

# Living with dementia magazine December 2010/January 2011

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[Carer](#) Susan Doggett opens up about the benefits of [counselling](#), and encourages others to consider it, too. 'You think too much' was one of the apocryphal sayings of my mother. I recalled these words recently when my head felt as if it might explode with the myriad thoughts constantly swirling around inside.

My husband, Graham, has [posterior cortical atrophy \(PCA\)](#), a condition caused by [Alzheimer's disease](#) which mainly manifests itself by a gradual loss of sight. Consequently, any jobs in the house or garden which rely on vision now have to be done by me.

Graham was [diagnosed](#) with suspected [Alzheimer's disease](#) in 2005, though it wasn't until 2007 that we got the correct diagnosis of PCA.

I managed to keep myself buoyant for some time but eventually things just got on top of us. I'd been trying to keep Graham going and find ways of dealing with the situation, but we just seemed to be very much on our own as no-one we knew had the same symptoms as Graham.



In 2009, my [GP](#) prescribed anti-depressants to help manage the impact of [dementia](#) on my life. I was finding it hard to relax and concentrate and get back to sleep, and the lack of sleep only added to the strain. It's difficult with [PCA](#) as you are constantly on the alert because of the sight problems.

The medication certainly helped to take the edge off my stress. My GP also recommended [counselling](#), but I rejected it at the time as I felt it was a sign of weakness or not being able to cope. But on reflection, I decided to take up the GP's offer and I'm so glad that I did.

Starting in June, I had seven one hour sessions at my GP's surgery. I was a bit sceptical and wasn't really expecting it to make a great difference, but it definitely has. Just knowing someone is there for you and having someone to talk to every week made a lot of difference.

The counsellor, Judy, kept us strictly to time. Each week, she would start by asking me a relevant question, such as 'How has your week been?' or 'Has anything happened this week that you want to talk about?'

Conversation flowed easily as there always seemed to be something that I needed to talk about. We discussed practical issues such as how I could most usefully use my time so that Graham and I could enjoy life while still having time to do all the household chores.

Each week, I left feeling more in control of our situation. I found I became more efficient as I wasn't wasting time and energy feeling as though I couldn't cope.

We also spent time discussing personal problems and [relationships](#), and as time passed I felt more relaxed and able to discuss anything in the secure knowledge that nothing would be taken outside the four walls.

I found the counsellor's positive comments on certain aspects of caring helpful. I remember her saying, 'Be kind to yourself,' and to accept help from anyone who offers it. Judy made me feel more positive about the fact that I was doing a good job.

I found having an hour to talk uninterrupted to an interested person a great ego boost, and something I imagine would be good for anyone's morale. I think many carers look as though they are [coping well](#) and don't want to make a fuss, but I would encourage people to be honest with themselves and try it.

Although I finished my sessions several months ago, I still feel much more relaxed and able to cope. I think the sessions also increased my confidence. One thing which has stayed with me from Judy is that the [carer](#) has a right to a life of their own. Somehow, we need to try to remember that, without neglecting the people we care for.

Now, if someone else comes to look after Graham, he will go off and do things without me feeling [guilty](#), and this is good for me in many ways. I now say to myself that I shouldn't worry about things in the way that I was, and I'm doing the best I can. The counselling definitely has made me happier.

As the festive season approaches, I am looking forward to practising my new mantra: You are caring for two equally important people; yourself and your partner. I shall, if necessary, buy ready-prepared food, use disposable crockery and utensils, and phone or email friends to wish them Season's Greetings instead of sending lots of cards.



The most important thing in life now is for Graham and I to enjoy joy and peace together for as long as possible.

Read the factsheet on our website [Counselling: how can it help?](#) (445) or call Xcalibre on 01628 529240 to order a paper copy.

## Words of encouragement

Christopher Devas and Ann Johnson both have [Alzheimer's disease](#) and gave presentations about life with dementia at the UK Dementia Congress in Bournemouth in November. Here are extracts from their speeches

### Ann Johnson

I was diagnosed with [Alzheimer's disease](#) five years ago when I was 52. I am now 57. This is not a nice disease to have. A big problem I have is short term memory, but there are other things tied up with it.

