

Liverpool & South Sefton Branch News

June 2006


Alzheimer's Society
Dementia care and research

Welcome! New Faces at the Branch.

Welcome to the Newsletter of the Liverpool and South Sefton Branch of the Alzheimer's Society. While this edition may look a little different, we hope we get the balance of information and entertaining articles right.

We are open to ideas, and would love to hear any ideas/articles/jokes (clean ones please!) that you may have for future issues. Articles, poems, pictures or words of thanks are likewise very welcome.

NEW FACES

As many of you will no doubt already be aware, there have been some changes in personnel at the branch as of April. If you haven't already met us, here is a brief introduction to your new staff members.

MARTIN SMITH— ADMIN / HELPLINE

Martin is here to look after the office and finances, and he has lots of experience in other offices to help with this. He also looks after the Helpline (298-2444) so

he is likely to be the first person you speak to if you call. As a team, Martin and Michelle should be able to provide all the information you may need.

MICHELLE CULSHAW— FAMILY SUPPORT WORKER

Michelle may be young but she brings lots of experience to her role. A carer for her Gran (who had Alzheimer's for 17 years) and a worker in the care sector for 5 years, she has a clear understanding of the

Inside this issue:

<i>New Faces</i>	1
<i>Fond Farewells</i>	1
<i>Aims of the</i>	2
<i>NICE Guidelines</i>	2
<i>Events</i>	2
<i>Research</i>	3
<i>Quiz</i>	5
<i>Calendar</i>	5

needs of people with dementia and their carers. Michelle also has a Degree in Psychology. She will spend her time providing advice and support, in drop-in and outreach sessions, as well as visiting people in their homes.

Fond Farewells

Josie McDonald writes:

"As most of you already know, Barry Foxon was made redundant due to changes being made within the society. His last day was Friday 30th April 2006.

I personally found it very hard to say goodbye to him. Not only has he been a tremendous asset to the branch, he is also one of the most loyal, honest and hard-working colleagues it has been my pleasure to work with. He also became a very good friend.

I know most of you will

feel the same way I do—he was always there for you. You could phone him in the office at any time and he would put you at ease and help to solve your problems.

So, on behalf of all of us at the branch, I wish Barry good luck in the future. At the moment we have two new branch staff, Michelle and Martin. I think that we are lucky to have two such dedicated workers. I'm sure it won't be too long before you are calling them 'Pinky and Perky' also! We also have the two Regional staff who I personally feel are the

best we've had. I can only see the branch going from strength to strength. "

We also asked Barry to write his own goodbye to you all:

"I should like to take this opportunity to say goodbye to all of you who have become friends over the years. I want to say how grateful I am for your friendship and how much I treasure it. I hope we have the chance to meet again in the not-too-distant future.

I offer my best wishes to the new members of

staff at the Branch office. I'm sure you will find them always eager and willing to help—they're just a phone call away. I want to thank the branch chairperson, Josie McDonald, and the other members of the management committee, past and present, for their friendship and for their loyalty, help, advice and support without which I would not have been able to fulfil my role. Until we meet again, take care.

With very best wishes,
Barry Foxon
Branch Support Worker
(1998-2006)

Aims Of The Branch: Now and In the Future

Support group members will be aware that we recently carried out a small survey of people currently providing care for someone with dementia.

The idea behind this survey was that we now have some awareness of what it is that people with dementia and their carers want from their branch. We hope then to be in a good position to provide the tailor made services that people want and need.

We aim to do our best for you and the communities of Liverpool and South Sefton.

The future will see our branch providing respite care in the home (in the form of a "sitting

service"). We also aim to increase the number of support groups at times and in the areas most convenient for the people who use them. We will continue to have our current Monday group as it stands, and we will add new services and new groups to expand the services we provide. . Perhaps you would like us to arrange a "music and memories" event for this group, or maybe you have some ideas of your own?

We aim to publicise the branch in as many places as possible—to have posters in GPs surgeries, care homes and care agencies. If you can think of any other

places in which a poster can help publicise us and our activities, please let us know.

