



Dementia in Scotland



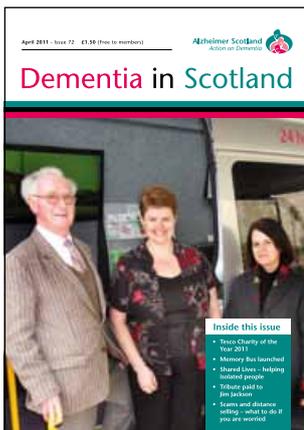
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Give us a break!

With the summer approaching, most of us start looking forward to our holidays and a change of scene but the options for people with dementia and their carers can be limited.

On page six you will find an article about Shared Lives schemes – where a person who needs support is matched with a Shared Lives carer who takes the person into their own home for a short break, or even permanently. For many people with dementia, the only option for a short break is a stay in a care home. This does not suit everyone and schemes such as Shared Lives and the Home from Home service provided by the Joint Dementia Initiative in Falkirk offer a welcome alternative.



Memory Bus 'on the road' in Helensburgh



What about those people who want a break away together? More providers are now able to offer accommodation suitable for people with physical disabilities but we struggle to find dementia-friendly accommodation, or accommodation where paid carers can be supplied for at least some of the time.

If you have stayed in a hotel, B&B, guest house, or self-catering accommodation that catered well for people living with dementia, why not tell us about it so we can pass it on? Or if you have tried any other short break options which worked for you, let us know by writing to the Information Manager, Alzheimer Scotland, 22 Drumsheugh Gardens, Edinburgh EH3 7RN; email alzscot.org

You can also help shape the short break and respite care services you receive by taking part in one of the Inspiring Breaks workshops being arranged by Shared Care Scotland until June in various parts of Scotland. At the workshops, you can share experiences of finding, arranging and funding short breaks; find out the different ways short breaks can be supported; and learn a new approach to planning short breaks and achieving the outcomes you want.

To find the workshop nearest you, reserve a place, or get more information, contact Lesley Gudgeon at Shared Care Scotland on 01383 622462; email lesley.gudgeon@sharedcarescotland.com

Maureen Thom
Editor, *Dementia in Scotland*



Chief Executive's **comment**



With the Scottish General Elections just round the corner on the 5th of May, it is critical that every current or potential MSP understands that dementia is the most significant public health issue of our time and we must do all that we can to tackle it.

That is why this edition of Dementia in Scotland includes a Scottish Election - Campaigns Pack. I realise that some of our readers will not be too interested in this, but I would urge those of you who are interested to use the pack to get in touch with your candidates, find out if they are going to support the priorities we have outlined, and make sure that if they are elected to represent you they understand the issues you are facing and what you want given priority.

In these difficult financial times, we are not setting unrealistic demands. We believe that the National Dementia Strategy will help improve the way people are treated and supported across the health and social care sector. We think the Strategy is a good start, but it is only a start and much more needs to be done. We believe that the lessons learned and knowledge gained during 2010-2013 must be used to develop a more precise and more extensive strategy in 2013. That is why we have asked that all political parties commit to this and agree to continue to make dementia a national priority.

We have also asked for the following commitments:

- £8 million a year for the development of comprehensive post-diagnostic and early intervention teams across Scotland, linked into GPs from the point of diagnosis and supporting people with dementia and their families for a minimum of one year following diagnosis.
- A specialist Dementia Nurse Consultant in every acute general hospital in Scotland at an annual cost of £50,000 per nurse.
- £1 million a year for continued funding for the Scottish Dementia Clinical Research Network – which contributes to ensuring there is an effective research base in Scotland and attracts further research funding.

You might ask why we have asked for such a small number of specific commitments. We believe that these investments will not only help meet the increasing demands of those living with dementia, they will also return substantial savings in formal support costs by delaying and avoiding admission to longer term care.

Our argument is that proper and effective post diagnostic support can, for example, lead to significant delays of two to three years in admission to residential care, as well as other formal services. You only need a two to three week delay for one person entering long term care to fund one year of post diagnostic support.

Also, by supporting people much more effectively during their time in general hospital it will mean that they can return home much more quickly and avoid any unnecessary admissions to long term care.

These are basic investments that will improve people's lives and, in the long term, save significant resources that can be reinvested in dementia care. We must also keep a focus on research. Many people can't quite believe that we still only have four drugs available for dementia and that none of these treat the illness, only help abate the symptoms. This is not acceptable, and Scotland must play its part in breaking through this immense barrier

We have so much still to do and the Scottish Parliament is central to this. We must make sure they are fully committed to truly improving the lives of everyone living with dementia.

Henry Simmons
Chief Executive

You can also access the Election Pack on our website at www.alzscot.org/pages/info/scottish-general-election-2011.htm

Can you help the **Helpline?**



Along with this issue of Dementia in Scotland, members will receive a small supply of Dementia Helpline cards.

This may seem like an odd (and possibly extravagant) thing to do – after all, surely our members already know about the Helpline? But do you tell other people about it?

