

Brain Health News for Sept 2015

The next community Memory Café for Pewsey, called the Care Café, takes place on Tuesday September 8th to avoid clashes with Pewsey Carnival.

Aimed at those caring for and living with dementia, the Care Café is held in the Scout Hut, Aston Close, Pewsey, Wiltshire, SN9 5EQ at 2pm. It usually takes place the third Tuesday of each month. October 20th and Nov 17th are the next two dates

An Occupational Therapist is on hand and in this session we will be taking a look at the assistive resources donated by Designability and EL2 such as the Blys nightlight, a one button music player and a wander reminder.

Contact Susie Brew – PCAP coordinator -pcap@hotmail.co.uk tel 07802 444022.

Join in with Road Art this Carnival

Remember this from last year?



Back by popular demand (weather permitting as it cannot take place



Write to PCAP c/o Giddings Cottage, Huish, Marlborough. SN8 4JN.

with rain) Local artist [Sue Faux](#) of Faux Arts will be back and we will be painting the Road across the bridge again for this year's Carnival on September 10th from 6pm. This is a community event supported by Pewsey Community Area Partnership the [Pewsey Local Youth Network](#) and [Pewsey Carnival](#) that is free and open to anyone to participate. So why not join in or just come down to watch it take shape. See you there.

Pewsey Arts Group

The art group, supported by Alzheimer's Support, is for people living with dementia and family carers in the Pewsey area and meets at the Bouverie Hall every Wednesday morning from 10am to 12 (term time). Carers welcome to stay or have time out

This is a relaxed and informal group where individuals may take part in various fun and engaging art projects. There may be a small charge for materials. For more information or to book a place, contact Jackie Allen on: **07776 455018**.

Email jackiesallen3@gmail.com

Memory Group at Pewsey Library

Come along and relax whilst listening to stories and poems in a small friendly shared reading group. The sessions are free of charge, and refreshments are provided. The groups offer an enjoyable, relaxing opportunity to meet others and stimulate positive memories.

Venue - Pewsey Library

Date - every Thursday from 28 May, 2015 until 24 September, 2015 excluding bank holidays

Time- 2.00pm to 3.30pm

Telephone- 01672 562265

[Singing for the Brain](#)

The groups run by Alzheimer's Support, are friendly and inclusive. Being good at singing is not necessary, and we have plenty of laughter along the way. For general information about Singing for the Brain®, contact Stephany on 01225 776481 or go to www.alzheimers.org.uk/singingforthebrain

Lockeridge, near Marlborough
Thursday mornings at Kennet Valley Hall, Lockeridge, SN8 4EL.
Call Jackie on 07777 655018C



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East Wilts Alzheimer's Café

The East Wilts café meets at Coronation Hall, East Grafton, about five miles south of Marlborough on the A338. They meet from 2pm to 3.30pm on the first Monday of each month (or the following week if a bank holiday)

A typical afternoon will include a talk or discussion on an aspect of living with dementia, followed by afternoon tea.

Sept -Pewsey Vale Belles Choir

Oct -Alex the puppeteer about Punch & Judy

Nov -Paula Holford doing movement

Dec -Christmas songs with Chris stone

Please let us know if you would like to come along to help us plan for catering.

Contact Gaynor Mapp on 01380 739055

New Website [Your Care Your support](#) for Wiltshire.

This website contains information for adults; information for people with disabilities; information to help keep healthy and well; information on

social care; and information for people who care for someone in Wiltshire. It also has a section on dementia.

[John's Campaign – listing hospitals that welcome carers](#)

The list is growing. Now more hospitals need to encourage carers to stay with their loved ones.



Campaigners Nicci Gerrard and Julia Jones with Jo James, lead nurse for dementia medicine, and Josephine Tapit, ward manager, at St Mary's Hospital, Paddington, London. Photograph: Richard Saker for the Observer

[John's Campaign](#) was launched in the *Observer* in November 2014 after [the death of Dr John Gerrard](#). The aim of the campaign is to give the carers of those living with dementia the right to stay with them in hospital, in the same way that parents stay with their sick children – a campaign also supported by *The Observer* 50 years ago.

