



Project Blog and Catch-Up August 2017

Hello everyone,

In order to try to ensure that as many as possible of those who participate in the Project, i.e. carers, cared-for, volunteers, donors and others, are kept in touch with our progress and other items of interest we send out this blog by e-mail and facebook. It is also available on our website. Please can those who organize the various groups within the Debenham Project, make hard copies available for their participants to look at. You will see that it also includes links to the regular articles that are published in the Debenham Parish Magazine as some of those who participate in the project may not have regular access to the magazine.

This time, I want to highlight an aspect that is increasingly dominating the thinking of the Government, the Local Authorities, and the NHS: How important are communities and volunteers in meeting the needs of our elderly and frail relatives, friends and neighbours? They all have cited The Debenham Project as an example of best practice but they are all unwilling to invest in the long term sustainability of ours and other community-based support projects. They offer grants for groups to initiate new projects but a year or two later "there is no money" to keep going. They agree that such projects make a significant difference (i.e. reduce demand and cost to the NHS and Social Services) but assume that volunteers "come for free". So here is a factual assessment of what The Debenham Project delivers, what it costs, and should they "be biting our hand off" to support us? – but aren't!

Value for money? At the beginning of April we reached the end of the financial year and it began a time when we reflect on what we have achieved and how we view the future for the Project. I, as the chairman and Roger Cockerton as the treasurer have to prepare and present our report and accounts to the Charity Commission. Putting it simply, we must demonstrate that we continue to "provide a positive contribution to the public good" and that we are "properly governed and managed in the interests of the community". Broadly, this comes down to whether we can show that what we have tried to do can be shown as "value for money" in the terms of the government's ideas of community support, public health, reduced demand for NHS services, etc. This will be the seventh time and each year we have been able show that we provide help to an increasing number of those who have to cope with the impact of dementia on their lives. Roughly, The Debenham Project spends about £8,500 annually in funding our voluntary support groups, services and other activities amounting to over 200 person sessions per month of support. This approximates to £85 per family who are living with the impact of dementia on their lives in our catchment area. Another way to think of it is as £3.50 per session for each individual who participates in our activities. A further way to assess it is as £1.00 pa per member of the population of our catchment compared with over £1,500 pa for the total cost of Health and Social Care for each of our elderly residents.

However, does this represent value for money? Well, it rather depends upon your viewpoint. As far as Debenham and its surrounding villages are concerned the Project has

clearly helped – sometimes a lot, sometimes a little - to improved wellbeing, reduced isolation, better understanding of dementia, peer group support, quality information and advice, easier access to professional services, etc. for carers and cared-for coping with dementia, and others who may be elderly and frail in Debenham and the surrounding area. Ultimately, it has contributed to an improved quality of life for them. 0.7% of what we all currently pay to the NHS Suffolk and the Suffolk County Council for the care of our over 65s seems to me like a good deal.

An alternative viewpoint is that of the NHS: Although it is difficult to quantify in exact numerical terms, improving well-being and quality of life, even if only by small amounts, has; certainly prevented and/or delayed crises; helped those living with dementia to manage their situation; improved their physical and mental health. When each day spent in a bed in Ipswich hospital costs around £350, and the average stay for all those admitted who are over 65 is in excess of 5 days (for those with dementia it is generally very much more!), it is easy to see the incredible value of preventing or delaying a crisis. When we also take into account that The Debenham Project is entirely volunteer-based and receives no funding from the NHS, perhaps they should prioritise "investing" to encourage the initiation and growth of more "zero cost" projects similar to ours.

Then there is the viewpoint of the Social Services. We are all aware that providing the essential care for those with limited financial assets is a major (and statutory) commitment for Suffolk County Council. Clearly, the two sides of the equation (Funding and Need) do not match. It is very unlikely that there will be any realistic increase in funding for social care in the near to medium future and so we are left with the reality that families, friends and neighbours will have to "fill the gap". In supporting those "families, friends and neighbours", The Debenham Project provides a wide range of services and activities, including CAMEO (activities and social sessions), the Carers Club and Info Café (peer group support), Fit Club (chair based exercises), Way Back When (reminiscence therapy), Food 'n' Friends (lunch clubs), Transport (medical appointments), Information and Advice (access to quality information), Signposting (access to professional services), One to One (regular support from trained volunteers), Dementia Together (rapid access to professional assessments, advice and NHS and Social Services), etc., all designed to make their life a little bit easier. Whilst, we are eternally grateful for the initial and following financial support from the Local Strategic Partnership of Mid-Suffolk District Council, and for a grant from the Mental Health budget, the actual financial cost to Suffolk's Social Services has been nominal. I guess that that the Suffolk County Council view is that The Debenham Project is a "zero cost" solution to dementia support and hope it can be replicated across the County. How I wish it was that simple.