Despite the work we do throughout the year to make people aware of this lifeline service, we still find that many people are not told about the Helpline at all, or not until they have been coping on their own for several years – years during which having support at the end of the phone could have made a huge difference.

If you know of a friend, family member or neighbour who might benefit from knowing about the Helpline, please pass on one of these cards. If you would like a larger supply to distribute to groups and organisations in your area, call the Dementia Helpline on 0808 808 3000 or email helpline@alzscot.org

Nice news from NICE

On 23 March, the National Institute for Health and Clinical Excellence (NICE) released its final guidance on the four dementia drugs. From now on, Aricept, Exelon and Reminyl will be available on prescription to people in the early and moderate stages of Alzheimer's disease. This alters previous guidance from 2007 which said these drugs should only be given to people in the moderate stages.

The latest guidance also states that Ebixa is now recommended as an option for managing moderate Alzheimer's disease for people who cannot take the other drugs, and as an option for managing severe Alzheimer's disease.

Prescribing decisions for individual patients will still be determined by the clinical judgement of each patient's consultant.

Jim Jackson (1947-2011)



All at Alzheimer Scotland were devastated by the news of the sudden death on 12 January of Jim Jackson, our former Chief Executive. The following is an abridged version of the obituary written by Deputy Chief Executive Kate Fearnley for the national press, one of many national and international tributes.

Jim Jackson OBE, Chief Executive of Alzheimer Scotland from 1993 to 2008, was a man of many enthusiasms and much energy. His unexpected death from a heart attack at the early age of 63 seems particularly cruel in a man who had an enormous love for the challenges of life.

Jim was born in Bradford and educated at Stand Grammar School and West Ham College of Technology, where he was involved in Labour politics and was an active human rights campaigner. Jim's outside interests proved too much of a distraction at college and he did not achieve his degree, but he more than made up for this later on.

His first job was in the adventure playground movement in Telford New Town, where he met Jennie, to whom he was happily married

for over 40 years. In 1970, they moved with Jim's work to Stevenage, where he later became a Community Development Officer, and where two children, Fiona and Tim, were born. Further job changes and challenges came along, leading eventually to a move to Edinburgh in 1984 when Jim was appointed Assistant Director of the Scottish Council for Voluntary Organisations (SCVO), where he quickly adapted to the Scottish scene and his reliability, sense of justice and clarity were much appreciated.

He came into his own when he was appointed as Chief Executive of the newly formed Alzheimer Scotland – Action on Dementia. In his 15 years as Chief Executive, Jim oversaw a huge expansion in the organisation, both financially and in service delivery. He ensured that these developments were always diverse and innovative, such as services for younger people with dementia, specialist post-diagnostic support, a palliative approach for those in the last stages of dementia and services for those from ethnic minorities.

Jim was particularly proud of his influence on some significant national policy developments, including the addition of dementia requirements to GP contracts from 2004, and he laid the groundwork for the current Scottish Government Dementia Strategy. He also put great energy into the eventually successful campaign to reverse the NICE restrictions on the prescription of drugs for dementia. Jim was both honest and direct and showed how a friendly but robust relationship with government can bear fruit.

He pioneered the direct involvement of people with dementia in the work of Alzheimer

Scotland and in the wider political arena. He was particularly proud of the foundation of the Scottish Dementia Working Group for people with a diagnosis of dementia - a landmark in user involvement with enormous influence both in Scotland and abroad.

Jim's work did not stop when he retired in 2008. He continued his long-standing interest in dementia research and the way research findings can be translated into useful practice with an MSc in Translational Medicine in 2010. He pursued this interest with great energy, and at the time of his death was in the early stages of a PhD.

Jim's influence extended internationally through his work with Alzheimer's Disease International (ADI) and Alzheimer Europe and his support of Alzheimer associations across the world, including Romania, Lebanon and Sri Lanka. He co-authored the very influential World Alzheimer Report in 2009, and was ADI's Policy Adviser.

Jim's work and other interests overlapped and nourished each other. A keen hillwalker, his office included a map of Alzheimer Scotland services and favourite hill climbs; service visits could double as opportunities for a walk. His love of literature and poetry was shown by his habit of peppering any speech with apt, and sometimes not so apt, quotations. He had an abiding love of music - classical, jazz and folk. And he relished arguing about all manner of subjects. He prided himself on his Yorkshire bluntness, which particularly showed if he thought things were not being done to the high standards he expected. He is remembered with great affection by all who knew him.

Shared Lives – helping isolated people

What is NAAPS?



NAAPS is the UK network for family-based and small-scale ways of supporting adults. Our members are individual Shared Lives carers, Shared Lives schemes, Homeshare providers and micro-enterprises. They use different approaches to enable people to achieve goals such as:

- being in control of their services and their lives
- pursuing ordinary lives within their chosen families and relationships
- being valued by their communities and feeling like they belong.

NAAPS' members deliver or coordinate services which:

- are built around individuals, their strengths and potential;
- promote equality and value diversity;
- are safe but support people to take risks in pursuit of their goals;
- are cost-effective, with consistently better outcomes than alternatives.

