

This is: THE DEBENHAM PROJECT



October 2012



**Winner of the Probert Trophy
For Community Achievement 2011**

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“DEMENTIA - CARING FOR THE CARERS”

&

“A VISION OF CARING”

Foreword by Lynden Jackson, Chairman

The Debenham Project

Sometimes something comes along about which people ask “why hasn’t this happened before”. There is no answer other than - it just has! - “it’s the right project, at the right time, and the right place”. **The Debenham Project** is exactly that. Dementia is an illness that affects so many of our husbands, wives, parents, grandparents, friends, and neighbours that we cannot “stand aside” and hope that the nation will “look after them”. Unless you have been there it is difficult to imagine the physical, social, health and emotional cost involved in caring for someone with the illness. It can dramatically reduce quality of life – but most family carers feel that they have no choice – **“It’s my Mum, my Dad, my Husband, my Wife, my son, my daughter”** – so many people in our community are putting themselves second (or third, or fourth)! Eventually, medical research will come up with better treatments and perhaps even a cure but until then families and friends will have to shoulder the burden. “A helping hand”, “someone who is there for you”, and “well designed local services” can make a big difference – we know because we have seen it. **The Debenham Project** has been set up to do just this – “what can be done, will be done”.

The Debenham Project



On April 23rd 2009 a public meeting took place which was pivotal in the way that Debenham and its surrounding villages are addressing the challenges of their ageing population. It has led to a unique project in which our community has taken responsibility for the welfare and support of those who are family carers looking after someone with dementia, and of meeting the health and social needs of those that they care for.

In just over a year, from a standing start, it developed a comprehensive range of local volunteer-based services which “draw in” the best professional support. The breadth and quality of the facilities are now “second to none” in the County (and perhaps the UK) and will be expanded and developed in the future.

The project has become recognised as an example of innovation and best practice across Suffolk and beyond. It challenges the public sector to respond by initiating, encouraging and supporting its “roll out” to all rural and semi-urban communities. The Debenham Project is established and will continue to evolve and develop its caring approach (Caring in the Community, Caring for the Community, and Caring by the Community) throughout the coming years. Our plans are ambitious, and our aspirations are governed only by:

“If it is not good enough for my mother, it is not good enough”

THOSE WHO HELP

The Debenham Project relies totally on the dedication and support of the Trustees, Volunteers, Professional Co-workers, and Partners of the charity.

THE TRUSTEES

The Trustees are legally charged with faithfully managing the Debenham Project in meeting the needs of the community by tackling the problems presented by dementia and an ageing population.

Lynden Jackson (Chairman) Roger Cockerton (Treasurer)

Paddy Fielder Michael Rouse Gillian Shacklock

THE STEERING GROUP

The Steering Group advises and makes the practical arrangements so that support is ‘delivered’ to those who we seek to help.

Paddy Fielder (Chair) Mary Morley (Secretary) Lynden Jackson

Sue Jackson Alison Gravatt Gillian Shacklock Roger Cockerton

Joy Walton Peter Holme Richard Blackwell

THE VOLUNTEERS

The support and goodwill freely given by individuals in our community has been truly amazing. At that first meeting over 20 people offered their time – “just tell us what to do and we will get on with it”. Now, there are 80 “on the books”, over 50 have already

been directly involved, and about 30 help on a regular basis. We cannot say more than “Thank you”. The role of the volunteer is to “be there” for the carer, to create a friendly and social atmosphere, to know how to “press the right buttons” to get the best professional care and support, but, and most of all, to “make a difference” to the quality of living for those who seek our help.

