



Newsletter – May 1st 2012

Hello everyone,

In my last newsletter I talked about the importance of top quality paid personal care and the need for short-time emergency and respite cover. Encouraged by the scheme at Wickham Market we are initially setting up a “**Register of Local Professional Carers and other Domiciliary Help Services**” so that when needed we can point families, etc. to a number of known local people who can provide the support they are looking for. Following on from this we are exploring how, in collaboration with a professional organization, we may be able to develop a new model for the provision of such care in and around the Debenham area. One thing which does seem to emerge is the theme of “local carers for local people”. Whilst caring for those with dementia and helping their family and friends will always be a major aspect of these initiatives, both initiatives are intended to be for all who need support irrespective of the nature of their frailty.

Over the last couple of years the project has become well known throughout Suffolk, and we have tried to make a few contacts at national level who might promote our views and ideas about ensuring no one, no matter how frail they become, should have to leave their own community to receive the care they need. I admit it feels like a massive challenge when all the trends are towards centralisation of health, residential and nursing care into large units located in and around the major towns. It seems there is no longer any place for the smaller facilities which are appropriate to rural communities such as ours. And yet we know that when it comes to quality of care and quality of life there is no substitute for being cared for within your own community by your family, neighbours, and the professionals you know.

So you can imagine my delight when, completely “out of the blue”, we received an e-mail on behalf of **The Joseph Rowntree Foundation** - one of the major national players, alongside The Wellcome Trust, in seeking better health and social care, and in funding innovative approaches - asking if **The Debenham Project** might be used as a case study for how communities can take the lead in supporting the elderly frail, and especially those with dementia. We knew that the project was unique in Suffolk but it seems that there are no similar projects across the UK! The Foundation wants to study the “Debenham” approach as a model that other UK rural communities might adopt/adapt. It is not only an opportunity to gain some “street cred” with the academics and professionals, but also to “advertise” our approach at a National level. The recommendations of The Rowntree Foundation can directly influence government health and social care policy. Our trustees have agreed that we should

make the most of this opportunity and we will host a 2 day visit later on this month.

When do “a few odd symptoms” turn into a “niggling concern”, when does that “concern” become “serious”, and when does it become sufficiently “serious” to take to the doctor? With any potentially serious illness these are not easy questions to answer. However, when it comes to dementia they are doubly difficult. It is not just a matter of awareness of the illness and overcoming the fear that it engenders, but it is also tied up with deep seated social stigmas, overwhelming psychological issues, potential loss of driving license, financial and legal control, etc. For someone and/or their partner to seek a diagnosis has massive implications. From a professional (health and social care) viewpoint it is believed that the earlier the carer/patient engages with support and seeks a diagnosis (or preferably reassurance that it is “just getting old) the more chance there is of avoiding a major crisis and of enhancing future quality of life. From a personal viewpoint as a patient or family carer it is not that simple.

As a project which is focused on the individual family carer and those they care for, we feel that it is important to understand their experiences and how they feel about the whole issue of seeking earlier support and earlier diagnosis (and if it might be a practical possibility). It is something of a recognition of the nature and importance of The Debenham Project that The Norfolk and Suffolk Mental Health Trust has asked us to carry out a programme of research with the aim of exploring how to “Help carers and cared-for to ask for help before the crisis”. The Debenham Project is particularly well placed to do this as we have a strong relationship with a community of family carers, volunteers and professionals all of whom have direct and personal experience of the practical and psychological problems associated with dementia. It is a year-long project which will seek to capture their experiences, views and opinions and to identify the things which either encourage or discourage families from seeking support, and to develop improved local awareness, and services based upon the findings.

Moving on, one of the recent successes is **Fit Club** - a group of us slightly older people who could benefit from some ‘gentler’ chair based exercise to improve our posture, flexibility, mobility, balance, coordination, etc. It has proved to be great fun and very beneficial. It has proved so popular that we have a full membership – if there is enough positive commitment from potential participants we will consider starting another group.

Finally, once again, I would like to thank all those individuals and local organisations who have made generous donations to support the work of the project.

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,
Lynden