For more information go to www.naaps.org.uk or phone 0151 227 3499

Anne Fernie, Development Worker with NAAPS Scotland describes how Shared Lives schemes can support people with dementia. NAAPS was originally the National Association of Adult Placement Schemes but now calls itself NAAPS and has replaced the term “Adult Placement” with Shared Lives, which better reflects the nature of these schemes.

How does Shared Lives work?

Shared Lives is a regulated service where a family includes an individual in their family and community life. This can be temporary to give the individual and/or their family carer a break but, in many cases, a disabled or older person becomes a permanent part of a supportive family.

Shared Lives aims to enable people to experience ordinary life, with real relationships, and to be part of a local community. It is not an “off the peg” service – it is highly personalised, relying on achieving a match between the individual needing support and the Shared Lives carer who wishes to support them. Shared Lives carers are paid a fixed amount, rather than an hourly rate. Some receive up to four weeks paid breaks per year, when the person living with them receives respite care.

How are Shared Lives schemes regulated?

Shared Lives carers are carefully selected and trained by a regulated Shared Lives scheme. In Scotland, all schemes are registered with the Care Commission (from 1 April 2011, with Social Care and Social Work Improvement Scotland) and have to comply with the National Standards for Adult Placement schemes.

Who uses Shared Lives?

Shared Lives has traditionally been a service for adults with learning disabilities, matching individuals with families where they will live permanently or with whom they have regular visits, such as every weekend, in order to give family carers a break. Shared Lives is increasingly being used for people with a range of disabilities or illnesses, and for older people.

There is growing interest from organisations and local authorities in developing Shared Lives schemes because they can deliver not only high quality support but are also cost effective when compared with other, more traditional, models of support and can produce cost savings of up to 60% on residential services.

Shared Lives in Scotland

In Scotland, there are now 35 schemes providing a range of services from short breaks and day support to long term care to a wide variety of people with different support needs. The number of schemes has more than doubled since 2006 and there is further scope to develop schemes for people with a diagnosis of dementia.

Shared Lives fits well with Scotland's National Dementia Strategy because services:

- are local, flexible and personalised
- can help prevent inappropriate admissions to hospital and lengthy stays in hospital
- support can be provided within or outwith the person's own home.

¹ Baldwin H (2009) The Business Case for Shared Lives Improvement and Efficiency South East in association with NAAPS

Shared Lives - case studies

Jean and Tom live near Margaret, a Shared Lives carer who normally takes people into her own home for short breaks. Margaret's house has been adapted with a ceiling track hoist and wet room. Tom has advanced vascular dementia and has become immobile. Tom receives home care and nursing support. He has had breaks in a care home, but finds unfamiliar surroundings distressing. Now, Margaret helps Jean to take Tom to favourite places and stays with him at home or sometimes overnight to give Jean a break. Normally, the Shared Lives carer would bring the person to the carer's home for support but there is enough flexibility to do it the other way round, particularly where someone has dementia and is best supported in their own familiar surroundings.

Harriett is an 84-year-old woman with dementia living on her own in a small rural community. Rhona, a family friend, would visit twice



a day but became increasingly concerned about Harriett being on her own. Rhona trained as a Shared Lives carer and Harriett moved in with her. Harriett had been a visitor to Rhona's house for many years and instantly felt at home. She has been able to keep up with all

of her friendships and community connections and is doing well.

These two examples of Shared Lives highlight the flexibility and responsiveness of the model which can adapt to people's changing needs.

Prescriptions now free in Scotland

The Scottish Government has fulfilled its pledge to make prescriptions free of charge to everyone. From 1 April 2011, there will be no charge for NHS prescriptions. This is the final stage of a four year plan which saw charges reduce each April, from a high of £6.85 in 2007.

New regulatory bodies for Scotland

Also from 1 April, there will be two new public bodies operating in Scotland which will take over the work of the Care Commission, the Social Work Inspection Agency and NHS Quality Improvement Scotland – these organisations will cease to exist from that date.

Social Care and Social Work Improvement Scotland (SCSWIS) replaces the Care Commission and the Social Work Inspection Agency and will inspect, regulate and support improvement of care and social work and child protection services across Scotland. This includes care homes and home support services and most of the services provided by Alzheimer Scotland.

SCSWIS will occupy the same offices as the former Care Commission, including the HQ in Dundee. For more information, visit www.scswis.com or phone 0845 600 9527.

Healthcare Improvement Scotland (HIS) takes over the regulation of independent healthcare services, previously carried out by the Care Commission. It also takes over the work of NHS Quality Improvement Scotland (NHS QIS), which will no longer exist.

Independent healthcare services includes:

- independent hospitals
- independent hospices
- independent specialist clinics.

HIS aims to support healthcare providers in Scotland to deliver high quality, evidence-based, safe, effective and person-centred care; and to scrutinise those services to provide public assurance about the quality and safety of that care. HIS has offices in Edinburgh and Glasgow.