Taking my medication, [Aricept](#), means everything to me. When I started taking it I became alert again. Before that, it was like living in a mist and a fog all the time.

My specific problems are a little difficult to explain because you can't see them. I have great difficulty remembering things, working things out and interpreting things. I use a dictaphone which helps considerably. I can't use a normal watch so I've gone digital, but that has its limitations. I can't read very well so I use audio books. I can't count money, but I haven't found a way around that yet so any suggestions will be gratefully received! So, I've developed strategies to help. These can be very simple but effective if they work. Often it is the simplest things that get the better of us - things we have done all our lives without a problem. But now, because we can't do them, it is very frustrating.

Frustration itself can lead to problems. It may evoke a change in behaviour which we may be unaware of. When frustration gets to me, I am not a nice person to know, but I would rather be told if my behaviour is unacceptable as I may not be aware.

Sometimes I feel useless and rubbish, and that is when the tears start. The realisation that you are losing your abilities is difficult to come to terms with. I am a trained nurse and was a lecturer in nursing so it is difficult for me when I can see myself disappearing.

Although medication helps to keep things stable, when I see changes happening to me and things getting worse, it is difficult to handle. I often wish I hadn't got insight.

I find myself in a life-changing situation, but I give thanks for the things I can still do rather than moan about what I've lost. I was asked at a talk what keeps me going. I said my friends, my faith and doing talks. Without any one of these I would be sunk.



### Christopher Devas

Pictured right (courtesy of Daily Echo, Bournemouth)

I am 66 years old and was diagnosed with [Alzheimer's disease](#) two years ago. I prefer to call my [dementia](#) 'Altz.' She has come to live with me without asking!

Prior to 2008 I didn't realise that Alzheimer's disease was invading my life. At the time I wasn't sure what was wrong. I wasn't quite on top of things at work or at home. My doctor referred me to a specialist. I was diagnosed and prescribed [Aricept](#) which has, I think, kept me on a plateau, although I don't know where I would now be without the pills. It was very reassuring to know that I was being helped.

Early [diagnosis](#) is the key. I told my friends and family that I had Alzheimer's disease, so they wouldn't be embarrassed if I was struggling to find a word or two.

After my [diagnosis](#), we rang Alzheimer's Society in Dorset and they gave us all the avenues to go down. Through attending the Memory Café, we met the Community Mental Health Team, which is wonderful and a great support.

From then on, it was a matter of finding things that would be useful. Often, an idea or thought would come into my head which I knew I'd forget. I now have a little dictating machine which I take everywhere.

My phone, dictating machine, biro, money, car and door keys now all have a place to 'live' so that when I go out, I know where to find them. I find reciting the alphabet slowly is a good way to find the name you are looking for.

Having a wife who doesn't mind how weird my shopping is or that her drink has been put in the fridge is a great comfort.

I would like to say to other people who have problems with their memory to try not to be afraid to face your Alzheimer's disease, and try not to let it get you down. I find that a positive attitude is essential!

You could try something new. I went to [Singing for the Brain](#) and have now joined a choir. They told me at school I couldn't sing. This time I haven't asked anybody!

For the last two years I have been able to help a friend on a part-time basis to deliver parcels, which has been a huge help and good fun.

If you know somebody that you think might have [Alzheimer's](#), please persuade them to go to their [GP](#). It is most important that people have an early diagnosis so they then can move on.

I would like to finish with a quote from the book, Still Alice, by Lisa Genova: 'My yesterdays are disappearing and my tomorrows are uncertain, so what do I live for? I live for each day, I live in the moment.'