OUR PARTNERS

The Debenham Project could not succeed without support from a wide range of professional and local organisations connected with the provision of care in our communities. The Trustees are so grateful for all the support that has been forthcoming from them all:



Tel: 01449 724500

www.midsuffolk.gov.uk



Tel: 08456 066 067

www.suffolk.gov.uk

Debenham GP Surgery



01728 860248

www.debenhamgrouppractice.co.uk



www.suffolkfoundation.org.uk

Christies Care



www.christiescare.com

CAMEO

Come And Meet Each Other
01728 860977



01728 861940

www.suffolklibraries.co.uk

Sue Ryder

www.sueryderforlife.co.uk

Tel: 01952 913113

Suffolk Family Carers

0844 225 3099

www.suffolk-carers.org.uk

Debenham Post Office



01728 862057

Coopersfield Sheltered Housing



01728 860135

www.sanctuary-group.co.uk



01473 359911

www.ageuksuffolk.org

Debenham Parochial Church Council



01728 861073

Fit Club

Stonham Barns ~ www.fitclub.org.uk
Get Fit ~ Feel Fabulous ~ Have Fun

Stonham Barns - Stonham
Aspal, Suffolk

Reception: 01449 710389

Debenham Pharmacy



01728 860421



www.dementia-alliance.com



www.nwmhft.nhs.uk

And many others, including Debenham Leisure Centre, Debenham Parish Council, Debenham Women's Institute. In fact, whenever we have asked for professional help from any organisation, they have been eager to give their support.

THE PROFESSIONAL CO-WORKERS

All our services start with our volunteers, but they cannot replace professionals when it comes to the detailed knowledge, advice, consultation, counselling, assessment, and so on that are necessary. Everything we do draws in the skills and experience of professionals to give the best quality of care locally. Our project is developing a new way for the vital support workers from the local authorities, the charities and the NHS to work with the community.



The project relies on large numbers of volunteers together with a wide range of professionals from many different organisations.

OUR CARERS AND THOSE THEY CARE FOR

In a community such as ours, it is all about everyone getting together to make things better. So! Some of us could do with a bit of help, understanding, and support whilst others want to give a bit of help, understanding, and support – how we care for each other defines our community. Those family carers who look after someone close to them contribute to The Debenham Project just as much as the rest. It is their thanks and willingness to accept a bit of help that makes it all worthwhile – it is not easy for a husband, wife, son, daughter, neighbour, or friend to say “I could do with a hand” but when it happens it opens doors and offers hope. To watch the difference that, for example, a carer gradually joining in with others at our Carers’ Club and Info Café is a joy, and to see how they give their understanding and experience to other carers is a privilege.

We estimate that there are already more than 100 in our community who have significant symptoms of dementia. To date we have provided some level of support – ranging from information and advice, to personal and telephone contact, and on to luncheon clubs and social activities – to almost 60% of their family carers.

OUR FUNDERS AND DONORS

All voluntary organisations need money in order to achieve their aims and most are limited by their struggle to find those funds. However, The Debenham Project has been very fortunate in receiving the support of the Mid Suffolk Local Strategic Partnership – managed by Mid Suffolk District Council. They have thrown their weight behind the project and enabled us to be secure until at least

the end of 2012 and some way beyond. In a time of financial constraint this commitment is a testament to their willingness to back innovative community projects. In addition we have been funded by Suffolk County Council, The Suffolk Foundation, and The Norfolk and Suffolk Dementia Alliance for special projects.

It is important to us that the local authorities and the NHS have acknowledged the value of The Debenham Project in tackling the problems that dementia and an ageing population present. However, what really matters is how individual carers, volunteers, community groups, friends, neighbours and families respond to the need. We have not hitherto “fund raised”, neither have we organised fund raising events or canvassed for financial support. Yet so many local groups and individuals have spontaneously come forward with donations - even from Sweden - to give a “little” or a “lot” to help us make a real difference in the future. Thank you.

WHAT WE DO

The Debenham Project currently provides the following help:

I. Confidential Telephone Support Line



When you are finding it hard to cope with the practical and emotional difficulties of looking after someone with dementia, a listening ear may make the

difference. When things can be getting on top of you, just unloading on someone who understands can be a life saver. The support line is staffed by trained volunteers, most of whom have experienced, either professionally or personally the difficulties and traumas of being a carer of someone with dementia. It operates over the Friday/Saturday/Sunday evening periods which are traditionally times when it is hard to get support.