For more information, visit www.healthcareimprovementscotland.org or phone 0131 623 4300 or 0141 225 6999.

Spotlight on your National Office Fundraising Team



Glenda MacKenzie
Deputy Director-Fundraising
Glenda came on board in June 2010 and has over 24 years fundraising experience. Her first few months were spent evaluating Alzheimer Scotland's current fundraising activities. We then developed a new

fundraising strategy to secure additional funds immediately and give longer term security and sustainability to the organisation. The main thrust of the strategy is to be more knowledgeable about who currently supports us and why; to ask for money in a more targeted and sophisticated way; and to reach more of our 'natural' audience - the thousands of people in Scotland living with or having experience of dementia.



Lucy Christopher
Trusts and Corporate Fundraiser
Lucy joined Alzheimer Scotland in summer 2010. She is focusing on writing applications to charitable trusts and liaising with companies to support their fundraising. Lucy is always

ready for a challenge and she organised our biggest ever corporate volunteering day last autumn, which took place in Dunblane and Crieff and which involved nearly 100 staff from PwC.



Gillian Dimmock
Events Administrator
Gillian joined Alzheimer Scotland permanently in January 2011 having worked in the post on a temporary basis since October 2010. She has worked in fundraising administration since 2003, with a previous

background in computing. She is responsible for the administration of sponsored and community events, responding to enquiries, sending out registration packs, sponsor forms and events merchandise. Gillian also deals with online sponsorship and acknowledges all gifts received through sponsored and community events.



Shona Blakeley
Head of Fundraising Development
Shona has been with the organisation for six years and has just rejoined the team after a period of maternity leave. Her role includes the expansion of existing fundraising activities

whilst developing new opportunities within the new strategy.



Catherine Thomas
Trusts and Corporate Fundraising Manager
Catherine joined Alzheimer Scotland in 2009, having worked in fundraising since 2003. She manages relationships with charitable trusts and companies, with the aim of increasing the

donations we receive from these sources, identifying new sources of support and ensuring we work efficiently and cost-effectively.



Nicola Brown
Fundraising Administrator
Nicola has worked in the fundraising team for several years since joining us as a volunteer. She works two days a week and focuses on claiming Gift Aid, which is a huge job requiring a lot of attention to detail, but

which is incredibly valuable to Alzheimer Scotland. She also acknowledges donations from donors and helps with the processing of Christmas card orders.



Gillian Messelink
Corporate Fundraiser
Gillian joined us early in 2011 to work on co-ordinating major corporate partnerships. Although she has only been with us a short time she is passionate about raising funds for our cause and helping putting the 'fun' in

fundraising for our corporate supporters!



Dareena Scott
Fundraising & Membership Administrator

Dareena worked for us part-time for two years as HR Administrator before joining the Fundraising department full-time for the past two years. Her main responsibilities are for

joining and maintaining our Membership records. This includes liaising with our Branches as well as Services. Dareena ensures that our Direct Debit donations are collected each month and other forms of donations are acknowledged, including those left to us in the form of Legacies.



Vera Haringman
Fundraiser for Northern Scotland

Vera joined the organisation in November 2010 with a background in facilities, event management and extensive experience in fundraising. She works part-time and is based at

the regional office in Inverness. Covering Highland and Grampian Regions, Vera will be linking in with our charity shop volunteers in Golspie and Forres and assisting with local fundraising events. During her first months in post, she has been very encouraged and impressed by the enormous amount of fundraising that is already happening in the north.



Gillian Smith
Fundraising Administrator

Gillian joined in December 2009 after a year as a volunteer, coming from a business background and many years in HR. She works part-time and is responsible for thanking our donors and recording their gifts

on our database. She also deals with merchandise orders including our Christmas cards and administers the Give As You Earn scheme donations. Her Mum has been diagnosed with Alzheimer's disease.



Valerie Weir
Events Manager

Val joined Alzheimer Scotland in July 2010, coming from a corporate events management background. Her first few months focused on learning about the ins and outs of fundraising, along with the many sponsored

and community events that are held each year, throughout Scotland. Val's role now concentrates on introducing unique new events, designed to increase income and raise the profile of Alzheimer Scotland, while overseeing the running of the sponsored and community events.



Angie Smith
Donor Development Manager

Angie joined Alzheimer Scotland in 2000, initially working part time as administrator at our Lothian Early Onset Support Service and part time as fundraising administrator at National Office. She moved

to the fundraising department on a full-time basis in 2002 and is now responsible for managing and developing our direct marketing appeals, in memoriam giving, legacy marketing and managing our merchandise programme including Christmas cards. She also manages and develops our database, manages volunteers and oversees other fundraising functions including Gift Aid and committed giving.



