

This is:
THE DEBENHAM PROJECT



Winner of the Probert Trophy

For Community Achievement 2011

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Registered Charity 1133501

“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 it has developed a comprehensive range of local volunteer-based services which

“draw in” the best professional support. The breadth and quality of the facilities are “second to none” in the County (and perhaps the UK).

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 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 advise and make 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: 08088 004005

www.suffolk.gov.uk

Debenham GP Surgery



01728 860248

www.debenhamgrouppractice.co.uk

Suffolk Mental Health 
Partnership NHS Trust

Tel: 01473 329000

www.smhp.nhs.uk



**Come And Meet Each Other
01728 860977**

Debenham Post Office



01728 862057

The Alzheimer's Society

01473 211050

www.alzheimers.org.uk

Suffolk Family Carers

0844 225 3099

www.suffolk-carers.org.uk

Coopersfield Sheltered Housing



01728 860135

www.sanctuary-group.co.uk



01449 674266

www.ageconcernsuffolk.org.uk

Debenham Parochial Church Council



01728 861073

Debenham Pharmacy



01728 860421

Debenham Library Resource Centre



01728 861940

www.suffolk.gov.uk

And many others, including Debenham Leisure Centre, Stonham Barns Fit Club and Vibro Club, 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 luncheon clubs and social activities – to over 40% 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 “after the Olympics” and a bit beyond. In a time of financial stricture this commitment is a testament to their willingness to back innovative community 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 Luncheon 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 family 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 ‘family’ 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 The Alzheimer’s Society for you to talk with.

7. A Specialist Memory and Support Clinic

Most carers and those they care for will take their concerns to their GP, but when it comes to seeking a formal diagnosis or just asking for more detailed information, hospital clinics can be frightening and disorientating. They can often lead to difficulties in achieving accurate results. Holding clinics locally greatly reduces the stresses experienced by those undergoing the treatment and also avoids sometimes lengthy and disorientating journeys to Ipswich or Stowmarket. Working closely with the Mental Health Trust the project has arranged for monthly clinics to be held in Dove Cottage, Debenham to provide:

- diagnostic assessments

- longer term monitoring of patients
- memory screening
- clinical information and advice
- social and health care information and advice
- support information and advice
- informal drop-in advice



This goes well beyond the normal NHS clinical service in that it seeks to provide a professional team who are not only concerned with a medical diagnosis, but are committed to advising how you can be helped to cope with the problems that dementia presents to you. Perhaps, more importantly, the friendly and social approach says “we are here for you”.

8. 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.

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 – **“If it is not good enough for my mother, it is not good enough”**. 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 rectangular box containing a handwritten signature in black ink on a white background. The signature appears to read "Lynden Jackson".

Lynden Jackson (Chairman)

TESTIMONIALS TO THE DEBENHAM PROJECT

Daniel Poulter, (MP for Central Suffolk and North Ipswich): “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.”

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

REFERENCES AND BIBLIOGRAPHY

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



Welcome to Debenham – A Caring Community