2. Activities and Social Support Sessions

Being active, whether it is socially, physically or intellectually, can make a big difference in the quality of life of both carers and those they care for. The project has regular sessions aimed at encouraging all sorts of activity, but mostly about getting together and having fun. They also give carers and cared-for the opportunity to meet and interact with others. The sessions are designed to cater for a wide range of interests, physical and mental capabilities, and to assist in reducing isolation from the community as a whole. They are a joint venture with CAMEO (Come And Meet Each Other) and St Mary's Church.

3. Food 'n' Friends Lunch Clubs

Sometimes it would be good to just go and have lunch with friends who wouldn't notice (or worry) that your partner's, mother's,



father's, friend's, or neighbour's conversation might be a bit strange or that their behaviour was different.

To have somewhere to go and enjoy a social meal is great. When you care for someone with symptoms of dementia taking them to a public café or restaurant can be stressful. We have arranged a number of lunch clubs (usually only for a few guests) which offer a friendly, chatty, and comfortable occasion to relax and be with others who you can “talk to”. Maintaining social contact is very important and joining in on a regular basis can help to develop and enjoy friendships in a safe social environment. These clubs have been developed jointly with Age UK.

4. Information and Advice Centre

It is often said that “get connected with the web and all your questions can be answered” – not so easy when you try! Mostly, we need a bit of help in accessing and interpreting the information – “too much!” and “what does it mean for me”? Ideally, we want someone who can help to sort out what you really need to know to manage your future, and what you can “leave to another day”. When it comes to dementia there are a number of excellent and accredited sources of information – there are also sources of commonsense and wisdom. The Debenham Project can offer both, through its Information and Advice Centre – a Website, Phone line, Information leaflets, library staff-assisted access and one-to-one confidential assistance. It can also link you to professional support workers when you need detailed advice and information. This has been achieved with the support of the Debenham Library Resource Centre and Debenham Post Office.

5. Medication and Pharmacy Support

It may seem obvious that someone with memory problems might need help with making sure they take the right medication at the



right time. Add to this that many have additional health problems e.g. diabetes and chronic heart disease for which a failure to take “the pills” (or to take them twice!) may lead to a serious medical

crisis, it is important that help is available to carers and those they care for to reliably manage their 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 addition, the pharmacist can assist in liaising with the GP surgery, and ‘signposting’ to other professional support.

6. Carers’ Club and Info Café

Living in a rural community we get used to carers saying “we can manage” – “we don’t need help” – “we don’t want our neighbours and friends to know”. The project cannot take the load away, but some things can help to make it easier to bear. To get together with other carers and volunteers who understand is a very positive step. The Carers’ Club and Info Café alternate fortnightly to offer a very

friendly and social atmosphere where you can come and enjoy an afternoon without worry (heavily lubricated with tea and luscious cakes!) where you can talk with a professional support worker, chat with those around, or “just be!” This is a fortnightly social get together with other carers and cared for, where the major charities generously offer their professional support services. If you just want to drop in and have “a coffee and a piece of cake” its “no problem”. We always have someone from either Age UK or one of our local carers for you to talk with.

7. Exercise Therapy – The Fit Club

What a difference can be made with some simple exercises that can be done whilst sitting in a chair – removing stress, reducing pain, improving posture, increasing mobility, enhancing coordination and balance, and so on. It has proved a very popular weekly activity and currently has a full membership each time. It has shown just how much it is needed, and how important the social aspect is.

The Fit Club is run in collaboration with a local professional, Zoe George of ‘FitClub and VibroClub’, and who is keen to specialise in helping those with dementia, and other older persons.

8. Specialist Memory and Support Services

It is a big step for family carers and those they care for to take their concerns to their GP. If he/she suspects dementia as the possible cause, this can be very stressful and disorientating - it will involve being referred to a consultant and attending a memory clinic for a diagnostic assessment. Ideally, we would like this to be in a friendly, familiar and local location and where information and advice on all

health and social care aspects is available but this is not possible just yet. However, working closely with the Norfolk and Suffolk NHS Foundation Trust we are offering a new approach which goes a long way towards meeting the original hopes. We have trained several volunteers who are happy to accompany carers / patients to their appointments as a “friend” who can help explain things and provide information, advice and useful contacts. In addition, carers will still be able to make an appointment to talk confidentially with the specialist nurse or support worker at either our Carers’ Club or Info café.