Martin Quigley
Sponsored & Community Events Fundraiser

Martin worked as a Regional Events Fundraiser at Marie Curie Cancer Care before joining Alzheimer Scotland in January 2011. He also works as a volunteer at the Sick Kids Friends

Foundation. He manages the running of all sponsored and community events within Alzheimer Scotland, such as the Edinburgh Marathon Festival and the Adrenaline Drop. Martin's main focus is to bring in as many participants as possible to these existing events as well as focusing upon generating additional income through introducing new fundraising events.

Alzheimer Scotland and Alzheimer's Society chosen as Tesco's Charity of the Year 2011.

On behalf of the hundreds of thousands of people in Scotland who are affected by dementia, we'd like to say a huge thank you to Tesco for choosing Alzheimer Scotland and Alzheimer's Society as its Charity of the Year for 2011. We are absolutely thrilled to be working together.

From 1 March 2011, staff and customers at Tesco stores across the UK will be raising money to help people with dementia and their families.

Henry Simmons, Chief Executive of Alzheimer Scotland, said "Alzheimer Scotland's mission is to make sure no one goes through dementia on their own. This support and commitment from Tesco and all their staff will truly help us and our partners take a major step closer to achieving this. We are extremely grateful to Tesco and look forward to demonstrating the real difference that their support and the support of all their customers will make. Dementia is not a normal part of growing old, but it is a part of life for many families and we must do all that we can to ensure that they never face this alone."

The money raised will fund Dementia Community Roadshows at Tesco stores across the UK, Dementia Advisors and Dementia Support Workers who will work in local communities, and medical research. By supporting Tesco's efforts you will be supporting people with dementia in your local area as well as helping to fund research to create a better future for people with dementia in years to come.

You can help! We will be holding a nationwide collection at Tesco stores throughout Scotland on 27 and 28 May 2011 – if you can shake a bucket, even for an hour, or if you would like to know more about the partnership, do please get in touch with Gillian Messelink on 0131 243 1453 or email gmesselink@alzscot.org. Keep an eye out for more news at www.alzscot.org.

Thank you Tesco!

Martin Currie Rob Roy Challenge



Places for the Martin Currie Rob Roy Challenge on 18 June 2011 are going like hot cakes. By 7 March, 660 places had already been allocated, with just 90 places remaining. So don't delay – get signed up today to secure your place! And make sure you tell your family, friends and colleagues so they don't miss out either.

The Martin Currie Rob Roy Challenge involves walking or running 16 miles, then cycling 39 miles, along the beautiful Rob Roy Way. There's still time to train and it's the ideal challenge if you are aiming to get a bit fitter in 2011. Or if it doesn't sound like your cup of tea, you can enjoy the scenery and the fantastic atmosphere by helping out as a marshal! For more information about the Martin Currie Rob Roy Challenge visit www.alzscot.org/pages/fundraising/rob-roy-challenge.htm or call our Events Line on 0845 260 0789.



Boost to Dementia Nurse Appeal

Our Dementia Nurse Appeal received several fantastic boosts in January.

First, Kay, Duchess of Hamilton, kicked off the New Year by taking part in the annual Dementia Dip in the chilly waters off North Berwick, raising over £1000.



All money raised from the Dementia Dip goes towards Alzheimer Scotland's Dementia Nurse appeal. Our Dementia Nurses work with NHS colleagues to increase staff understanding of dementia and improve standards



Henry Simmons, Kay Hamilton, Dementia Nurse Colin Macdonald and John Brodie from Scotmid

of care. Lady Hamilton has called for improved dementia training for nurses and doctors, following her husband's deeply upsetting experience of acute hospital treatment. The 15th Duke of Hamilton was diagnosed with vascular dementia in 2006, at the age of 66. He passed away in June 2010.

Secondly, we were delighted to receive £60,000 raised by the staff and customers of Scotmid,

Semichem and Morning, Noon and Night. This was raised mainly through collecting cans at their counters, and it shows that the pennies really do add up.

The Scottish Government then surprised us during a debate on dementia in the Scottish Parliament on 27 January. Shona Robison MSP, Minister for Public Health & Sport, announced that the Government is to invest £300,000 in our Dementia Nurse programme.

Wedding favours & Forget Me Not pins

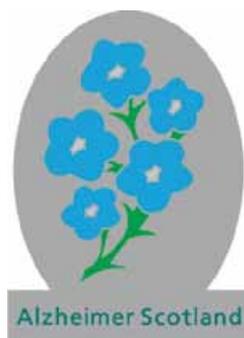


Lynne and Stewart Dow made a donation of £100 to Alzheimer Scotland in return for 100 of our Forget Me Not wedding favours which they gave to wedding guests.

Lynne said: "We had an amazing day and everything went according to plan. Even the weather was lovely! All our guests thought it was a great idea having the pins as favours as it was a meaningful way

to say thank you to them all for sharing our special day with us".

They made this kind gesture as Lynne's papa has Alzheimer's disease and was unable to be at their wedding.



New for spring 2011 – help us raise more pennies, while you look after yours! Branches of Santander will be selling our new Forget Me Not pins, and Yorkshire Building Society will be selling exclusive nail care sets – all to raise funds for Alzheimer Scotland. The more we sell, the more funds we will raise to help us make sure no one goes through dementia on their own - show your support in true style.

