



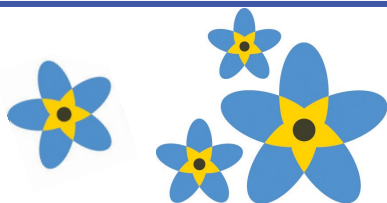
---

# THE DEBENHAM PROJECT



**Dementia -  
Caring for  
the Carers**

5<sup>th</sup> Edition - May 2023



Working to become

**Dementia  
Friendly**

[www.the-debenham-project.org.uk](http://www.the-debenham-project.org.uk)

---



# Dementia - Caring for the Carers

## A Vision of Caring

*Foreword by Lynden Jackson,  
Chair - The Debenham Project*

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 in the right place”.

**The Debenham Project** is exactly that.

Dementia is an illness that affects so many of our husbands, wives, partners, 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 partner, 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 23<sup>rd</sup> April 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 (Chair)    Roger Cockerton (Treasurer)  
Paddy Fielder    Michael Rouse  
Richard Blackwell

### 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    Mary Morley (Secretary)    Lynden Jackson  
Sue Jackson    Chris Bishop    Roger Cockerton    Peter Holme  
Richard Blackwell    Carol Garrett    Caroline Manning



We believe that this is the only way that truly 'person-centred care' can be delivered – caring for the community, in the community, by the community.



## Our 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 120 “on the books”, over 65 who help regularly, about 40 help on an occasional basis, and others have offered their time should it be needed.

**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:



[www.midsuffolk.gov.uk](http://www.midsuffolk.gov.uk) 0300 1234000



[www.suffolk.gov.uk](http://www.suffolk.gov.uk)

Crisis Line 0808 917 1109



**SUFFOLK**  
Community  
Foundation

[www.suffolkcf.org.uk](http://www.suffolkcf.org.uk)



Dementia Support Line - 0330 150 3456

[www.dementiaconnect.alzheimers.org.uk](http://www.dementiaconnect.alzheimers.org.uk)



The Highwayman Norwich Road, IP8 6PD

[www.exercisetherapyonline.com](http://www.exercisetherapyonline.com)

01449 710389



Debenham Parochial Church Council 01728 860222





Debenham GP Surgery

01728 860248

[www.suffolkprimarycare.uk/debenham-group-practice.co.uk](http://www.suffolkprimarycare.uk/debenham-group-practice.co.uk)



01728 861940 [www.suffolklibraries.co.uk](http://www.suffolklibraries.co.uk)

Norfolk and Suffolk   
NHS Foundation Trust

[www.nsft.nhs.uk](http://www.nsft.nhs.uk)

Referral Line 0300 123 1334

And many others, including Debenham Leisure Centre, Debenham Parish Council, and the 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 whole community  
is eager and willing  
to lend its 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.



"I feel reassured when trained and experienced carers look after my Dad."







## 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, partner, 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 made when, for example, a carer gradually joins 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.

When a relative asks for help, it opens doors and offers hope.



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 over 65% of their family carers.



## Our Funders

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 threw their weight behind the project and helped us to be secure in the medium term.

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, Sports Relief, Axa Insurance, Waitrose, Comic Relief, Yorkshire Building Society, The Norfolk and Suffolk Dementia Alliance, the local Co-op, The Forge Church, and also collection boxes in every local business. The project has also been presented with an award of £10,000 by The Suffolk Community Foundation.

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 “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.





## What we do

The Debenham Project currently provides the following help:

### TLC - Talking, Listening, Caring

This group is led by two of our past carers who know how helpful it is for carers to talk with each other about the challenges of being a family carer. It is an opportunity to share problems and experiences, to seek advice with managing the stress and exhaustion, to share tips about coping, and just have space to off-load.

I just needed to talk to someone who would listen and understand



### Lunch Clubs – *Two clubs now operate*

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 and behaviour might be "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 were originally developed jointly with the help of Age UK.





## 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!”, “can it be trusted?” and “what does it mean for me”? Ideally, we want someone who can help to sort out what we really need to know to manage our future, and what we 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 common-sense and wisdom. The Debenham Project can offer both, through its Information and Advice Centre a Website, 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.



## Post Diagnosis Support

Consulting a GP about symptoms of memory loss or changes in behaviour of yourself or someone you are caring for requires great courage. The fear that they might be associated with dementia can be overwhelming. And, should that lead to a positive diagnosis of one of the many forms of the illness, coping with it, and adapting to its impact on your future can feel very frightening.

Our experienced team of local retired health and social care professionals is on hand to support you, to offer information and advice, be someone who knows, and to be a friend for as long as it takes.





## 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 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. If you just want to drop in and have “a coffee and a piece of cake” its “no problem”. We always have someone with experience to talk with you and, monthly, a professional dementia advisor.



