



Newsletter – December 2013

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Hello everyone

1. The Christmas Season is Here! Christmas is almost upon us and we are all looking forward to those delightful bits and pieces – the mince pies and sausage rolls, the wine and chocolates, the party hats and crackers - that will make our activities, lunches and clubs just that extra bit special for our family carers, those they care for, and all who join in. For most of us that are - how shall I put it? – “a bit further from our middle years than we like to think we are”, it is very much a time for enjoying being with our families and “sharing our memories” of when we were their age. When we were younger the songs were “just a little” different and seemed to be so special that, even now, we have no difficulty in bursting into song just as soon as we hear the “opening chorus”. Steve McKie has very kindly offered to become our very own “Music Man” and, hopefully with one or two others lead us occasionally in “Songs for Sharing”. Our first session will be at our Christmas Carers Club this month, and then we will see where we go after that. Incidentally, Steve has compiled a brilliant set of “Songs for Sharing” songbooks with a music copy – If anyone else wants to use them they will be very welcome.

2. Major Research Study Reports! We believe that it is very important that we "feel" and "understand" the lives of family carers, and those they care for, in order that we can, not only decide what services and activities to offer, but also to help the NHS and the Social Services provide the best support. In July last year with funding from The Norfolk and Suffolk Dementia Alliance we embarked on a research project to comprehensively survey the circumstances, experiences, and perceptions of those who are coping with dementia in our community. We were especially interested in exploring what encourages/discourages families in seeking early support and

diagnosis. Tim Mason and Gordon Slack contacted and talked to, it seems, almost everyone connected with the Debenham Project. Their report has just been published and clearly identifies a number of important issues – I have picked out just a few examples:

Many carers have physical health issues that can impede looking after the cared-for. One in three carers report financial difficulties.

Carers felt not supported but isolated, perplexed & ignorant. Some fell back on their own resources (initiative, family etc) or had to wait for a crisis. Carers reported too many agencies to deal with – one gateway is needed, to ensure people have the knowledge and tools to identify what they need at the right time.

The diagnosis is seen as the primary gateway to services but people with memory loss/dementia can have needs before the point of diagnosis. This raises questions about the formal diagnosis-led approach.

There is significant disquiet among carers about professional service provision – knowledge, availability, appropriateness/person-centredness & quality. Peer support, greater knowledge, and training were the key benefits foreseen of early support intervention.

1 in 5 cases reported the dementia situation is directly exacerbated by a perceived shortcoming of the statutory health and/or care/support agencies. To obtain results and action (for appropriate support) takes energy, assertiveness and tenacity. However, carers were frequently exhausted, depressed or demotivated.

In terms of the Debenham Project's helpfulness, the sample group reported a wide range of ways the Project had helped them to cope. In essence these were through the meeting of needs through services not available elsewhere. However, in practice it is difficult to envisage such a community-based organisation reaching or supporting more than about 75% to 85% of this target population.

As far as we can tell, this is the first time that any community in the UK has carried out such an analysis and it is already attracting the interest of those responsible for designing Suffolk's future dementia services. What makes this research important is that by developing a person-centred approach Tim and Gordon have been able to gather insights that cannot be obtained by using on-line, postal or telephone surveys. We are also confident that the results are representative of similar rural and semi-urban communities across Suffolk and

other rural counties. I wish to express our very many thanks to all – and especially our family carers – who have participated in the study. I know that in many cases it has been difficult to relive your experiences.

The full report can be accessed by clicking on:

http://www.the-debenham-project.org.uk/downloads/research/reports/DebProjResearch_Final_Report311013.doc

3. Grants and Donations!

People are so kind and I want to gratefully acknowledge their private gifts - some modest, some large – that help to pay for what we do. Especially, I would like to thank Sue Vickress, together with her family and friends, for their most generous donation made in memory of her husband Alf. In addition, very many thanks to the customers of Waitrose in central Ipswich for contributing to a cheque we received under their “Community Matters” charitable giving scheme. Also, just before I sat down to write this newsletter I had an envelope quietly given to me containing a cheque towards our expenses. Thank you so much.

Finally, on behalf of the Trustees I would like to wish everyone a very happy Christmas and every good wish for the New Year.

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 Jackson (Chairman)