Move over Mark Beaumont – here comes Andrew!

It's good to know that in every service Alzheimer Scotland has heroes; at our Lothian Early Onset Support Service (LEOSS) we have a team full of them. We are losing one of our heroes, Andrew Dickson, who has been an outstanding Support Worker over the last few years. Andrew is known for going the extra mile but has taken this to extremes in his latest venture as he plans to cycle 4,500 miles West to East across the USA in memory of his wife Aileen and to raise the profile of dementia and raise money for Alzheimer Scotland.

If you would like to make a donation to Andrew's cycling challenge, you can do so at www.justgiving.com/AndrewKDickson You can also follow his exploits online at www.bikingacrossusa.blogspot.com/

Alan Midwinter
Service Manager, LEOSS

Publications

Communicating with Someone who has Dementia: 12 Helpful Hints

People in the Glasgow area may have spotted this small bright yellow leaflet in various places and wondered how to get hold of a copy. Developed by Nicky Thomson, Manager of the Good Morning Project, and Glasgow North Dementia Forum, the leaflet has been designed to fit easily into a wallet and provides a useful aide-memoire of the key things to remember when communicating with someone with a diagnosis of dementia.

There are two versions – one aimed at people in the Glasgow area, the other suitable for readers across Scotland. Both can be downloaded from the Good Morning Project website at www.goodmorning.org.uk/dementia_forum/. There is also an A3 poster version.

More than 100,000 copies have been distributed and hard copies are limited but if you are unable to access the internet, contact the Good Morning Project to request a copy: Tel: 0141 336 7766, preferably after 12.30 pm.

New Information sheets from Alzheimer Scotland

Two new information sheets are now available:

Anti-psychotics: what to do if you are worried is based on the article which appeared in the December issue of Dementia in Scotland.

Pain in dementia is aimed mainly at family carers of people with dementia and lists the signs to look for which might indicate someone is experiencing pain.

Both of these information sheets can be downloaded from the Alzheimer Scotland website at

www.alzscot.org/pages/info/publistforinfosheets.htm or requested from the Dementia Helpline on 0808 808 3000.

Book Review



Jill Eckersley. Coping with early onset dementia. Sheldon Press, 2011. ISBN 978-1-84709-130-7. £7.99

Do you need to know the basic facts about early onset dementia but don't know where to begin? Then this publication, written from a layperson's perspective, is a good starting point. Written in an easy to understand style, it avoids medical jargon where possible and is aimed at a general audience. At £7.99, it makes a worthwhile investment for those who think a family member may have early onset dementia. It will also make an informative addition for existing carers and professionals alike.

It usefully highlights the different characteristics of some of the conditions that cause dementia in younger people, including Frontotemporal dementia (Pick's disease), leaving carers better placed to have productive discussions with GPs and other professionals. Using the testimony of people with dementia and carers throughout, it accurately describes the often difficult and lengthy road to diagnosis that families face.

Apart from the process of getting a diagnosis, the book also addresses other practicalities. It covers issues such as employment, driving, holidays, finance and benefits. Commendably, it does not shy away from the matter of debt,

which can be a major factor when the main "breadwinner" is diagnosed. It gives sound advice and directs the reader towards agencies that can assist. Overall, the subject has been well researched and experts in the field have been consulted to inform the reader. The chapters on diagnosis, treatments and the impact on carers and families are particularly useful and clearly written.

Unfortunately, there are some significant omissions that make it less useful for readers in Scotland. All references to legal issues, such as capacity or paying for care, relate to England but this is not clearly spelled out in the text. Indeed the chapter on 'Getting Help' focuses on developments in England, such as the Dementia Strategy, which are different in Scotland. Crucially there is no mention of any support services in Scotland with the exception of Crossroads. More glaringly, Alzheimer Scotland does not feature at all, even in the list of useful addresses at the back of the book. Another opportunity missed is the lack of any information relating to Direct Payments or other forms of Self Directed Support.

While it is disappointing that readers in Scotland will find some sections of this book unsuited to their needs, *Coping with Early Onset Dementia* is well worth reading and returning to throughout the course of the illness. This is a book to keep on your bookshelf and to dip into when you want to know more about particular topics or remind yourself about issues such as coping with changes in behaviour.

One would hope that the gaps in its coverage will be rectified in future editions.

Anne Marie MacDonald
Glasgow Younger Persons
Support Service
Alzheimer Scotland

Memory Bus launched



On a cold, foggy 17 February, outside the Lesser Town Hall in Falkirk, Alzheimer Scotland launched its first Memory Bus. Falkirk Provost, Pat Reid was on hand to cut the ribbon for the new vehicle, watched by local people with dementia, carers, staff, branch members, local politicians and volunteers.



