

## **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.**



## **SUPPLEMENTARY REPORT December 2013**

Commissioned and funded by



## SUPPLEMENTARY REPORT – DEBENHAM PROJECT RESEARCH

*Tim Mason & Gordon Slack, December 2013*

### SYNOPSIS

**This report is supplementary to the researchers' Final Report<sup>1</sup> for the Debenham Project. Its purposes are to include information not included in the Final Report, and to expand it where pertinent. It includes:-**

- Further themes emerging about the carer/cared-for journey & early diagnosis and early engagement with services
- Narrative which broadens or fleshes out themes already highlighted/ included in the Final Report
- An outline of current structures, practice and policy
- Discussion about practical and policy changes to planning and delivery of services and to what extent they are improving life for people with memory loss/dementia and their carers in the Debenham area
- The researchers' conclusions.

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<sup>1</sup> [http://www.the-debenham-project.org.uk/downloads/news/DebProjResearch\\_Final\\_Report\\_311013.pdf](http://www.the-debenham-project.org.uk/downloads/news/DebProjResearch_Final_Report_311013.pdf)

**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. Final Report 2013

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Tim Mason & Gordon Slack, December 2013

### 1. INTRODUCTION – WHY A SUPPLEMENTARY REPORT

- 1.1. This report is supplementary to the researchers' Final Report<sup>2</sup> for the Debenham Project, and is funded by the Norfolk and Suffolk Dementia Alliance
- 1.2. Its purposes are to include information not included in the Final Report.
- 1.3. The information in it comes from material gathered through the Structured Interviews, Volunteer Questionnaires and meetings with professionals. The previous, Final Report dealt primarily with the findings of our questionnaire to primary family carers.
- 1.4. It provided hard data concerning the memory loss/dementia 'journey' experienced by the carer and cared-for, and investigated the upsides and downsides of early diagnosis and early intervention by support and other services. It provided largely quantitative information, giving detailed results, categories and trends emerging accordingly, with a number of consequent conclusions. It brought in some information and narrative obtained from the follow-up structured interviews of the primary carers, and some themes emerging from the interviews held with relevant professionals. It included some data from the questionnaire sent to volunteers within the Debenham Project. Further, it gave a picture of changes in policy and practice for dementia nationally and locally which at the time of the research (July 2012-August 2013) was rapid and significant, and still in a state of flux.
- 1.5. This further, Supplementary Report adds to these findings by providing further detail from the sources listed above. The aim is to provide a more rounded picture of the key areas of the research (the experience of the dementia 'journey', the advantages/disadvantages of early intervention/ support). Hence it a) includes additional narrative information; b) returns to existing themes where the additional narrative information indicates they need more prominence; and also c) introduces some new themes that have become apparent from the narrative.
- 1.6. This approach means that a much fuller picture of the carer journey and their experiences, wishes, feelings, values and beliefs was obtained. This Supplementary Report can therefore include comments that are unique to one carer or situation which may not highlight a trend but nevertheless make an important point. It thus adds to the understanding of the journey the carer and cared-for have made as memory loss becomes dementia, is diagnosed, progresses and hopefully supported.
- 1.7. The researchers have also revisited the policy and practice situation, laying out here their understanding of how it currently is being rolled out for dementia. They have reviewed it to see how the changes address the concerns and issues identified in their research.

NB. Where the term 'carer' is used, this refers to the primary family carer unless otherwise stated.

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<sup>2</sup> [http://www.the-debenham-project.org.uk/downloads/news/DebProjResearch\\_Final\\_Report\\_311013.pdf](http://www.the-debenham-project.org.uk/downloads/news/DebProjResearch_Final_Report_311013.pdf)

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## 2. ADDITIONAL OR ENHANCED THEMES EMERGING FROM THE STRUCTURED INTERVIEWS, VOLUNTEER QUESTIONNAIRES & PROFESSIONAL INTERVIEWS

This is the main section of this supplementary report. It lays out:-

- a) Themes that were covered in the Final Report but where further depth and perspective is gained from the structured interview narrative or the interviews with professionals, or where the data from the volunteer questionnaire also adds to the picture;
- b) Individual comments (mostly from carers during the structured interviews) which throw additional light on the memory loss/dementia journey, the pros and cons of early diagnosis and early engagement with support services, and
- c) Themes that were either not apparent or were not explicit in the data gathered for the Final Report, but which come to light from the further narrative/data as in (a) and (b) above.