9. Other Activities and Events

The Debenham Project has, and will, put on or sponsor other things – like a “1940’s Tea Dance”, an “Afternoon at the Mid Suffolk Light Railway”, “Having fun with Fitness and Exercise”, and a “Harvest Festival Exhibition of Model Agricultural Vehicles and Tools” together with professional seminars and meetings. We also have “special afternoons” when we invite local professionals to offer their skills – so far we have had reflexology, film archives, reminiscence boxes, and chair-based exercises. We are always open to suggestions about new and alternative events that will brighten up people’s lives.

WORK IN PROGRESS

The Debenham Project is developing all the time. We want to do the very best we can to support carers and those they care for, and so we are anxious to “get on and do new things” and to “try out new ideas”. Some will blossom and become an integral part of what we do, but others may not be quite so successful and have to be set to one side for the time being. Here are just three examples of our current ideas for the future.

I. Research Project

In July 2012 the Debenham Project commenced a community focussed and professionally led research project to establish why the early diagnosis of dementia in the community does not always occur. Recognising the symptoms early, and consequently enabling early treatment, is widely acknowledged as a vital step in keeping the condition under control for as long as possible. Two researchers, Tim Mason and Gordon Slack, will undertake a 12 month project to engage with the community as much as possible to establish what the barriers are to early diagnosis. The results will be used to guide the way the Debenham Project delivers its services and will also be shared with the NHS and Social Care services to better inform their strategy for dementia care in the future. This is the first time anyone has tried to comprehensively study a single community in this way and is funded by The Norfolk and Suffolk Dementia Alliance. It has already attracted interest at regional and national levels.

2. The Carer's Co-op

The project has appointed Sam Cage as our project co-ordinator and facilitator to work with Christie's Care to investigate setting up a network of self-employed professionals to offer excellent standards of personal care when this becomes necessary. Professional support may be needed as a permanent arrangement, in times of crisis when a few extra hours of help are required, or simply to allow the family member to have some time for themselves every now and then. As a vision, we hope eventually to facilitate the provision of all forms of domiciliary care, including rehab, specialist, end-stage, and end-of-life in collaboration with Sue Ryder Care. This is a new approach – an alternative to the standard agency approach with its inherent problems in rural areas - which we believe is ideally suited to communities such as ours.

3. Debenham On Call

The Debenham Project is seeking to build a small team of fully trained volunteer carers to “stand in” and provide a short-time care service when there is an emergency, an urgent hospital appointment, or just a desperate need for a little time for the family carer.



BEHIND THE SCENES

Everything we do is focused on helping family carers and those they care for in Debenham and the surrounding villages. The vast majority of the project's efforts come from all our volunteers, assisted by professional workers from our partners, helping regularly with activities and services. However, working behind the scenes with the local authorities, the local GPs, the NHS, the charities, and other organisations, by sharing our experience and understanding, is very important in both securing our funding and enabling the project to continue to develop.

1. Awards

The project has been given awards at local, district and county levels in recognition of its innovative approach to the problems that dementia presents to rural communities. Apart from receiving Suffolk Acre's Probert Trophy for Community Achievement 2011, we were also presented with an award of £10,000 by The Suffolk Foundation (supported by Suffolk County Council). This money is currently being used to fund our Carers co-op and Volunteer Carers initiative.

2. The Joseph Rowntree Foundation

During the first half of 2012, The Debenham Project was approached by the Joseph Rowntree Foundation to become a 'case study' for their 'Not a One Way Street' research project. The research is focusing on 6 case studies across England, Scotland, Wales and Northern Ireland and looks at innovative and different ways that 'mutuality and reciprocity' can work in society.

The project was delighted to be asked to contribute to the research being done and a very busy two days were arranged for Sian Lockwood to visit Debenham and meet as many of the involved partners as possible that we have working on the project. Sian is undertaking the research on behalf of the Joseph Rowntree Foundation and she was extremely impressed with the overall achievements to date of The Debenham Project. We eagerly await the findings of her research.