Henry Simmons, Chief Executive of Alzheimer Scotland, said: "This launch is just the start of what will be a grand tour for Alzheimer Scotland's latest venture. We want to make sure that no-one goes through dementia on their own, but that's easier said than done, particularly in Scotland's remote, rural communities. Even in our towns and cities, people with dementia and their families often find it difficult to access support or get information when they need it – and not everyone is connected to the Internet or feels comfortable discussing their concerns over the phone.

The Memory Bus is a mobile information unit which will help Alzheimer Scotland reach people across Scotland face to face, wherever they are, bringing information and advice to those living with dementia and raising

awareness of dementia in our local communities. We want to take the bus to shopping centres, car parks, village halls, farmers' markets, and high streets, from Yell to Yetholm, and all points in between.

The money needed to buy the vehicle (a Volkswagen Crafter van) and adapt it to use as a mobile information and advice service has come entirely from fundraised income. This is a significant investment of funds, so we want the Memory Bus to be in use as many days of the year as possible. The bus will be manned by experienced Alzheimer Scotland staff, including our team of Dementia Advisors, and supported by volunteers.

The itinerary for the Memory Bus will be advertised in local press and on our website at www.alzscot.org, so keep an eye open for the Bus coming to your area.



Did you know?

There are several ways you can get help with council tax bills – often a substantial part of a household's monthly outgoings.

A house may be completely **exempt** from council tax if, for example, it is solely occupied by a person or persons with a "severe mental impairment". If only one person lives in a house or counts as living there, a **discount** of 25% would apply. The local authority also disregards certain people when deciding who is living in a house, so the discount could be as much as 50%. Another way of cutting the bill can be via a **disability reduction** which involves a reduction in the council tax band of a house to the band below, for example a band D property would be reduced to a band C.

You can find more detailed information on these ways of reducing your council tax bill in our booklet *Dementia: money and legal matters* or our information sheet on council tax, both of which are available via the Dementia Helpline on 0808 808 3000. Your local welfare rights service, Citizens Advice Bureau and local council finance department should also be able to give you information.

Scams and distance selling – what to do if you are worried about someone with dementia



Some people with dementia can end up being persuaded to hand over large sums of money or even their entire life savings to scammers or to salespeople using dubious, but persuasive sales methods. This article suggests ways to prevent or stop someone being scammed. In the next issue of *Dementia in Scotland*, there will be an article on bogus callers and bogus workmen.

Scams

If it sounds too good to be true, it probably is.

Most people would agree with the statement above, but it doesn't stop three million of us each year becoming victims of scams. Scamming is big business. Many scams take the form of bogus and fraudulent offers sent by post, telephone or e-mail. Though anyone can fall for a scam, elderly and vulnerable people are particularly targeted.

Some people fall for just one scam; others become chronic scam victims, being repeatedly taken in. What starts with a reply to a single scam mailing or phone call can quickly escalate once the person's contact details are added to a "suckers list" and they end up getting hundreds of calls and mailings a week and being persuaded to part with ever increasing sums of money.

There are thousands of ways in which scammers will try to con people out of their money, including bogus lotteries, get-rich-quick schemes, offers of large fees to help transfer huge amounts of money out of a foreign country, miracle health cures, fake psychics, prize draws and sweepstakes, and bogus calls or emails supposedly from banks, the Tax Office or parcel delivery firms. The scammers are always trying new scams or variations on old scams.

Warning signs

Family members, friends and neighbours can look out for warning signs suggesting someone with dementia has been drawn into ongoing scams:

- lots of junk mail arriving and piling up
- a houseful of particular products, like "vitamins" or health cures
- lots of phone calls from strangers
- the person suddenly becoming very secretive about discussing money
- unusual numbers of regular transactions in bank and credit card statements
- "final demand" letters about unpaid bills because funds are being diverted to the scammers.

How you can help

Criticising or confronting the person directly about your suspicions might do more harm than good. They may be too embarrassed to admit to falling for a scam or refuse to accept they have been conned. Being too heavy handed could lead to the person becoming frightened or simply refusing to listen.

Instead, try explaining that it is a common problem, and that scammers can be very clever in their tactics, resulting in all sorts of people being conned. You could raise the subject indirectly by talking about "a friend" who has been duped or about a case you've read about in the papers. You may

want to talk to the person about giving you, or someone else they trust, power of attorney so you can help sort out their finances and have the authority to act for the person.

If you believe that someone you care for has already been targeted or is vulnerable, talk to them about the letters or phone calls they receive, and pass on some simple tips to help them avoid being scammed further. Try writing up these tips and getting the person to keep them by the phone and beside where they usually keep their post, as a reminder.

Simple Tips

- **Never** reply straight away to an offer, even if someone says it's for that day only. Speak with [name of relative, friend, neighbour or carer] before you send or hand over any money or bank details
- **Never** trust anyone who says you have won the lottery or a big prize draw – they will always want you to send them a fee or order something, and you will never see any winnings or prizes
- **Never** dial any premium rate numbers (starting with 090) to claim a prize or "free" gift
- **Never** give your bank account or credit card details to strangers on the phone or at the door
- **Never** give out personal or financial information unless you are the one who made the call and you are 100% sure who you are speaking to
- **Don't** call back a number you don't recognise – if it's important they will call you back
- **Remember** – if it sounds too good to be true, it probably is.