### 2.1. CARERS & CARED-FOR

#### 2.1.1. Life of carer/Burden of caring

This theme was reported in detail in the Final Report, where the effects were summarised thus<sup>3</sup>:

- **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
- **Social/lifestyle** effects (deriving from eg isolation), and the
- **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.
- **Money:** Significant concern was also reported about insufficient funds to live on
- **Anguish:** The data reveals the anguish involved in caring for someone with dementia
- **Commitment:** A very high level of commitment from carers is evident – despite a lack of support

The sources quoted in this Supplementary Report throw additional light on the life of the carer and their burdens, and so some additional detail & pertinent quotations broaden the picture quoted above.

In the volunteer questionnaire, strain & the all-consuming nature of caring were the overriding factors reported. Additionally, as part of this issue, 20% saw frustration & anger as key features of the carer's burden; 13% saying loneliness or isolation and 9% voiced financial problems and worries.

These factors were apparent in the Final Report, a picture that was confirmed and enlarged on in the structured interviews. One family carer summarised the 24/7 nature of caring and its effect: *"I ignored my own health problems... I had no choice... it was hard as they were exacerbated when I was exhausted."*

<sup>3</sup> Final Report, 58f

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It was noted by some carers during the structured interviews that the weight of caring tended – beyond the spouse – very often to fall on one of their (adult) children. In some cases this was due to the other children’s own family commitments or distance away, but other spouse carers and family carers felt it was due to the other children being in denial or oblivious to the burden/need.

At least one carer added (in the structured interviews) that the frustration/anger also emanated from the cared-for and means they live in some fear of violence – and one reporting that the cared-for will only reveal this side of themselves when alone with the carer.

In one structured interview, the family member pointed out the strain between the parents, and how the primary carer shouted and picked on the cared-for – the reverse of previously.

Another carer in a structured interview highlighted the sense of commitment: *“Being able to help my wife was a real plus in my own life. It’s a real privilege; your spouse is part of your life and vice-versa. What would they do without you [when the dementia occurs]? That’s the privilege. It’s a mental approach, really.”*

However, a very different perspective is seen from another spouse carer in a structured interview. It does not in fact show any less commitment, but is very shocking at first, and invites careful ethical consideration: *“I just knew I was in for a rocky ride. The sooner he died the better for him. [True] care for people with dementia is not to prolong their lives, but if you can shorten their lives, so much the better. It’s ridiculous extending life for people with dementia.”*

### 2.1.2. Isolation

While isolation was an issue raised in the Final Report and touched on in 2.1.1 above, it was highlighted more robustly in the structured interviews and also as a significant factor in the volunteer questionnaire responses. It was essentially about carers’ lives as a result of the burden and intensity of caring. For probably most carers, there was no time or energy to socialise or even get away from the cared-for or home – rather, there was exhaustion. The cared-for provided no conversation or support – rather, the reverse.

Respite or even a break for a few hours was frequently longed for by many carers; sometimes family, friends or paid carers were available for very short breaks, or indeed respite was available for some but for a proportion was then coupled with guilt from the carer at leaving the cared-for or not being able to manage. Family was the main source of support, and friends in a number of cases [see 2.1.13 below as well]. A significant proportion of carers perceived a stigma or label which perhaps prevented them asking for help or taking up offers of help, and so the loneliness of isolation was thus exacerbated. Also, of course, for those who have never been in this situation, it is difficult to imagine the burden:

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*“Friends have said, ‘You know where I am if you need me’, but they don’t know the half of what you are going through. It just adds to the isolation.”* – Carer during structured interview.

### 2.1.3. Stigma

The word ‘dementia’ is difficult, according to some carers in the structured interviews and also some dementia advisors and volunteers. A professional even stated *“Dementia has now almost replaced cancer as THE fear”*. Its connotations perhaps are of ‘demented’, frantic, random craziness or insanity, which are not helpful in portraying dementia as an organic illness to the population at large. Volunteers and one or two carers also reported the link between the stigma and consequent perceived or actual ostracisation/isolation. These points came up in the first report, but perhaps were given more emphasis by the volunteers and so need some further highlighting.

### 2.1.4. Respite

The need for more (and local) respite was also a theme emerging from the volunteers and professionals [See also 2.1.2 above]. According to one professional working directly with carers and cared-for, what is required is not just more respite, but respite appropriate to the person. If the cared-for goes for respite, they can often return worse and subsequently can no longer manage at home.

