THE DEBENHAM PROJECT

RESEARCH INTO THE DEMENTIA/MEMORY LOSS JOURNEY FOR CARED-FOR AND CARER - 2012-13

Including investigation of the advantages & disadvantages of early diagnosis and early engagement with care/support services.

Commissioned and Funded by:

Norfolk & Suffolk DEMENTIA ALLIANCE
comfort • compassion • dignity

CONTENTS

SYNOPSIS

This report lays out the findings of research carried out between July 2012 and August 2013 for The Debenham Project in Suffolk, funded by the Norfolk & Suffolk Dementia Alliance.

The research sought to obtain information from family carers and cared-for about the memory loss/ dementia journey; a profile of the 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 research used a methodology devised by the researchers working to an agreed project plan from the Debenham Project Trustees. In essence, this methodology sought to:-

a. Devise questionnaires for family carers
b. Trial the questionnaire with a limited number of family carers known to the Debenham Project, and then refine and roll it out to the full survey population
c. Conduct structured interviews with as many family carers as possible of the survey population
d. Devise and launch a questionnaire for volunteers in the Debenham Project
e. Interview relevant professionals including GPs and voluntary sector.

The principal survey group was forty-two family carers of people with memory loss/dementia living either presently or in the recent past in the area covered by the Debenham GP practice including its two surgeries in Otley and Grundisburgh.

The aim of this research is to inform the funders; local and regional authorities and national government as well as the Debenham Project and partners to enable robust planning of future services and support for people with dementia and their carers.

This report:-

- Lays out the responses to the family carer questionnaire, question by question
- Examines and computes these responses, categorising where clearly possible & helpful
- Incorporates experiences and views from the structured interviews, Debenham Project volunteer questionnaires and relevant professionals in social care and health services, including the voluntary sector
- Discusses the findings and draws conclusions

The research is felt to be unique in its person-focused methodology and approach, and this is evidenced through the high returns and response rates. The researchers are trained & experienced in ‘non-instructed’ advocacy thus were able to engage empathetically with the client group while maintaining a professional and critical distance.

B. EXECUTIVE SUMMARY

This report lays out the findings of research carried out between July 2012 and August 2013 for The Debenham Project in Suffolk, funded by the Norfolk & Suffolk Dementia Alliance.

1. The Debenham Project

The Debenham Project [1] is based in the eponymous village in mid-Suffolk. It is a unique, community-based project which has, of its own initiative, developed a comprehensive range of local services to support carers of those with symptoms of dementia, and those they care for.

2. The Research

The research sought to obtain information from family carers and cared-for about the memory loss/ dementia journey; a profile of the 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 principal survey group was forty-two family carers of people with memory loss/dementia living either presently or in the recent past in the area covered by the Debenham GP practice including its two surgeries in Otley and Grundisburgh.

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This report lays out the responses to the family carer questionnaire, question by question; it examines and computes these responses, categorising where clearly possible & helpful. It also incorporates experiences and views from structured interviews with the family carers, Debenham Project volunteer questionnaires and relevant professionals in social care and health services, including the voluntary sector; and discusses the findings and draws conclusions

The research is believed to be unique in its person-focused methodology and approach, and this is evidenced through the high returns and response rates.

The researchers are independent of the Debenham Project, and have a background in non-instructed advocacy, engaging empathetically to elicit information from those who are not necessarily able to give it verbally. They also are experienced in older people's services and other support and housing.

3. Context

This research has taken place at a time of change. The researchers have therefore set it against the background of these changes, which include national and local dementia strategies and changed ways of working among health, social care and the voluntary sector

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[1] www.the-debenham-project.org.uk

4. Data

4.1. PROFILE OF THE CARER & CARED-FOR

The carers indicated physical and/or mental strain and money are problems. Carers and cared-for are mainly older – three-quarters of cared-for are over 80. 19% of cared-for had moved into the area in the last five years – a higher proportion than for carers. Half the cared-for had poor physical health, a third of carers had financial problems. Roughly half lived with the carer. Changes were noted in the cared-for including character, mood, frustration, and for the carer the strain & sense of loss and sadness.

Key issues & concerns:-

a. Many carers have physical health issues that can impede looking after the cared-for
b. One in three carers report financial difficulties
c. One-third of cared-for had moved to a care setting, but there is no such provision within the vicinity, causing hardship for some carers and families
d. There is severe physical and emotional cost to the carer.

4.2. EVOLUTION OF MEMORY LOSS/DEMENTIA

Each responder was at very different stages of the memory loss/dementia journey. The most frequent first signs reported were forgetfulness; difficulty doing familiar things; misplacing things; and changes in mood. Signs that it was more than age-related included memory loss; personality change; problem or inability with familiar tasks; lack of motivation.

Key issues & concerns:-

a. Some carers and cared-for found it difficult to grasp, confront or accept the changes to the cared-for – and the burden of caring was seen as heavy.

4.3. AWARENESS, KNOWLEDGE & UNDERSTANDING OF DEMENTIA AND THOSE FIRST TURNED TO FOR HELP

Numbers stating there were signs that could have been detected earlier, point to the lack of understanding, information or pathway that carers state elsewhere. Family ties are very important and they are typically turned to first for help. The GP is first 'external' port of call – often after consultation with the family. Three-quarters of carers saw the GP's input here as beneficial.

Key issues arising:

a. More education & training is clearly needed for carers to understand what is happening and what to expect and how to care & live with it.
b. Given they are typically the first port of call beyond the family, GP practices could perhaps be the place for this role and offer advice and information
c. Literature & publicity could be further developed to highlight likely first signs, what to look for, what to expect and where to seek help[2].

4.4. IMPACT OF CARING FOR SOMEONE WITH DEMENTIA

The impacts are emotional/psychological; social/lifestyle; then practical. Chief factors are fear/worry, guilt, exhaustion, constant vigilance & attendance, and isolation. Physical health

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[2] This could be similar to the stroke leaflet *When Stroke Strikes, Act F.A.S.T:* NHS, 2009, 293293a 1p 1050K Feb 09 (Colibri), http://www.nhs.uk/actfast/documents/act-fast-a5-leaflet-white-woman.pdf

deterioration is also reported. Commitment from carers is high, despite the frequent lack of support reported beyond the family or GP.

Key points/concerns:

a. These impacts are crucial to supporting particularly the carer. Is current support here appropriate & sufficient?

4.5. AWARENESS OF HOW TO ACCESS HELP, CARE & SUPPORT & WHO FROM

Carers contacted the GP first, for help, services or signposting. Next came the Debenham Project and carers' use of their own initiative. Social Care then Health were next. The media was a source of information for some. Some help was difficult and took unacceptably long to obtain. There was too much paperwork and too little personal contact. Carers are typified by one comment: "I learnt as I went along" – a recurrent theme.

Key points or issues

a. Carers felt not supported but isolated, perplexed & ignorant. Some fell back on their own resources (initiative, family etc) or had to wait for a crisis.
b. Responsive, adequate and trusted local[3] services, advice, care & support are required.
c. Carers reported too many agencies to deal with – one gateway is needed, to ensure people have the knowledge and tools to identify what they need at the right time.
d. Given the proportion spontaneously seeking help from the GP, there could be a wider role for the GP as the access point or gateway. However, concerns were raised about the GP's knowledge, and improved training is needed
e. Help/support from other agencies was of mixed value

4.6. DIAGNOSIS, ITS EFFECT, EFFECTIVENESS & TIMELINESS

Most diagnoses were given by a consultant but 14% were reported as given by the GP. There was a mixed view about whether an early diagnosis is of value: 42% positive, 31% negative & 23% a mixed blessing. Main benefits seen were the ability to plan for the future; confirmation of the problem; early medical and other intervention; the delaying effect medication can have; improved quality of life. Main drawbacks were that it made little or no difference; confirmed worst fears; & that it provoked a sense of ignorance or helplessness about dementia. Understandably, it had mostly a negative effect.

Key Points or issues

a. There is a need for enhanced training for professionals and education of carers to ensure greater clarity about what constitutes a diagnosis, who gives it and what it gives access to.
b. Dementia is often diagnosed as a result of another presenting problem which requires eg hospital admission
c. The diagnosis is seen as the primary gateway to services but people with memory loss/dementia can have needs before the point of diagnosis. This raises questions about the formal diagnosis-led approach.

4.7. SERVICES, SUPPORT & HELP: ACCESSIBILITY, USEFULNESS & TIMELINESS

As a result of diagnosis, 50% of responders were offered a service (but for 2 out of 5 it was insufficient or late), while 40% report they were not. One-third of services offered were from the voluntary sector, a quarter from Health and less than a fifth from Social Care. Half the carers were positive in some way about the help or service offered as a result of the diagnosis, while just under half said it was not helpful in at least some way, and nearly three times as many

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[3] Local means "within the community" e.g. the local GP practice or community support project.

saw some benefit in *early* support. Prime responses to what early support would have helped were: peer support, knowledge of who to ask & what is available, and training. Most of the reasons why early support was seen as not beneficial stemmed from the cared-for baulking at it.

Key points/issues

1. Significant disquiet among carers about professional service provision – knowledge, availability, appropriateness/person-centredness & quality.
2. The most frequent service offered from the diagnosis was a list of organisations to contact.
3. It is of concern that the proportion of social care services offered/provided[4] is so low (16%), not least since this should include a benefits check.
4. The health services offered/provided figure is also comparatively low (26%), considering it includes the GP service.
5. A majority saw the services or help offered/provided as of benefit, and a strong majority saw early help & support as beneficial. Peer support, greater knowledge, and training were the key benefits foreseen of early support intervention.
6. Other health conditions precipitated a hospital admission which led to a diagnosis of dementia

4.8. CARERS' VIEWS ABOUT IMPROVEMENTS THAT COULD BE MADE & WHAT MIGHT ENCOURAGE OR DISCOURAGE SEEKING HELP

Scope for improvement was seen by carers in the services offered by professionals, mostly in the statutory sector. 2.6 times more reasons were given that *discourage* seeking help than encourage, chiefly a) emotive & reactive (eg guilt, pride, fear, denial); b) problems between cared-for/family/carer; c) problems with services; and d) the issues causing or stemming from isolation. The main areas seen as potentially *encouraging* seeking help were: a) emotive/reactive (eg desperation or dealing with the fears); b) greater publicity and awareness; c) upskilling volunteers, NHS staff & GPs; and d) increased peer support, knowledge and education of carers. Overall, half said, in different ways, that they wished they had acted sooner and/or have been more assertive.

Key points & issues

1. Even though there were fair levels of satisfaction with the services provided following the diagnosis, there is evidence that additional services were needed along with improvements to existing. 1 in 5 cases reported the dementia situation is directly exacerbated by a perceived shortcoming of the statutory health and/or care/support agencies.
2. Frustration, feelings of inadequacy, isolation, unsupportedness and bleakness are common among carers. The existence of a clear care pathway for dementia (comparable for example to that for cancer) could have eased these.
3. The encouragements & discouragements *(above)* to seeking help point very directly to areas needing development – publicity and awareness, improved services, greater education.
4. Obtaining results and action (eg for appropriate support) takes energy, assertiveness and tenacity. However, carers were frequently exhausted, depressed or demotivated.

4.9. THE DEBENHAM PROJECT & ENGAGEMENT WITH IT/ITS USEFULNESS

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[4] Notwithstanding the shift by social care away from direct provision & towards sub-contracted services via the voluntary sector

Responders had mainly heard of the Debenham Project through informal local networks, most commonly through the GP. Other sources were local publicity, the Debenham Project itself, and some other professionals were also making referrals to it. Principal benefits were seen as: contact with other people in the same situation, friendships and reduction of isolation; support, reassurance & understanding; and advice and information. There was overwhelming (but not unanimous) praise for it.

Key points/issues

1. The Debenham Project's penetration of the memory loss/dementia population appears to be reasonably effective in the light of the estimates. Responders had heard through a variety of methods.
2. There is room for greater penetration. The more informal, local networks appear relatively effective but referral from other agencies appears very low in this (historic) research sample. So there is scope for further work here.
3. In terms of the Debenham Project's helpfulness, the sample group reported a wide range of ways the Project had helped them to cope. In essence these were through the meeting of needs through services not available elsewhere.
4. Given this – and also the climate of service provision and funding – it is very important that a project which is voluntary, for and inspired by the community, continues to provide and expand its services, to work towards as close to 100% penetration as possible of the group in its area affected/likely to be affected by memory loss/dementia. However, in practice it is difficult to envisage such a community-based organisation reaching or supporting more than about 75% to 85% of this target population.

5. Conclusions

A new methodology was developed which achieved high response rates and depth of information. The purpose of the research was to illuminate the dementia 'journey' by the carers and cared-for; to investigate the pros and cons of early diagnosis and early engagement with services. The following issues emerge as the main concerns:-

- Lack of knowledge and unpreparedness of carers
- Greater range and depth of person-centred support
- Addressing the needs of a rural community e.g. transport to, and distance from, care homes
- Financial worries of carers
- Isolation of carers and the burden of caring
- The focus on the diagnosis as the gateway to services and support
- Obtaining services before diagnosis
- A single point of contact for carers and people with dementia/memory loss
- Training needs of GPs, other health and social care professionals

SECTION ONE: INTRODUCTION

1.1. The Debenham Project

The Debenham Project[5] is based in the eponymous village in mid-Suffolk. It is a unique, community-based project which has, of its own initiative, developed a comprehensive range of local services for the support of carers of those with symptoms of dementia, and those they care for.

1.2. A New Research Project

Through its work with people with memory loss or dementia, and their carers, the Debenham Project identified that there was a need for a study which would establish a clear understanding of the factors for and against early diagnosis and early engagement with advice and support services. Tim Mason & Gordon Slack were appointed by the Debenham Project in July 2012 to research what encourages or discourages families and carers in the Debenham area to seek early support and an early diagnosis for memory loss and dementia. It is believed that this will be the first project in the UK rigorously to explore these critical issues in a rural community. This research is funded by the Norfolk & Suffolk Dementia Alliance.

1.3. The Research Project Itself

The ultimate aim of the research is to enable the Debenham Project and its partners to plan what services and support should be provided locally and potentially across the region[6]. The results will also enable planning about how best to publicise what is available, so that other people in the locality (who may perhaps be experiencing difficulties or are on their own) can be assisted now and in the future.

The research plan envisaged the following steps: a) Research the context of the project and ascertain what other research had been previously carried out in this field; b) Devise & pilot a methodology using confidential questionnaires followed by one-to-one structured interviews with carers; c) Seek views and information from volunteers and professionals in the locality, including liaising with the local GP regarding possible early indicators; d) Report back & produce a final report; e) Implement a local awareness programme.

As the project unfurled, some amendments to this plan were made, as the project plan allowed for. The results of the research (suitably anonymised) were to be documented in a report and, potentially, published in one or more academic journals.

The plan envisaged that the study would establish an understanding of a) the development of the memory loss and dementia along with its impact on carer and cared-for; b) the factors which influence seeking early diagnosis and early engagement with services.

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[5] www.the-debenham-project.org.uk

[6] Debenham Project: *Helping Carers & Cared For to Ask for Help Before the Crisis* V1.4 June 2012, http://www.the-debenham-project.org.uk/downloads/steeringdocs/Dementia_Alliance_Funding_aaljm1.pdf

1.4. About the researchers

The researchers come to this project as independent workers. They were appointed because of their recent background as independent advocates working with people who potentially lacked mental capacity. Both are trained & experienced in 'non-instructed' advocacy and thus are able to engage empathetically with the client group, eliciting information about wishes, feelings, values and beliefs while maintaining a professional and critical distance. They have extensive experience in older people's services (including dementia), housing & support and also with a number of other client groups including people with a learning disability.

Acknowledgements

The researchers wish to express their appreciation to a wide range of carers, families, volunteers and professionals who responded to the request to help in this research, and for the time, sincerity and consideration they gave to it. The researchers in particular wish to thank the family carers for their willingness to share some highly personal and often difficult experiences. Their commitment and dedication was impressive and has been crucial in making this research – we hope – accurate and with a wide application.

The researchers also very much appreciate the help, insights and support they received from Lynden Jackson (the chair) and other members and trustees of the Debenham Project.

SECTION TWO: CONTEXT

2.1. Frail Older People in Suffolk

"In Suffolk, in line with global trends, people are living longer and year on year the number of people over 65 and in particular over 85 is increasing... People over 65 make up a large percentage of volunteers, and the over 65s are increasingly providing child care for grandchildren, not to mention the revenue they contribute to the economy. Ageing also brings challenges for individuals, communities and society as this is also the time in life when people are most likely to require support by health or social care. The ageing population will affect all communities and all services, from getting around (transport) to accommodation. It will touch most people's lives either directly as you age yourself, or as a family carer or indirectly as the person living next door or down the street."[7]

"One in three people aged over 65 will have dementia by the time they die. And as life expectancy increases, more and more people will be affected. Dementia is one of the biggest challenges we face today – and it is one that we as a society simply cannot afford to ignore any longer. We have made some good progress over the last few years, but there's still a long way to go."[8]

"The number of people living in Suffolk affected by dementia is set to rise by 65% for those aged 65 and over – from 9,870 people in 2008 to an expected 16,327 people in 2025. Over the same time, there will be a rise from 199 to 232 of those people aged between 30 and 64 diagnosed with dementia."[9]

2.2. Geographic Area of the Research

The area covered by this research is basically a 4 mile area around the large 'hub' village of Debenham in Mid Suffolk and covered by the Debenham GP Practice and its other surgeries at Otley and Grundisburgh, although the Debenham Project does offer a service beyond these GP areas if required, and the questionnaire reflected this in places.

