

# for dementia

training ■ development ■ admiral nurses

Newsletter Issue Number 15 / 2007

## Jane Jason awarded OBE



for dementia was delighted by the news, in June this year, that Jane Jason, founder trustee of the charity, had been made an OBE in the Queens Birthday honours, for services to those with dementia.

Jane's father, Joseph Levy had vascular dementia. Jane reflects, "When my father was diagnosed with dementia, the whole family was touched by this cruel illness and became determined to make a difference to others similarly affected. We were particularly concerned about the effect on my mother, as the principal carer, and aware of the need to substantially improve understanding of a carer's experience".

With her mother, Mrs Ninot Levy, and Dr Monica Greenwood and Margaret Butterworth, Jane was instrumental in spearheading a number of initiatives. A specialist training programme for

care-workers was established in 1988 and the first Admiral Nurses were appointed in 1990. Admiral Nurses were named in memory of Joseph Levy whose nickname was 'Admiral Joe'. The charity, the Dementia Relief Trust, was established in 1995. Jane was Chair of the Board of Trustees from then until 2005 when she stood down at the end of the charity's tenth anniversary year.

Jane remains a trustee and now chairs *uniting carers for dementia*, a recently established dimension of the charity which seeks to engage and encourage carers to contribute to the dementia field by sharing their experiences of caring and the impact of dementia.

On receiving her OBE, Jane commented, "It is a great honour, not only for me personally, but also for the charity. This award belongs to the many people who have contributed to our success. We have weathered many storms to get this far but it goes to prove that if you believe strongly enough in something it will succeed"

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*for people who care*

# Admiral Nursing DIRECT

**Admiral Nursing DIRECT was launched at a breakfast reception at the Imagination Gallery in London on 28th February 2007.**

Hosted by Katie Derham and attended by many of the charity's supporters, including GMTV presenter, Fiona Phillips and actor Leonard Fenton, the event served to raise the profile of this important new service.

Admiral Nursing DIRECT is a telephone information and support service for people with dementia, those caring for someone with dementia and professionals working with people with dementia and their carers. The aim is to make information and support available to people in areas not yet served by community based Admiral Nurses.

Jules Jones, Project Lead for Admiral Nursing DIRECT, co-ordinated a series of presentations from Admiral Nurses and others that demonstrated the range of enquiries and requests for help to which the service is responding.

The launch of Admiral Nursing DIRECT took place on a day when dementia was very much in the news. A national report commissioned by the Alzheimer's Society and produced by Kings College London and the Institute of Psychiatry, entitled *Dementia UK*<sup>1</sup> highlighted alarming projections of the numbers of people expected to be experiencing a form of dementia. The report indicates that almost 700,000 people have dementia in the UK today and that by 2021 this figure will have risen to more than 900,000. By 2051 the forecasted number is 1.8 million.

The most common form of dementia is Alzheimer's disease, affecting 62% of people with dementia. Vascular dementia and mixed vascular and Alzheimer's accounts for a further 27% of cases.

**for dementia** aims to increase the number of Admiral Nurses working in local communities, within the NHS and in partnership with other organisations, in order that all parts of the UK will be served.

Admiral Nursing DIRECT is available on **0845 257 9406** on Tuesdays in the daytime and on Tuesdays and Thursdays in the evening, from 6pm until 9pm. The service is also available by email **direct@fordementia.org.uk** *for dementia* is seeking funding to enable the availability of the helpline to be extended.

1. The full *Dementia UK* report can be downloaded from: [www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2)



## Fiona Phillips

"If only I'd known about Admiral Nurses when my mother was suffering with Alzheimer's Disease. Apart from the fact that she was terrified by her condition, I think all of us as a family felt very alone and confused. It is the most helpless feeling in the world knowing that you cannot help someone who is crying out for help. If we'd known about Admiral Nurses it would have made the whole frightening experience a lot more manageable."



Learners and supporters from *Friends of the Elderly*.

## Certificate Programme Annual Award Ceremony

On 5th October 2007, **for dementia training** held the Annual Award Ceremony for learners who had recently completed the certificate programme, 'Working with People with Dementia and their Carers'.