...a friendly and social atmosphere plus great cakes!







## Exercise Therapy

Such 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. It has shown just how much it is needed, and how important the social aspect is. The club is run in



collaboration with a local professional, Zoe George of 'Exercise Therapy', who provides specialist exercise therapy to recovering patients in the NHS and is totally committed to supporting older persons and those with dementia.

## Signposting and Professional Liaison

Living with the impact of dementia on your life, whether you are a family carer, or the one with the illness, is a journey that sometimes goes well but sometimes can become overwhelming, and on the edge of breakdown.

It is at these times you will need the support of professional agencies e.g. Norfolk & Suffolk NHS Foundation Trust, Suffolk CC Adult Care, Dementia Connect etc. The Project can advise on how to contact those which can quickly help.





## Personal Care and Domestic Help Register

This is a routinely updated list of professional organisations, agencies and individuals who offer personal care and domestic help in and around Debenham - an informal local network. So if you need some help please ask. Although we do not “recommend” or “guarantee” their services, they are not just “pulled out of the hat”, and when it comes to those providing personal care we do try to make sure that they are either experienced local self-employed carers or are registered care agencies. As time goes by it will become more comprehensive. Do please remember that a recommendation from a trusted friend is one of the best ways of finding someone.



## Transport

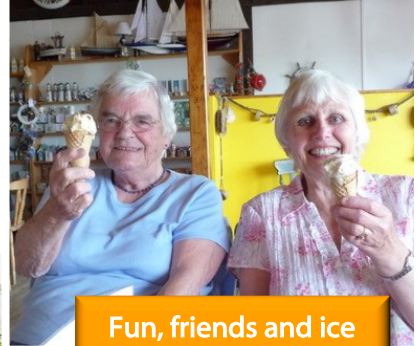
Worries about how to get to a GP, hospital, dental, or other medically related appointment are a great concern for elderly or frail people who cannot (or should not) drive themselves, may not be able to call on a relative or friend to take them, and can't depend upon public transport. The Project has created a small network of volunteer drivers who are more than happy to help out and, not only take someone to and from the appointment, but also be there as a friend/companion throughout the visit - no one will be left alone.





## Other Activities and Events

The Debenham Project has, and will, put on or sponsor other things – like an “Afternoon at the Mid Suffolk Light Railway”, “Having fun with Fitness and Exercise”, a “Day out at the Seaside”, our “Annual Garden Party”, together with professional seminars and meetings. We are always open to suggestions about new and alternative events that will brighten up people’s lives.



Fun, friends and ice cream at the seaside



Special events can really brighten up people’s lives







## Please Tell Me

The long term memories of those with dementia are often amazingly intact and they greatly enjoy chatting about the “old days” and their past adventures – who doesn’t? Old photos, music, objects, personal memories, etc. that have meant a lot can be used to stimulate conversations. “Please Tell Me” is a very simple way of not only helping a family carer to start

this but also to make it something that they can enjoy doing with the person they love – a scrapbook of pages that can capture the best bits of the past – a “Life History”. But it can be much more than that. Anyone, friend, neighbour, carer, or relative, can be involved and contribute when they visit, or they can simply use it to open up a conversation.



Questions can act as prompts for conversations and memories.

## Work in Progress

The Debenham Project has always been committed to providing the best community-based support that it can. It looks towards other projects and research that might suggest something we could learn from and try. It also seeks to use its wide range of contacts to recommend caring people to contact us with ideas that have real potential to help those struggling with the impact of the illness on their lives.



## 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. It helps in both securing our funding and enabling the project to continue to develop, and also in influencing the future pattern of care in Suffolk and the UK.

The Debenham Project has been recognised for its innovative and community-based approach, and that it seeks to play a part in advancing the level and quality of support available to the increasing numbers of family carers and those they care for. It has done and continues to do this in many ways – by being involved in key advisory groups, developing proposals, membership of Healthwatch, contributing to consultations, giving presentations, carrying out research studies, etc.

Spending time with other people who have similar problems is always helpful.







## Research

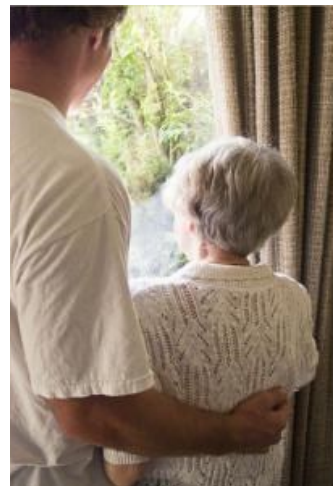
Over the years the Debenham Project has developed a unique place for its community based dementia support approach. This has enabled it to explore and research this very neglected segment of health and social care.