The villages specifically covered or touched on were:

IP14	Debenham, Framsden, Helmingham, Little Stonham, Mickfield, Cotton, Pettaugh, Winston
IP6	Crowfield, Wyverstone, Otley, Coddenham
IP23	Rishangles, Thorndon, Beddingfield, Southholt, Wickham Skeith,
IP13	Grundisburgh, Clopton

Debenham is described as a large village in the Mid Suffolk district of Suffolk. In the 2001 census the population recorded was 1,728. In 2005 the population was estimated to have increased to 2,040 mainly as a result of the building of a new housing estate. Debenham has shops including a

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[7] *Suffolk Joint Strategic Needs Assessment*, Suffolk County Council, Suffolk PCT et al, http://www.suffolkobservatory.info/JSNASection.aspx?Section=8&AreaBased=False

[8] Prime Minister's Foreword; *The Prime Minister's Challenge on Dementia*, DH, March 2012 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133170;

[9] *Living Well With Dementia*, NHS, Suffolk County Council et al, 2011, http://www.suffolk.nhs.uk/LinkClick.aspx?fileticket=Z4byParH7Yg%3D&tabid

small supermarket, greengrocers, butcher, florists, antiques, hardware and newsagents. There are two pubs and cafes in some shops. Services include a post office, library, pharmacy, doctors, police station and fire station.

2.3. Demography

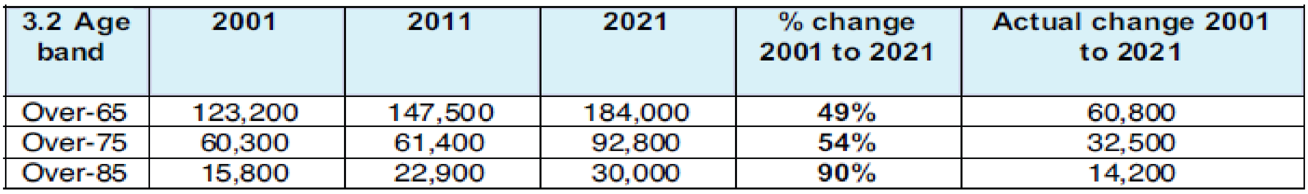
The population of Suffolk at 2001 was 668300 and estimated to rise to 755200 in 2021. In the district of Mid Suffolk the population at 2001 was 86800 and estimated to rise to 96800[10].

Number of people 65 and over in Mid Suffolk compared with the whole of Suffolk in 2001 and 2021[11]

	2001		2021	
	65 & over	**Total population**	**65 & over**	**Total population**
Suffolk	**123,200**	**668300**	**185,700**	**755,200**
Mid Suffolk	**15,200**	**86,800**	**26,100**	**96,800**

Significantly the proportion of those 65 + in Mid Suffolk is due to rise from 17.51% in 2001 to 26.96% in 2021 (compared with the rest of the county where the rise is from 18.43% to 24.59%[12]. This compares nationally with a rise of 15.86% to 19.20%[13]

Projected Change in Suffolk of the Older Age Groups[14]



3.2 Age band	2001	2011	2021	% change 2001 to 2021	Actual change 2001 to 2021
Over-65	123,200	147,500	184,000	49%	60,800
Over-75	60,300	61,400	92,800	54%	32,500
Over-85	15,800	22,900	30,000	90%	14,200

2.4. The Policy Framework

The researchers are conscious that this research has taken place at a time of change.

In Feb 2009, The Department of Health published *Living Well with Dementia: a National Dementia Strategy*, the key document for change to the way dementia is treated in the UK. Then in August 2009 the Suffolk strategy deriving from this was published: *Living Well with Dementia: Transforming the Quality & Experience of Dementia Care for People in Suffolk*. In March 2012 the *Prime Ministers Challenge on Dementia* followed. Policy and practice nationally and locally therefore is changing and consequent of this Suffolk County Council and NHS Trusts acknowledge the need for change within their organisations and have reviewed and revised their practices, processes and procedures.

2.4.1. The Norfolk & Suffolk Dementia Alliance

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[10] Source: Suffolk County Council Population projection of Suffolk and Districts from 2001 to 2021 - RSS dwelling-led projection dated 30 March 2005 http://msdc.onesuffolk.net/assets/UploadsMSDC/Economy/Strategic-Planning-Policy/LDF/Stowmarket-AAP/Population-Projection.pdf

[11] Suffolk *Joint Strategic Needs Assessment 2008-11*, Suffolk County Council, Suffolk PCT et al, *http://www.suffolk.nhs.uk/LinkClick.aspx?fileticket=OTJZVJu3B2A%3D&tabid=2896&mid=5680*

[12] Population Projection of Suffolk and Districts 2001-2021 http://msdc.onesuffolk.net/assets/UploadsMSDC/Economy/Strategic-Planning-Policy/LDF/Stowmarket-AAP/Population-Projection.pdf

[13] National Population Projections, Office for National Statistics, 2006 based, http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2006-based-annual-reference-volume/2006-based-reference-volume-no--26.pdf

[14] Suffolk *Joint Strategic Needs Assessment 2008-11*, Suffolk County Council, Suffolk PCT et al, p 17. Hyperlink as footnote 11

The funder of this research project, the Norfolk & Suffolk Dementia Alliance[15], is a strategic alliance 'committed to achieving the vision of comfort, compassion & dignity for people with dementia'. It brings together all elements of the dementia pathway (health, social care & education providers from across the statutory, independent & voluntary sectors) across the two counties. It is of note that the Alliance is currently enabling a network of dementia education hubs across the two counties, starting with Norfolk.

2.4.2. Suffolk County Council

SCC undertook their review "*Supporting Lives, Connecting Communities*"[16] which was published initially in November 2012 and rolled out through a series of staff seminars and community workshops in the spring and summer of 2013.

This proposed a new operating model part of which included the development of Neighbourhood Partnership Teams to:-

- Developing integrated locality teams where staff from different organisations work more closely together to serve their local area
- Teams based around GP surgeries and will hold regular meetings to discuss people considered at risk
- Aim to have a more collaborative approach and a better understanding of what people can offer and avoid unnecessary duplication"

This will be achieved through a three-tier model of:- early signposting; 're-ablement' through early support; and then meeting ongoing and long-term/complex care needs.

2.4.3. Norfolk and Suffolk NHS Foundation Trust

NSFT launched their "*Service Strategy 2012 –2016*"[17] which was rolled out in May, June and July 2013. This report has a section entitled "Dementia in Later Life" which states

> "This service line is for people of all ages with dementia and people with mental health problems who also have complexities associated with ageing. This service line places emphasis on early detection and initiation of treatment for dementia through a shared care arrangement with GPs. Intensive support teams will provide rapid and intensive care for people with dementia or functional mental health problems (e.g. depression) to help them to stay at home for longer.
> Hospital acute assessment beds for people with dementia will be part of the service line discharge planning and alternatives to admission will always be sought to ensure that people are admitted to hospital only when necessary. Community staff will work within integrated care teams with social and community care staff."

2.4.4. Commissioning for quality and innovation (CQUIN)[18]

This was published in February 2013. This had as one of its goals:-

> "To incentivise the identification of patients with dementia and other causes of cognitive impairment alongside their other medical conditions, to prompt appropriate referral and

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[15] www.dementia-alliance.com
[16] http://www.thesuffolkcongress.org.uk/files/health-subgroup/2012-11-15%20Suffolk%20Adult%20Care%20presentation.PDF
[17] http://www.nsft.nhs.uk/PageFiles/4479/TSS_FINAL.pdf
[18] http://www.england.nhs.uk/wp-content/uploads/2013/02/cquin-guidance.pdf

> follow up after they leave hospital and to ensure that hospitals deliver high quality care to people with dementia and support their carers."
>
> One of the impacts of this in Suffolk hospitals was to introduce a question to the assessment process at the time of an admission to hospital for people over the age of 65 (60 in West Suffolk) – "Have you had a significant memory problem in the last 12 months?". The potential impact of this would increase the number of people being referred to a consultant psychogeriatrician and the mental health services.

2.4.5. Department of Health

DH produced a report in May 2013 ("*One year on from the Prime Minister's Challenge*"[19]). Within this was an announcement of

> "A new Enhanced Service for take up by GPs as part of the GP contract for 2013/14 to reward practices for having a pro-active, case finding approach to the assessment of patients who may be showing the early signs of dementia".

Thus GPs are further operating in a climate of change which also includes a change from use of the established mini-mental test for patients with presenting memory problems to the use of GPCOG[20] (The General Practitioner Assessment of Cognition) Screening Test

2.4.6. The Voluntary Sector

This sector equally is having to be responsive. There has been the development of the Suffolk Dementia Partnership between Age UK Suffolk, Sue Ryder, Suffolk Family Carers and the Alzheimer's Society. This has seen the introduction of Dementia Advisors, Suffolk Dementia Helpline and a Dementia Enabled Village Project. The Dementia Advisors have been specifically active with carers and cared for within the Debenham Project and the Village Project has evolved from the example that the Debenham Project sets as a "Dementia Friendly Community". The Debenham Project itself has developed providing a range of local support to people with memory problems and their carers.

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[19] https://www.gov.uk/government/news/dementia-diagnosis-to-be-overhauled

[20] http://www.gpcog.com.au/

SECTION THREE: THE RESEARCH – AIMS & METHODOLOGY

3.1. Aims & Purpose of Research

The aim of the research is to enable the Norfolk & Suffolk Dementia Alliance, other agencies & Debenham Project and its partners to plan what services and support should be provided locally and potentially across the region. The results will also enable planning about how best to publicise what is available, so that other people in the locality (who may perhaps be experiencing difficulties or are on their own) can be assisted now and in the future.

This research uses a targeted, person-centred and conversational approach to elicit (1) the experience and perceptions of (and the learning from) caring for and witnessing memory loss/dementia and its evolution; (2) the pros and cons of early diagnosis and early engagement with services and (3) the help and services that are needed in/near Debenham

It provides solid and specific (albeit local) data to (a) assist the Debenham Project to improve on what it already does and (b) compare the assumptions behind national, regional & Suffolk policy and thus help test their robustness.

This open-ended and informal methodology lends itself to being replicated by others.

3.2. Methodology

3.2.1. Rationale

The researchers, in conjunction with the Debenham Project Chair, developed a complete methodology to fulfil the aims of the research plan. An outline of this has been written by the Chair[21].

In summary, it involved capturing the experiences and perceptions of family carers, volunteers and other interested parties. A discrete methodology was deemed necessary because it is unclear that current methods (eg online questionnaires, postal surveys, focus groups and service user forae, service user champions, consultation workshops etc) could be shown to meet the project criteria.

The key concepts of the methodology lie in recognising that the form of interaction with the participant is critical to obtaining a positive and accurate response. Hence the focus on user-friendliness and personal, conversational contact by using open questions and structured interviews. There is also a distinction between the data capture and the data analysis.

The methodology is possibly even an unexpected outcome of this project, since it appears to stand on its own to an objective observer. For this reason, it is available for other research where potentially useful. Therefore the full documentation is referenced below[22].

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[21] *A Basic Survey Methodology*, L Jackson, 28 6 13 http://www.the-debenham-project.org.uk/downloads/research/reports/Survey_Methodology.docx

3.2.2. Survey Groups

1. Family Carers known to Debenham Project

Questionnaire

The questionnaire was designed, piloted and then refined. It was designed either to be posted or emailed. The postal version included post-it notes for lengthier comments, while the email version allowed for each response box to expand as typed. A stamped, addressed envelope was included, along with a covering letter. The design was purposely informal, jargon-free and the questions were open-ended to elicit as full responses as possible.

Face-to-face interview

A list of prompts was designed to elicit more detail in face to face interviews by the researchers. They met with as many as possible of the family carers who had returned the questionnaires. The aim was a relaxed, conversational style in order to add depth to the picture already gained from the questionnaires. When making the appointment to meet, the researchers asked for an hour for meeting but in the great majority of cases, the conversation extended well beyond this at the carer’s volition. While these interviews dug deeper, they confirmed the questionnaire findings.

2. Debenham Project Volunteers

A questionnaire was designed and posted/emailed to volunteers with the Debenham Project. The object of this was to obtain a range of views, information and opinions about the research topics from a cross-section of those engaged in various roles to do with dementia locally.

3. Professionals

Interviews were arranged and conducted with relevant professionals across Health, Social Care and Voluntary Organisations. This included local GPs, particularly in order to obtain their views regarding the dementia journey as well as early indicators of memory loss/dementia. The intention in approaching this group was to flesh out and interrogate the narrative obtained through the family carers. These interviews also provided a more up-to-the-moment picture of current policy, practice and performance.

3.2.3. Devising and Trialling the Methodology

During Stage One of the research from July to December 2012, the researchers devised and tested a means of engaging with carers in the Debenham area.

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[22] *Family Carer Questionnaire; Volunteer Questionnaire; Structured Interview Template and Prompt, at*
http://www.the-debenham-project.org.uk/downloads/research/reports/CarerQuestionnaire_version3_12_3_13. doc
http://www.the-debenham-project.org.uk/downloads/research/reports/DebProjVolunteersQuestionnaire_050813.doc
http://www.the-debenham-project.org.uk/downloads/research/reports/Brief_for_Structured_Interviews_Oct12.doc
http://www.the-debenham-project.org.uk/downloads/research/reports/Structured_interview_guide_questions251012.doc

The methodology trialled by the researchers comprised a questionnaire and a follow-up face to face structured interview. The first iteration of the questionnaire was designed as a specification for the information sought. It was then redesigned to be informal with open-ended questions avoiding technical language, seen as more appropriate to the target population of older people. The face-to-face interviews involved going into greater depth through structured conversation and listening by the researchers. The captured data and informal contributions were analysed and restructured into the final format.

The level of engagement obtained by this methodology was very strong and a significant depth of information was obtained. There was a high response rate, and the data obtained was pertinent to the aims of the project. Thus this methodology appeared to be a robust means of engaging with carers and obtaining detailed and accurate information. It was established that the methodology developed appeared to be complete and potentially sufficient for use by others seeking to engage with people, in a non-prescriptive and personalised way, in this and other areas of research.

3.2.4. Rolling out the questionnaire

From January to July 2013, forty-two questionnaires were sent to family carers. Data from this group was both quantitative and qualitative (i.e. statistical and narrative) and formed the heart of the research. The core data in the research was that gathered in the questionnaires, while the narrative data obtained through the interviews to add depth is reflected in this report and will be reported in further detail in a supplementary report to be produced later.

The researchers reported to the Trustees and Steering Group of the Debenham Project at the beginning of July with an analysis of some headline statistics, initial observations and conclusions.

During this period, the researchers held interviews with a number of professionals from statutory and voluntary organisations, and Debenham Project volunteers again reflected in this report and to be reported in greater detail in the same supplementary report.

SECTION FOUR: DATA GATHERING

4.1. Engagement with Target Groups

The researchers made contact with everyone appropriate on the Debenham Project's database caring for someone with dementia currently or in the recent past. This was a key aspect of research. The estimated universe is between 70 and 100, and the research has engaged with 42 of these, approximately 40% to 60%[23] [24]. This is a high penetration figure, and the researchers appreciate it may not be possible to reach this figure in all other communities were the research to be replicated.

Other research in this field appears increasingly to be undertaken online. However, as can be seen from Question 2 of the family carers' questionnaire below, 71% of the target group of carers are over the age of 60. This group may be less computer proficient and so less penetration is likely. The questionnaire was offered online but only a few (four) chose to return it in this way. This indicates that the methodology is more appropriate to this client group as can be seen by the very high response rates.

The table below shows the returns from the questionnaires despatched.

Family Carers			
1. Questionnaires sent out in total		**42**	
• **Completed and returned**		**37**	**88%**
• *Unable to complete due to illness*	3		
• *Not returned as not immediate carer*	2		
2. Interviews taken place		**32**	**76 % of questionnaire universe or 86% of responders**
• *No response to request*	1		
• *Not possible to interview*	2		
• *Carers/cared-for too far away to be feasible or relevant*	2		

Volunteers[25]			
Questionnaires despatched		37	
Replies received		25	68% response

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[23] *Prevalence & Growth of Dementia in Debenham*, Debenham Project, July 2009, http://www.the-debenham-project.org.uk/downloads/articles/0907prevalence.pdf

[24] The researchers' own analysis of village populations by parish, Oct 2013, http://www.the-debenham-project.org.uk/downloads/research/reports/ResearchersAnalysis_Villagepops.xls

[25] Responses from volunteers involved with the Debenham Project were received from trustees (4); steering group members (5); lunch club helpers (6); phone helpline volunteers (7); food 'n' friends volunteers; carers' café helpers (2); fit club helps (2); carers (2). Of the 25 responses from volunteers, 15 had been involved for more than 4 years (the inception); 3 -4 years 4; 2 – 3 years 3; under 2 years 3. Asked how they had heard about the Debenham Project, 9 had heard from the current chairman and 5 from their attendance at the initial meeting. Of the 25 who responded, 11 had experience of caring through an immediate family member; 4 had been involved professionally with people with memory problems; 5 had no previous direct experience of people a memory problem.

The researchers interviewed 12 Professionals, from Health, Social Care & Voluntary Organisations.

4.2. Objectivity, Accuracy, Weighting & Reliability of Raw Data

4.2.1. Those approached

The people who were sent questionnaires were all provided from the database of the Project. There were some names not given to the researchers because of current sensitivities e.g. crisis of cared for. It is acknowledged therefore that responders were familiar with Debenham Project and thus could have some loyalty to that project. However much this is the case, their responses are still the views of a large proportion of the total dementia population and their carers.

The responders were carers rather than people with dementia themselves. Thus this study reflects the views of the carers principally, followed by the views of volunteers and professionals rather than the direct views of the cared-for.

4.2.2. Those not approached

The research did not question or interview the cared-for directly. This was not allowed for in the project plan, and in essence the reason is that for this research, experiential yet concrete observation is required. Also, accuracy and objectivity in recording are important. Consideration of the situation of the cared-for reflected on the fact that they would most likely be at different stages of the memory loss ‘journey’. Categorising memory loss into mild, moderate and severe, it might be possible to gain some useful data from people in the mild category, but because they would not have experienced significant changes in eg behaviour, memory, personality, their responses would be hypothetical. By the same token, the moderate and severe cared-for would for the very same reasons be strongly likely to yield progressively less reliable data. See Section Six, Question 19 below. Therefore the information was obtained from the carers principally since it was they who were taking the initiatives. The information was supplemented and broadened by information from the volunteers and professionals. It was person-specific, observational and lived-with. While it was not always objective, it was most certainly experiential and concrete, and in turn has been recorded accurately and objectively.

The researchers attempted to see if there were any people who had received a diagnosis currently living in the Debenham area who might not be known to the Project. This they did through contact with statutory and voluntary organisations. Unfortunately, it proved not possible to get that information in the timescale as there were issues of confidentiality and consent.