Learners from the biannual programme delivered in London, and those completing the pilot partnership programme with Friends of the Elderly, from the Bernard Sunley Nursing Home in Woking and the Old Vicarage in Oxfordshire, were presented with their certificates by Jane Jason OBE.

The ceremony was concluded with the presentation of the Margaret Butterworth Award 2007. This year, learners Festus Awogboro, Kobra Moosavi and Patricia Williams were selected for the Award in recognition of the quality of the work they had produced whilst undertaking the programme, which clearly demonstrated their commitment and dedication to people with dementia.

Following the presentation, everyone enjoyed drinks and canapés in the atrium of the Methodist International Centre.

*Applications are invited for the next certificate programme which begins in January 2008. Please contact Emma Hewat for more information on 020 7874 7222 or email [training@fordementia.org.uk](mailto:training@fordementia.org.uk)*

## Open Courses

**Journey's End:  
end stage dementia care**  
11th January 2008

**Depression in Later life**  
5th February 2008

**Introduction to Dementia**  
19th February 200

**Fancy Footwork**  
3rd March 2008

**Time management and  
getting the best out of  
meetings**  
10th March 2008

**Developing positive  
relationships with relatives  
and carers**  
12th March 2008

**Developing Services:  
consulting and involving  
people with dementia and  
their carers**  
14th March 2008

**Working with Assistive  
Technology**  
17th March 2008

**Management, Leadership  
and Teambuilding**  
25th March 2008

All one day courses cost £90,  
or £70 if your booking is  
received three months or more  
in advance of the course date.

*For further information  
please call for dementia training  
on 020 7874 7222 or email  
[training@fordementia.org.uk](mailto:training@fordementia.org.uk)*

# Providing enabling care for people with dementia: risks, rights and decision-making



Rosemary Clarke

At this conference, organised by Trent Dementia Services Development Centre, held on 11th September 2007, I regained inspiration as a campaigning carer through hearing several dementia

professionals speak so passionately about people with dementia as human beings just like themselves and like you and me.

One story represents this, telling, as it did, of attempts to do things well for a particular woman, of mistakes made, of continuing learning, of intelligence and compassion and common sense.

Grace spent the first few days in the residential home in her room, to get used to it, then was brought down to the drawing room, where she screamed and screamed. At first the manager called the GP intending to ask her to check that Grace was not in pain. But immediately, the GP was offering sedatives.

The manager now realised that Grace was probably not in pain as she only screamed when she was in the drawing room. It was reasoned that she must not like being in a room full of people doing odd things, and a pleasant little niche was found for her along a corridor, where she spent her days apparently content, certainly not screaming, and in splendid isolation. Problem solved, it seemed. Until a care worker not knowing the arrangements sat her in the big room, this time entirely alone, where Grace began screaming again. The worker looked around and realised that the wallpaper was reflected so as to make it seem that there was a crack in the big mirror at the end of the room. Grace was very superstitious and when put in a chair in a different place was now fine to be in that room with the others.

The speaker talked of one of his "irrational" fears and engaged us all in recognising that we are all a mass of anxieties, worries, superstitions and histories, and that all that is needed is for these to be allowed and understood. If it ever happens to me I just hope that people like these are around.

*Rosemary Clarke*

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## Profile: Catherine Quinn



Catherine Quinn is a PhD student based at the University of Wales Bangor who has been working with the Admiral Nurses since September 2005. Her research explores why

people become caregivers, what helps caregivers keep going in their role and how caregiving may affect the relationship between the caregiver and care recipient.

Catherine is working with the Manchester and Bolton Admiral Nurse teams, interviewing caregivers, care recipients and Admiral Nurses. She is also designing a questionnaire which will be sent to all caregivers in receipt of Admiral Nursing support. This will further explore factors that can have an impact on the caregiving experience. All of the findings of Catherine's research will be reported back to the Admiral Nurses to inform practice development.