### **Carers' Experiences in Rural Suffolk**

In July 2014 the Debenham Project completed a community-focused and professionally led research project to explore the experiences of family carers (and those they care for) in and around Debenham. This was the first time anyone had tried to comprehensively study a single community in this way and was funded by The Norfolk and Suffolk Dementia Alliance. The research sought to obtain information from local family carers and cared-for about the memory loss/dementia journey; a profile of our carers and cared-for; their experiences; and also views from them and others on the positive and negative aspects of early diagnosis and early intervention of/by services. The purpose was to illuminate the reality of coping with the impact of dementia. The study and its findings have been published in *The Journal for Dementia Care* – one of the leading UK journals in the field.

### **Putting it all Together – A Vision of Caring”**

When the Debenham Project was launched in order to address the problems that dementia presents, we were also asked to think about how we would like all elderly frail members of our community to be cared for. This request led to a 4 year research study which proposes a “new way of caring” – a way which more nearly matches the needs of an ageing population. Our research has shown that integrating health,





social, and housing support in the local community can offer not only better person-centred care, but also offers significant cost savings, and it has positively contributed to the County and National debate concerning the future structure of Health and Care.

### **University of Suffolk—Evaluating the Provision, Availability, Cost and Quality of Health and Social Care for Older People in a Rural Community—May 2022.**

The Debenham Project, with the support of the Parish Council, asked the University of Suffolk to research how to achieve a realistic picture of



“The Provision, Availability, Cost and Quality of Health and Social Care for Older People in a Rural Community” - specifically, Debenham and its surrounding villages.



## **Contributing**

Over many years we have represented those who are living with the impact of dementia on the mental health focus group of Healthwatch Suffolk. More recently, as a founder member, the Project helped develop “The Suffolk Dementia Forum” which brings together the organisations and individuals who are the primary experts and practitioners of dementia support in the county.

The Project was also a major contributor to the development of the county’s “Dementia Connect” support service.



Additionally, we are regularly contacted for visits to see our work (which we rarely agree to as the project is all about providing a safe space for our participants, which is free from any publicity). However, we have shared our experience with other local authorities, NHS managements, government, and academic establishments. These include, The Welsh Government, Northumbria University, Cardiff University, Warwick University, Manchester Council, and various community groups.

## Professional and Academic Recognition

Whilst recognition at a national level is not a high priority – we are much more concerned with contributing to the development of high quality dementia support services here in Suffolk – it is a confirmation that what we do here in Debenham has at least some small impact on improving dementia care services beyond our own boundaries. The project has given invited papers and presentations at national conferences and been quoted in research case studies for academic reports.

The Project has also been given awards at local, district and county levels in recognition of its innovative approach to the problems that dementia presents to rural communities. For instance, we received Suffolk Acre's Probert Trophy for Community Achievement in 2011, and were delighted to receive the 'Inspiring Age Award 2014' from Age UK, in recognition of our contribution to the local community.

### Social Care Institute for Excellence

The "The Social Care Institute for Excellence" (a leading national health and social care organisation) has included The Debenham Project as an example of best practice in its on-line guide on home (and community) care for older people.





## Royal College of Psychiatry 2018



The Debenham Project has been quoted in their “Dementia Evidence Based Treatment Pathway” as an example of best practice. The title sounds highly academic but, basically it is about achieving better access to quality dementia care by

Although our ethos is to just ‘get on and do it’, such recognition does reflect very positively on the way that everyone supports the project.

identifying innovative and leading support activities across the UK.

## Where Next?

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:

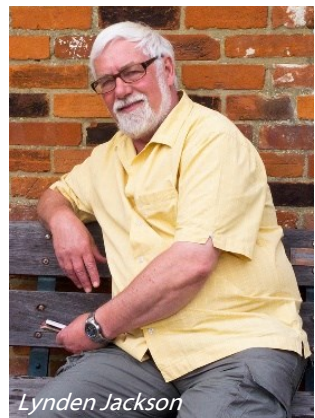


- ◆ No one should have to leave their friends, family and neighbours in order to be cared for with love and dignity – **“7, 10, 14 miles is too far”**.
- ◆ No matter how frail we might become, we will still be able to be part of our community – to visit the shops and cafe, to have our grandchildren pop 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.

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?”

*Lynden Jackson (Chair)*



*Lynden Jackson*



# Welcome to Debenham - a Caring Community



The Debenham Project	01728 862003
Dementia UK (Helpline)	0800 888 6678
Dementia Connect Support Line	0330 150 3456
Alzheimer's Society	0330 150 3456
Debenham Library	01728 861940
Suffolk County Council - Crisis Line	0808 917 1109
Debenham GP Surgery	01728 860248
Suffolk Family Carers	01473 835477