4.2.3. The Dementia Universe & Penetration of the Target Group

The aspiration of the research project was to enable the Debenham Project (after the research) to increase its contact with the dementia population from its current 50% to 70%. Estimates[26] shows between 70-120 people in total currently likely to have dementia within the study area, the Debenham Project supplied 42 names to the researchers.

The Debenham Project is well known to most if not all organisations involved with memory loss/dementia and has active relationships with those organisations. In the light of work done in 2010 with the GP practice, the Debenham Project believe that people with memory loss/dementia are referred by the GPs to them. The Debenham Project’s database at the time of the research contained 51 family carers, of whom 42 were appropriate to be contacted as in 4.1. above. There are additionally between 21 and 26 other people/families known to the Debenham Project who

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[26] See footnote 23 & 24

have either a) received support in the past; b) currently receive some level of support but were not appropriate; and c) who they know of but who are not supported at present.

The researchers are thus satisfied that the response rate is significantly high.

The Debenham Project has a good network within the community and has a very active publicity and publications programme. The GPs surgeries all display literature, the Post Office and library prominently display posters and leaflets. Articles are a regular feature of the Parish newsletter. There was very significant publicity of the Project at the time of the launch.

While it is felt that the responses do show significant reliability, the researchers do recognise that there is quite a strong commitment and bond with the project and its personnel. However, this does not diminish the value of the responses in terms of the aims and objectives of the research.

4.2.4. Individual Perspectives

Even though the responses have in many places been categorised, the analysis captures all perspectives. For example where a single response is given this will be shown as 2% or 3% (depending on the number of responders to that question). This highlights the range of responses, the uniqueness of each responder and their journey – and so the importance of capturing each response.

4.2.5. Snapshot

The researchers recognise that, of those carers who were sent questionnaires and later interviewed, the majority started the dementia journey some years ago. Equally, the researchers acknowledge that there are and have been major changes to the commissioning and delivery of services. Therefore, most carers who responded had experiences of services which related to systems that previously existed, or at least began then.

Thus comments which carers made, particularly about what they perceived as poor practice, may possibly no longer be applicable and service providers are certainly looking to improve their procedures.

This data will nonetheless still be key. It provides a picture in its own right, and most of the responders are still caring today for someone with dementia; they have not indicated that there has been a dramatic change in approach by services, or in effect on the person they care for or indeed on themselves. Further, the data will provide a baseline to compare against once there is a bank of data about how services are post the changes, and so to test whether the points raised have been addressed.

4.2.6. Uniqueness

The research is felt to be unique. It appears to be the first in-depth survey of its kind which does not rely on a tick box approach, and thus goes into a greater depth than any research so far identified by the researchers. The methodology permits a high level of freedom of response among the survey group through its person-focused, jargon-free informality and personal contact. It has obtained a very high level of response and has returned a very in-depth picture of the experiences of those on the dementia/memory loss ‘journey’. The researchers are trained & experienced in ‘non-instructed’ advocacy thus are able to engage empathetically with the client group while maintaining a professional and critical distance.

SECTION FIVE: DATA GATHERED

5.1. Introduction

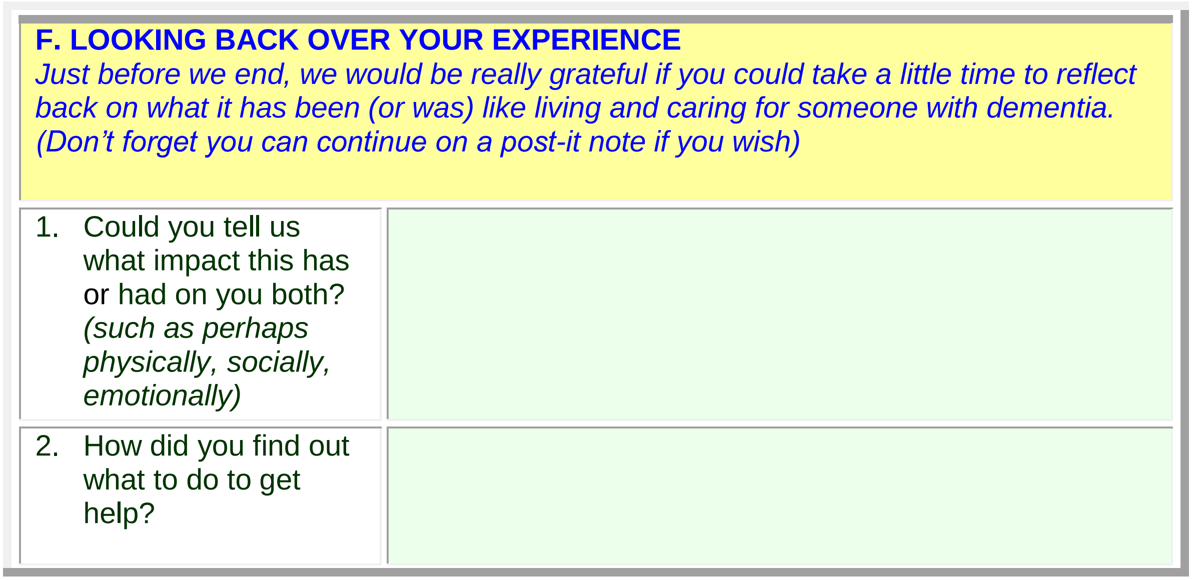
This section details the actual responses to the questionnaire that was sent out to 42 carers of someone with dementia known to the Debenham Project. It relays the answers given question by question and gathers these together where possible while showing individual responses where this is not possible. Every person's situation was different: ergo likewise their responses. This is a very important factor in this research, which the methodology both enables and captures.

It will be seen that individual situations and responses have been drawn out. The researchers have been very careful to ensure that every response is captured, and to try to draw out factors rather than to read them in to data. However – and equally – commonalities, trends and overarching key factors have been categorised where clearly possible. Almost all responses were unprompted beyond the basic question; where there was a prompt, it is highlighted under the relevant question.

The commentary and conclusions are also informed by the supplementary views, comments and perceptions gathered through face to face interviews with the questionnaire responders. The responses of Debenham Project volunteers (who returned a separate questionnaire designed for their use) have provided additional colour to the commentary and hence conclusions, as have the comments of the dozen professionals interviewed.

The commentary is the researchers' and is their view only: other people may reach additional or different conclusions.

Below is an ***excerpt*** from the original questionnaire to carers, for the reader to obtain a flavour of the style and questioning[27].



F. LOOKING BACK OVER YOUR EXPERIENCE
Just before we end, we would be really grateful if you could take a little time to reflect back on what it has been (or was) like living and caring for someone with dementia. (Don't forget you can continue on a post-it note if you wish)

1. Could you tell us what impact this has or had on you both? *(such as perhaps physically, socially, emotionally)*	
2. How did you find out what to do to get help?	

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[27] It highlights also that the responder had the ability to give as long or detailed a response as they wished (i.e. through the post-it notes supplied). If (as only a few did) they had elected to respond via email, the form would expand automatically as they typed.

3. What do you feel are the things that might encourage or discourage seeking help?	
4. Looking back, from what you know now, what if anything would you do differently?	
5. Knowing what you know now, what if anything are the benefits and/or downsides of an early diagnosis of dementia?	

5.2. Reading the Data

In the following section, each table below lays out the responses to an individual question. There are forty-one questions in all. A percentage is given for each response listed. Where a level of 2% or 3% is shown, this will indicate a single response. The number of responders is listed out of a possible thirty-seven as per Section 4.1 above.

Comments, conclusions and comparisons are given for each question, or in a number of cases several questions are compared and joint conclusions drawn.

The questionnaire (as used by responders as below) was divided into sections A to E, with 41 questions. These sections were:-

Section	***Questions***	***Topic***
A	Questions 1-8	About the Carer
B	Questions 9-18	About the Cared-For Person
C	Questions 19-26	First Signs That All Was Not Well
D	Questions 27-30	Diagnosis
E	Questions 31-33	Getting Help
F	Questions 34-41	Looking Back Over Your Experiences

The findings from each question are investigated below, using the sections and question numbers from the questionnaire.

SECTION SIX: DATA – RESPONSES

Section 5.2 immediately above lays out how to read this data. It follows the format of the original questionnaire to family carers of someone with memory loss/ dementia. This section gives the results of the research itself.

A. About The Carer

The questionnaire was sent to family carers, who were either the primary carer or the next closest carer.

First, a preliminary question was posed:-

Relationship of carer to cared-for	34 responders
Spouse or partner	53%
Daughter	26%
Son 12%	12%
Daughter-in-law or son-in-law	9%

So approximately half the carers are the spouse/partner of the cared-for and half their children/ children-in-law.

From here on, questions were posed in this section of the questionnaire that sought to build a picture of the carers themselves.

Question 1[28]:

Time in or near Debenham Total responders: 31	
	19 carers reported:-
Lived in the area for more than 10 years	85%
of which: Lived in area more than 31 years or all their life: 48%	
Ditto 1-5 yrs	10%
Ditto 6-10 yrs	5%
	12 carers reported:-
Live within either the Debenham surgeries area or 5 miles of it	92%
Live elsewhere	8%
Of which…	
Cared-for lives with them (or vice-versa) or within walking distance	42%
Live within 4 miles of the cared-for	25%

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[28] This question was altered during the survey from ‘How long have you lived in or near Debenham?’ to ‘Please say where you live and how far is it from the person you care (or cared) for?’. Hence the lower response nos. for each part.

within 10 miles	8%
within 30 miles	8%
elsewhere	17%

85% reported they had lived in the area for more than 10 years, with 48% of the 19 having lived there more than 31 years or all their life. Then of the further 12 carers responding, 92% stated that they live within either the Debenham surgeries area or 5 miles of it. Of this 12, 42% said the cared-for lives with them (or vice-versa) or within walking distance, 25% that they live within 4 miles of the cared-for, 8% within 10 miles; 8% within 30 miles and 17% elsewhere.

Thus the great majority of responders are very familiar with the area and have lived there in excess of 10 years. Two-thirds of responders to the second iteration of the question live very locally to the cared-for or even with them.

Question 2:

Carers' age	35 responders
Under 50	3%
50-60	26%
61-70	23%
71-80	23%
81-90	25%

Thus 71% of carers are over the age of 60 and approximately a quarter of responders fell into each decade between 50 and 80 years old.

Question 3

Please say what you do or did as a job or occupation	35 responders
Leadership, management or business ownership	49%
Clerical, skilled or sales	29%
Education/health or public sector	14%
Manual work	6%
Retired	3%

It can be seen that broadly the carers were comparatively well-educated and/or used to some level of responsibility in their past or present working lives.

Question 4:

Who else do you live with? *(eg husband/wife, partner, children, family, other carers)*	35 responses
Spouse or partner	52%
Spouse and children	6%
With family	11%
Alone	31%

An analysis of carers and cared for living at the same address shows that of the 34 people who responded, 16 were living at the same address as the person they cared for.

Table A below lists age of carer in descending order, giving the age of the cared-for in the next column. Table B shows the age of the cared for in descending order.

Table 4A

Age of carer	*Age of cared-for*
90	90
89	87
88	90
87	87
84	87
83	82
81	83
80	80
77	83
77	72
76	84
76	80
71	78
70	76
59	84
51	73

Table 4B

Age of cared-for	*Age of carer*
90	88
90	90
87	84
87	89
87	87
84	59
84	76
83	77
83	81
82	83
80	76
80	80
78	71
76	70
73	51
72	77

This shows that 8 carers over the age of 80 are living with the cared-for who is also over the age of 80; and 5 of the 16 cared-for over the age of 80 are living in the same house as and being supported by a family carer also over the age of 80.

Question 5

What kind of property do you live in & how many bedrooms	35 responders
Type	
Detached house	54%
Semi-detached house	11%
Bungalow	31%
Flat	3%
Accommodation	
1-bedroom	3%
2-bed	20%
3-bed	37%
4-bed	23%
5-bed	11%
6-bed or more	6%

Again, the profile is of a largely fairly affluent group, and it is interesting to note that 34% live in a bungalow or flat – which is likely to be more suited to those with increasing physical or mental frailty.

Question 6:

How is *your* health – are there any particular issues?	38 responses from 35 responders
Osteo-skeletal	43% (arthritis 29%)
Heart/lung (inc blood pressure, asthma etc)	24%
Sight	9%
Multiple	9%
Cancer	5%
Balance	5%
Stress-related	5%

Of 35 responders, 56% said they were in excellent or good health; 36% in fairly good or moderate health; and 8% in poor health. Many of these conditions are likely to inhibit carers in physically strenuous or other key parts of the role.

It should be noted that the impression from the structured interviews was that the carer downplayed their own physical health.

Question 7:

Sufficient income/savings – carers	32 responders
Yes	44%
Yes at moment/yes with care	16%
Borderline/maybe/depends	19%
No	13%
Not applicable	8%

While 60% of responders are saying they are managing financially, 32% are saying they are either not managing or that they may not be now or in the future. Coupled with data further below about how stressful and full-time the caring role is, plus the inability to know what is coming their way, this is a worrying proportion and the statutory organisations do not seem to be of much help.

Question 8: Anything else

5 comments were made but not pertinent here

B. About The Person You Care For

This section asked similar questions but about the person with memory loss/dementia. NB it was the carer reporting.

Question 9:

Time in Debenham area	32 responders
Lived in area 1-5 years	19%
Lived in area 6-10 yrs	3%
Lived in area 11-20 yrs	16%
Lived in area 21-30 yrs	16%
Lived in area 31+ yrs	34%
Lived in area all life	12%

This shows a somewhat different pattern to that of the carers in Question 1, although it should be noted that this question was asked of a greater number of respondents here. It is noteworthy that 19% have moved into the area in the last 1-5yrs, compared to 10% for the carers. The number reporting 6-10 years is lower than for carers while those indicating 11-20 years and 21-30 years has moved from circa 10% to 16%. However, the numbers here who have lived in the area for 31+ years (including all their lives) is close to that of the carers.

But overall, apart from the numbers having lived in the area for 1-5 years having increased sharply compared to the carers, the picture is still of a group settled in the area for a significant period of their lives. This would tend to indicate strong local links/networks & knowledge.

Question 10:

Age of cared-for	34 responders
50-60 years old	0%
61-70	0%
71-80	26%
81-85	26%
86-90	33%
91+	15%

This reveals that there were no cared-for people under 71 years of age, with the bulk being 86-90. This contrasts with the carers, where 3% were under 50, and roughly 25% were in each succeeding decade up to (but not including) 91+ which was empty.

Question 11:

Health of the cared-for	35 responders
Excellent/good/much improved	31%
Moderate	20%
Poor	43%
Death (rapid decline – cancer)	3%
Difficult to assess	3%

Thus just over half (51%) reported the cared-for being in moderate to excellent physical health, while just under half (46%) reported poor physical health (including death in one case). From this it can be evidenced that dementia/memory loss does not necessarily precipitate physical decline and that physical health problems are reported in less than half the cases. Elsewhere though it will be noted that it can be the physical health issues that precipitate health intervention which results in a dementia being noticed and possibly diagnosed.

Question 11a:

Health conditions listed	37 responses (ex 22 responders)
Osteo-skeletal	23%
Heart/lung (inc asthma)	20%
Physical disability/reduced mobility	9%
Progressive condition (eg Parkinson's)	9%
Hearing	6%
Sight	3%
Cancer	3%

Epilepsy	3%
Kidney	3%
Incontinence	3%
Psychological	3%
Hypochondriac	2%
Other medical condition	13%

Ten people recorded more than one condition, and it should be noted that responders here included not just those who said the health of the person they cared for was ‘poor’ but also ‘good’ or ‘moderate’. One carer noted that they (and their family) felt the dementia had come about or accelerated as a result of two strokes.

Question 12:

Job/Occupation of Cared-For	34 responders
Professional/management/director	47%
Sales/clerical/skilled/catering	21%
Education/public sector/health	12%
Housewife	12%
Manual	6%
Disability pension	2%

The percentages here are mostly very similar to those of the occupations of the carers (Question 3), although no housewife category was recorded there. Thus as with Question 3, a fairly well-educated, comparatively affluent profile is revealed, many of whom who were probably used to taking responsibility and initiative in their working lives.

Question 13:

Do/did you live at same address as person you care/d for	31 responders
Yes	52%
No	48%
4 (13%) ex 31 gave further explanation:-	
Yes – cared-for now lives with one of children who has own family	1 person i.e. 3% of total
No – now in long-term care	2 people i.e. 7% of total
No – carer is cared-for’s child with own family	1 person i.e. 3% of total

Question 14:

If no to Q13 – What kind of accommodation (if the cared-for does not live with carer completing the questionnaire)	15 responders
3-bed council house	7%
Bungalow	26%
Next door	7%
Now with us	7%
Sheltered	20%
Registered Care Home	13%
Nursing Home	20%

Question 15:

Has the cared-for's memory loss/dementia caused a move	23 responders
Yes	39%
No	61%
Further comments	
Yes's	
Moved to be near family	33% of 9 yes's
Not safe on own	11%
Eventually	11%
Not entirely due to memory, but our cottage was too old fashioned	11%
Had to sell cottage due to dementia, as it was too far away	11%
No's	
Current familiar surroundings help – esp garden & workshop	7% of 14 no's
Had aids & adaptations fitted	7%
Didn't but very nearly did	7%
Didn't have memory loss	7%

Question 16:

Does/did where the cared-for lives/lived suit their needs	31 responders
Yes [predominant response]/ yes at present	65%
Yes after aids & adaptations	10%
Mostly	10%
Became unsuitable	15%

Conclusions to Questions 13-16: These questions were included partly to verify the suitability of the accommodation in the light of advancing mental and potentially physical frailty caused by progressive memory loss/dementia.

At first reading, there may appear to be some anomaly between the answers to all these questions. In Q15 nearly 40% (i.e. 9) of the 23 responders report that the cared-for has moved due to the memory loss/dementia. In Q 14, 15 carers reported the cared-for lives separately from the carer (though only 14 actually do – one reports that the cared for is 'now with us'), but of course this does not necessarily denote that they have moved because of the memory loss/dementia.

