dementia a priority*



**Alzheimer Scotland**  
Action on Dementia

**The dementia manifesto**

# Let's make dementia a priority

In 2007, there are 58,000 people in Scotland with dementia. And they and their carers are suffering, because Scotland is not coping.

As our population ages, the numbers of people with dementia will grow rapidly. In the life of the next Scottish Parliament, the number of people with dementia will grow by almost 4,500. In less than 25 years' time, in 2031, there will be 102,000 people with dementia in Scotland.



**We must make dementia a priority now.**

**We urge the new Scottish Parliament to pledge an additional £15m to tackle this epidemic.**

## 2 Early diagnosis and support

About 6,500 people are diagnosed with dementia every year. Early diagnosis is important so that people can be involved in discussions about their present and later care and can make decisions about their future, and for better long-term outcomes. But they, and their carers and families, need support to do that. They need help to adjust: information, emotional support, rehabilitation services, counselling and support groups as well as diagnostic and treatment services. This doesn't always happen - many people aren't even told about the 24 hour Dementia Helpline when they get their diagnosis, and it's still a minority who can join a local support group.

*A diagnosis of dementia isn't something people should have to face on their own.*

**Target:** Full post-diagnostic support services provided in every area.

£1m

## 1 Make dementia a national priority

Scotland needs better strategic planning for dementia and better funding for dementia care. At present the care you get depends on where you live. Take overnight care - some local authorities can provide it as part of your package of care; but more than half cannot.

We need a strategy to make sure that there is an equal level of service provision across the country. In 2004 the Scottish Executive published a template for dementia care - but one in five local authorities aren't using it. And some local authorities are tightening eligibility criteria, limiting the services people receive.

Most people with dementia are over 65. They deserve personalised services<sup>1</sup> to meet their needs as much as younger people do. But the amount spent on supporting people to stay in their own homes is almost always limited to the cost of a care home place - and average care home fees in Scotland are more than 50% higher for people with learning disabilities than for older people.

**The cost of dementia in Scotland is estimated as more than £1.4 billion. It needs to be a national priority.**

### Targets:

- Dementia declared a national priority.
- Increased funding for services.
- All local authorities and health boards to work to the same set of dementia care standards.
- Entitlement to a minimum level of respite, as recommended by the Care 21 report<sup>2</sup>



£3m

### More and better respite and short breaks

Carers and people with dementia living at home benefit from short breaks of anything from a few hours to a few weeks, as part of their package of care. Yet only 27% get a week's short break in a year<sup>3</sup>, only 10% get home care and only 11% get day care.

How much respite you're offered can depend on where you live and how old you are, and so does quality and flexibility. For example, young people with dementia may have to go into hospital because there are no suitable facilities; people reaching 65 may find imaginative options such as respite in a holiday setting suddenly disappear and a care home becomes their only option.

*Regular respite helps people with dementia and carers cope for longer.*

## 3 Better dementia training

People with dementia deserve appropriate care of a high standard from all the services they use. But that's not always what they get. In hospital, they may risk malnutrition and dehydration, because staff don't realise they need help to eat or drink. In care homes they may be restrained or sedated because staff don't know how to cope.

Working with people with dementia is challenging and staff need training in understanding the illness and positive approaches to communication and care.

**People with dementia use a whole range of services - it isn't only specialists who need to know how to help.**

**Target:** Every service used by people with dementia to have at least one member of staff appropriately trained in dementia care - for example, every GP practice should have at least one doctor or nurse with recognised dementia training



£3m

## 4 Make dementia drug treatments available on the NHS

Scottish clinical guidelines<sup>4</sup> recommend drugs for people in the early stages of Alzheimer's disease; but the NHS won't pay. The cost? About £1,000 a year per person to the NHS. The benefit? For those the drugs help, the chance to function as normally as possible for as long as they can, to stay independent and to make legal and financial arrangements, saving expense and heartache for them and their families now and in the future. Early treatment is the only chance people have of getting back close to their normal ability - there is no chance of this if they have to wait.

**If dementia affected people in their 20s, would they have to wait until they were seriously impaired before getting treatment?**

Carers facing the challenges of looking after someone with severe dementia are also denied the chance to see if Alzheimer's disease drugs might help. They need all the help they can get.

**Denying people the drugs they need on the NHS will increase health inequality, as only those who can afford to pay get the treatment they need.**

**Target:** Drug treatments available on the NHS for every patient with mild, moderate or severe dementia, where clinically appropriate.



£2.75m



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## 5 Free personal care

Free personal care is a policy Scotland can be proud of. It means that people over 65 who need care because they have an illness such as dementia don't have to pay out of their own pockets, though in a care home they still pay for their accommodation. But it's important that it's implemented properly and fairly. Some councils have waiting lists which mean that people assessed as needing personal care are having to pay. The allowance towards care home fees hasn't increased since 2002, but the fees have gone up by more than 20%. And the 1,400 people with dementia under 65 are not eligible to claim at all for personal care.

**Let's make free personal care work for everyone who needs it.**

### Targets:

- Ring fenced funding for free personal care.
- Free personal and nursing care allowances uprated to keep pace with the increases in care home fees.
- Free personal care extended to people with dementia under 65.



£4m

## 6 Raise public awareness

Alzheimer Scotland's public awareness surveys show that while 98% of Scots are now aware of dementia, a third of them hold serious misconceptions, such as that it is a normal part of ageing. Stigma and public ignorance affect the lives of people with dementia and carers daily, from the man with dementia refused the help he needed at an airport because his disability is not physical, to the carer whose friends have drifted away because they don't understand her husband's behaviour.

And there is now good evidence that lifestyle changes can reduce the risk of dementia - we need to take action now to reduce the future burden of dementia.

**Let's make Scotland dementia-friendly and help people reduce their own risk of dementia.**

### Target:

Funding for high-profile campaigns to increase public understanding of dementia and reduce stigma, and to help people reduce their risk of dementia.

£0.25m

## 7 Research funding

Dementia is the 4<sup>th</sup> biggest killer for women in Scotland, after lung cancer, heart disease and strokes, and the 9<sup>th</sup> for men<sup>5</sup>. It's going to touch almost everyone at some point in their lives - because they or someone in their life develops dementia. Yet only 2% of UK government funding through the Medical Research Council is spent on Alzheimer's disease research<sup>6</sup>.

And it's not just medical and scientific research. We need to know more about how best to care for people with this complex condition.

**Research into dementia causes, diagnosis and treatment and care needs higher priority.**

**Target:** Funding for the dementia research priorities published by the Scottish Intercollegiate Guidelines Network.

£1m



### About Alzheimer Scotland

Alzheimer Scotland is Scotland's leading dementia charity. We provide services for people with dementia, their carers and families across the country and campaign to improve public policies.

[www.alzscot.org](http://www.alzscot.org)

<sup>1</sup> Scottish Executive (2006) *Changing Lives*

<sup>2</sup> Scottish Executive (2005) *Care 21: the Future of Unpaid Care in Scotland*

<sup>3</sup> Alzheimer Scotland (2004) *Short break services for people with dementia and their carers in Scotland*

<sup>4</sup> Scottish Intercollegiate Guidelines Network (2006) *Guideline 86: Management of patients with dementia - a national clinical guideline*

<sup>5</sup> General Register Office for Scotland

<sup>6</sup> Medical Research Council