# The Language of Dreams

There is a conundrum at the centre of my life at the moment. When I dream about my mother, as I do regularly, does she speak to me and if so is it in her own voice or the fractured, distorted language of her illness: half-words; sighs; linked syllables that make no known words but in their delivery carry a kind of sense, or at least a kind of communication? Rhythms of old conversations: annoyed; amused; concerned.

Last night I dreamt she ran a small junk shop. At the centre of it was a floppy, knitted sailor-doll. I was assisting her place items for sale on the pavement outside the shop – move this here – place the electric fire beside the wooden kitchen chair, place the sailor on it. So perhaps she was speaking in the old way. Or, was I merely questioning her, as I do each day when I visit her – shall I put it here? Over here? Do want this? Would you like that?

In the dream I drove her home at the end of the day and as I did so I had my arm round her, as I do each day as we sit quietly together looking out onto the garden that seems to give her so much pleasure and fill her with wonder.

I am pleased I am going through this period of dreaming, for I hope that my subconscious is quietly processing away what had befallen us – she and I, and that the pain I live with – a combination of anger and outrage, sadness and regret, will eventually subside.

I do not dream of the life she could be leading at eighty-four, and I am glad of it. Enjoying the flat she moved to a year or so before the dementia took hold, shopping trips with friends who have now disappeared; trips out with me. I do not dream of them, and I am glad of it. It try not to even think of that denied life, for it provokes the sort of impotent, savage rage that can destroy us if we let it take hold.

So. In reality. All dreams apart. We still have the laughter, she and I, and the garden. And I still have the immeasurable joy of seeing her face light up when I enter the room. And the noises? The secret, primitive cry to communicate – *It's you*, I am sure she is saying. *It's you. You're mine.*

*Mick Scully*

## Joy Watkins



Joy Watkins took up the post of **Resource Co-ordinator** for **uniting carers for dementia** in April 2007.

Joy's role is to activate the network's membership and develop opportunities for family carers (former and current) to contribute to the field of dementia care in a variety of ways, including research, education and training, writing for publication, campaigning and fundraising.

The aim of *uniting carers for dementia* is to raise awareness and increase understanding of dementia and carers' issues and to improve the quality and range of services available. There are many ways for carers and former carers to get involved and *for dementia* will provide support and training and will reimburse out-of-pocket expenses.

If you would like to find out more about becoming involved with *uniting carers for dementia* please contact Joy Watkins on 020 7874 7209 or email [carers@fordementia.org.uk](mailto:carers@fordementia.org.uk)

# George Melly

17 August 1926 – 5 July 2007

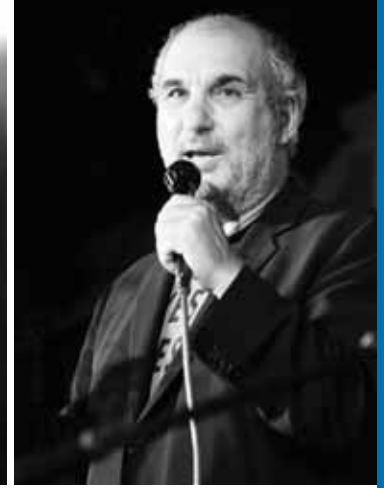


Jazz fans and charity supporters joined together at the 100 Club in Oxford Street on 10th June 2007 to enjoy a very special evening with George Melly and friends.

Compered by Paul Jones, the performances began with a set by George Webb and his Band of Brothers. This was followed by an energetic performance by Kenny Ball and his Jazzmen, featuring special guests Terry Lightfoot and daughter Melinda.

Alan Yentob, Creative Director at the BBC, took the stage in the interval, as auctioneer, and raised significant sums of money by auctioning a Champagne dinner for four at the Wolseley, a Limited Edition Bottle of Penderyn Whisky and George Melly's distinctive J&B Whisky striped suit, which was sold for an impressive £1,200.

The highlight of the evening was George Melly's performance. He was brought onto stage in his wheelchair and, after talking to the audience for several minutes, accompanied by



Photography by eddiemacdonald@edmacphoto.co.uk

Digby Fairweather and his Half Dozen, he broke into song. It was an impressive performance, despite his obvious frailty.