The further comments in Q15 indicate some of the reasons why the cared-for did (6 responses) or did not (4 responses) had to move. The reasons for moving include risk to self (cared-for), distance from family/family potentially taking on primary caring role, and unsuitability of the property. The comments on why a move was not necessary refer to the importance of familiar surroundings and activities, and the capacity in some cases to adapt the property to make it suitable for changing needs. The responses to Q16 throws further light on whether or not their housing suits the needs of the cared-for. While 15% said that it became unsuitable (reasons included 'remoteness from family' or 'not as the dementia advanced'), 75% were unequivocal about its suitability, at least at the present. With the remaining 10%

indicating 'mostly' alright[29], 85% were saying that the accommodation for the people cared for is at the very least mostly alright.

A point of note is that 36% (of 13 responders to Q14) live in specialist provision with full care on site (i.e. care home or nursing home); 21% live in housing with some innate suitability to physical frailty with perhaps a modicum of housing-related support (i.e. sheltered); while 29% live in a bungalow which can offer pretty much the same suitability as sheltered (given the general reduction in wardens' remit and given other visiting or telephone support or technology available) depending on aids & adaptations installed or whether they are of mobility standard or fully wheelchair accessible.

Of the full 15 responses to Q14, two-thirds are living in a homely/domestic environment while one-third are living in an institutional environment. While the latter may provide necessary care and support, they are environments where residents/patients have to conform in many ways to an imposed routine rather than being able to continue familiar life patterns. This may be counter-productive for people with dementia, as one of the further 'no' comments in Q15 implies.

33% of those responding to question 14 state that the person they had cared for had move to a care home or nursing home – yet there is neither of these provisions in Debenham. The nearest is a minimum of 7 miles away while others are more distant still. Thus significant travelling is involved to see relations and there is no direct public transport.

Question 17:

Do you or did you feel they have (or had) enough income or savings to live on?	31 responders
Yes	58%
Just about/ probably/ at the moment	35%
No	7%

93% were affirmative or cautiously affirmative regarding the cared-for's sufficiency of income. Part of this may be due to benefits and allowances

But whatever the reasons, it contrasts with the carers' picture in Q7. There, 32% were saying their income/savings were either borderline or insufficient. Another potential ingredient may well be that (Q4) 31% of carers live alone, and paying in some way for two establishments will be more costly – especially where (Q14) 33% of the 15 cared-for live either in nursing or residential care, where the fees (if partially or wholly funded by the cared-for/carer) will be a large drain on capital or income.

Notwithstanding the very high percentage indicating sufficient income/savings, the 7% reporting insufficient income is important as in each case it is ultimately unsustainable.

Question 18:

Any other information you would like to add here	9 responders
Spouse [i.e. cared-for] gets frustrated as can't do what used to	1 responder
Cared-for won't communicate with spouse [carer] since hospital – blames her?	1 responder

---

[29] One comment here, 'Wet room/improved bathroom needed', occurred in different places across the questionnaire from different responders.

'Dementia has changed my mother – only upside is she's not aware'	1 responder
Cared-for had to move to sheltered when daughter (who lived with) lost home	1 responder
GP said carer could no longer cope	1 responder
Cared-for's poor physical health more difficult than the dementia	1 responder
Emotional pressure from cared-for to family to keep her in own home	1 responder
Carer feels 2 sons diagnosed with cancer caused cared-for's depression	1 responder
Had a happy marriage	1 responder

These comments together start to give a wider picture of the impact of memory loss/dementia on the carer and the cared-for – such as the change in character and mood, frustration, strain for the carer of coping, their sense of loss and sadness, and perhaps the way that sometimes it takes an outside person (eg GP) to 'legitimise' what the carer needs.

C. First Signs That All Was Not Well

From deducing a profile of the carer and the cared-for person, the questionnaire now moves to onto the memory loss/dementia itself. This section examines the beginnings of the 'journey'

Question 19

What were the first signs that all was not well?	81 responses from 35 people
Difficulty with familiar tasks (inc 6% driving erratically)	28%
Forgetfulness/memory loss	25%
Changes in mood or behaviour	16%
Misplacing things	7%
Lethargy/ less motivation	6%
Changes in personality	3%
Problems with language/vocabulary	3%
Decreased judgement/confusion	9%
Repetition	3%

The responses have been grouped into 12 headings rather than listing the 27 separate conditions stated from the 81 responses, which equates to an average of 2.3 comments per responder. Unlike most other questions, this one gave some prompts – "*eg. forgetfulness, difficulty doing familiar things, misplacing things, changes in mood etc*". This most probably explains why these four issues had the highest responses. However, the four prompts do represent probably the most common areas generally for dementia, and together accounted for 'only' 65% of the total responses (albeit numbers for the other responses are small. But it is perhaps probable that the prompts were merely an aide-memoire to start carers' responses off here.

Question 20

How did things change?	59 comments from 33 people
Greater difficulty with familiar tasks	16%
Greater memory loss	14%
Decreased judgement	8%
Wandering/running away	3%
Changes in personality	11%

Changes in mood/behaviour (inc depression)	22%
Decline in physical health	3%
Collapse	3%
No change	2%
Less motivation	2%
Rapid change over 18 months	2%
(Very) slowly worse	4%
Hospital admission	2%
Needed support	2%
Spouse lacks understanding and can be cruel	2%
Carer isolated and stressed	2%
Dementia improved when physical health improved	2%

Question 21

How are (or were) things most recently?	60 responses from 33 people
Died, or home-then-hospital-then-nursing-home-then-died	8%
Same or similar to previously	10%
Greater memory loss	12%
Physical health worse	8%
Greater difficulty with familiar tasks	12%
Good days & bad	10%
Increased problems with daily living tasks	10%
Frustration	5%
Worse	7%
Same	2%
Improved	5%
Changes in mood/behaviour (depression)	3%
Moved to nursing or residential care	5%
Needed (paid) support/care	3%

Summary/comparison between Q19, 20 & 21:-

Condition/issue *(NB. Condition increased left to right)*	**First signs all was not well?** (81 responses ex 35 people)	**How did things change?** (59 comments ex 33 people)	**How are/ were things most recently?** 60 responses ex 33 people
Difficulty with familiar tasks	28%	16%	12%
Forgetfulness/Memory loss	25%	14%	12%
Changes in mood or behaviour	16%	22%	3%
Misplacing things	7%		
Changes in personality	3%	11%	
Problems with language/vocabulary	3%		
Decreased judgement/confusion	9%	8%	
Repetition	3%		
Less motivation	6%	2%	
Wandering/running away		3%	
Decline in physical health		3%	8%

Collapse		3%	
No change		2%	2%
Rapid change over 18 months		2%	
Worse		4%	7%
Hospital admission		2%	
Needed (paid) care/support		2%	3%
Spouse lacks understanding and can be cruel		2%	
Carer isolated and stressed		2%	
Dementia improved when physical health improved		2%	
Same or similar to previously			10%
Good days & bad			10%
Improved			5%
Increased problems with daily living tasks			10%
Frustration			5%
Moved to nursing or residential care			5%
Died, or home-then-hospital-then-nursing-home-then-died			8%

Each responder was at a very different stage of the memory loss/dementia journey. While the number of respondents to each of these three questions decreased after after Q19, it is noteworthy that the top issues in all were difficulty with familiar tasks, memory loss and mood or behaviour.

The answers to Q19, Q20 & Q21 give a wide picture of the progress of the memory loss/dementia journey. The picture is one of progressive decline, although in Q21 there was 25% reported some levelling out or even improvement.

Question 22

What made you think it might be more than part of the ageing process?	56 responses from 31 people
Short-term memory loss/repetition	19%
Personality/mood/behaviour change	13%
Problems or inability re familiar tasks	11%
Lack of motivation	11%
Inability to concentrate/vagueness	5%
Didn't absorb things	5%
Not sure/difficult to pinpoint	5%
Fantasising/hallucinations	5%
Confusion	4%
Didn't detect/ didn't detect at first	4%
Didn't detect – masked by severity of physical health condition	2%
Carer/carer & cared-for covered it up/wouldn't face it	4%
'Just had to be'/ carer recognised signs of dementia	4%
Misplacing things	2%
Sudden change	2%

Language difficulties	2%
Daughter noticed	2%

As can be seen clearly here, there are four major reasons why the carer considered that what they were observing in the cared-for was more than age-related memory loss – primarily memory loss (1 in 5), then (each with almost half the number of responses) personality change, a problem or inability with familiar tasks, then a lack of motivation – which could also be seen as a personality change as well, as indeed could many or most of the other factors listed.

It could be felt that the more of these conditions listed by each responder, the more certainty there might be in their mind that it was more than age related, given the 56 responses from 31 responders. But in fact 19 responders listed a single condition while 12 listed multiple conditions.

A selective comparison between Q19 and Q22 reveals the following overlaps:

Issue listed where there is a significant overlap	Q22: More than age-related memory loss	Q19: First signs all was not well
Forgetfulness/memory loss/repetition	29%	28%
Changes in personality, mood or behaviour	13%	19%
Difficulty with familiar tasks	11%	28%
Decreased judgment/confusion		9%
Lack of motivation/ lethargy	11%	6%
Confusion	4%	5%
Misplacing things	2%	7%
Problems with language/vocabulary	2%	3%
Repetition		3%
Language difficulties	2%	2%

It can be seen that there was overlap between the issues which triggered the carer to see it was more than age-related and the first signs the carer noticed that all was not well.

Q22 provides additional depth to the ‘first signs’ of Q19. Firstly, it lists additional behavioural conditions that the carer noticed over and above those listed in Q19. Secondly, it adds to the overall picture of the carer and their knowledge, insight and clarity of thought against a background of exhaustion, eg where some listed that they had not detected it while others just knew it had to be dementia.

It also highlights again the issue discussed elsewhere that dementia can be hidden by severe health conditions. Further, it highlights the fact that a not insignificant minority of carers and cared-for find it difficult to confront what is happening.

Question 23

When did you start to think this (i.e. that it might be more than the ageing process**)?** *(NB periods of time are those stated by responders)*	**(Approx year)**	26 responses from 27 responders (sic)
A few months ago	2013	4%
2 yrs ago	2011	13%
3 yrs ago	2010	4%
3½ - 5 yrs ago	2008-2010	7%
4 yrs ago	2009	7%
c.5 yrs ago	2008	19%
5-6 yrs ago	2007-2008	4%
6 yrs ago	2007	4%
8 yrs on	2005	4%
Over 11 yrs ago	2001-2	4%
When GP did memory test		4%
After diagnosis		4%
At time of very stressful events		7%
By cared-for's driving		7%
Difficult to know		4%
Can't remember		4%

Two types of response have been given here, showing two ways of answering the question.

Firstly there are time-related answers, which reveal that the biggest group of responders (19%) have felt or known that the cared-for has more than an age-related memory problem for some 5 years, followed by 11% who have known or suspected for 2 years. In total, 17 responders (65%) have known or suspected it for 2-11 years, with 9 (35%) having known or suspected for 5 years or more. These are long periods of time to care for someone with increasing needs, particularly given some of the health conditions listed by carers about themselves in Q6.

Secondly, there are event or milestone answers, indicating that for some carers the date is probably less important than certain events. Others (8%) do not appear to have noticed or confronted the issue until the GP memory test or diagnosis itself. Although numerically less significant, nonetheless these answers help reveal another angle of life with dementia/significant memory loss.

Question 24

Might there have been signs you could have picked up earlier?	33 responses from 33 responders
Yes	31%
Probably/possibly	24%
No	24%
Probably not	9%
Don't know	12%

The researchers perceived a slight reluctance in many cases to answer this question or to engage with it fully. This may have been because it could feel like an admission of guilt, and in fact responders were noticeably more open about this question when they were interviewed.

It is notable here though that 55% of responders gave ‘yes’ or ‘probably’ or ‘possibly’ replies, while 33% reported ‘no’ or ‘probably not’, with 12% saying they didn’t know. This 55% figure is very important, since it points decisively to the lack of knowledge, information or pathway carers state elsewhere. This is clearly an area where more education is likely to be needed.

Question 25

Can you recall who you turned to for help *(eg family member, friend, professional etc)*	59 responses from 31 responders
Daughter(s)	5%
Son(s)	3%
Carer’s spouse (eg daughter or son in law)	7%
Other family	14%
Friends/colleague	12%
GP	37%
Consultant	3%
Other professional	15%
Voluntary organisation	2%
Debenham Project	2%

This question was about who the carer spontaneously turned to for help in the first instance. It can be seen that family/friends account for 41% of all responses, GPs 37% and consultants and other professionals 17%. (GPs were often consulted only after the carer first turned to the family). It can be concluded therefore that in the Debenham area at least, family ties are very important and it appears that the GP is seen as the primary port of call after the family.

Question 26

a) Did this help at all?	32 responses from 32 responders
Yes	69%
Perhaps/Yes & No	6%
No	22%
Cared-for died	3%

Including those who indicated ‘yes & no’ or ‘perhaps’, ¾ of responders found seeking help was of benefit. Given the absence of information or knowledge of what was taking place, or any pathway to help, this help from family/friends/colleagues and then GPs would seem both essential and perhaps a base on which to build further knowledge.

b) Please say how this helped	31 responses from 31 responders
Family there to help & support	16%
Talk over & share	3%
Community very supportive	3%
Referred to Memory Clinic, Ipswich	3%
Referred to specialist unit 9 months after diagnosis	3%
GP very helpful	3%

Referred to NHS	3%
Consultant very helpful	6%
Consultant diagnosis led to medication tho' can't measure effect	3%
Aids & adaptations provided	3%
Literature given by Age UK Suffolk who were very helpful	3%
Carers brilliant	3%
Helpful knowing others saw it too	3%
At least we knew what was wrong	3%
All organisations advised on care & financial support	3%
General moral support	3%
Realised my limits & needed help for Dad to accept	3%
Delays in referral to hospital & follow-ups	3%
Felt I was wallowing in a morass – and patient confidentiality obstructive	3%
Dementia excluded [by diagnosis] but depression unchanged	3%
Died so nothing I could do – son made arrangements	3%
GP ignored it [memory loss/dementia]	3%
GP not impressive so got help in Harley St – very good	3%
GP & consultant very unhelpful & no NHS help beyond clinic visit	3%
NHS no help at all	3%
Copy of assessment left for cared-for who then blamed carer for treatment/involving profs	3%

While these responses show little grouping overall, it is clearly the family presence to help and support that is most valued, followed by that of the GP. It can be seen from Q26(a) that 69% said that turning to others (chiefly family & GP) helped (and this view is the case in Q25 too), while in 26(b) the highest-scoring response was the 16% who confirmed the family's presence and help/support was key.

But when asked in Q26(b) ***how*** the help given aided them, apart from this16% who reiterated that the family support was important (and another 6% of comments that could also be attributed to family support or perhaps GP support), many of the other comments were about the professional support or service given. The responses in Q26(b) can be broken down thus:-

32% of comments were positive about the professional service received
29% of comments were negative about the professional service received
13% of comments were neutral about the professional service received
26% of comments were not about professional services.

D. Diagnosis

From investigating the first signs that all was not well (i.e. the beginning of the ‘journey’), the area that the questionnaire next examines is the diagnosis itself and the process of obtaining one

Question 27a

Has or did [the cared-for] ever received a proper diagnosis of dementia?	34 responses from 34 responders
Yes	79%
No	12%
Don’t know	6%
Excluded dementia	3%

While the positive responses are high, the ‘no’s and ‘don’t know’s are significant. In the case of the negative responses, it is of concern that more than 1 in 10 people responding are reporting they have never received a diagnosis, despite being the family carer. Equally concerning is the 6% reporting that they don’t know whether they have received a proper diagnosis. This suggests that either the diagnosis process for them was/is not overt or sufficiently demarcated, not remarkable, not properly explained – or not done.

Question 27b

Who gave it?	29 responses from 34 responders
Consultant/specialist	86%
GP	14%

This confirms that overwhelmingly most diagnoses are received from a seemingly appropriate specialist. However, given that a formal diagnosis can only be given by a consultant, the 14% GP response exacerbates the situation revealed in Q27a. While a GP typically carries out the preliminary memory tests, this is not a formal diagnosis but is apparently taken by these 14% of responders as such. This again points to lack of knowledge or clarity about the process, pathway, outcomes and explanations given or retained. Hence it suggests a need for more clarity of information, training of professionals and education of carers.

Question 28

Please say how this [diagnosis] happened	31 responses from 31 responders
Admitted to hospital with other health problem	13%
Memory clinic/doctor (some explicit re referral from GP)	55%
Consultant told others but not carer	3%
Tests/scan	10%
GP (one responder stated GP & OT)	9%
Told by hospital social worker	3%
Didn’t find out results for some time	3%
Cared-for refused to visit GP/lack of GP continuity	3%

It can be seen straight away that over half reported receiving the diagnosis via the memory clinic or following a visit to it. Another 10% received a diagnosis following tests or scans, but in the case of tests it is not possible to say whether these were from the GP or consultant/memory clinic. Taking this figure plus other settings reported which indicate possible or definite consultant involvement, it indicates that the potential figure for a diagnosis via the consultant/specialist service route could be up to 87%. This confirms the figures in Q27b, although this still highlights the other 13% or 14% who appear to have received no formal diagnosis but rather an informal diagnosis via the GP.

It may be of course though that the presenting condition of the cared-for needed no further confirmation. However, this perhaps begs the question of where this leaves the formal diagnosis-led approach as the gateway to dementia treatment and services

Another important point is the way dementia can come to light as a result of other health conditions precipitating a hospital admission.

It was noted that in the questionnaires returned, four or more (13%+) of the responses evinced a certain anger or frustration about the method, methodology, timing, or communication of the result by the consultant or possibly GP.