## Brightening up the day

We all need a little bit of music in our life, and this applies to [people with dementia](#) and their [carers](#) as much as anyone else. Luke Bishop visited a [Singing for the Brain](#) group in Salisbury to find out how being part of a music group can help. From its small beginnings as a pilot project between a [local Alzheimer's Society office](#) and the University of Reading, [Singing for the Brain](#) has blossomed into a nationwide, award-winning service. Its mix of group singing, physical and memory exercises and social interaction has helped to change the lives of both people with dementia and their carers. The project got underway in 2003 as the brainchild of Chreanne Montgomery-Smith, Dementia Support Worker at the Society's West Berkshire office, and Dr Nicholas Bannan, then Director of the Music Teaching in Professional Practice at the University of Reading.

The findings of their project suggested that the singing group had positive effects on [relationships](#) and allowed [people with dementia](#) to engage positively with others and build friendships within a group.

Today, Singing for the Brain is a thriving service provided by the Society in 30 locations stretching from Jersey in the Channel Islands to Hambleton in North Yorkshire. The Salisbury group is particularly popular. In October, the Salisbury Journal presented a Local Hero Community Team Award to Julia Burton, who co-ordinates the group.

More recently, the service was awarded a £50,000 grant by the People's Millions after winning a public vote. This will enable eight new groups to get started.

Julia is certain of the positive effects the project has on people with dementia. She says,

'People will tell you that it is the highlight of their week. For many people, it is the only time that people with dementia and their [carers](#) can go out together, get involved with something together and be part of a big social group.'

The group meets every Thursday morning at a church hall in Harnham, near Salisbury. Ensuring that everyone gets involved is of utmost importance. Each session begins with a welcome song and then features a series of



warm-ups involving physical activities which are linked with the songs and music. Although many of the songs performed are familiar from previous sessions, new songs are also introduced to ensure participants are being challenged by learning new things. Julia adds,

'We start off with the welcome song which welcomes everybody to the session by name. Then we go into warm-ups where we do silly actions and songs and physical routines, some of which can be quite challenging. We use repetition to help with memory. Through the new songs people learn, they are able to recall information. It shows that new information can be gained, and retained, through singing.'

Mike Marsh, 61, has [Alzheimer's disease](#) and attends the group every week. He says,

'Coming here is wonderful and I find that it makes such a difference to my week. It really lifts you up outside of yourself, otherwise you would be absolutely fed up. It just brightens up your day.'

Jeff Baillie, 66, was diagnosed with [Alzheimer's disease](#) two-and-a-half years ago and has been attending the group for the last 18 months. He says,

'It is the camaraderie that I enjoy. When I am here I'm not concerned about telling people how I feel. I often stand up in public and say that we have all got the same problem, it is not going to go away but we can make the best of it, particularly in this environment.'

[Carers](#) also benefit from the sessions. Mary Howard cares for her mother, Phyllis, who has had [posterior cortical atrophy \(PCA\)](#) for seven years which has left her blind. PCA is a rare condition caused by Alzheimer's disease. Mary brings her to the group every week.

She says,

'Mum enjoys the experience of [Singing for the Brain](#) so much that coming along regularly enhances our [relationship](#). It's so nice for people and such a happy group. It gives people with dementia a chance to take part in everyday life, because these are the kinds of activities that people without dementia do.'

'I think it helps carers because caring can be a very solitary thing. Coming here means we can mix with other carers and volunteers and it helps us to feel less isolated.'

As a testament to the group's strength, last December it recorded a version of Handel's Hallelujah Chorus which was featured on a BBC Radio 3 programme.

To find out about [Singing for the Brain groups](#) in your area, contact your [local Society office](#). The majority of the groups are based in the West region, however we hope more will develop elsewhere in the future.

## A promising therapy

[Research](#) funded by the Society shows how extra support can enable people in the early stages of [Alzheimer's disease](#) to retain and learn new skills, by Caroline Bradley.

Many people with [dementia](#) can find themselves withdrawing from [activities](#) and hobbies they once enjoyed. Problems with memory loss and cognitive abilities can also make it more difficult for people to carry out everyday tasks.