Encouraged by his wife Diana, George sang three numbers to rapturous applause, and then left the stage to a standing ovation. It was highly emotional: everyone knew that this was the very

last time this great figure of jazz and blues would appear and sing in public.

Paul Jones joined Digby Fairweather and the band on stage to round off the evening and those who stayed to the later hours were treated to some extraordinary harmonica playing by the Manfred Mann frontman.

*Limited edition 'Melly & Friends' commemorative T-shirts were on sale on the night (price £15) and some are still available.*

*Programmes, for £5 each, and a CD recording of the concert, price £20, can also be purchased.*

*Please contact the Events Office on 020 7874 7203 for further information.*

## Diana Melly becomes patron



Diana and George Melly made it publicly known that George had vascular dementia at the time of the launch of Admiral Nursing DIRECT in February 2007.

Diana had been referred to Admiral Nurses by her GP. She describes the support provided by Admiral Nurse, Madeline Armstrong, as 'a lifeline'. Diana first recognised that something was amiss when George didn't recognise her in the street. Diana says, "When I called Admiral Nursing DIRECT, I was immediately put through to Madeline. I talked to her for about an hour and I think that was quite important, that I knew I could go on talking and that she wasn't going to rush me. I told her everything that was going on".

George, who also had lung cancer, died in August this year, just over three weeks after performing the benefit concert at the 100 Club. Diana says, "We were fortunate that George did not experience the final most devastating stages of dementia - and he kept his humour right to the end".

Donations in memory of George Melly can be made by telephone 0845 257 3310 or by downloading a donation form from <http://www.fordementia.org.uk/melly.htm>

# Malcolm and Barbara: Love's Farewell

This very moving documentary by film-maker Paul Watson was shown on ITV on 8th August 2007. Malcolm Pointon was diagnosed with Alzheimer's disease in 1992, at the age of 52. In 1995, Barbara and Malcolm agreed to the filming of their life together with Alzheimer's, little realising, at that time, just how their journey would take shape. Barbara explains their reasons for agreeing to make the film: "We wanted to peel away the stigma attached to dementia and to help people to understand more about dementia and what it can do to the patient and family".

Malcolm and Barbara: a Love Story was aired in 1999 and was nominated for a BAFTA. In the new film, much of the original footage is included; added in is the story of the later years of Malcolm's life, and Barbara's battle to continue to care for him at home, a challenging enough task, made all the more difficult by her continual fight with the health and social care system to secure the resources required to meet Malcolm's needs.

Malcolm and Barbara: Loves Farewell shows, with no holds barred, the physical impact



of dementia in its final stages. This is an issue which Barbara is very keen to emphasise: "For the first time on TV, the documentary revealed the physical ravages of the severe stage of Alzheimer's disease. It showed that dementia is a killer - 1 in 3 older people will end their lives with dementia".

As a result of her experiences, Barbara has published a 'wish-list' which details what needs to be done, in her view, to improve treatment, care and research. This includes: a speedier diagnosis, better education for GPs and general nurses, specialist dementia nurses, such as Admiral Nurses, as part of mainstream provision, and compulsory training of all care staff who come into contact with people with dementia. Barbara's complete 'wish list' can be downloaded from [www.fordementia.org.uk/documents/press\\_release1\\_09.08.2007.pdf](http://www.fordementia.org.uk/documents/press_release1_09.08.2007.pdf)

Malcolm Pointon died peacefully at home on 6th February 2007. He was an acclaimed musician and composer. A memorial concert was held at Homerton College, Cambridge on 28th April 2007.

# The Carer Voucher Scheme pilot in Redbridge

Following consultation with carers, a need was identified for more control and flexibility over the access and use for carer's breaks and home support services. Carers said they wanted a flexible system that could respond to their needs at short notice, without having to consult with Community Mental Health Team (CMHT) staff on every occasion.

As a result, discussions took place between the Community Mental Health Team for Older People and the Commissioning Department of the London Borough of Redbridge. £30,000 of the Carers Grant had been under-spent and it was decided to use this to develop a flexible home support service for carers of people with dementia.