Question 29

How did you feel about the process of getting a diagnosis?	37 responses from 27 responders		
Can be categorised into:-			
a) Emotive responses	Positive	Negative	Other
Numbed, confused, unhappy, very sad, shocked, cared-for shattered, sad but relieved, worst fear confirmed but relieved	5%	28%	
Angry – with professionals		2.5%	
Denial		2.5%	
Pressurised by conflicting needs of cared-for and their spouse		2.5%	
Relieved	2.5%		
Fine, good	5%		
Sub-Totals	*12.5%*	*35.5%*	
b) Practical responses			
Didn't seek help as capable of caring on own			6%
Didn't progress			2.5%
Unpleasant necessity	2.5%	2.5%	
'Needed to trick cared-for into getting diagnosis'		2.5%	
Very sudden – no prior warning		2.5%	
Haphazard – depends on GP knowledge		2.5%	
Unsupported initially		2.5%	
Lack of explanation re type of		2.5%	

dementia			
More community support needed		2.5%	
Home assessment is preferable		2.5%	
UTI made diagnosis worse		2.5%	
Limited by it		2.5%	
Confirmed what I already knew			2.5%
Satisfied it was done competently	2.5%		
Very technical & matter of fact	2.5%		
Social worker very helpful	2.5%		
Don't know/not sure			6%
Sub-Totals	*10%*	*25%*	*17%*
Brought forward	*12.5%*	*35.5%*	
TOTALS	*22.5%*	*60.5%*	*17%*

In summary therefore, 48% of responses were emotive and 52% were practical. 28% of all responses depicted some form of anguish; 12.5% of all responses were some form of positive emotion, even if 5% here were balancing the good and bad. Negative emotive comments outweighed positive by nearly 3 to 1. The other emotive comments, small though the numbers are, are important as they again reveal something of the actual experience of caring for someone with dementia.

In the practical responses, the first comment about coping on their own starts to show what the researchers found elsewhere: the determination and commitment of the carers – and in some cases perhaps their pride, or fear of getting outside help. But although the other comments here were all single responses, it should be noted that negative practical comments outweighed positive by 2½ to 1.

The weight of negative comments is to be expected given the diagnosis, but all the comments warrant careful perusal and evaluation, particularly perhaps the ones which highlight how professional involvement is seen.

Question 30

The question here was ***"Can you say if and how having a diagnosis made a difference?"*** The two parts are split into different tables, with the responses broken down according to the each part of the question:-

Question 30a:

Can you say *if* having a diagnosis made a difference?	26 responses from 26 responders
Yes/yes possibly	42%
No/not really	31%
Yes and No	23%
No firm diagnosis yet	4%

Question 30b:

Can you say *how* having a diagnosis made a difference?		33 responses from 27 responders	
	Yes's to 30a	*Yes & No's* to 30a	*No's* to 30a
Didn't change anything/ made no			12%

difference			
Made things worse			3%
(Still) knew nothing re dementia			3%
Didn't know how to handle cared-for			3%
Cared-for still in denial			3%
Confirmation of suspicion/ worst fears/ decline inevitable			9%
Made carer v suspicious of NHS - incorrect diagnosis?			3%
Access to meds	16%		
Greater acceptance of condition/ behaviour changes/reality/ need for patience	12%		
Enabled planning ahead	9%		
Confirmation of condition by others	6%		
Accessed support/care	6%		
Enabled claims for benefits & exemptions	3%		
Enabled letting go & accepting help	3%		
Precipitated carer taking charge	3%		
Accessed support but too inflexible/inconsistent & carer refused		3%	
Decided on support but cared-for refuses to participate in anything		3%	
TOTAL	58%	6%	36%

In the first part of the question, 4 out of 10 people were saying that getting a diagnosis made a positive difference, while 3 in 10 were saying it made a negative difference. If the ‘yes **&** no’ responses are included, it appears that over half of the responders felt that a diagnosis was either not an advantage or a mixed blessing.

In the second part of the question, there were marginally more responders (27 as opposed to 26), with more than one comment in 6 cases, giving a total of 33 responses. Here, nearly 60% of comments were positive about *how* a diagnosis made a difference (indicating there was more than one reason why), while negative comments to ‘how’ were roughly the same number as in the first part of the question, especially given the additional responder here. This indicates that there was usually a solitary reason given as to why a diagnosis did not make a difference. The ‘yes & no’ comments were notably fewer than those in the first part of the question – i.e. many of those reporting that a diagnosis had upsides and downsides did not elucidate how.

Of the negative comments, it could be argued that all these ‘no’ comments (36%) were effectively saying that the diagnosis made no difference other than in name. The highest percentage reported that it changed nothing or made no difference (12%) followed by confirmation of worst fears/suspicions (9%). Breaking these ‘no’ responses down further, 15% of the comments on the question as a whole point perhaps to a sense of resignation or feeling of pointlessness regarding having a diagnosis – or even that it makes it worse; and 9% highlight the sense of ignorance or helplessness that many carers reported here and elsewhere to do with understanding or coping with progressive memory loss/dementia.

Both ‘yes & no’ responses highlight a tendency that was noted elsewhere in the questionnaire and also in the interviews: the unwillingness of a significant proportion of cared-for people to accept or comprehend what appears to be in their best interests, in these cases regarding support. One of the responses also points to some of the potential shortcomings of domiciliary support – lack of flexible or person-centred timing and high staff turnover or changes.

The ‘yes’ responses indicate the importance of the diagnosis as the gateway to medication for the cared-for (16% of comments); also its importance to carers as a watershed point to turn and face what was happening and that in the process they themselves would need to change (eg to become more patient) and put themselves second (12%). Being able to plan for the future was also significant at 9%. 12% either were able to access help, support and/or benefits as a result of the diagnosis (or enabled to accept they needed it or could not do it all themselves). The final comment about the diagnosis meaning the carer took charge (of decisions etc) points to another factor discovered during the structured interviews – that in some cases the carer had to take on unfamiliar roles, such as finances, which had probably previously been done by the cared-for.

Overall, the responses reveal that 42% of responders felt that the diagnosis did make a difference, provoking more than one comment each regarding how. Importantly though, 31% did not and 54% either did not or were ambiguous. In terms of how the diagnosis made a difference, 58% of the further comments were positive, 36% negative and 6% saw mixed benefits.

E. Getting Help

This section of the questionnaire asked for information on any support received.

Question 31a

When the diagnosis was made, was any help or service offered?	30 responses from 30 responders
Yes	30%
Yes when carer took the initiative	3.3%
Insufficient/ late	20%
Not really	10%
No	30%
Not at first – didn’t seek it	3.3%
Still awaiting results	3.3%

Question 31b

What help or service was offered	37 responses from 30 responders
A list of organisations to contact/ information to read	16%
Alzheimer’s Society	8%
Debenham Project	8%
Local charity	8%
Age UK Suffolk	5%
Suffolk Family Carers	5%
SCC Adult & Community Services	8%

Benefits	8%
GP	8%
Occupational therapy	8%
Medication	5%
Care from nurse	5%
Registered Care Home	4%
Carer had to take initiative	4%

There is a wide spread of help or services here. The voluntary sector makes up 34% of the list; social care (and hence access to a benefit check) comprise 16%; and health services comprise 26%. The social care figure is surprisingly low, as is the health service figure comparatively, considering it includes the GP service. It is startling perhaps that the most numerous offering of help or service was a list of organisations for the carer to contact or information for them to read.

Question 32

How helpful was any of this?	21 responses from 21 responders
Very helpful	19%
Helpful	5%
Partly helpful	32%
Not really	10%
Not helpful	5%
Not at all helpful	24%
Not so far	5%

It should be noted that responses were fairly low for this question.

57% in this question reported the help or support offered at least partly helpful, while 44% said it was not helpful in at least some way. It is important, though, that only 24% appear to have found it adequately helpful and that 24% reported finding it not at all helpful. However 33% reported it was partly helpful and 19% very helpful.

Question 33

Can you think of anything else that would have helped?	24 responses
Explanation (at the outset) of dementia & what to expect in the future	8%
One point of contact	8%
Information re allowances & benefits – and eligibility	8%
Being listened to by professionals	4%
More services tailored to the person	4%
More information	4%
Home visits	4%
Training for physical & mental health problems	4%
All GP consultations logged centrally to ensure availability to different GPs	4%
Referral from NHS to Social Care	4%
Help from NHS rather than dismissiveness	4%
A long, more in-depth trial (medication?)	4%

Primary carer present at tests at memory clinic to ensure accuracy	4%
More contact with Social Care	4%
Staffed phone lines at times of desperation (eg Alzheimer's Soc)	4%
Much more community help	4%
Befrienders	4%
Professional carers for respite	4%
More respite	4%
More time for carers to themself	4%
No – it takes its course	4%

There is a wide spread of responses here, and often each represents a sole comment. However the percentages are perhaps less important for this question than the comments, which are based on carers' direct experience and hence may well be worthy of objective consideration. This is perhaps particularly true since at least 14 of the responses are either overtly or by implication referring to some shortcoming in the services provided by the statutory sector. That said, there are also five comments which point to potential areas for the voluntary sector or local community to consider as well.

These (Q33) responses can be categorised into main areas for service enhancement/development as suggested by carers:-

Category	*Main potential areas for improvement*
1. More Information (20%)	Generally re dementia & its care/support (4%)
	Welfare Benefits etc (8%)
	Improved explanation at outset re: diagnosis & what to expect in the future (8%)
2. Improved inter-agency working/ intra-agency working (16%)	Within health inc GP – all consultations centrally logged (4%)
	Within Social Care
	Between services - NHS to Social Care (4%)
	One point of contact for carer/cared-for (8%)
3. Improved support (32%)	Better training re physical & mental health issues (4%)
	Much more help from the community (4%)
	More befrienders (4%)
	More respite; more professional carers for respite; more time for carers to selves (12%)
	Help rather than dismissiveness from NHS (4%)
	More contact with Social Care (4%)
4. Greater person-centredness in services (24%)	Input by & information from carer at consultations re needs & situation (4%)

	More tailored to person (4%)
	Improved listening by professional & services (4%)
	Staffed phonelines at crisis times (4%)
	Home visits (4%)
	Longer medical trial (4%)
(5. Nothing to be done) 4%	

F. LOOKING BACK OVER YOUR EXPERIENCE

This was the final section of the questionnaire. It aimed to elicit further, wider information from the carer about the whole memory loss/dementia journey that they were or had been on. It asked questions that invited the carer to reflect back on their experience of living with and caring for someone with dementia. The researchers are extremely grateful to the responders throughout for all their answers, but nowhere more so than in this section given that it explored such personal and often highly sensitive memories.

Question 34a

Primary impact:-

Could you tell us what impact this [i.e. the dementia journey] has had on you and others in the family? (such as physically, socially, emotionally)				33 responses from 30 responders	
Primary Impact	*Social/ lifestyle*	*Emotional/ psychological*	*Practical*	*Health/ physical*	*Across the board/ in multiple ways*
Considerable/quite considerable					5%
OK but…					3%
All aspects changed					6%
Family had to adapt					3%
Hard for family					3%
Relief for carer/shock for cared-for		3%			
Constant brick wall			3%		
Very anxious time		3%			
Anxiety/depression		3%			
Stress for carer		3%			
Strain for carer much of time		3%			
Emotionally draining & fearful		3%			
Terrible time emotionally		3%			
Drained carer physically & mentally		3%		3%	
Impacted physically	3%			3%	

& socially on carer					
Complete inertia		3%			
Restricted life			6%		
Social life diminished	3%				
Much reduced free time	3%				
Carer doing all			3%		
Life on hold	3%				
Difficulty/reluctance accepting situation		5%			
Avoidance		3%			
Carer happy to care but their health affected				3%	
Cared-for's horizons closed in on carer considerably					3%
Prime carer (spouse of cared-for) couldn't cope					3%
Very difficult for sole carer					3%
Just most unpleasant					3%
TOTALS	12%	35%	12%	9%	32%

Probably unsurprisingly, the responses to this question were almost entirely downbeat, although in a few examples only, the carer attempted to include some balance in their comments, for example that it was a relief for them (the carer) but a shock for the cared-for; or in another case that the carer was happy to care but it affected their own health; and finally where one carer stated that it was 'ok but…'.

Each response is naturally enough very individual and so the list is quite long (also given the methodology used). Hence the low percentages. It is interesting to note that unlike earlier in the questionnaire, responders did not list the prompts in the question necessarily in the order given or often at all.

The table above shows clearly how the principal or secondary carer sees that dementia impacts on the lives of and wider family group. The emotional or psychological impact (35%) is the most dominant; multiple impacts is nearly as prevalent (32%); and then still significant but much less widespread are the social or lifestyle effects and the practical impact (12% each). The health or physical impacts are significant at 9% but the least reported category of impact.

Additional comments were given in answer to this question, which help further to build up a picture of the impact on the carer and family. These are categorised by type of impact and whether positive and negative as below.

Question 34b

Additional comments on: **'Could you tell us what impact this [i.e. the dementia journey] has had on you and others in the family?'**	31 responders & 68 responses	
	Negative comments	Positive comments
1. Mentally/ emotionally	31 responses	
On carer/family		
Denial	2	
Depression	1	
Shock	1	
Carer's life 'stolen'	1	
Daughter (i.e. carer)'s stress & lack of sleep affected cared-for	1	
Frightened	2	
Drained	3	
Visiting tiring	1	
Guilt	3	
Worry	1	
Grandchildren very saddened	1	
Life bad	1	
Carer had hoped to be on own if this happened	1	
Support from husband crucial for daughter (i.e. carer)		1
Relief for carer		1
Not a surprise to carer		1
Glad did what did – no regrets		1
On person cared for		
Personality changed (inc inert, withdrawn)	5	
Sometimes present still		1
Strong character with unrealistic perception re capacity for independence	1	
Has '2-year old tantrums'	1	
Sub-total	26 responses	5 responses
2. Practically	27 responses	
On carer/family		
Hard for carer living so far away	1	
Met brick wall at each advance of the dementia	1	
No (proper) holidays	2	
Difficult to be constantly 'on cover' & to check constantly	1	
With cared-for 24/7 thus sleep-deprived	1	
24/7 commitment very tiring. Cared-for follows carer everywhere	1	
Couldn't leave cared-for for any time	1	

Carer & family can never be far away	1	
Having to take over all roles	1	
At times nigh impossible to live together	1	
Burden of caring curtailed carer's involvement with own daughter	1	
Family had to give up time – cared-for top of agenda	1	
Had for cared-for's spouse – only carer but poor communicator	1	
Help needed with personal care	2	
Carer had to put self second	1	
Carer physically ok		1
Carer (offspring) moved in with cared-for		1
Parents moved close to carer		1
Family share 24/7 cover with cared-for's spouse		1
Cared-for's daughters very helpful		2
Carer very committed		1
Could get help		1
On person cared for		
Inability to walk concerned carer most	1	
Cared-for never wanted carer to be absent	1	
Sub-Total	19 responses	8 responses
3. Socially	10 responses	
On carer/family		
No conversation	1	
No social life/minimal social life	5	
Carer has to do things on own since cared-for doesn't want to go out	1	
Carer's children wonderfully natural with cared-for	1	
Local people quite supportive	1	
Some friends still visited	1	
Sub-Total	10 responses	
TOTAL ADDITIONAL COMMENTS	**55 responses**	**13 responses**

These comments give a detailed picture of the impact of dementia has had on the carer, family and cared-for. We have already noted the main groupings the comments fall into – mental/emotional, practical and social (and in 34a, health/physical), and which relate principally to the cared-for and which to the carer. The themes emerging from Q34b are important: the table below groups these main impacts of the dementia journey thus:-

Type of impact	*Issue reported*	*% of total comments*
Emotional or mental	Change of character (cared-for)	9.5%
	Tiredness/exhaustion	8%
	Fear/worry	6.5%
	Guilt	4%
Practical	Negative consequences of constant vigilance/attendance	20%
	Importance of family help	8%
Social	Isolation of carer	11%

Question 35

How did you find out what to do to get help?	36 responses from 31 responders
GP	24%
Own initiative	14%
Debenham Project	14%
Social Care Services	11%
Voluntary organisations/ private care orgs	11%
Health services	8%
Local meetings	6%
Didn't/unable to	6%
Friends	3%
TV/Press	3%

The results here should be compared to Q25 – *"Can you recall those you turned to for help?".* The percentages and order here in Q35 are very different. The two sets of responses reveal that there is a difference between those turned to when the situation first gave cause for concern, and those who responders (when reflecting back over the whole journey) indicated gave either signposting to or provision of services.

While the GPs were the largest single source of information here in both cases, it is apparent that although the family were very significantly turned to initially (when as a number of responders have stated, they did not know what was going on or who else to turn to. The family are thus absent here as a group, as carers looked back over the whole path. It is noteworthy also that 14% of carers giving an overview in Q35 report they used their own initiative; this may reflect on the profile of carers reported in Q3 where at least 49% reported they had held positions of responsibility in their working lives. Both the Debenham Project and other voluntary organisations appear to have been significantly greater sources of information/help in Q35 than in Q25.

Question 35 – Comparison with Question 25

Q25: Can you recall who you turned to for help *(eg family member, friend, professional etc)*	59 responses from 31 responders	**Q35: How did you find out what to do to get help?**	36 responses from 31 responders
GP	37%	GP	24%
		Own initiative	14%

Debenham Project	2%	Debenham Project	14%
Voluntary organisation	2%	Voluntary organisations/ private care orgs	11%
Consultant	3%	Health services	8%
Other professional	15%	Social Care Services	11%
Family	29%		
Friends/colleague	12%	Friends	3%
		Didn't/unable to	6%
		Local meetings	6%
		TV/Press	3%

Further comments were made in response to this question:-

Question 35 – Additional comments

Press & TV said early diagnosis good
Information from Social Services was usually volunteered
All voluntary organisations were helpful and kind
GP referred us to memory clinic
Health professionals seemed unable to support
It was 2 years before he was told he could have help, but it was not simple to get: Too many forms and too little verbal contact
Didn't find out anything for 10 yrs – but now there's the Debenham Project
I learnt as I went along
But what help can be given?
I can't ask for help in case cared-for hears about it

Of these 10 responses, 4 were positive and interestingly each was about a different source of information/support: the media; social care services; voluntary sector; GP service. 3 comments reveal a lack of support or information from the statutory services. 4 comments (including two of those already revealing a lack of information or service) infer or expressly say that there was a lack of information or knowledge of what if any support was available; 1 of these comments also highlights the hopelessness some carers see in the situation ("*But what help can be given?*"). The final comment reveals the difficulty some carers have with the cared-for person when trying to pursue their best interests.