There is already good practice within individual hospitals and we celebrate this. Nevertheless, access to a vulnerable patient should not depend on geographical location

or individual decisions. The list will remain open until November 2016 and the campaign challenges all acute hospital trusts to make the small but significant commitment to ensure that they are included.

Source *The Guardian* July 25th.

[There's no need to fear dementia. The end of the epidemic is in sight](#)

The risk of getting dementia is actually decreasing and the prospect of living to a fulfilled old age is better than ever before.

Only few want to grow old, as most of us are afraid of becoming senile. But now that our bodies last longer in better health, our brain being no exception, the prospect of living a fulfilled old age is better than ever before.

It is not difficult to think of somebody really old who is still as sharp as a razor blade. That sole fact is scientific logic against the notion that old age turns you confused. Old age and dementia are two separate entities that, although often coming together, are as different as old age and grey hair. Why then do so many people believe that the two are closely attached?



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Colleagues in Denmark and independently in Sweden provided remarkable confirmation of this general improvement of body and mind. They showed irrefutably that the physical and mental functions of people now in their 90s are simply better than those of nonagenarians born 10 years earlier. They believe this is due, in part at least, to the fact that today's old people generally enjoyed a much better education early in life. Their brains were better nurtured. It does not come as a surprise that a large scale population survey in the United Kingdom has prompted researchers to report a 30% drop in the risk of getting dementia over the past 20 years. The end to the epidemic is in sight.

Source *The Guardian* July 31st.

[Government boosted in drive to cure dementia after 60% rise in volunteers](#)

Number of research participants soared to 22,000 during last year as Downing Street aims to find a cure or disease modifying therapy by 2025.

The government's ambition to find a cure for dementia by 2025 has been boosted by a big rise in people

volunteering to take part in ground-breaking research studies.

During the last year, almost 22,000 people have taken part in research studies to tackle the condition – a 60% rise – according to figures from the National Institute for [Health](#) Research.

The increased participation in 100 dementia research projects across the UK will boost scientists in their bid to find new treatments to prevent, treat and eventually cure the illness.

Research projects include testing whether antibiotics slow cognitive decline, investigating the role of the immune system in dementia, identifying genetic risk factors and improving end of life care for people with dementia.

George Freeman, minister for life sciences, said: "Dementia is a devastating condition that can have a significant impact on the lives of those affected and their families."

Dr Doug Brown, director of research and development at Alzheimer's Society, said: "We are delighted that more people affected by dementia are being given the opportunity to take part in vital research.



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www.pewseycap.org.uk www.facebook.com/pewseycap <https://www.facebook.com/PewseyValeDAG>

"Not only is it essential for us to make progress towards new treatments and better care, but it could also empower people to learn more about their condition and benefit from additional support."

[Dementia](#) affects 850,000 people in the UK and this figure is expected to rise to more than 2 million by 2051.

The boost in participation was in part triggered by the prime minister's challenge on dementia, launched in March 2012. David Cameron called on the public, charity and private sector to do more to improve diagnosis, care and research into the disease.

Following the success of this initiative, Cameron launched the Dementia2020 Challenge, which aims to make England the "best place in the world to undertake research into dementia and other neurodegenerative diseases".

The fight against dementia has also been helped by the \$100m Dementia Discovery Fund, announced in March by health secretary Jeremy Hunt. The fund, which brings together investment from the government and a number of charity and private sector partners, is an innovative way of

financing research into new dementia drugs and treatments.

In 2013/14, 13,583 people took part in dementia research. This increased to 21,791 in 2014/15.

Source *The Guardian* Aug 15th.