The Joseph Rowntree Foundation, alongside the Wellcome Trust, is among the organisations in this country which have the government's 'ear'. As a consequence it can and does influence government thinking and strategy on such things as care for the elderly.

3. The Prime Minister's Challenge on Dementia

This is a national effort to make a difference to the way we care for those with dementia and for those family members, friends and neighbours that care for them. One of the key threads of the challenge is to help communities become "dementia friendly" so that those who need help, can receive the best possible services, understanding, and support on their doorsteps – so that they are encouraged to seek help early - and so that the stigma associated with dementia may be eliminated. By virtue of the Debenham Project's work and its reputation, Debenham is in the forefront and we have been approached at county, regional and national levels to share our understanding.

WHAT NEXT? – “A VISION OF CARING”

There are three things that have guided The Debenham Project. The first is to listen to carers and those they care for, the second is to “get on and do something”, and the third is to “have a vision”. So far, we have managed to make a real difference to a significant number of those who, otherwise would have been just about coping, and we have gone a long way towards many others knowing that they are not alone, and that, when they really need help, it will be there. The success of the project is exceptional both in the proportion of carers it has helped and in the difference it has made to individual carers and those they care for.

However, at that first meeting in April 2009 it was made clear that we should not limit our aims – that we should not be afraid to “have a dream” in which:

No one should have to leave their friends, family and neighbours in order to be cared for with love and dignity – “7, 10, 14 miles is too far”.

No matter how frail we might become, we will still be able to be part of our community – to visit the shops and cafe, to have our grandchildren pop in, and to pass “the time of day” in the High Street.

No one should have to be admitted to hospital, or stay in hospital when they can be cared for in the community, by the community.

This **DREAM** has become a **VISION** – the “Vision of Caring” – and it is becoming a **PRACTICAL** plan in which Debenham will lead the way in caring for its elderly frail and ageing members of the community.



The project is working to **REALISE** this vision – it is a massive challenge, but “what you don’t start you cannot finish”.

We think that it will require an investment of a little over £10M and the running cost will be about £2M each year. It seems an enormous financial cost but in just our area alone, the annual cost of health and social care for the elderly is nearly £7M. “The Vision of Caring” will save more than 10% on that bill!

It will mean drawing together the NHS, the Social Services, the community, and the major charities to integrate care on a local basis. It will mean building and staffing future generation accommodation and nursing facilities appropriate to a rural community. It will mean creating a model of what is best practice. It will mean “**breaking the mould**” of how the NHS and the Social Services have worked in the past.

We believe that it can be done – and we have the figures to prove it!

We have done the groundwork – now comes the hard part – finding the funding and making it happen.

The Debenham Project has proved what a community can do for those who give up their lives to care for someone close. Whatever financial difficulties the future might bring, it will continue to provide whatever help it can. The project will grow and evolve over the coming years.

“If this has been achieved in such a short time, why should we not believe that it is possible to care for those who have become frail, as we would hope to be cared for?”



A handwritten signature in black ink, appearing to read 'Lynden Jackson'.

Lynden Jackson (Chairman)

TESTIMONIALS TO THE DEBENHAM PROJECT

Daniel Poulter, MP (Parliamentary Under Secretary of State for Health): “The Debenham Project is an outstanding example of integrated and holistic community-focused care and support, for people with dementia and their families and carers. Suffolk is very lucky to have such a dedicated team of volunteers to drive this project forward, The Debenham Project is helping to set new standards of care and support for people, and the families of people, with dementia.”

Sian Lockwood OBE (Chief Executive, Community Catalysts CIC): “What is great is this is a group of people really trying to do something. They are all local people and they actually care. The Debenham Project is an inspiring example of what can happen when local people decide to take action themselves to tackle a problem affecting friends and neighbours in their community. I spent two days with people involved in the project and was just so impressed by their focus on ‘big vision’ and practical action. The project has already made a positive difference to many local people’s lives – the ‘big vision’ (when it is achieved – and I know it will be) will benefit many more. Now we just need to find a way of extracting the lessons from this approach and sharing them with other communities.”