Question 36

What do you feel are the things that might encourage or discourage seeking help?	45 responses from 27 responders
1. Encourage	
Greater awareness	
• Publicity – including leaflets/info in eg GP surgery	3%
• Increased public awareness means greater acceptability of dementia	2%
	5%
Support/knowledge/education - carer	
• Peer discussion	2%
• Awareness that the benefits (eg of early diagnosis & drug	3%

treatment) can buy time	
	5%
Support/knowledge/education – professionals, carers etc	
• Better response/ awareness from NHS & GPs	5%
• Well trained volunteers	2%
	7%
Emotive/reactive	
• Frustration/desperation	7%
• Acceptance of condition/ dealing with fears	4%
	11%
Sub-total: Encourage	**28%**
2. Discourage	
Awareness/situational	
• Stigma/being labelled	7%
• Reaction of others	2%
• Isolation caused by people falling away	2%
	11%
Problems – cared-for, carer, family	
• Cared-for not understanding/accepting diagnosis	5%
• Personality of cared-for	2%
• Family trying to manage by themselves	2%
• Disagreement among family	2%
• Diagnosis hanging over you	2%
• Transport difficulties	2%
• Confronting the problem	2%
• Giving in to old age too easily	2%
	19%
Problems with services	
• Lack of co-ordination within Social Services	3%
• Time spent trying to make contact with Social Services	2%
• Lack of knowledge by profs of services available	7%
• Excessive form-filling	2%
• NHS avoiding giving treatment	2%
• Disinterest by services due to self-funding: everything fell on carer's shoulders	2%
	18%
Emotive/reactive	
• Guilt	3%
• Pride	7%
• Feeling of over-self reliance so shouldn't bother services	2%
• Sadness	2%
• Fear of loss of independence	2%
• Denial of problem	2%
• Diagnosis/prognosis hanging over you	2%
• Fear of having to go into residential/nursing care	2%
• What's the point?	2%

	24%
Sub-total: Discourage	**72%**

There are 2.6 times more reasons given that discourage seeking help than encourage (72% compared to 28%). So the fact that carers do actually seek help points to their dedication and commitment to the cared-for. The highest scoring reasons that discourage *and* encourage are emotive/reactive reasons – chief among which are frustration or desperation (as reasons to seek help) and pride (as a reason not to seek help).

The level of these and the other negative emotions seen as discouragements is important since they indicate that gloom, inadequacy and bleakness are common among carers. Coupled with the other issues stated as discouragements, a picture emerges of carers despondent or at least very anxious about the state of the person they care for. It appears the situation in 18% of reported reasons is either influenced, caused or exacerbated by a perceived shortcoming of the statutory health and/or care/support agencies. Likewise in 19% of reasons given, there is a problem either with the cared-for, the family or practical issues to do with managing or living with the diagnosis. Then finally, there is the stigma and isolation (11%) on top of all this. Even 7% of the reasons given that encourage seeking help are kind of 'double negatives' – frustration or desperation.

The reasons that encourage seeking help should not be overlooked. They point very directly to areas needing development – publicity and awareness, improved services, greater education.

Question 37

Looking back, from what you know now, what if anything would you do differently?	34 responses from 27 responders
Nothing	35%
Become involved sooner/taken action sooner	26%
Be more assertive/confident	12%
Look for more information re: early signs, financial benefits, rights/responsibilities, etc	6%
Sought more help/activities/support	6%
Not trusted others/services	6%
Ensure fewer people involved	3%
Been more patient	3%
Just tried to cope as best as could	3%

This question builds on the responses to Q36. That question effectively asked what carers had experienced on the 'journey' that made seeking help easier or more difficult, while Q37 asked people to reflect back and state what their learning had been during the journey. This obviously has applications not only as a snapshot of the picture for this group but also has direct applications for the future.

The biggest response is 'nothing', at 35%. This is important, although the researchers found in the structured interviews that a significant proportion of carers went into greater detail here.

However, the key points to be noted here are that 26% said they would become involved sooner/take action sooner; and the 12% who said they would be more assertive or confident.

Coupled with those saying in other ways that they would take more action, this is a total of 50% reporting that, knowing what they know now, they would do and seek out more and sooner – and by implication, stand their ground/be more assertive.

Question 38

Knowing what you know now, what if anything are the benefits and/or downsides of an early diagnosis of dementia?	42 responses from 27 responders
1. Benefits	*32 responses (77% of total responses)*
Plan for/be more prepared for future	20%
Confirmation (of what's wrong, or of exclusion of dementia)	15%
Getting early help &/or medical treatment	13%
Medication slows process down	6%
There are only benefits	5%
Accepting things will never be the same	2%
Doing things together while still able to	2%
Less loneliness for carer	2%
Ease & support family/improve quality of life	2%
Obtain financial support earlier	2%
Helps carer to cope	2%
Avoidance makes matters worse	2%
Stigma lessening now	2%
The Debenham Project	2%
2. Downsides	*10 responses (23% of total responses)*
No/probably no benefits	10%
Depressing/traumatic prognosis	7%
Want to know how to avoid being like cared-for	2%
Labels make it worse for both cared-for and carer	2%
Lack of continuing support from Debenham Project now cared-for in Registered Care Home	2%

Since this question was about an early diagnosis, the responses given should be seen not necessarily as comments about the impact of a diagnosis per se, but instead about what is unlocked by receiving that diagnosis early, and whether/how there are benefits to this. This explains perhaps why there were three times as many benefits listed as downsides. This view about the benefits is reiterated by the professionals interviewed, reflecting their wide experience.

The key benefits reported are being able to plan for the future (20% of the total responses); confirmation of what the problem is (15%); early medical and other intervention (13%); and the delaying effect medication can have (6%). The remaining 23% reported in one way or another that an early diagnosis improved quality of life, particularly perhaps for them as carers.

The negative responses here in Q38 (especially the first 19%) show something of the bleakness and isolation that receiving a diagnosis can reiterate or deepen for the carer, whether it is early or not.

Very broadly, these positive and negative responses follow those to Q30 ("*Can you say if and how a diagnosis made a difference?*").

Question 39a

Likewise, do you think it would have helped to have had support earlier or not, and why?	27 responses from 27 responders
Definitely	7%
Yes	38%
Possibly	15%
Positive	60%
No	15%
Probably not	7%
Negative	22%
Don't know	11%
Not applicable	7%

As can be seen, 3/5 of responders gave positive comments about the benefit of early support while 1/5 had a negative view of its value. Another 1/5 though recorded uncertainty or that it did not apply in their case. The reasons given are listed below.

Question 39b

1. Why [would early support have helped]?	13 responses ex 27 responders (48%)
	Of 17 responses to 39b:-
Being able to share with others in same predicament	12%
Builds up knowledge of who to ask & what is available	12%
Could have upskilled carer re managing cared-for, condition & options	12%
Reduced loneliness, depression etc for carer	6%
Time for planning & creating new life together	6%
Relieves stress/guilt of not knowing what to do	6%
Could have enabled other interests for carer	6%
Could have taken initiative early with sons' support	6%
Help to cope	6%
Support needed but cared-for refused	6%
2. Why [would early support NOT have helped]?	4 responses ex 27 responders (15%)
	Of 17 responses to 39b:-
Stubbornness/lack of insight of cared-for	6%
Introversion of cared-for	6%
Cared-for would have fought it – only wanted carer's care & attention	6%
Very personal and not easy to go outside family	6%

Peer support, knowledge of who to ask/what is available, and training to manage the situation, and support the cared-for (12% each of the total responses here) are the prime responses about why early support would have helped. Interestingly, most of the reasons given why early support would not have helped relate to lack of perception/acceptance by the cared-for (18% of all responses to 39b).

Question 40a

How did you first hear of the Debenham Project	24 responses from 24 responders[30]
Local GP	21%
Local advertising/publicity	17%
Debenham Project itself	17%
Friend	13%
Local knowledge/word of mouth	13%
Age UK Suffolk support worker	8%
Church	4%
Online	4%
Health session (eg flu jab)	4%

Everyone completing a questionnaire had had contact with the Debenham Project in some way. The GP clearly emerges as the single most common first point of contact with the Debenham Project, at 21%. This concurs with the responses referred to earlier in this report about who was first turned to and who first gave help. But informal local networks (including local knowledge, word of mouth, friends, and church) are the largest group of first contact points along with the Debenham Project itself, a total of 51%. The response re local publicity (including online) is noteworthy too, at 21%. Along with the other professional contact points (Age UK, health sessions) and the direct networking that the Project itself does, these are all key ways to investigate for further future penetration of the group affected/likely to be affected by memory loss/dementia.

Question 40b

How has the Debenham Project been of help?	47 responses from 35 responders
Contact with other people in the same situation/friendships/combating isolation	22%
Support/reassurance/understanding	20%
Advice/information	11%
Greatly	9%
Help when needed	6%
Meeting professionals eg Age UK Suffolk workers	4%
A regular outing	2%
Forget things for a while	2%
Dealing with people you trust	2%
There for future need	2%
Increased awareness in Debenham & thus support for people with dementia	2%
Helping to cope	2%
Continuing past death of cared-for	2%
Gateway to everything else	2%
Total reporting Project of help	*88%*
Not really a help	2%

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[30] The first 11 responders were not asked this part of Question 40

Not really a help – have to sort yourself out in the end	2%
No information I didn't already know	2%
Project wasn't sufficiently developed when cared-for needed help	2%
Didn't suit cared-for	2%
Total reporting not of help	*10%*
Not had much to do with it	2%
Total reporting not sufficiently engaged to say	*2%*

There is thus overwhelming benefit seen by responders in the Debenham Project and what it offers. Of course the group of responders were well-disposed to it and no doubt often loyal to it. But there is undoubted sincere gratitude for its existence. It is clear that particularly a) contact with other people in the same situation/friendships/combating isolation (22%); b) support/ reassurance/ understanding (20%); and c) advice/information (11%) are key services, and this is also evidenced elsewhere in this report.

Notwithstanding all this, there is a small minority of responders who found it was not responsive to their need or that of the person they care/d for. Further detail was obtained in the structured interviews in some cases, and it will be important to review this to ensure maximum responsiveness.

Question 41

Is there anything else at all you would like to say?
I am a strong and capable person and I cope at the moment. We had lots of help at the beginning which then fizzled out and everyone seemed to disappear
This reopened memories of dark places I would prefer to forget
Too worn out to think
A wet room is a great help to shower the cared-for
Will stay in touch with the Debenham Project even though cared-for has now died. Want to help others now starting journey
Experienced a confusion re dual diagnosis, re which is the presenting issue
Has dual diagnosis of dementia and epilepsy: these don't follow usual pattern & so have clouded firm diagnosis of the other
Cared-for has prostate trouble, catheter, pace maker, then 2 strokes which we feel led to dementia
NHS must put patient first
Patients need to deal with people they know and can trust
Need maximum information on how dementia can affect person & also likely effects on carer
Applaud Debenham Project

SECTION SEVEN: SUMMARY OF FINDINGS

7.1. PROFILE OF THE CARER

7.1.1. Relationship to cared-for: Roughly half the responding carers are the spouse/partner of the cared-for and half are their children/children-in-law. 52% of carers lived with their spouse or partner; 31% lived alone

7.1.2. Familiarity with area: The great majority are very familiar with the area, with many if not most living very locally to the cared-for or even with them.

7.1.3. Age: About ¾ of the responding carers are aged between 60 and 90, split approximately as ¼ in each decade. The remaining ¼ are between 50-59

7.1.4. Health: 56% of carers reported good health; 36% fairly good health; and 8% in poor health**.** However most of the specific conditions reported potentially affect the carer’s ability to care: 43% had Osteo-skeletal issues (including 29% reporting arthritis); 24% had heart/lung issues. It should be noted though that in the structured interviews, the researchers observed that the carers tended to play down their own health issues.

7.1.5. Articulacy: Broadly the carers were comparatively well-educated and/or used to some level of responsibility in their past or present working lives

7.1.6. Finances: While 60% of responders are saying they are managing financially, 32% are saying they are either not managing or that they may not be now or in the future.

7.2. PROFILE OF THE CARED-FOR

7.2.1. Familiarity with area: More cared-for people than carers move into the area to be nearer family. This is due probably to their age-related care/support needs such as dementia/memory loss. Overall though the cared-for have been settled in the area for a significant period of their lives. This indicates strong local links/networks & knowledge

7.2.2. Age: All cared-for are reported as 71+ years, with ¾ being 81-90+. This contrasts with the carers

7.2.3. Physical health: Just over half of the cared-for were reported as being in moderate to excellent physical health, while just under half were reported as in poor physical health.

7.2.4. Socio-economic profile: As a group, the cared-for were either/and fairly well-educated or used to responsibility, comparatively affluent

7.2.5. Living circumstances: Just over half live with carer; just under half at a different address. Nearly 40% of cared-for moved due to memory loss/dementia. Reasons for moving include risk to self (cared-for), distance from family/family potentially taking on primary caring role, and unsuitability of the property. 85% were saying that the accommodation for the cared-for is at the very least mostly alright. 2/3 are living in a homely/domestic environment while 1/3 have moved into care –ie an institutional environment.

7.2.6. Finances: 93% were affirmative or cautiously affirmative regarding the cared-for’s sufficiency of income. 7% reporting insufficient income is important as in each case it is ultimately unsustainable

7.2.7. Unprompted comments by carer on cared-for: Include change in character and mood, frustration, strain for the carer of coping, the carer’s sense of loss and sadness, and perhaps the way that sometimes it takes an outside person (eg GP) to ‘legitimise’ what the carer needs

7.3. EVOLUTION OF MEMORY LOSS/DEMENTIA

7.3.1. Range of memory loss/dementia of cared-for: The journeys reported by carers ranged from a gradual process of decline right through to those who are experiencing major behavioural issues. Each responder was at very different stages of the memory loss/dementia journey

7.3.2. Initial signs: *Forgetfulness, difficulty doing familiar things, misplacing things, changes in mood etc* - these four issues had the highest responses

7.3.3. Next signs: the highest responses were *(greater) difficulty with familiar tasks* and *(greater) memory loss*. But they were reported by fewer people, so it might be possible to deduce that the greatest degree of memory loss and to a slightly lesser extent the greatest degree of *difficulty* with memory loss come at the beginning of the journey. The picture is one of progressive decline

7.3.4. Indications why more than age-related:

a. Four major reasons were given: Memory loss (1 in 5); personality change (1:10); problem or inability with familiar tasks (1:10); lack of motivation (1:10).

b. Four further signs were listed: Inability to concentrate/vagueness (5%); non-absorption of information (5%); fantasising/hallucination (5%); and a sudden change in the cared-for's condition (2%).

7.3.5. Emotional and practical effects: on people with dementia and their carers

7.4. AWARENESS, KNOWLEDGE & UNDERSTANDING OF DEMENTIA AND THOSE FIRST TURNED TO FOR HELP

7.4.1. Duration of Dementia: Two-thirds of responding carers had known or suspected dementia for at least two years. A third had lived with it (or suspected it) for 5 years or more.

7.4.2. Could signs have been detected earlier: Over half said there might have been signs they could have picked up earlier. The responses indicate the lack of knowledge about dementia and how to access help.

7.4.3. Who carer first turned to for help: 41% reported turning to family/friends first. GPs were next at 37%. Consultants and other professionals were 17%. It should be noted that GPs were often consulted only after the carer first turned to the family.

7.4.4. Was seeking help of benefit: ¾ of responders found seeking help (chiefly from family was of (at least) some benefit. t is clearly the family presence to help and support that is most valued, followed by the GP. A significant lack of knowledge was apparent among carers and the person they cared for. There was no clear grasp of what was happening to them, what services were available (or not) and how they might be accessed:

> *"I didn't know what I was looking for since I knew nothing about dementia"*; *"I felt I was wading in a morass"*. – Quotations from carers from structured interviews.

7.5. IMPACT OF CARING FOR SOMEONE WITH DEMENTIA

7.5.1. Discrete: Each response is naturally enough very individual

7.5.2. Downbeat: The primary responses were predominantly (not surprisingly) downbeat. Some of the secondary responses were more positive – eg about the family's support in providing cover.

7.5.3. Description: The most dominant responses were:

a. Emotional or psychological impact (35%) deriving from eg cared-for's change of character, exhaustion, fear/worry, guilt); multiple impacts (32%); and then still significant but much less widespread are the

b. Social/lifestyle effects (deriving from eg isolation), and the

c. Practical impacts (eg negative consequences of constant vigilance/attendance) - 12% each. The health or physical impacts are significant at 9% but the least reported category of impact.

d. Money: Significant concern was also reported about insufficient funds to live on

7.5.4. Anguish: The data reveals the anguish involved in caring for someone with dementia

7.5.5. Commitment: A very high level of commitment from carers is evident – despite a lack of support

7.6. AWARENESS OF HOW TO ACCESS HELP, CARE & SUPPORT & WHO FROM

7.6.1. Family: Again, the responses highlighted the importance of family for support and help

7.6.2. GP Service: The carer was not always aware from the GP of what constitutes a diagnosis. Is GP skilled enough?

7.6.3. People or agencies whom responders approached: There is a difference between those turned to when the situation first gave cause for concern (summarised in Paragraph (4) above, and those who people or agencies whom responders approached later for either signposting to or provision of services. The GP was the main category approached (24%); 14% used their own initiative to find help; 14% sought out the Debenham Project; with 11% contacting social services and 8% making contact with Health. Other reported categories were local meetings, friends, TV/press, while 6% did not make contact or were unable to find out whom to approach.

7.6.4. Usefulness of help: A variety of comments were made revealing attitudes to the helpfulness of organisations.

Press & TV said early diagnosis good
Information from Social Services was usually volunteered
All voluntary organisations were helpful and kind
Health professionals seemed unable to support
It was 2 years before he was told he could have help, but it was not simple to get:
Too many forms and too little verbal contact
Didn’t find out anything for 10 yrs – but now there’s the Debenham Project
“I learnt as I went along”
“But what help can be given?”
Plus “I can’t ask for help in case cared-for hears about it”

7.7. DIAGNOSIS, ITS EFFECT, EFFECTIVENESS & TIMELINESS

7.7.1. Obtaining a diagnosis: 4 out of 5 had had a diagnosis. But the other 1 in 5 either had not had a diagnosis (12%) or did not know. Therefore either the diagnosis process for them was/is not overt or insufficiently demarcated, not remarkable, not properly explained – or not done.

