

**A SUMMARY OF THE  
PATIENT EVENT HELD ON SATURDAY 9<sup>TH</sup> APRIL 2016**

**Gina Awad**

**Dementia Friends Champion and Lead of the Exeter Dementia Action Alliance**

About 18 months ago Gina set about finding out what was happening in Exeter and where people should go for support. Although the Dementia Action Alliance was already in existence, there was no local network working towards developing a dementia friendly community. So Gina went about setting one up.

Gina explained her passion and mission to empower dementia sufferers and inspire businesses to join the Alliance.

A minimum three point action plan is required for organisations to join the Alliance.

Five local Practices have already signed up.

43 local organisations have also signed up so far. These include the RD&E Hospital, Waitrose, Barclays Bank, Devon & Cornwall Police, West Exe School and the University.

There are now 217 Alliances across the UK. Their overall aim is to foster more patience and compassion, enabling people to approach dementia sufferers appropriately through training and awareness.

Exeter City Council is slowly coming on board. They had a lack of awareness initially but Gina is meeting with them again soon.

Plymouth City Council is already on board and have created some dementia friendly parking spaces, displaying the forget-me-not emblem. There are also possible changes to the blue badge scheme being discussed.

**Dementia Friends** is a government funded (via public health) initiative and the aim was to have 1 million friends by March 2015. This was achieved.

Those wishing to become dementia friends can either attend a meeting or watch a 5 minute video.

The staff at St Leonards, Barnfield Hill and Southernhay Practices have all taken part in a dementia friends training session.

Dementia is the biggest challenge for health and social care with 850,000 sufferers in the UK. It is predicted to rise to over 1 million by 2025.

Diagnosis can be scary, as there are many perceptions of what it is. There are also over 100 different types of dementia, all of which manifest in different ways and behaviours.

Alzheimer's is the most common form of dementia (up 60% of sufferers) with memory loss being the most common problem.

It can be very challenging for family members providing support and it is important they look after themselves too.

Ideally we're all working towards reducing the stigma of dementia and by sharing difficulties encountered, we can lessen these.

Attendees shared their experiences:

- Husband wouldn't accept his diagnosis but the wife found the support from the Alzheimers support worker very beneficial. The support worker was happy to meet up regularly and gave lots of information and helpful tips.
- Mother had alzheimers and the attendee lived with her to provide support until she went into residential care. It was a very stressful experience and the attendee struggled with anger and anxiety, dealing with the repetition was very tiring.

Gina used to visit care homes with her grandmother, assisting with creative arts projects and it always seemed to her that there were people on the periphery who, to a child, seemed scary. They also seemed to be excluded.

One attendee expressed that in her experience, creative arts can enable dementia sufferers to be very expressive. Their inhibitions are not there, so they are able to open up and be creative.

Some difficulties encountered by those present:

- How to access money if the person forgets their PIN number? Some Banks are already working on this, using technology to assist e.g. fingerprint recognition.
- Shop-lifting can be a common problem. How can the Police avoid an unnecessary criminal process? Gina is working with Devon & Cornwall Police on this. One idea is for them to hold/have access to a list of those diagnosed with dementia (they have this in Tavistock). Plans are being drawn up which will be shared across Devon and Cornwall.
- If a person goes missing, who do we ring? Gina recommended calling 999 for police assistance. The same goes if you find someone who is clearly lost.
- One attendee expressed concern about the link between alcohol abuse and dementia (Korsakoff syndrome). The Alzheimer's Society is a good resource for help and information.

### **Memory loss – when to seek advice?**

The question was posed by an attendee. There's no clear answer to this, as everyone's experience is different, but key questions are:

- Is it really memory loss or just brain overload?
- Is there a pattern to it?
- Is it impacting your life?
- Are friends/family concerned?

Dr Bethune confirmed that if patients present complaining of memory loss the GP would usually run a few blood tests and complete a standard memory test. If appropriate, the patient would be referred to the memory clinic for a more thorough review.

Gina has visited the memory clinic, which she feels provides a very good holistic review of the patient. As well as conducting tests they will talk to family/friends and compare how the patient is now with how they've been in the past.

The problem could be mild cognitive impairment rather than dementia.