[Mum has early Alzheimer's and needs 24-hour care. Where's the help we were promised?](#) Chris King

A report suggested that [dementia](#) might not be the epidemic we had been led to believe, showing that there were [22% fewer people aged over 65](#) with dementia in 2011 than had been predicted in 1990. But even one case of this devastating illness is one too many. My mum was diagnosed with [early onset Alzheimer's disease](#), which affects about [14,000 people aged under 65](#) in the UK, three years ago. At the time, my dad said she "would not be what she was", and he wasn't wrong.

It is a uniquely cruel disease that [dismantles personalities](#) and strips away the ability to perform basic tasks, such as washing and getting dressed, while triggering deeply upsetting behaviours.

My mum did nothing to bring on her Alzheimer's, but there is no way to



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prevent it. That is what makes dementia so terrifying: it can happen to any of us. When my mum was diagnosed, we were unprepared. We should have been told what to expect and when to expect it. My mum was given [sage dietary advice](#), and told to do crosswords and take exercise, but not helped to plan for what would happen when the disease took hold.

Her deterioration was so rapid that it completely overwhelmed us. Doctors, when you can access them, only provide more tablets, one of which made my mum extremely aggressive. Everything we have done since has been reactive, such as obtaining power of attorney: an unnecessarily complicated and costly means of managing her finances in order to care for her properly. Individuals with dementia and their families are essentially cast adrift, and the only sources of useful information are underfunded, over-stretched charities.

Many of these, such as the [Alzheimer's Society](#), have done amazing work [to educate](#) the public about dementia, but where they succeed, institutions fail. There are [850,000 people](#) in the UK with

dementia, but the support available ranges from the comic to the tragic. David Cameron has promised [£300m for dementia research](#), but since he took office, the care and assistance provided at a local level has been swept away by councils needing to cut costs. People with more than £23,500 in assets or savings have to [pay for their own care](#), which can cost as much as £50,000 a year for a residential home. By postponing the [£72,000 cap](#) on lifetime care costs it promised, the Conservative party has condemned thousands of people to continue losing savings built up over a lifetime, and some to have to sell their homes to fund care.

This means the fairest and most sensible option is caring for loved ones at home. Despite my mum's deterioration, we are determined to do this, but it places enormous demands on us all. My dad just about manages to work part-time while my sister and I try to fill in the gaps. With the help of carers costing upwards of £15 an hour, we provide 24-hour care. Given her propensity to seizures and confusion, coupled with a tendency to wander off, this patchwork system is essential for my mum's safety.



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Figures show that [one in four hospital beds](#) is occupied by someone with dementia. By putting councils in a position where they cannot provide genuine respite care or day care services, the government is driving thousands of people with Alzheimer's into hospitals. Having spent several nights in hospital with my mum, because there was nowhere else to go, I know how distressing it was for her. She was tested for every possible illness over eight hours, only to be told she was physically fine. Even specialists do not always understand the condition.

Respite care is expensive, extremely difficult to arrange and, even if you find a place, the standard of care your loved one receives varies wildly. Some of the respite homes we were allocated had been rated inadequate by the Care Quality Commission, but desperate people have no choice. And respite is just a short break from what feels like a never-ending nightmare. I spend many of my non-working hours looking after my mum, and it is a lonely and isolating existence. I feel alienated and detached from other 25-year-olds. My tiredness comes not from too many nights out, but being awoken at 4.30am by someone with no awareness of

what time it is. Not only am I grieving for a parent far earlier than anyone should, but I am trapped in a world that few people my age can comprehend.

My mum did everything right in her life. Now she is being catastrophically let down by those who should be helping her. While the care and support available remains so inadequate, Alzheimer's disease will continue to inflict unnecessary suffering both on those living with the disease, and their families. If and when we can no longer look after my mum, I want her to be cared for by attentive, experienced staff members who have the time to do their job properly and are paid fairly. Too many care homes are poorly staffed, overburdened and lack a sense of dignity. This country owes my mum and the thousands like her so much more.

Source The Guardian Aug 25th

This is a collation of news posted on the [Pewsey Vale Dementia Awareness Groups](#) Facebook Page.

Comments on this newsletter can be made to the address below, or emailed to pcap@hotmail.co.uk



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