7.7.2. Who gave it: Overwhelmingly most diagnoses were received from a seemingly appropriate specialist. However, 14% of responders stated that the GP gave it. Given that a formal diagnosis can only be given by a psychogeriatrician, this presumably refers to the preliminary test – eg GPCOG – a GP typically carries out. However

7.7.3. How did you feel about process of getting a diagnosis: The responses can be categorised into 48% emotive and 52% practical. Of all the comments, not unsurprisingly 60.5% were negative, while 22.5% were positive and 17% other. The lists of comments are detailed below as they help to build the picture of what obtaining a diagnosis is like – and how professional involvement is seen.

a. There were three times as many negative *emotive* responses. They referred to responders feeling numbed, confused, unhappy, the cared-for shattered, very sad, shocked, sad but relieved, worst fear confirmed but relieved, angry with professionals. Some responses evinced a certain anger or frustration about the method, methodology, timing, or communication of the diagnosis result by the consultant or possibly GP. The positive responses indicated the carer felt ‘relieved’ or ‘’fine’ or ‘good’

b. There were 2½ times more negative *practical* responses than positive, included eg didn’t seek help as capable of caring on own; didn’t progress; unpleasant necessity; ‘Needed to trick cared-for into getting diagnosis’; very sudden – no prior warning; haphazard – depends on GP knowledge; unsupported initially; lack of explanation re type of dementia; more community support needed; home assessment is preferable; UTI made diagnosis worse; limited by diagnosis. Positive practical responses were: Satisfied it was done competently; Very technical & matter of fact; Social worker very helpful.

c. The responses about the diagnosis also evinced the determination and commitment of the carers – and in some cases perhaps their pride, or fear of getting outside help

7.7.4. Did a diagnosis make a difference:

a. 4 in 10 people reported that getting a diagnosis made a positive difference, while 3 in 10 reported that it made a negative difference. If the ‘mixed benefits’ responses (i.e. indicating pros *and* cons together) are included, over half of the responders felt that a diagnosis was either not an advantage or was a mixed blessing.

b. However there was a slight anomaly in that of those who responded with comments about *how* the diagnosis made a difference (see immediately below), these further comments were 58% positive, 36% negative and 6% saw mixed benefits. This is presumably to do with the self-selectivity of those choosing to give additional information.

7.7.5. How the diagnosis did/did not make a difference:

a. Key advantages seen: Access to medication; greater acceptance of condition/ behaviour changes/reality/ need for patience; enabled planning for the future; access help; confirmation of condition by others; obtain support and/or benefits; enabled letting go & accepting help; precipitated carer taking charge. In some cases the carer had to take on unfamiliar roles, such as finances, which had probably previously been done by the cared-for.

b. Negative comments included: it changed nothing or made no difference; confirmed worst fears/suspicions; a sense of resignation or pointlessness of having a diagnosis; a sense of ignorance or helplessness about dementia.

c. ‘Mixed blessing’ responses reflected the diagnosis resulting in an offer of support but inability to take it up or sustain it due to *either* the cared-for being unable to accept or comprehend it; *or* the lack of flexible or person-centred timing re domiciliary care and the high staff turnover or changes.

7.8. SERVICES/SUPPORT/HELP: ACCESSIBILITY, USEFULNESS & TIMELINESS

7.8.1. Help offered when carer first sought it (Section C): Family/friends accounted for 41% of all responses; GPs 37% and other professional 17%.

7.8.2. Did this help at all & how: 75% found it of at least some benefit. While there was a wide spread of how it helped, it was family help that was the most widely reported as helpful. Many of the other comments were about professional support or help; 32% of these comments were positive; 29% of comments were negative; 13% of comments were neutral. (26% of comments were not directly about professional services).

7.8.3. Services offered/stemming from when diagnosis was made: 50% of responders were offered a service (though 2/5 of these reported it was insufficient or late). 40% of the responders reported a service was not/not really offered.

7.8.4. What help/service offered: 34% of the list was from the voluntary sector; social care (and hence access to benefits?) was 16%; and health services comprise 26%. The highest percentage for help or service offered was a list of organisations for the carer to contact or information for them to read.

7.8.5. How helpful was this service/help: 24% reported it was very helpful or helpful; 32% reported it was partly helpful; 20% reported finding it not or not really helpful or not helpful so far; and 24% said it was not at all helpful.

7.8.6. Would earlier support etc have helped or not: 60% of responders gave positive comments about the benefit of early support while 22% had a negative view of its value. 18% though recorded they didn't know or that it did not apply in their case.

7.8.7. Q39b: Why would/would not early support etc have helped: Equal highest responses were: Being able to share with others in same predicament; Builds up knowledge of who to ask & what is available; Could have upskilled carer re managing cared-for's condition & options. Equal next highest responses were: Reduced loneliness, depression etc for carer; Time for planning & creating new life together; Relieves stress/guilt of not knowing what to do; Could have enabled other interests for carer; Could have taken initiative early with sons' support; Help to cope; Support needed but cared-for refused. The comparatively low number of responses to 'Why' (63%) indicates perhaps that for a significant proportion of responders it was not easy to pinpoint the reasons.

7.9. CARERS' VIEWS ABOUT IMPROVEMENTS THAT COULD BE MADE & WHAT MIGHT ENCOURAGE OR DISCOURAGE SEEKING HELP

7.9.1. Anything else that would have helped: (See question 33 for detailed comments). The responses were nearly all about improvements to the services offered by professionals. The exceptions were comments about eg more befrienders and about more community involvement. The responses can be categorised into ***improved or greater*** support & care 32%; information 20%; inter- or intra-agency working 16%; person-centredness 24%.

7.9.2. What might encourage or discourage seeking help (See Q36 above for greater detail):

7.9.2.1. Responders saw many more reasons that would **discourage** than encourage: 72% against 28%.

7.9.2.2. The issues that might **encourage** were:-

Emotive/reactive: Frustration/desperation; acceptance of condition; dealing with fears 11%

Greater publicity & public awareness – eg literature 5%

Improved training/knowledge/education for volunteers, NHS staff & GPs 7%

Peer support/ knowledge of advantages eg medication/ education for carer 5%

7.9.2.3. The issues that might **discourage** were:-

Emotive/reactive: Guilt; Pride; Feeling of over-self reliance so shouldn't bother services; Sadness; Fear of loss of independence; Denial of problem; Diagnosis/prognosis hanging over you; Fear of residential/nursing care; What's the point? 24%

Problems – cared-for, carer, family: Cared-for not understanding/accepting diagnosis; Personality change of cared-for; Family trying to manage by themselves; Disagreement among family; Diagnosis hanging over you; Transport difficulties; (not) confronting the problem; giving in to (carer's) old age too easily 19%

Problems with services: Lack of co-ordination within Social Services; Time spent trying to make contact with Social Services; Lack of knowledge by professionals of services available; Excessive form-filling; NHS avoiding giving treatment; Disinterest by services due to self-funding (& consequent workload on carer) 18%

Awareness/situational: Stigma/labelling, others' reactions, isolation 11%

7.9.3. Looking back, from what you know now, what if anything would you do differently (Q37): The biggest response was 'nothing', at 35%. This is important, although the researchers found in the structured interviews that a significant proportion changed their mind here. However, 26% said they would become involved sooner/take action sooner; and 12% said they would be more assertive or confident. Coupled with those saying in other ways that they would take more action, this is a total of 50% reporting that, knowing what they know now, they would do and seek out more and sooner – and by implication, stand their ground/be more assertive.

7.10. THE DEBENHAM PROJECT & ENGAGEMENT WITH IT/ITS USEFULNESS

7.10.1. Q40a: How first heard of the Debenham Project:-

7.10.1.1. Everyone completing a questionnaire had had contact with the Debenham Project in some way.

7.10.1.2. The GP was the single most common first point of contact with the Debenham Project, at 21%. But the informal local networks (including local knowledge, the Project itself, word of mouth, friends, and church) were the largest group of first contact points with the Debenham Project, at 51%. The response re local publicity (including online) is noteworthy too, at 21%. Professional contact points (Age UK, health sessions) were also stated, and the direct networking that the Project itself does.

7.10.2. Q40b: How the Debenham Project has been of help:-

7.10.2.1. There is overwhelming (88% overall) benefit seen by responders in the Debenham Project and what it offers, and sincere gratitude for it.

7.10.2.2. Most common responses were that it provided a) contact with other people in the same situation, friendships & reduction of isolation (22%); b) support, reassurance & understanding (20%); and c) advice & information (11%).

7.10.2.3. Some other positive factors were help to cope when needed and which was timely and trustworthy; a regular outing; a place to forget things for a while; local awareness and thus support for others with dementia.

7.10.2.4. Notwithstanding all this, 10% of responders found the Debenham Project was not of help. Reasons included that it is the carer/cared-for who have to sort themselves out in the end; it gave information the carer did not already know; the project was not sufficiently developed when the cared-for needed help; or that it did not suit the cared-for.

7.10.2.5. One responder (2%) replied that they had not had much to do with it.

7.10.3. Gratitude for the Debenham Project:

Elsewhere in the questionnaire and across the research, the researchers found real gratitude for the Debenham Project among carers and people with memory loss/dementia – factors highlighted included the contact, responsiveness, warmth & friendship and hence the meeting of needs through services not available elsewhere.

SECTION EIGHT – DISCUSSION OF FINDINGS & PRELIMINARY CONCLUSIONS

8.1. Recap of Aims & Purpose

The principal survey group for this research was forty-two family carers of people with memory loss/dementia living either presently or in the recent past in the area covered by the Debenham GP practice including its two surgeries in Otley and Grundisburgh.

The purpose of the research was to obtain information from family carers and cared-for in Debenham & area about the memory loss/ dementia journey; a profile of the 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 aim of this research is to inform the funders; local and regional authorities and national government as well as the Debenham Project and partners to enable robust planning of future services and support for people with dementia and their carers. The research project has been undertaken between July 2012 and October 2013.

This report:-

- Lays out the responses to the family carer questionnaire, question by question
- Examines and computes these responses, categorising where clearly possible & helpful
- Incorporates experiences and views from the structured interviews, Debenham Project volunteer questionnaires and relevant professionals in social care and health services, including the voluntary sector
- Discusses the findings and draws conclusions before making some recommendations

The research is felt to be unique in its person-focused methodology and approach, and this is evidenced through the high returns and response rates. The researchers are trained & experienced in 'non-instructed' advocacy thus were able to engage empathetically with the client group while maintaining a professional and critical distance.

8.2. Usefulness of research

As laid out in Section 2 above, dementia is a growing problem in terms of the existing and projected population increases of people over retirement age and the increasing likelihood of dementia among this population as age advances. Statutory and voluntary services are responding to government initiatives and policy to adapt and respond to this issue. The diagnosis is seen as the gateway to receiving treatment and services. During the research, policy and practice by statutory and voluntary agencies has been changing apace. There is though a need to measure whether policy and practice changes locally and nationally are effective.

This research is very much person-focused and based on open-ended listening. Most of the study group in this research began their journey and were diagnosed prior to the national dementia strategy and the derivative Suffolk 'Living Well with Dementia' or other local and government challenges or initiatives in the different services. This data provides a 'freeze frame' in one small area, but an area where the community has banded together to provide advice, support, care and information. The research has provided a wealth of data against which to measure the effectiveness of changes and the existing situation for people with memory loss/dementia.

The data from this research project records experiences, perceptions, insights, learning, and reflections as reported by carers themselves about their own experiences and those of the person they care for. It is given breadth through the interviews with professionals and the feedback from Debenham Project volunteers, the majority of whom have been family carers themselves and who additionally have been given training in their volunteering role.

8.3. Discussion of Findings & Preliminary Conclusions

8.3.1. PROFILE OF THE CARER

The group of reporting carers are thus half and half spouse or offspring/offspring’s spouse/partner. They have overwhelmingly lived in the area for a long time, hence are most likely very familiar with it and many of the facilities/ services. They mostly have a reasonable level of education and/or were used to responsibility in their working lives. One-third live alone, which coupled with levels of physical ailments in half the responders, indicates increasing physical and/or mental strain which causes the carer not to be able to manage at some point. Money is a problem for a third of responders.

Key points & Issues
The profile of the carers reveals two key concerns:- a) The carer profile is largely of advancing or old age that is often overlaid with physical ailments that can impede the carer from caring; and b) One in three responders reporting actual or potential financial difficulty now or in the future.

8.3.2. PROFILE OF THE CARED-FOR

All the cared-for in the sample were over 70 years old, and three-quarters of them were over 80 or into their 90s. 19% had moved into the area in the last five years – a higher proportion that the carers. However, 78% had lived in the area for over 30 years. Roughly half of the cared-for lived with the carer. 40% of cared-for had moved to their current location due to their dementia; specific reasons given were a) risk to self or others, b) distance from family or c) unsuitability of property. 85% were reported as appropriately housed. One-third have moved into residential or nursing care. The cared-for’s physical health was excellent to moderate for just over half, while just under half were reported as in poor physical health. They were a moderately well-educated group, often used to some responsibility in their working lives. Financial problems were highlighted for 7%. Carers highlighted changes in character and mood; frustration, and for the carer the strain & sense of loss and sadness – and also that it can take an outside person eg GP to ‘legitimise’ their own needs.

It is an older group – all are over 71 and ¾ are over 80. Approx half had physical health issues which also needed caring for. 2/3 were living in a domestic, familiar environment which largely meets their needs. But 1/3 had moved to a care setting. There is no care or nursing home within 7 miles of Debenham so travel is needed to visit: potentially a significant problem for those older, frail carers and/or those requiring public transport: there is no direct service to the nearest care/nursing home.

Key Points & Issues
The financial picture of cared-for contrasts with the carers’ picture. While 32% of carers reported actual or latent financial concerns. ‘Only’ 7% of carers reported financial inadequacy. Part of this

may be due to benefits and allowances for the cared-for. Although 7% is statistically small, it is a real problem for those carers and cared-for. 31% of *carers* live alone, and paying in some way for two establishments will be more costly – especially since 33% of cared-for live either in nursing or residential care, where the fees (if partially or wholly funded by the cared-for/carer) will be a large drain on capital or income.

This section gave the first glimpse of the effects of dementia on the cared-for, and the physical and emotional cost to the carer. The individual comments are important – one here revealing how the carer perhaps cannot give themself permission to consider their own needs.

8.3.3. EVOLUTION OF MEMORY LOSS/DEMENTIA

There was a broad range of evolution of memory loss/dementia, from a gradual decline right through to those who are experiencing major behavioural issues. Each responder was at very different stages of the memory loss/dementia journey. The most frequent first signs reported were forgetfulness, difficulty doing familiar things, misplacing things and changes in mood. The most commonly reported next signs were (greater) difficulty with familiar tasks and (greater) memory loss. In terms of what made it clear to the carer or others that it was more than age-related, the highest scoring reasons were memory loss (1 in 5); personality change (1:10); problem or inability with familiar tasks (1:10); lack of motivation (1:10). Four further signs were listed: Inability to concentrate/vagueness (5%); non-absorption of information (5%); fantasising/hallucination (5%); and a sudden change in the cared-for's condition (2%).

Key Points & Issues

The data highlights that a not insignificant minority of carers and cared-for found it difficult to confront what is happening. Many of the signs that it was more than age-related could also be seen as a personality change as well, as indeed could many or most of the other factors listed (each with almost half the number of responses).

8.3.4. AWARENESS, KNOWLEDGE & UNDERSTANDING OF DEMENTIA AND THOSE FIRST TURNED TO FOR HELP

Carers reported long periods of knowledge/caring for someone with increasing needs. This is an issue particularly given some of the health conditions listed by carers earlier. Numbers stating there were signs that could have been detected earlier point clearly to the lack of knowledge, information or pathway that carers state elsewhere. In the study area at least, family ties are very important: it is the family (plus, on occasions, friends/colleagues) who are turned to first for help. The GP is first 'external' port of call – often after consultation with the family. Given the 'fog' or absence of knowledge (reported elsewhere) re what was taking place, or any pathway to find help, this help from family etc and then GPs would seem both essential and a base on which to build further knowledge

Key points & issues

The Carers' lack of knowledge and awareness of dementia: In view of the responses above, more education & education is clearly needed to enable carers to pinpoint the condition and learn what to expect and how to care & live with it.

Family ties were very important and the first "port of call" for many in seeking help. GPs were a close second, but often in fact approached only after discussion with family.

So where these are absent, the GP (and others likely to be turned to) should be trained to pick up this role and offer advice and information**.**
Literature should be considered (hard copy and online) to highlight likely first signs, what to look for, what to expect and where to seek help. [This could be similar to the stroke leaflet '*When Stroke Strikes, Act F.A.S.T.*'; e) What happens if the carer and family live some way from each other?

8.3.5. IMPACT OF CARING FOR SOMEONE WITH DEMENTIA

The impact on carer is predominantly negative. While this is already widely understood, this data starts to quantify the issues. The impact appears to be firstly, emotional/psychological; then social/lifestyle; then practical. Much of the emotional/psychological impact appears to derive from the cared-for's changed character. Chief factors stated are fear/worry, guilt, exhaustion, impact of constant vigilance/attendance and isolation. Physical health deterioration is also reported. Other significant impacts reported include the consequent anguish of carers, deterioration of relationship between carer and cared-for – and worry about insufficient money. This said, the level of commitment from carers is strongly evident, despite the frequent lack of support reported beyond the family or GP. The family support (eg in providing physical care support to relieve the primary carer) is a noteworthy upbeat factor in a number of secondary responses.

Key point or Issue
The support for these impacts – is there sufficient? Is it apposite?

8.3.6. AWARENESS OF HOW TO ACCESS HELP, CARE & SUPPORT & WHO FROM

The GP is the first person or organisation the carers turned to for help, services or signposting, with the Debenham Project second equally placed with the carers' use of their own initiative. Social Care then Health were next. It is noteworthy that 6% could not or did not make contact or discover who to approach.

The comments made here about the various agencies are important to note. The media had an impact for some; social care usually volunteered information; health did not provide support for cared-for. Carers see voluntary organisations as helpful and kind. Some help was difficult and unacceptably long to obtain. There was too much paperwork and too little personal contact. One carer owned: "I learnt as I went along" – which as we will see elsewhere is a recurrent theme. One carer highlighted the view that no help is really possible for someone with dementia. The final comment reveals stubbornness as a trait that the researchers heard repeated a number of times in the structured interviews.

