



Newsletter – 21<sup>st</sup> March 2013

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Hi Everyone,

I had hoped that having had a few lovely days that Spring was well and truly on its way. Sadly, as I write this newsletter the cold and damp has returned. Never mind, I am reliably informed that good weather is on the way – just not how much and when! However, it is a good time to be looking forward to outings and garden parties and to putting the dark days behind us. If there is a theme to this newsletter, it must be “Awareness and Understanding”. A great deal has been done to remove the general lack of knowledge about dementia, and the stigma and misunderstandings that are associated with it. However, we still have a long way to go.

**1. Change has Happened and GP Commissioning takes Charge:** It was back in 2009 that the National Dementia “Living Well with Dementia” strategy was first published and, since then, it has guided activity in the NHS, the local authorities, the charities, and other care providers. In addition, there have been major changes in how the NHS and the local authorities are managed. However, at the community level it is difficult to see what difference has been made in the care and support that is available “on the ground”. Unfortunately, new approaches always take a lot longer to bring into existence than we think – large organisations have an enormous inertia and can’t respond as we can in The Debenham Project! **But it is happening.** The services provided by Adult Care (Social services) have been restructured to be much more responsive to the needs of those trying to cope with dementia. The **Suffolk Dementia Helpline**, the **Dementia Advisor Service**, and a more local management focus through the creation of the “**Dementia Clusters**” have all been initiated. We have also seen that the **Dementia Intensive Support Team** has been instrumental in helping families in crisis and avoiding breakdown and hospitalisation. These are very positive steps but, of course, there is still a great deal to do to create the sort of environment, support, and services that will mean that those with dementia (and those who care for them) are given the same care, empathy, resources, understanding, etc. that are accepted as essential for those diagnosed with cancer.

In April the most important change in the NHS initiated by the Government comes into practice – GP commissioning – the principle is that health care should be guided, managed, and prioritised to meet the individual needs of its customers, and that the professionals best placed to make those judgments are GPs. Recently I was invited to a special “consultation” meeting to advise the Ipswich and East Suffolk Care Commissioning Group (CCG)\*. I have to be honest and say that I usually try to avoid these occasions, but this proved to be a very positive and productive exercise. The CCG is showing its determination to rapidly re-commission dementia services to make them much more effective and responsive to the needs of those who are worried about seeking a diagnosis and are seeking to make “taking the first step” easier. A key element, we believe, will lie in establishing a number of “local” GP led specialist memory and dementia diagnostic clinics.

\* The new title of the **GP** Care Commissioning Group (they are the people who will be responsible for all of the NHS funding in our area – pretty important for the future care of the elderly frail residents of our community!)

**2. Debenham Police join the Team:** You will know that over the last few months Sam Cage has been working hard to set up Debenham On-Call, our volunteer carers group who can be called on for support in a crisis, when a family carer must attend an important appointment, or when they just need a bit of space to themselves. In January we were delighted to be approached by one of our local policemen, Chris Bales, to find out how we might help when they have to attend an incident, be it a road traffic accident, a burglary, a fire, or a medical emergency, where someone with dementia may be affected. It seems that this is quite a common occurrence and if the officer involved could have someone on hand to give advice, or just to care for the person while the situation is sorted out it, it would be a great benefit. After a couple of brief chats with Chris – “as you do” – The Debenham Project has recruited Chris to be our liaison with all the emergency services. He is making sure that that the Police, the Fire Brigade, and the Ambulance Service, know that if we can help in an emergency, we will be on hand.

**3. Understanding Dementia!** I mentioned in my last letter that the Alzheimer’s Society is leading a campaign to help communities, organisations, and individuals become “dementia friendly”. The aim being that no one who is coping with dementia, be they the person with the illness or the person who is caring for them, should feel excluded and isolated, and not knowing to whom or where to turn for support or a shoulder to lean on. The aim is to encourage a network of dementia friendly communities across the UK and to recruit a million “dementia friends”. How can this happen? The idea is that people will offer to become trained “champions” and then they will share their experience and understanding with local groups of “friends”. One or two of those “friends” may also train as “champions” and so it goes on. At the same time whole communities and organisations will be supported, through on-line packages and support, to explore how they can take part. It has already started - over 12,000 people have expressed a desire to become a “friend”, over 4,000 have already registered as “friends”, together with nearly 2,000 “champions” who are in the process of being trained. We hope that what will follow will be a desire to translate their awareness into providing voluntary services, similar to those in The Debenham Project, across the UK i.e. to “get on and do something”.

But what of us in Debenham? Well, it’s been a very busy couple of months for Sam Cage. Alongside all she does as the project’s Carer Liaison and her management of both Debenham On-Call and The Carers Coop, she has put on a couple of evening training courses in dementia awareness and support, led by a great friend of the project, Louise Diss, and

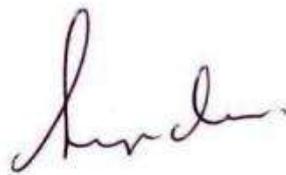
supported by our local dementia advisor Sara Mellor. Many thanks to both of them for giving up so much of their own time to help the project. The first course, over 4 sessions, was for our team of volunteer carers to help them in their Debenham On-Call role. The second, over 2 sessions, was aimed at raising understanding and awareness in local businesses, organisation and individuals – very much the objective of the national campaign. We were all delighted with an attendance of 33 which included representatives from the High School, the Police, Rotary, Coopersfield Sheltered Housing, the Women’s Institute, Castle Vets, the Parish council, etc, etc. This is exactly what we hoped for.

**4. Research Project Passes 1st Milestone!** One of the keystones of the project is that, being local, we seek to provide the services, activities and support that are best for family carers, and those they care for, in our particular community. We also want to encourage carers to seek support earlier in their journey. To do this we began a major research project last year which is seeking to gather the experiences and perceptions of local family carers about their journeys. We believe that by doing this it will lead to a much better and more accurate understanding of the barriers and difficulties that people face when they become concerned that they or their partner may be developing symptoms of dementia. We believe that it will help us to develop the right support for those in our community. We believe that it will help us with the way we try to increase local awareness. We also believe that it will be valuable evidence for health and social care professionals in developing community-focused support services.

In January our researchers, Tim Mason and Gordon Slack, successfully completed the first phase which was to develop and trial a method which combines a user-friendly questionnaire with a conversational-style interview. The results and feedback have been excellent. Phase two is now well under way and gathering the bulk of the data. We hope to involve almost every family carer we know of, a significant number of our volunteers who have had direct experience of coping with dementia, and some others who, although not having direct experience, may offer further insight.

If you would like to know more about our work and services please see our display in the Post Office, ring 01728862003, call in at the Library Resource Centre, or visit our website at <http://www.the-debenham-project.org.uk/>. Past newsletters are archived on the website.

With my very best wishes

A handwritten signature in black ink, appearing to read 'Lynden Jackson', written in a cursive style.

Lynden Jackson (Chairman)