If you want to make your views about the future of the branch known to us, please call us on the Helpline and we will make a note of your ideas.

OUR DAY OUT

Would you like an outing organised in July or August?



Perhaps a trip to Llandudno to walk the prom, or the grand ballroom in Blackpool. Please let us know your preference and we will try to arrange something for later in the summer.

NICE publish guidance about Alzheimer's drug treatments.

The National Institute of Clinical Excellence (NICE) published a report on the prescription of drug which can be used to treat Alzheimer's, such as Aricept, Reminyl and Exelon.

The news is not good, as the recommendation is that these drugs should only be prescribed to people in the moderate stages of Alzheimer's.

NICE has also restricted access to Ebixa, except as part of a clinical trial.

Those already taking the drugs will not be affected, but newly diagnosed people will find that these drugs are only available during the early stages. The Alzheimer's Society is calling on the support of members, branches and campaigners to support a push to overturn this decision.

The decision comes a few days after a separate report from NICE about the level of care and support available to

people with dementia (entirely separate from the medication issue). The Society will be commenting on this report in due course, following consultations with carers and people with dementia.

"This decision is outrageous. It will rob families of precious time in the early stages of dementia and deprive people of comfort and dignity in the final stages of their lives."

Neil Hunt, Alzheimer's Society Chief Executive



RADIO DAYS

The branch were recently well represented by Barry and Doreen Smith on the Pete Price show's "Alzheimer's Phone-In". We can make up CDs of the show for anyone who'd like to hear Barry's dulcet tones again. Price: £1 donation.



Social at Aintree Conservative Club

A social event has been organised for Friday 30th June, at Aintree Conservative Club, Lancing Drive (off Aintree Lane). The evening will start at 8 pm, and entertainment will be provided by Tom Barrie and Ray Wilde, as well as a raffle and bingo. Profits will go to the Alzheimer's Society and the Woodlands Hospice. Tickets, priced at £5, are available from branch staff.

Research Round-Up: Cause Cure and Care

Some of you have asked us to summarise the current trends and ideas in Alzheimer's and dementia research. While we can't go into too much detail now, we hope you find this helpful. We have broken this report up into three sections based on the "three Cs" – Cause, Cure and Care. The three Cs come from the Fisher centre for Alzheimer's research in the USA.

<p>CAUSE</p> <p>According to current theory, there is no single cause of Alzheimer's Disease. Early onset Alzheimer's disease is most often caused by genetic factors (therefore called familial Alzheimer's). Late onset, also called sporadic Alzheimer's disease is caused by a combination of genetic, environmental and lifestyle factors. These include events throughout the person's life (such as head injuries), diet and exercise. We do still not have a clear picture of what is most important here, but high blood pressure and obesity in middle age are clear risk factors for the later development of Alzheimer's disease.</p>	<p>Alzheimer's disease have plaques between their nerve cells made from amyloid and tangles within their nerve cells made from tau a protein that helps the transport in the cells to function.</p> <p>It was thought for a long time that the amyloid plaques prevented nerve signals, but we now know that they are just the end products from a long cascade of events of processing of a particular protein in the membrane of the nerve cell gone wrong. The plaques may contribute to the problems by clogging up space, but the real damage is probably caused much earlier in the series of events that lead to their formation. One of the intermediary stages is believed to be toxic to nerve cells.</p>	<p>publicised study was stopped in 2002, though, due to safety concerns. However further analysis of the results as well as post mortem material has indicated that there is great potential for this approach and several studies are underway in USA to develop a safer vaccine.</p> <p>Dr Zlokovic of the University of Rochester is looking into a drug which improves the repair of blood vessels in the brain. Increased blood flow is thought to remove the toxic compounds that make up amyloid plaques. The researches have given their drug the eye-catching (if slightly misleading term) "mental Viagra".</p>
<p>One gene is of particular interest in late onset Alzheimer's disease. It is called ApoE and one variant of this gene is a risk factor for the development of vascular disease as well as Alzheimer's disease. It is likely that other genes will eventually be identified that are associated with small levels of increased risk. The previously held view, that aluminium was a major factor in the development of the disease, has not been proven</p> <p>While there may be a confusing tangle of evidence, scientists, many funded by the Alzheimer's society, have made amazing progress recently in getting to the heart of the matter.</p> <p>It now appears that the memory loss and personality changes which appear in Alzheimer's are accompanied by certain changes in the structure of the brain. Brains from people with</p>	<p>CURE</p> <p>A number of studies are taking place to identify potential cures of Alzheimer's disease.</p> <p>Dr Liesi of the University of Helsinki, is looking into KDI, a drug which helps nerve cells to heal themselves. Dr Liesi says that they are several years away from human clinical trials.</p> <p>Dr Po Lu of the University of California has been investigating the effect of the male sex hormone, testosterone, on the quality of life of Alzheimer's patients. However, Testosterone Replacement Therapy (TRT) has had only temporary results, and only in a small number of the men tested.</p> <p>Several groups are researching potential vaccines which encourage the bodies own immune system to reduce the build-up of amyloid proteins in the brain. One such highly</p>	<p>Stem Cells are the body's own way of producing new cells. Normally, once a nerve cell is damaged, the body cannot replace it, but researches are looking at ways of encouraging the bodies own stem cells to repair and rebuild damaged nerve cells in the brain.</p> <p>If you search for "Alzheimer's" on the Internet, you will be bombarded by many sites advocating; folic acid, oily fish and omega-3 fatty acids, vitamin B supplements, vitamin E and multivitamins, even cigarettes. It is important to realise that these are suggested as potential preventative measures, not cures. Whether they slow down the development of the disease is not yet clear and anyway, most of these should be part of a healthy diet anyway (except cigarettes of course!)</p>