Key Points & Issues
Given the high proportion spontaneously seeking help from the GP, is there a wider role for GP being the access point or gateway? However, there were questions about the skill of the GP re dementia & support, and these point to several interlinking training needs for GPs.

It is clear that other help offered/provided by various agencies was a mixed bag with some good practice and some poor, and that more needs to be done to highlight where to obtain help, what can be offered and to simplify how to obtain it.

The research data reveals that many respondents have not felt supported but rather have felt isolated, perplexed and ignorant and thus have either had to fall back on their own resources (initiative, family etc) or wait for a crisis. Many reported too many agencies to deal with – so one gateway is needed. It seems the need is to ensure people have the knowledge and tools to identify what they need at the right time. Likewise responsive, adequate and trusted local services, advice, care & support are required.

8.3.7. DIAGNOSIS, ITS EFFECT, EFFECTIVENESS & TIMELINESS

Most diagnoses appear to have been given by an appropriate consultant, although 14% were reported as given by the GP. More responders saw an early diagnosis as making a positive rather than a negative difference although a significant minority saw it the other way round and some saw it as a mixed blessing. The main benefits reported are being able to plan for the future; confirmation of what the problem is; early medical and other intervention (13%); and the delaying effect medication can have (6%). The remaining 23% reported in one way or another that an early diagnosis improved quality of life, particularly perhaps for them as carers. The main drawbacks were seen as it changing nothing or making no difference; confirming worst fears/suspicions; a sense of resignation or pointlessness of having a diagnosis; a sense of ignorance or helplessness about dementia.

Key Points & Issues
14% of diagnoses were reported as given by the GP. However this is not a formal diagnosis but probably a tool such as GPCOG. It is evidently assumed by these responders to be formal or complete, either since the GP indicates this or because it is not clearly or sufficiently explained to or absorbed by the cared-for or carer – who are after all in a very stressful situation. However, discussions with GPs indicated that possibly they may at times feel that the dementia is so obvious from these tests or from presenting behaviour that no further assessment is needed.

This points to lack of knowledge or clarity by the responding carers about the process, pathway, outcomes and explanations given or retained. Hence it indicates a need for more clarity of information, great clarity yet sensitivity by the GP in this highly intense situation, and so training for professionals and education of carers.

Since this question was about an early diagnosis, the responses given should be seen not necessarily as comments about the impact of a diagnosis per se, but instead about seeking or receiving that diagnosis early, and whether/how there are benefits to this. This explains perhaps why there were three times as many benefits listed as downsides.

People with dementia have a lot of needs before the point of diagnosis. Dementia is often(?) revealed through another presenting problem which requires eg hospital admission. Why is the diagnosis the primary gateway to services when people appear to need many services at different times beforehand? Where does this leave the formal diagnosis-led approach as the gateway to dementia treatment and services?

Support being refused due to obstinacy/incomprehension of the cared-for or the inflexible times given or high staff turnover. The negative responses here in Q38 (especially the first 19%) show something of the bleakness and melancholy that receiving a diagnosis can bring or reiterate, whether it is early or not.

8.3.8. SERVICES/SUPPORT/HELP: ACCESSIBILITY, USEFULNESS & TIMELINESS

Family are the primary people turned to for help in the first instance. The GP is a close second, although many contacted the GP following discussion with the family. ¾ of responders saw this help as beneficial, particularly family assistance. Slightly more positive than negative comments were received about professional help at this stage – likely to be largely the GP.

At or as a result of diagnosis, 50% of responders recorded being offered a service, while 40% report they were not. 2 in 5 of those offered a service said that it was insufficient or late. 34% of services offered were from the voluntary sector, 26% from health and 16% from social care.

56% were positive in some way about the helpfulness of the help or service offered as a result of the diagnosis, while 44% said it was not helpful in at least some way. Nearly three times as many responders indicated some benefit in early support rather than not.

Prime responses to why/what early support would have helped fall into: benefits of peer support, knowledge of who to ask/what is available, and training to manage the situation & support the cared-for (12% each of the total responses here). Interestingly, most of the reasons given why early support would *not* have helped relate to lack of perception/ acceptance by the cared-for.

Key points/issues

Even though 56% reported some level of satisfaction, significant disquiet was evident among carers about professional service provision – knowledge, availability, appropriateness/person-centredness & quality.

It is startling that the highest percentage for any service offered (when the diagnosis was made) was a list of organisations to contact. Notwithstanding the shift by social care away from direct provision & towards sub-contracted services via the voluntary sector), it is perhaps of concern that the proportion of social care services offered/provided is so low (16%), not least since this presumably include benefits etc.

The health services offered/provided figure is also comparatively low (26%), considering it includes the GP service.

The researchers noted there was a lack of one key person/anchor person in support provision. For most of the survey group, diagnoses were before the existence of the Dementia Advisory Service (DAS). The data here can be compared with post-DAS cases.

A majority though saw the services or help offered/provided as of benefit, and a strong majority saw early help & support as beneficial. Peer support, greater knowledge, and training were the key benefits foreseen of early support intervention.

Another important point is the way dementia can come to light as a result of other health conditions precipitating a hospital admission *(insert under 'getting help'?)*

8.3.9. CARERS' VIEWS ABOUT IMPROVEMENTS THAT COULD BE MADE & WHAT MIGHT ENCOURAGE OR DISCOURAGE SEEKING HELP

Carers' responses to Question 33, about what else might have helped them and the person they care for were nearly all about improvements to the services offered by professionals, largely either overtly or by implication referring to some shortcoming in the services provided by the statutory sector, and a few comments which point to potential areas for the voluntary sector or local community to consider as well.

There are 2.6 times more reasons given (in answer to Question 36) that discourage seeking help than encourage (72% compared to 28%). The main areas cited that might discourage seeking help were a) the emotive or reactive to the memory loss/dementia; b) problems between cared-for/family/carer; c) problems with services; and d) the situation causing or stemming from isolation.

The main areas seen as potentially encouraging seeking help were: a) the emotive/reactive; b) greater publicity and awareness; c) upskilling volunteers, NHS staff & GPs; and d) increased peer support, knowledge and education of carers.

A further perspective was obtained from Question 37 – looking back, from what you know now, what if anything would you do differently. The biggest single answer was ‘nothing’, although this changed for many in the face to face interviews. Overall, however, half said in different ways that they would have acted sooner and/or have been more assertive.

Key points & issues

There are clearly further issues here for the statutory and voluntary services to learn from here in order to improve their practice, and this section is perhaps more specific about what these are. Even though the section above reports a majority finding fair levels of satisfaction with the services provided following the diagnosis, here there is evidence that both additional services were needed – and improvements to the existing. It appears that in 1 in 5 cases, the situation is directly influenced, caused or exacerbated by a perceived shortcoming of the statutory health and/or care/support agencies.

There are 2.6 times more reasons given that discourage seeking help than encourage (72% compared to 28%). The highest scoring reasons that discourage *and* encourage are emotive/reactive reasons– chief among which are frustration or desperation (as reasons to seek help – a kind of double negative) and pride (as a reason not to seek help). There is a problem also with the cared-for, the family or practical issues to do with managing or living with the diagnosis. Further, there is the stigma and isolation on top of all this. So the fact that carers do actually seek help points to their dedication and commitment to the cared-for.

The responses here thus draw out much of the reality of life with dementia –particularly for the carer. The level of these and the other negative emotions reported seen as discouragements is important since they indicate that eg frustration, feelings of inadequacy, isolation, unsupportedness and bleakness are common among carers. A point to be made here in conclusion is that this state of affairs would potentially have been greatly eased by the existence then of a pathway for dementia comparable for example to that for cancer. Equally, the Dementia Advisory Service could have perhaps helped, had it existed, although questions were voiced by professionals about the scope and capacity of the service to cope with current and future demand

Hence the reasons that *encourage* seeking help should not be overlooked. They point very directly to areas needing development – publicity and awareness, improved services, greater education.

The question about what carers would do differently now, obviously has applications not only as a snapshot of the picture for this group but also has direct applications for the future. Two points are noteworthy. First, that in the questionnaire, many answered ‘nothing’ here yet revealed more face to face. The implication perhaps is that it can be hard to admit that as a carer that they feel they could have done more, particularly in the light of the guilt a number of respondents touched earlier. Second, that those who gave a fuller answer here owned to realising that they now would have taken more action and/or been more assertive. This seems to imply that to obtain results and action (eg for appropriate support) often takes energy, obtaining help, support or a service beyond the family often required considerable effort, assertiveness and tenacity. However, the research has also established that carers were frequently exhausted, depressed or demotivated.

8.3.10. THE DEBENHAM PROJECT & ENGAGEMENT WITH IT/ITS USEFULNESS

Responders had heard of the Debenham Project through a variety of means. Chief were informal local networks, although the single most common route was through the GP. Local publicity was close behind, as was the Debenham Project itself, and there was evidence that some other professionals were also referring to it.

It was seen by most responders as of benefit and viewed likewise with gratitude. Key benefits were seen as a) contact with other people in the same situation, friendships & reduction of isolation (22%); b) support, reassurance & understanding (20%); and c) advice & information (11%). Factors reported elsewhere were the contact, responsiveness, warmth & friendship.

12% of responders had not found the Debenham Project to be of much or any help, for a number of reasons.

Key points/issues
The Debenham Project's penetration of the memory loss/dementia population appears to be reasonably effective in the light of the estimates[31]. Responders had heard through quite a variety of methods.

However there is room for greater penetration, which of course is one of the reasons for this research. The more informal, local networks appear relatively effective but contact or referral from other agencies appears very low in the research sample in this albeit historic sample. So there is scope for further work here.

In terms of the Debenham Project's helpfulness, the sample group reported a wide range of ways the Project had helped them to cope. In essence these were through the meeting of needs through services not available elsewhere.

Given this – and also the climate of service provision and funding – it is very important that a project which is voluntary, for the community and inspired by the community continues to provide and expand its service to its community, to work towards as close to 100% penetration of the group in its area affected/likely to be affected by memory loss/dementia.

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[31] See footnotes 23 & 24

SECTION NINE – CONCLUSIONS

9.1. General

As far as the researchers know, there has been no other extensive research carried out into the 'journey' for carers and cared-for.

It will lend itself to other research. The approach described in this report appears to be a complete methodology and potentially sufficient for use by others seeking to engage with people, in a non-prescriptive and personalised way, in this and other areas of research.

The research reveals a detailed picture of the dementia journey, the profile of carers and people with dementia, and concrete data to evidence commonly held views regarding dementia

There was a high response rate to the requests for information, and the data obtained was pertinent to the aims of the research project. The personalised and informal approach appears to have helped significantly to obtain this high response rate and pertinence

9.2. The dementia 'journey'

The survey sample of carers was generally articulate, reasonably financially comfortable in the main but with exceptions. However, whether or not this was the case, it was apparent very early on to the researchers that for the great majority of carers, there was little knowledge and great unpreparedness in the early stages and beyond of what a diagnosis of dementia entailed. This was evident in terms of changes in and behaviour of the cared-for; the path the disease could or would take; and where to go for information and help.

Most cared-for were in their eighties and even nineties, and those living with the primary carer were (with two exceptions) of similar ages to each other. Related to these ages, there were often significant physical frailties among the carers which made the caring task even more difficult, stressful and exhausting than it was without this.

One third of the cared-for had eventually moved into care. While there are debates to be had concerning the appropriateness of such a living environment for people with dementia, in the survey area the key issue is the distance of any care setting (satisfactory or otherwise) from many of the villages where carers were living. In the case of Debenham, it is at least seven miles. At this distance it is not a community facility, and transport is difficult for those carers/family who are frail themselves and/or reliant on public transport – particularly since there is no direct bus from eg Debenham to the nearest care home. Debenham is not unique in this.

Finance is an issue for a small but significant minority. There are some carers (and some cared-for) who report difficulty now or for the future. This is a critical issue, not least given what it adds to the carer's burden and stress.

There was a broad range of experience reported in the evolution of the memory loss/dementia, from a gradual decline right through to those who are experiencing major behavioural issues. Responders were at very different stages of the memory loss/dementia journey.

Changes in the cared-for were predominantly in character and mood along with frustration. The most frequent first signs reported were forgetfulness, difficulty doing familiar things, misplacing things and changes in mood. The most commonly reported next signs were (greater) difficulty with familiar tasks and (greater) memory loss. In terms of what made it clear to the carer or others that it was more than age-related, the highest scoring reasons were memory loss; personality change; problem or inability with familiar tasks; lack of motivation. Four further signs were listed: - inability to concentrate/vagueness; non-absorption of information; fantasising/hallucination; and a sudden change in the cared-for's condition.

The task of caring was seen predominantly as overwhelmingly exhausting, physically and emotionally, and about the carer putting their own life on hold. Carers reported experiencing worry, fear, guilt, strain and a sense of loss and sadness and did not give value to their own needs – or if they did, there was often no-one to share the load as is evidenced by the following quotation from one carer.

> *"I'm alone with (N) most of the time but have had no rational conversation about anything with [N] for years now. [N] can't support the TV or radio being on either. [N] just sits there and repeats the same thing over and over*".

The relationship between carer and cared-for frequently deteriorated significantly, and for the carer loneliness and isolation were much reported: it is perhaps 'Catch 22', since the 24/7 nature of the caring prevents the carer seeking much external stimulation and yet being with the cared-for provides the reverse of mental stimulus. Family ties were very important; it is the family who are turned to first for help, but it should be noted that of course not everyone has family. The GP is the first 'external' port of call – often after consultation with the family.

9.3. The perceived advantages and disadvantages of an early diagnosis

The main benefits reported of an early diagnosis are: - being able to plan for the future; confirmation of what the problem is; early medical and other intervention; and the delaying effect medication can have. The remainder reported in one way or another that an early diagnosis improved quality of life, particularly perhaps for them as carers. The main drawbacks were seen as it changing nothing or making no difference; confirming worst fears/suspicions; a sense of resignation or pointlessness of having a diagnosis; a sense of ignorance or helplessness about dementia.

There are important issues though about the use of the diagnosis as the gateway to treatment and services as the Government directs. The diagnosis did not usually overcome or reduce the physical and mental exhaustion, loneliness or worry, and frequently did not ease the condition or burden of caring for the cared-for. The researchers heard from carers, volunteers and professionals how interventions and support were frequently required before a diagnosis, and were often not forthcoming, only partial or late.

Given that a proportion of carers reported that the diagnosis had been given by the GP, there evidently is a lack of clarity about who gives it, what it achieves and what it leads to. In effect, at the time of the research there was no clarity of pathway, and this had a measurable effect on the help and services provided. Since then, the national and local dementia strategies are being implemented which may remedy this but there is still potential for people being misrouted, particularly given the evidenced lack of specialist knowledge or training amongst some GPs, consultants and other health professionals.

Given the high number spontaneously seeking help from the GP/ GP practice (and acknowledging that the GP is already the first port of call outside the family), there may be a wider role for the GP as the access point or gateway and this could be a logical extension of the 'Enhanced GP Service'[32] as identified by the Department of Health.

9.4. The perceived advantages and disadvantages of early support

Our data reveals that many respondents have not felt supported but rather have felt isolated, perplexed and ignorant and thus have either had to fall back on own resources (initiative, family etc) or wait for a crisis. Many reported that there are too many agencies to deal with – one gateway is needed. It seems there is a need to ensure people have the knowledge and tools to identify what they need at the right time. Likewise responsive, adequate and trusted local services, advice, care & support are required.

It was notable that a significant number of diagnoses were made following another presenting issue or crisis – eg hospital admission following say a fall. This indicates that the dementia or memory loss is not always being identified early, and so there an evident need for screening before the point of diagnosis. There is an issue about the fact that services will only respond once there is a diagnosis of dementia, and that this is seen as the gateway to appropriate support, information and guidance. However, professionals and others indicated that there were insufficient resources and a narrowing of remit within the support services, both those current and envisaged. With increased demand due to a growing older population likely to have greater levels of frailty (mental and physical), this may well mean a shortfall of services once a diagnosis has been given. There was also a lack of clarity about who to contact for help or support, and too much paperwork which was confusing. The need for a single point of contact was identified by carers, but it should be noted that the strategic solution to this issue is already facing reductions in its remit and resourcing, according to some professionals interviewed.

It was noticeable from the questionnaires but also, and particularly from the face to face interviews, that those who had been used to taking initiative or responsibility in their working lives seemed often to have received a better service.

A major problem for carers was their unpreparedness and lack of knowledge about dementia and what was unfolding for them and the cared-for. Overall support offered and/or provided tended to be patchy at best and at worst absent, inappropriate and inflexible, and it appears that staff often were unaware fully of what was available. This, with the levels of exhaustion and worry, adds to the burden of caring and makes the commitment and dedication by the carers additionally significant. The statutory services do not come out well in general, and even the GP service – while highly valued by many – does not escape criticism. Voluntary organisations were seen as supportive, and the Debenham Project was very well viewed and praised by a significant number of carers.

The chief apparent reason (reported by carers and volunteers) that the Debenham Project and its services are so highly viewed was the value of its informal and personal support where experiences can be shared. These provide a network, ranging from people who understand through experience, personalised advice and peer support. Also highly important were friendly, non-professional faces and hospitable social events and clubs, in settings that reassure and

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[32] See Section Two, 2.4. above, and http://www.england.nhs.uk/wp-content/uploads/2012/03/fact-enhanced-serv.pdf

affirm. This meets many underlying needs of the cared-for and carer that professional support may not be able to.

9.5. Concluding Remarks and Points for Further Consideration

A new methodology was developed which achieved high response rates and depth of information. The purpose of the research was to illuminate the dementia ‘journey’ by the carers and cared-for; to investigate the pros and cons of early diagnosis and early engagement with services. The following issues emerge as the main concerns:-

- Lack of knowledge and unpreparedness of carers
- Greater range and depth of person-centred support
- Addressing the needs of a rural community e.g. transport to, and distance from, care homes
- Financial worries of carers
- Isolation of carers and the burden of caring
- The focus on the diagnosis as the gateway to services and support
- Obtaining services before diagnosis
- A single point of contact for carers and people with dementia/memory loss
- Training needs of GPs, other health and social care professionals