The scheme, later to be named the Pilot Voucher Scheme, was set up in February 2005. We established the £30,000 would purchase 1500 hours of care, which would benefit 25 carers of clients with dementia.

Carers were identified within the CMHT and each were allocated 60 hours care for the year, in the form of vouchers. The carers were then able to use the vouchers to purchase



flexible care from a list of approved agencies for either planned or short notice care. It had been agreed that this service would be free of charge for carers, during the one year pilot.

The voucher scheme did not

replace existing care packages received by the person with dementia, but enhanced the quality of life for the carers. It enabled them to book flexible periods of care at home, in order that they could engage in other activities while the cared for person was being looked after in their own home.

An evaluation of the service has been completed and overall the response to the service has been positive. Many carers explained that they have benefited substantially from the Voucher Scheme, stating that it had made a big difference to their lives.

When asked what activities had the carers been able to do that they could not have done previously, the responses included; being able to go shopping without worry, being able to rest, taking grandchildren to the fun fair, going to boot sales, attending west end concerts and going to the hairdressers.

Many carers said that the Voucher Scheme had reduced their stress in terms of having time off and allowing them the time to do something they enjoy, without the rigmarole of having to wait for an assessment to purchase the service through the local authority.

Following a formal evaluation and presentation to senior management, the scheme is now to be mainstreamed and extended across other client groups in Redbridge, to bring benefit to all carers.

*Kevin Sole, Strategic Lead, Mental Health Care for Older People, Redbridge Locality, North East London Mental Health NHS Trust*

# Eddie runs the London Marathon



It was a hot and challenging time for all runners taking part this year. After the race, Eddie said, with relief: "It is all over! For most of Sunday, the finish line seemed like some unobtainable paradise. It was a truly unforgettable experience, the crowd and atmosphere was phenomenal and really helped me to keep running through the heat and pain, for the whole 26.2 miles."

I feel that *for dementia* is an extremely worthy cause. Anybody who has read of the gruelling demise of Iris Murdoch, as described by her husband, John Bayley, will realise the need for relief from the continual and lonely chore of round-the-clock caring. The kind of support that *for dementia* offers is crucial."

On 22nd April 2007 Eddie Wrey ran his first London Marathon and raised an impressive £4439.30 in support of *for dementia*.

Of his decision to support *for dementia*, Eddie said: "Having seen the regrettable decline of aged family members and friends through dementia,

Eddie finished in position 6,647 (out of 36,000) and 191 in his age group (20-24 years) clocking up a time of 3 hours, 48 minutes, 36 seconds.

A magnificent achievement!

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## Carers' Cream Tea Garden Party

A group of carers from Worcestershire, and their families and friends, held a Cream Tea Garden Party in July this year to raise money for the charity.

Jennie Hayward offered her home for the event and carers from the Admiral Nurses' Joe's Clubs worked extremely hard organising marquees and gazebos and setting out stalls selling plants, clothes, books and bric-a-brac. The cream teas were a great success and the sun shone throughout this very special afternoon. The carers' efforts raised over £2,550. *for dementia* is extremely grateful for the support of everyone involved with this impressive event.



*If you would like advice on how to organise a fundraising event to raise money for the*

*charity, please contact Community Fundraising Co-ordinator, Kirsty Marrins on 020 7874 7203 or email [events@fordementia.org.uk](mailto:events@fordementia.org.uk)*

## *In memoriam*

In memoriam donations are a lasting way to remember a loved one. We would like to extend our heartfelt thanks to the friends and families of those listed below for the donations received in their memory:

*Mrs Gladys Arrowsmith*  
*Mrs Gladys Ashby*  
*Mr Leslie Barry*  
*Dorothy Beaumont*  
*Mrs Cissie Biddle*  
*Lydia Bieber*  
*Norah Black*  
*Mr Arthur Blezard*  
*Amy Bond*  
*Irene Booth*  
*Cliff Bore*  
*Mr Albert Boundy*  
*Margaret Bridge*  
*Mrs Clara Margaret Budd*  
*Mrs Vera Cheetham*  
*Annie Clamp*  
*Mr David John Cole*  
*Florence Dale*  
*Renny Edmond*  
*Miss Edith Elsdon*  
*Mrs Mary Margaret Fegan*  
*Joan Finlayson*  
*Bridget Fitzgerald*  
*Mr Thomas Christopher Aquinas*  
*Fitzgerald*  
*Brian Flatt*  
*Mrs H M Fountain*  
*Mrs Penelope Frazer*  
*Mrs Patricia Freeman*  
*Mrs Christine Garsed*  
*John Gilbert*  
*Joan Laurie Gracie*  
*Helen Greenaway*  
*Mrs Ellen Gertrude Hancock*  
*Maurice Edward Harwood*

