



Dedicated to giving practical and emotional support to all in the Debenham area who care for those with Dementia.

5 October 2009

The Debenham Project - An Overview

DEMENTIA is the overall name that is used for the group of illnesses of which Alzheimer's and Vascular Dementia are the main two. It is, primarily, an illness of old age and, as we all grow older, it will come to affect more and more of us. Dementia progressively attacks our mental capacity. It seriously damages the structure of the brain leading to memory loss, disorientation, loss of visual awareness, mood and behaviour changes, loss of mental ability, etc. There is no cure and, currently, only limited treatment.

For those with Dementia the illness is generally frightening and deeply frustrating but, often, they are unaware of their symptoms or their behaviour. For the carer it is extremely difficult, exhausting, very stressful, isolating and, as the disease progresses, heartbreaking. Family and friends care for most sufferers for years until, eventually, they can no longer cope. Then, residential nursing care is essential.

There are probably between 70 and 100 people with Dementia in Debenham and its surrounding villages.

Debenham is a large rural village in Suffolk with a balanced mixture of medieval and modern houses and buildings. It is situated about 12 miles from the BT Research laboratories (Austral Park) and many people who have been, or are still, working there are residents here and in the surrounding smaller villages. It is a natural centre of population, with a number of shops, a small supermarket, a post office, a pharmacy, a GP practice, a couple of pubs, a primary school, a high school and a community centre. Its population is close to 2,500 and the total population within a radius of 3 miles is about 4,500. The nearest larger towns are more than 7 miles distant and the county town of Ipswich is 14 miles away. It is typical of many rural communities across East Anglia and the UK in general. It is important to distinguish such communities from the semi-rural towns and urban communities which are, so to speak, located further towards the more metropolitan centres of population. There are demographic and geographic differences that make the fair provision of health and social care services more difficult but, on the other hand, there are sociological features which are positively beneficial eg a strong community spirit, a "good knowledge of, and friendship with, our neighbours", and a general willingness to give time to the support of "good causes" (especially when linked to "having a good time!").

The unique nature of this project is that the Local Community has taken the initiative in seeking to tackle what is a very serious and growing problem; one for which the major health care and support sectors (the NHS, the Local Authorities and the Charities) may be developing strategies, but are experiencing difficulties as to how to achieve their objectives and deliver services to those who need support. The closest,

thus far, lies in the proposed experiments to provide Dementia Advisors. Our project, we believe, could provide a model that could be "rolled out" to other similar communities and rapidly begin to create a new understanding of Dementia and a new level of support to those with the illness and those who care for them. It is attracting considerable local interest and support at senior levels within all of the aforesaid sectors. We intend to present it to the public and to the media at a launch at the beginning of October - just 5 months since our first determination "to do something".

The guiding principles of the project are:

To provide the practical and emotional support that will really benefit carers

To provide easy access to straightforward information, and to guide carers towards professional advice and help

To maintain those with Dementia within their homes as long as is possible, and always within their own community

To ensure best practice and best quality in the provision of services and support

The project is centred on the community-led approach and on the importance of a strong local voluntary involvement but, crucially, to draw in and cooperate with all the professional agencies in the provision of services. The Debenham Project is working with Age Concern, Alzheimer's Society, CAMEO, Debenham GP Surgery, Debenham Pharmacy, Debenham Post Office, St. Mary's Church, Sanctuary Housing Association, Suffolk County Council, Suffolk Family Carers, Suffolk Libraries and Suffolk Mental Health Trust.

One of our key services offers emotional support through a confidential support line - a listening and understanding ear- for carers when the stress of their role needs to be shared with someone who "has been there", "who knows how it feels", "who can understand the guilt, anger and frustration that is a part of caring for someone you love who has Dementia".

Our other early services are:

A regular series of sessions aimed at encouraging both social and intellectual activity, and giving carers opportunities to meet and interact with other carers. They are designed to cater for a wide range of interests, and physical and mental capabilities and to assist in reducing isolation from the community as a whole.

A luncheon club inclusive of all the elderly and their carers but with a clear remit to support the carers of those with Dementia, and an emphasis on maintaining social contact in the community. Catering for, generally, between four and eight persons it is an opportunity to develop and enjoy friendships in a 'family' environment.

Prominent and easy access to quality information and support including displays of up-to-date information leaflets, booklets and available activities/services. Access through our website to extensive and accredited information, and a personal service to guide carers in their requests for information and in making contact with support agencies.

Medicine management. Many who have Dementia also have other ailments eg Diabetes, Chronic Heart Disease, etc which need daily medication. The number of pills that have to be accurately sorted can be large and confusing. The Pharmacy offers a personal service providing help to carers in ensuring that those they care for reliably take their medicine. Advice can be given regarding dosset boxes including special boxes which alert the person to the need to take their medication. In addition, the pharmacist can help in the doctor's role of monitoring and reviewing their

prescriptions, liaising with the GP surgery, and “signposting” to other professional support.

These are simple and practical services that we can implement in the short term. As we grow with time we will be seeking to extend and expand them, and add to them with, for example, Carers Clinics, A Story Board, A Carers Club, etc. Always with the theme of “let’s get on and do something”.

This is a unique and innovative project - a Community defining its needs and providing those needs through voluntary support, where possible, and drawing in the care that can be provided by the NHS, the Social services and charitable agencies, under an overall umbrella. This means that no carer or client needs to step outside their local community to access quality services, help, support and advice.

Providing support for carers NOW is our first priority but there is also a long term dimension. We believe that no one should have to travel 7, 10, or 14 miles to access services - and no one should have to leave their community when it is no longer possible for them to be cared for in their own home. In the longer term we are seeking to provide an integrated approach to day, residential, secure and nursing care. So that, not only, can the traumas of having to leave their home be minimised, but they can remain within a familiar environment in all their circumstances.

We are confident that this is a project with all the potential for creating a step change in the way we approach the care of those with Dementia, and particularly the way we support those who care for them. A project in which we can mobilise the inherent desire of communities to care - Caring in the Community, Caring by the Community, and Caring for the Community. Whilst this project is, and must be, firmly rooted in our local community, its ethos is one which will resonate across most of the rural counties of the UK (and beyond).

Lynden Jackson Chairman of The Debenham Project