Continued from page 3

CARE

Care is often the forgotten part of research, but there are some studies going on which look at how care can be improved.

Dr Kumar of the University of Miami has shown how **music therapy** can benefit people with Alzheimer's. A group of men were provided with 30-40 minutes of music therapy every day for a month, and were less disruptive, slept better, more active and cooperative than a group of men who had no music therapy. They also proved that music therapy benefits the carer as much as the person with dementia. The following guidelines may help;

- Pick familiar songs
- Encourage the person to clap, sing along or play an instrument.
- Match music to mood – eg quiet music for bedtime.
- Avoid over-stimulation – turn off the TV, close the curtains and door and try to avoid interruptions from the phone etc.
- Supplement music with photos and happy memories.

The Fisher Centre for Alzheimer's research has shown that **depression** may speed up the course of Alzheimer's. The opposite is also true – that if the person with Alzheimer's is happy and well adjusted, the disease may take longer to move into its later stages. It may be hard to avoid feelings of depression if you have been diagnosed with dementia, but if you feel that your loved one is overly anxious, lacking interest, sleeping and eating poorly or generally feeling sad or

apathetic, it is certainly worth discussing with your GP. Of course, music has often been shown to lift people out of depression (see above).

New York University is studying the effects of **counselling** on the person with Alzheimer's and their carers. It is thought that counselling (especially in the early stages of dementia) may ease stress and prevent depression, thus slowing the development of the disease.

Some ideas to come from counselling and support groups are listed below;

- **Education** can help us understand Alzheimer's and its effects.
- Because dementia can be so overwhelming, it may help to **break problems up** into small, easy to manage tasks.
- **Behaviour management** can help: remembering to remain calm; not rushing the person with Alzheimer's; to speak softly and try to understand the causes of problem behaviours.
- **Concrete planning** can support the caregiver. Family members can help (with, say, shopping or cleaning) and building up legal, financial and health advice for the carer helps share the load and helps the carer remain optimistic.

The above are "holistic solutions" – they deal with the **whole** situation instead of just one part of it. The idea is what helps the carer helps the person with dementia, and what helps the person with dementia helps the carer

Martin would like to thank Clive Evers and Dr Susanne Sorensen of the Alzheimer's Society for their invaluable guidance and advice with this article.