*Elsie Haslam*  
*Alan Hoop Hughes*  
*Mrs Gladys Jones*  
*Mr John Alan Chesher Kemp*  
*Sylvia Ann Laventure*  
*Mrs Florence (Frances) Lee-Douglas*  
*Bernard Levin*  
*Mrs Joan Lewis*  
*Doreen Betty Munro Manchester*  
*Mrs Elizabeth Mary Marshall*  
*George Melly*  
*Catherine Mitchell*  
*John Munro*  
*Betty Norman*  
*Mrs Evelyn Rose O'Sullivan*  
*James Pimbley*  
*Mr Robert Walter Patrick Powell*  
*Richard "Dick" Print*  
*David Rice*  
*Gilbert Alfred Richards*  
*Mrs Mattie Irene Rogers*  
*Mrs Helen Sargeant*  
*Irene Scott*  
*Mrs E Shepperson*  
*Mrs Nellie Sherrington*  
*Mrs Ivy Doris Spinks*  
*Mrs Gladys Amelia Stock*  
*Mr Jack Trevor Townend*  
*Mr James F Turner*  
*Mrs Jenny Walsh*  
*Chrissie Woolley*  
*Frederick Yard*





## Remember a Star...

**for dementia** is inviting friends and supporters to *Remember a Star* at Christmas, someone who has been affected by dementia, either directly or as a result of caring for a family member or friend. To sponsor a star, we ask for a donation of £20, this will help *for dementia* continue to develop services and deliver training with the aim of raising standards of care and improving people's lives.

For every person remembered, a decorative star will adorn the Christmas Trees at the *for dementia* Carol Concert, and the name of every 'star' will be acknowledged in the Carol Concert programme and in the next issue of the newsletter.

If you would like to *Remember a Star*, please complete the enclosed form and return it, with your donation, to the *for dementia* office. Additional forms can be downloaded from [www.fordementia.org.uk/us.htm](http://www.fordementia.org.uk/us.htm)

The Carol Concert will be held at St George's Church, Hanover Square, London W1 on 11th December 2007.



**for dementia**  
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6 Camden High Street  
London NW1 0JH

Telephone 020 7874 7210  
Fax 020 7874 7219  
Email [info@fordementia.org.uk](mailto:info@fordementia.org.uk)  
[www.fordementia.org.uk](http://www.fordementia.org.uk)

Registered Charity Number 1039404

**Shire**

Shire Pharmaceuticals  
is pleased to support  
**for dementia** with their  
continuing work in the  
field of dementia care

## DEMENTIA STRATEGY

"The Government is to produce the first ever national dementia strategy in response to one of the great challenges now facing society". This initiative was announced by Care Services Minister, Ivan Lewis, at a Press Conference held during a ministerial visit to St Charles Hospital, London, on 6th August 2007.

Mr Lewis said, "The scale of our ambition must now meet the scale of the challenge as demographic realities mean dementia will impact on an increasing number of families in our society. The current system is failing too many dementia sufferers and their carers. I am determined that this disease is brought out of the shadows"

The programme, which will take 12 months to complete, will be led by Professor Sube Banjeree, Professor of Mental Health and Ageing at the Institute of Psychiatry, King's College London and Clinical Director for Mental Health of Older Adults in the South London and Maudsley NHS Foundation Trust, and Jenny Owen, Executive Director of Adults, Health and Community Wellbeing in Essex and Joint Chair of the ADASS Older People's Committee.

For further information visit  
[http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/DH\\_077211](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/DH_077211)