New research has shown that cognitive rehabilitation can help to overcome some of these difficulties. Professor Linda Clare has recently published findings of an Alzheimer's Society-funded study into how this therapy can help people in the early stages of [Alzheimer's disease](#). The research was based at Bangor University in North Wales.

Cognitive rehabilitation has developed from therapies offered to people who have sustained a brain injury. It supports people to maximise their potential through the restoration of memory and develop compensatory strategies.

Professor Clare says,

'The idea is to take a general problem-solving approach and build on the skills that people still have.'

As part of the study, an occupational therapist worked with [people with dementia](#) to devise a plan to address their personal goals. The therapy consists of two processes: restoration and compensation. The therapist helped people to use their remaining brain capacity better and also identified how they could compensate for what is missing by doing things differently.

### A first

The Bangor research is the first randomised controlled trial (in which participants are randomly selected to receive the new treatment, placebo treatment or none, to safeguard against any bias) to investigate whether cognitive rehabilitation can help [people with dementia](#). It involved three groups of around 20 people in the early stages of [Alzheimer's disease](#), all of whom were taking [Aricept](#).

All participants set personal goals. These ranged from resuming enjoyable activities such as reading, knitting or going on day trips to more practical things such as remembering details of jobs to be done around the house, learning to use a mobile phone or maintaining concentration when cooking.

The researchers recorded how well people thought they were able to perform these tasks and how satisfied they were with their performance at the beginning and end of the project.

One group of people received eight one-hour sessions of cognitive rehabilitation therapy each week, during which they actively worked to achieve their goals. The second group (the placebo group) received eight sessions of weekly relaxation therapy and the final group had no additional therapy.

### Improved performance

The results showed that the people in the cognitive rehabilitation group significantly improved their



goal performance and satisfaction ratings, while scores in the other two groups did not change.

[MRI brain scans](#) showed an increase in activity in certain areas of the brain for these participants. Professor Clare says,

'This is difficult to interpret exactly, but we think it shows that the brains of people in this group were able to deal with the demands of the task more efficiently.'

Those with the most improved performance had regularly practiced between therapy sessions. Having a [carer](#) involved in the therapy generally also led to better results.

## Tactics

Professor Clare believes the approach can be applied to people at most stages of [dementia](#). She says,

'This is a very personal example, but my mum has just moved to a [nursing home](#) and is not sure where she is. To help I can either write it on a memory board for her to read; the compensatory approach, or I can teach her to remember where she is; the restorative approach.

'Teaching would involve a technique called spaced retrieval, which builds on the way we all learn. You tell someone the item of information and ask them for it almost immediately, after 30 seconds, say. You then ask them again after one minute, and keep on doubling the time, so you ask again after two minutes, then four and so on until the information moves into their longer-term memory.

'For the compensatory approach to work the person needs to practice finding the information once it has been written down so it will become a habit.'

## Making things possible

Professor Clare says,

'This approach is about finding ways of making things possible. Obviously you have to be realistic. You can't take away someone's memory problems, but you can address things to help people to remain engaged, and to help retain their dignity and self-respect.

This small trial has demonstrated the principle that this type of intervention can have a positive effect. A larger trial is needed to demonstrate the benefits in more detail. Professor Clare would also like to explore how cognitive rehabilitation techniques can be made available to people with dementia and their carers as a self-help tool.

## Further information

Occupational therapists, clinical psychologists or other staff at your memory clinic might be able to offer advice or information on cognitive rehabilitation.

## Reference

Clare, L., Linden, D.E., Woods, R.T., Whitaker, et al (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer's disease: a single-blind randomized controlled trial of clinical efficacy. American Journal of Geriatric Psychiatry. October 2010 - Volume 18 - Issue 10 - pp 928-939

A full description of the cognitive rehabilitation approach can be found in: Clare, L. (2008).  
Neuropsychological rehabilitation and people with dementia.  
Hove: Psychology Press

Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9.00am-5.00pm Monday-Friday

10.00am-4.00pm Saturday-Sunday

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