MEMORY WALK

On 24 September, we will be having a memory walk—walking a short distance to raise awareness of dementia and to do a little fundraising too. The branch staff will be doing the walk, but we will need as many people as possible to ensure we have maximum publicity. We've yet to finalise the details, but it will be gentle, not competitive and you will have the opportunity to just walk a suitable distance for yourself. We need walkers, sponsors, organisers and general support, so please let us know if you are interested in taking part.

ANSWERS To Page 5 Quiz

1. "Frankly my dear, I don't give a damn" from "Gone With The Wind".
2. None. They were Scott Engel, John Maus and Gary Leeds, and were completely unrelated!
3. 1891, to combat the growing use of handballs to score.
4. Handwriting.
5. Kids—as in "teapot lids".
6. "To Kill A Mockingbird", played by Gregory Peck.
7. The penguin.
8. Dom Perignon.
9. "Little" Jimmy Osmond in 1972—he was aged 9!
10. Sir Issac Newton.

QUIZ-TIME

1. Which 8 word phrase was voted the greatest movie quote of all time.
2. How many brothers were in the Walker Brothers?
3. When was the first penalty kick taken in a game of football?
4. What is graphology the study of?
5. In Cockney rhyming slang what are "teapots"?
6. In which film would you find "Atticus Finch"?
7. What is the only bird that can swim but not fly?
8. Who invented champagne?
9. Who was the youngest singer to have a UK number 1 hit?
10. Who discovered the law of gravity?

QUOTES AND POEMS

Because you are so dear a friend,
 Your cares are my cares too,
 And so as sorrow fills your heart,
 My heart goes out to you,
 And though my words cannot begin
 To ease the loss you bear,
 I only hope it helps somehow,
 To know how much I care
 ANON

"The art of being wise is knowing what to overlook" ANON



Our Family Support Worker has been liaising

with consultants in Walton Neurological Centre and Mossley Hill Hospital. The aim is to be one of the first ports of call for people diagnosed with dementia. We can fill the gap in support between diagnosis and receiving a care package. In future, this could extend to the provision of respite care once we have such a service set up. Even now, though, we can make a difference through providing, information advice and support. Ensuring that newly diagnosed cases are referred on to us makes sure that people are aware of us if and when they need our support.

HELPLINE: 0151 298 2444

Alzheimer's Society

Glaxo Neurological Centre
 Norton Street
 Liverpool
 L3 8LR

Calendar of Events

► The "Monday group" will meet at the Glaxo centre on the following dates:

5th June (2-4 pm)

3rd July (2-4 pm)

4th September (2-4 pm)

2nd October

6th November

December—Christmas lunch—tbc.

► Mon June 12—Friday June 16 is National Carer's Week. "Carer's FM" is a radio station broadcasting for one week only—find in at FM 87.7.

► July 4 will be the branch Alzheimer's Awareness Day and we are planning a media event. Please call if you'd like to get involved in some way.

► South-Sefton Drop-In—held at Sefton Carer's Centre, South

Road, Waterloo. Last Tuesday of each month, 10—2 pm.

27th June; 29th July; 29th August; 26th September; 31st October; 28th November.

► Michelle and Martin will be attending the Carer's Day event on 14 June (10:30-2:30). All carers are welcome, and there will be pampering, demos, stalls and lots of fun activities including prizes! It takes place at Liverpool FC, which may put off half the city's population, but put aside your differences and come along to what looks to be a great day!

► We will also be attending an information day in Dobson Court (off Belmont Road, again in Anfield) on 20th July, from 11—3pm. The event is organised by Health Inclusion for Men (HIM)

but women are just as welcome.

► There will be a new "Tuesday Group" starting very soon. This is specifically for carers to air their views and concerns in a supporting environment. The current support group agreed Tuesday to be the best day. We will be sending out invites to the current support group very soon.

► The Branch will be represented at a summer fair taking place on 25 June in the grounds of Aintree Hospital. Lots of stalls and events will be there, starting at 12 pm. Any offers of help on the day gratefully received—otherwise pop by and say hello on the day if you can.