Prevention is better than cure

It's impossible to stop all unwanted calls, junk post or emails but you can reduce the volume of these received by someone you care for and make it less likely they will become the victim of a scam. With each of these methods, you may also stop communication from companies and organisations the person might want to hear from, such as charities they support or organisations whose services they use.

Reduce unwanted phone calls

- Make the telephone number ex directory
- Bar calls from withheld numbers (this could also bar some genuine calls made through a switchboard)
- Speak to the person's phone provider about schemes such as Choose to Refuse where you can bar specific numbers
- Register for free with the Telephone Preference Service (for both landlines and mobile phones). It is illegal for UK companies to call anyone who has indicated they don't want the calls. Call the TPS on 0800 398 893; or via their website at www.tpsonline.org.uk It takes about 28 days after registering for calls to be stopped
- Register with Silent CallGard on 0844 3722325 to stop silent calls which are generated using 'automated diallers'. This registration needs renewed every 12 months. If the calls persist, you could dial 1471 to get the number then report it to the nuisance call department of the person's phone provider
- If the person gets unsolicited sales and marketing voice recorded messages and has not given consent to receive such messages, ask the marketer to stop sending these. They are legally obliged to act on your request. Be wary of following instructions in any of

these messages to dial a number to prevent you receiving more of these messages – you may be diverted to an expensive premium rate phone line.

Reduce unwanted mail

- Join the Mail Preference Service register at www.mpsonline.org.uk or by calling 0845 703 4599 (for mail with the person's name and address). The MPS can remove someone's name and address from up to 95% of Direct Mail lists. It will take up to 4 months for the Service to have full effect. The person can expect to continue to receive mailings from companies with whom he or she has done business in the past. If you want these to stop you will need to contact these companies directly.
- Where someone is already being bombarded by unwanted mail, you may want to persuade the person to get the Post Office to redirect their mail to you or another person they trust for a few months until the MPS service is fully operational
- For leaflets, flyers or unaddressed post delivered by the postman, contact the Royal Mail at optout@royalmail.com or send a letter to Freepost RRBT-ZBXB-TTTS, Royal Mail Door to Door Opt Out, Kingsmead House, Oxpens Road, Oxford, OX1 1RX.

Reduce unwanted emails

Email scams can be very sophisticated, but a few common sense precautions will help. Apply a spam filter – a computer program which works with an email package to sift through new emails, separating spam emails from wanted emails and blocking them. Putting up a warning list beside the person's computer will act as a reminder.

Simple tips for emails

- **Never** reply to a spam message
- **Never** reply asking to be taken off their contacts list – this just tells the spammer that your

email address is live so you'll get even more spam

- **Never** buy products or services advertised in spam from companies you don't know
- **Don't** click any links in a spam email
- **Be wary** of phishing – a technique used by scammers to get you to disclose sensitive information on a bogus website. These emails usually claim that it is necessary to "update" or "verify" your customer account information. Banks will never contact you by email to ask you to enter your password or any other sensitive information by clicking on a link and visiting a web site.
- **Don't** forward spam emails to other people you know, especially the ones promising good fortune if you do and bad fortune if you don't.

Can you get any money back?

In most cases, the person's money can never be retrieved, particularly if it has been sent abroad or if the recipient can't be identified. If the person has ordered goods or services in the UK, the odds are a bit higher depending on how the payment was made. If by credit card, the credit card company may compensate the card holder; if the payment was made using a debit card operated by VISA, you may be able to use VISA's chargeback scheme. There is no minimum or maximum limit on the claim under this scheme, but claims must be made within 120 days of the transaction. Ask your bank for details of how to apply under the scheme.

Get advice from:

Your local Trading Standards office (see the phone book under your local council); the Citizens Advice Bureau; or Consumer Direct Scotland www.consumerdirect.gov.uk; 08454 04 05 06

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Diary dates

Sunday 17 April	Virgin London Marathon Kilomathon Edinburgh
Sunday 8 May	Ignis Asset Management Glasgow Women's 10K Forth Rail Bridge Abseil
14-19 May	West Highland Way
21 & 22 May	Edinburgh Marathon Festival of Running
Sunday 22 May	City of Aberdeen Baker Hughes 10K Race
Monday 30 May	Bupa London 10K
May	Bupa Junior & Mini Edinburgh Run
Thursday 2 June	Sportsman's Dinner
Sunday 5 June	Challenge Scotland (Summer) Events Walk for Scotland Run for Scotland Toddle for Scotland
Monday 6 June	Dementia Awareness Week Conference, Glasgow
Saturday 18 June	Rob Roy Challenge
Sunday 19 June	Men's Health for Scotland 10K for Men, Glasgow
Sunday 10 July	British London 10K



Dementia Awareness Week 6-12 June 2011

Look out for events happening in your part of Scotland –
updates on our website at www.alzscot.org