Finally there is the viewpoint of the community: It is all too easy for the NHS and Social Services to assume that there is little or no direct cost associated with community-based support projects — "volunteers come free, and they fundraise, and they apply for charitable funding to cover their expenses"! Actually, they do not come free — they gladly give up their time and expertise to help those in need of support — but if they were fairly paid for their work, the cost to The Debenham Project would be in the region of £25K to £35K pa. To find this money would be a challenge. The chances of the current Suffolk County Council annually stumping up this sum for just one community, never mind the entire county, are indistinguishable from zero. Nevertheless, when set against the cost of residential care (£35,000 pa) and nursing care (£50,000 pa), if we can only help a few families to continue to care for their loved one at home for longer the financial equation makes absolute sense.

However, all this ignores the real cost to carers – the emotional cost – the potential mental health issues – the isolation – the stress - the guilt - the "if only" – and so on. The measure of a civilised society lies in how it cares for its vulnerable members – its children and its elderly. I believe that "value for money" is important but it should not dominate. I hope that we will always be guided by a desire for our care to be unconditional – "A freely given gift from society to all in need".

"Dementia Together" is launched. Dementia support for carers and those they care for has changed. A new Suffolk-wide community-based approach involving The Debenham Project has been launched which aims to focus on encouraging local support. A network of existing volunteer-based local dementia friendly and active support projects has been linked together and combined with a central hub which will provide professional support and straightforward referral to emergency and clinical services. It aims to offer immediate, personal and continuing support to those having to cope with the impact of the illness on their lives. I encourage everyone in our area living with dementia to register with this service so that we can improve communication with our professional partners and enable us to quickly call for their help when things get really difficult. If you, or someone you know, think it might help to be "on the register" please let me know asap. Click here for more information www.dementia-together.com

Other Activities and Opportunities.

The LadyKillers: The Wolsey Theatre is giving a Relaxed Performance on Tuesday 19th at 1.30pm of the "The LadyKillers" – a comedy farce. A Relaxed Performance is one which has been carefully adjusted to reduce anxiety or stress for those who might otherwise find the experience unsettling or difficult. I recommend it to anyone who looks after someone with dementia, mental health, autism, sensory, communication needs, and/or a learning disability who might be reluctant for a variety of reasons to attend public theatre performances. Please click here to find out more - https://www.wolseytheatre.co.uk/shows/the-ladykillers/

Sing-Along Sessions: Music, as we know, is a wonderful therapy. Many years ago, as a volunteer at St. Clements MH Hospital, I used to be a part of a weekly "sing-along" support group for the elderly patients, affectionately known as our old girls and boys, and whom almost all today would be diagnosed with dementia. It was amazing how important it was to them and how they looked forward to this couple of hours each week. Memory was not a problem – they all knew the old (and some not so old) time songs and the classic hymns, and with the help of a songbook would belt them out with enthusiasm. It taught me that simple things, often neglected by our clinical NHS and Social Services, can make a real difference.

So, we are hoping to start an old-time (and not so old-time!) sing-along and music group – you never know, we might even have a little bit of Karaoke! We are planning to try it out in Steve's "Way Back When" monthly events. We also want it to be "inclusive" – not just for those with dementia and those that care for them, but everyone who loves to sing the songs they remember, and to remember the times they sang them. If it proves something that people would like we will certainly find it its own slot in our regular calendar. We are hoping that it can begin sometime before Christmas.