Eddie Alcock (Chair, Suffolk County Council, 2010 – 2011): “When I first became aware of the objectives of The Debenham Project my first thought was: “It’s so obvious that this is needed and that Suffolk County Council must throw its weight behind it”. Now it is up and running it is already an exemplar – an incredibly important volunteer-based initiative that seeks to give valuable help and support to those caring for those with dementia. People, in fact, who themselves are

often forgotten as much as the people they are caring for! The Big Society personified! May it now be replicated nation-wide.”

Colin Noble (Adult Care portfolio holder, Suffolk County Council):
“Much is said about the growing problems we, as a society, face with dementia, much is said about the Big Society, and much is said about community engagement and involvement. The Debenham Project just "got on with it" and much should be said about its tremendous work and value, to the community it serves".

Joanna Spicer (Chair, Suffolk County Council, 2009 – 2010):
"Debenham is so wise to have recognised the increasing challenge of the growing number of people suffering from dementia and also the considerable stress and problems this causes for their families and friends."

Judith Hawkshaw OBE: “If it is not good enough for my mother, it is not good enough”



Baroness Sally Greengross (CEO, International Longevity Centre): “I was very interested and will mention this in all relevant debates in the House of Lords and to relevant Ministers at any meetings I attend”.

Lord Richard Best (President of the Local Government Association): “I am sure you

are very much on the right track and The Debenham Project could provide an exemplar for rural housing schemes for older people. I wish you every success”.

John Graham OBE: “I came away from the conference and was inspired by your talk to write about it in a blog I write on elderly issues”.

Prof George Giarchi (Ethics of Care, Gerontology and Dementia, Plymouth University): “Most impressed Lynden. Thanking you so much for the originality and for what you are doing for others”.

Prof. June Andrews (Director, Dementia Services Development Centre, University of Stirling): “I am on holiday, but addicted to emails, so this is a short note to tell you how impressed I am at your work and your energy for supporting carers and people with dementia”.

Final South Essex Commission Interim Report March 2011: “However, I think Professor Giarchi allowed us to re-connect with some very fundamental points about the human condition and I think, combined with Lynden Jackson’s example of The Debenham Project provided an inspiration to us all to think beyond services and see the potential within people and communities”.

Karen Mayhew (CEO, The Havebury Housing Partnership): “I think your project is exciting and inspirational”.

THANKS AND ACKNOWLEDGMENTS

This publication has been the result of input from many people but in particular the editorial and creative team:

Colin Archibald, Chris Bishop, Gillian Shacklock and Richard Blackwell (Editor).

Photography by Colin Archibald: www.reflectionsofreality.co.uk

USEFUL CONTACT NUMBERS

Organisation	Contact Telephone Number
Debenham Project (Advice & Information)	01728 862003
Debenham Project (Confidential Telephone Support)	01728 861865
Age UK Suffolk (Dementia Services)	01473 353055
Age UK Suffolk (General Enquiries)	01473 359911
Alzheimer's Society (East Suffolk)	01473 237301
CAMEO	01728 860977
Coopersfield - Debenham	01728 860135
Debenham GP Surgery	01728 860248
Debenham Parochial Church Council	01728 861073
Debenham Pharmacy	01728 860421
Debenham Post Office	01728 862057
Debenham Library Resource Centre	01728 861940
First Stop (on-Line Information)	www.firststopcareadvice.org.uk
Mid Suffolk District Council	01449 724500
Sue Ryder	01952 913113
Stonham Barns Fit Club	01449 710389
Suffolk County Council	08456 066 067
Suffolk County Council Social Services (Customer First)	0808 800 4005
Suffolk Dementia Helpline (Sue Ryder)	01473 353350
Suffolk Family Carers	08442 253099

REFERENCES AND BIBLIOGRAPHY

www.the-debenham-project.org.uk

www.the-debenham-project.org.uk/downloads/articles/breakingthemould.pdf

www.the-debenham-project.org.uk/downloads/steeringdocs/A_Vision_of_Caring_rltse7.pdf



Welcome to Debenham – A Caring Community