Gina is hoping to submit details of forthcoming events to the Express and Echo and then follow up with how those events went.

Anna-Marie Waite was present for the event. She is an activities co-ordinator and singer/song-writer. She has written a song for the Alliance called "In the Moment". 20% of all sales are going to the Alliance. She also organises and takes part in sing-alongs. You can listen to her song on <https://soundcloud.com/anna-marie-waite> or purchase it from iTunes.

#### **FURTHER INFORMATION:**

##### **Websites:**

Exeter Dementia Action Alliance [www.exeterdementia.org.uk](http://www.exeterdementia.org.uk)

Alzheimer's Society [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Age UK Exeter [www.ageuk.org.uk/exeter](http://www.ageuk.org.uk/exeter)

#### **Dementia Awareness Week – 16<sup>th</sup>-20<sup>th</sup> May 2016**

##### **Dementia Friends Events:**

17<sup>th</sup> May at Exeter Central Library

18<sup>th</sup> May at The Globe, Topsham 5.30pm

(booking required [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk))

##### **Dementia Friendly Events:**

Screenings at the Exeter Picturehouse

19<sup>th</sup> May – Calamity Jane Singalong 11.00am

19<sup>th</sup> May – Still Alice 6.30pm

RAM Museum – dementia friendly events throughout the summer  
(Details available [www.rammuseum.org.uk](http://www.rammuseum.org.uk))

## **Penny Scoynes – Westbank Wellbeing Referral Service Co-ordinator**

Westbank is a voluntary sector, charitable organisation. It celebrates it's 30 year anniversary this year!

Westbank was set up initially to provide befriending and transport services but now supports many other services and projects. It now has a day centre which provides meals and bathing facilities. They also have a gym and fitness facility and Devon Carers are also based in their premises.

Penny gave details of the one year pilot referral service currently being run at the three St Leonard's Practices. It is due to end in July 2016.

The wellbeing referral service is for those over 18 years who are experiencing non-medical challenges which are impacting on their health. Weekly clinics are held at each practice and referral is via a healthcare professional.

Following referral, the patient will be seen for an initial assessment appointment which can last up to 45 minutes.

Penny talks through the current situation with the patient, discussing challenges and issues and looking at the whole picture. Sometimes this is sufficient for the patient. If appropriate, after the appointment, Penny will research what is available to assist the patient.

If a second appointment is held, Penny will go through all of the different resources and options available and how to access them. Support or a referral may be required.

A telephone follow-up is conducted to see if the information has been acted upon and if it's been helpful.

Penny will continue to follow-up the patient by telephone for as long as is required, depending upon their needs.

Patients are very happy to attend their usual practice, which is familiar to them. The pilot has had the added outcome of fostering better relations between the practices and Westbank.

There are four main categories for referral:

- Physical – weight, diet/nutrition, exercise
- Psychological – feeling down or depressed, looking for support or social interaction
- Practical – this can range from financial concerns causing stress/anxiety to someone needing assistance with gardening
- Social – isolation and struggling to access services

The aim is to enable people to help themselves.

There are a lot of organisations, services and activities out there and it is very difficult for any one person to retain all of the information.

So far:

- 60+ referrals from the three pilot practices
- Only 3-4 of those referred decided not to use the service or did not attend – this shows appropriate identification of those referred.

The pilot will be evaluated, but so far all indications are very positive.

The funding has come from the ICE Board (Integrated Care for Exeter) and there is the possibility that it will be rolled out across all Practices.

**Cathy McGarvey** – developing a database of clubs and societies

Cathy has been working with Dr Niall Macleod (Heavitree Practice) in relation to developing sustainable healthcare. One of her tasks has been to develop a database of clubs and societies in the St Leonard's area.

She has discovered that there is a lot going on! However the information that she has gathered needs to be checked and kept up to date.

Volunteers are required to enable this information to be shared with the local community, healthcare professionals, organisations such as Westbank and there is the potential for this to be expanded for every locality within Exeter.

Anyone wishing to be involved in this work should contact Cathy direct:

Email: [catbrillmac@hotmail.com](mailto:catbrillmac@hotmail.com)

Tel: 07779-028-798