Indoor Curling: For some time now, "Active Lives" has been funding and organising weekly fun sessions of indoor curling. This is a sport that can be played by anyone, no matter that they may have a disability or are just feeling a bit frail. It combines gentle exercise with

improving coordination, balance, and mobility — The fear of having a fall, not having something outside the house to look forward to, and imagining that we are "past our sell-by date" are major concerns for older people. This project has made a real difference across Suffolk and for participants in Debenham. At the moment, perhaps because we haven't advertised its benefits enough, there are not quite enough participants for the regular Thursday sessions at the Leisure Centre to cover the costs and it may be that it cannot continue. I urge you to think about whether you or someone you know would like to "try it out" — every Thursday afternoon at The Leisure Centre. If it's not for you, or the person you are thinking of, that's fine, but you might find that it opens up opportunities for fun and friendship. http://activlives.org.uk/activsuffolk/

The Parish Magazine. And now to links to our contributions to recent Debenham Parish Magazines – And, for those who already subscribe to the magazine, I hope that they might be worth a reread!! The articles included in this blog share what some of our activities and services are all about.

March: Way Back When: The first of our series looked at "reminiscence therapy" which is a rather grand way of acknowledging that recalling our memories of the past is something that we all like to do. It connects our thoughts with old friends and a way of life which, although firmly in the past, reminds us of those times that we can look back on with pleasure and feel that we want to share them with others (lest they be lost!). http://www.the-debenham-project.org.uk/downloads/articles/2017/03.pdf

April: Fit Club: How often have we been told that we must exercise more – go to the gym, regularly go for a run, take up a sport, or plunge into the pool – but mostly, with the best of intentions, it isn't an option for us older persons who may be "over 60" (well perhaps a little more!) and, also perhaps, just "a bit stiff in the joints", "a bit out of puff", or find that our balance isn't too good. The evidence is that a big difference can be made with some simple exercises that we can do whilst sitting in a chair – removing stress, reducing pain, improving posture, balance and coordination, and so on. It's gentle and fun - not at all about "no gain without pain" – and you can do it at home - less of the gym and more of the lounge! http://www.the-debenham-project.org.uk/downloads/articles/2017/04.pdf

May: Carers Club and Info Café: There will be tea or coffee and the largest slices and the greatest selection of luscious cakes in Suffolk for all. It's just like an afternoon tea party and the cakes are stupendous! If you need some information or advice we can usually help. This is the philosophy of The Carers Club and Info Café that meet twice a month in Dove Cottage "powered" by Sue, Margaret, Carole, Tony, Jan, Steve, Jean and many other volunteers but primarily "lubricated" by chocolate cake – In fact, probably the finest cakes in Suffolk. http://www.the-debenham-project.org.uk/downloads/articles/2017/05.pdf

June: CAMEO: CAMEO was an initiative set up and supported by St Mary's church and was one of the very first support groups to become part of The Debenham Project in 2009. We meet on the first and third Tuesday of each month in Dove Cottage between 2:00pm and 4:00pm and all are welcome. Between 15 & 20 people usually attend, ranging in age from 65 to 95 and beyond - all are young http://www.the-debenham-project.org.uk/downloads/articles/2017/06.pdf

July: One to One: Many families successfully manage to cope with the impact of dementia on their lives in the early and middle stages of the illness without the need for intervention from the NHS and Social Services. However, they often say that they felt left to cope on their

own one following the initial diagnosis and that they would value being able to periodically contact someone familiar for assistance at times of difficulty. We have initiated "One to One" so that there will be someone who can "come alongside" who understands your situation and can "be there for you" to be a listening ear and help you through when times get really difficult. http://www.the-debenham-project.org.uk/downloads/articles/2017/07.pdf

August: The Annual Garden Party: Each year, on the last Saturday in June, The Debenham Project invites everyone - carers, those they care for, volunteers, donors, and other participants - to a very special garden party. They are the people who have made the project such an enduring success. Once again it was a wonderful occasion — an exceptional garden with marquee, a scrumptious buffet, live entertainment from Stephen McKie and friends, a sunny afternoon, and 140 happy guests. Who could ask for anything more? http://www.the-debenham-project.org.uk/downloads/articles/2017/08.pdf Please note that there may be a glitch in the website and that this download might not be available — when our webmaster, Chris Bishop, gets back from a well-earned holiday it will be fixed.

I hope you have found this e-mail of interest – there is quite a lot of boring stuff (meetings presentations etc) that goes on to do with trying to influence the authorities to give more community based support to carers and those they care for but this blog is intended to be all about "getting on and doing something", the why, the what, the how, and the where of The Debenham Project.

Kind regards,

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