### 2.1.5. Church & Faith

A theme which emerged only in the structured interviews was that perhaps 50% of the carers indicated that their church or faith was of significant help or benefit. Many churches/clergy/ministers were a definite support, for example some visiting regularly, bringing home communion, or simply providing background support, community or companionship. But some carers commented how little or no support was offered, even sometimes where the cared-for’s memory problems/dementia were known by the clergy and/or church. And in one or two places of worship the carer reported that cared-for was not made to feel welcome.

Some of this group stated that their (Christian) faith was very important to them and helped sustain them amid the burden and exhaustion of caring. Again, this did not come out in the questionnaire, but was volunteered during the structured interviews as part of their story. It appeared to go beyond formal churchgoing, and indeed getting to a church for a service was not easy for some carers.

A related perspective mentioned by one carer in a structured interview was *“Why has this happened to me? I haven’t done anything wrong”*; this perhaps overtly vocalises what others may think as well.

### 2.1.6. Perspectives of the Cared-for

The Final Report highlighted that the research did not attempt to obtain the direct views of the cared-for since the answers obtained would be likely to have been either hypothetical (in the case of mild) or unreliable (in the case of moderate to severe). Instead, the carers’

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observations of the cared-for were sought via (for example) perceptions of how their personality and behaviour changed and evinced a diagnosis of dementia.

The structured interviews have added to this and basically broadened the picture obtained through the carer questionnaire. However in a number of places, the information obtained through the structured interviews went deeper than for example factual observations and behaviour, and appeared to reveal thoughts and wishes even (at times) when the dementia was in late stages. One carer reported that their spouse, who never said much as a rule, said the diagnosis was “devastating”. Several carers reported that the cared-for, even in advanced stages of dementia, expressed a wish to die, and one carer noted that the cared-for (by then in nursing care) appeared to deliberately stop eating in order to die. Equally, another carer recalled that the first sign of dementia was when the cared-for said – uncharacteristically – that he was going to end it all. (This carer then took him to the GP who prescribed antidepressants – not an uncommon response by the GP in the researchers’ experience during their research).

From this and volunteers’ and structured interview comments, there is a need for accurate understanding of the cared-for by all. This is particularly so in the case of paid carers (both in care homes and domiciliary situations) responding to people whom they either do not know, or who present changing behaviour patterns.

Also, another carer noted that the cared-for had said when the family brought in carers: ‘Why have you abandoned me?’. This concurs with many carers who noted that the cared-for became very anxious when the carer was out of sight even for a moment or went out even for a very short while – compounding the unrelenting strain of caring.

### **2.1.7. Stimulation of the cared-for: the ‘care home effect’**

Although care and nursing homes were discussed in the Final Report at several points, some additional impacts were highlighted in the structured interviews and interviews with professionals.

It was noted that the standard of care/nursing homes varied greatly between homes, and some cases the carer was so unhappy with the standard that they managed to get the cared-for moved to another home, almost entirely with very positive effect. One carer even said of a care home where their spouse had been: *“I can’t speak badly enough of them”*.

The chief reasons for the dissatisfaction variously expressed appeared to be insufficient staffing or poor quality of care, although in a couple of cases there were concerns about the financial scrupulousness. Carers (and professionals) reported that worries about quality and cost of homes added to the burden of caring. In one case, the carer stated that the staff tried hard, but the care company was mean so there was a lack of activities. A lack of stimulation was reported on in several cases. One carer reported during a structured interview that the cared-for had lost all their interests/hobbies once in care. However, another carer felt that good residential care was preferable to the home environment since

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there was more stimulation there (the cared-for was “lonely and bored” at home), and in a structured interview a daughter commented that the relationship between her parents (i.e. the cared-for and primary carer) was better now the cared-for was in a care home.

In contrast to this though, a number of carers noted that the cared-for went into an accelerated decline & then death once in care – generally since they had lost interest in living. This situation was felt to be common by relevant professionals: ‘*The Care Home Effect*’. One professional stated that residential care is not now the option of choice, and typically leads to reduced life expectancy; another professional commented on the current vision of facilitating more people to stay at home or in supported living.

Other carers commented in the structured interviews about the issue of stimulation of their cared-for while living at home. One carer felt strongly that if they did not ‘push’ their cared-for, they would decline faster. As it was, the carer programmed the cared-for’s activities and felt it kept the cared-for more independent, and for longer.

Hospital was viewed with mixed feelings. While not all cared-for had spent time there, there was a feeling expressed in the structured interviews by a proportion of carers that (similar to residential/nursing care) home was greatly the preferred place for the cared-for, despite the pressures and burden. Probably the most extreme example of this was as one spouse carer expressed in structured interview:

*“I made a formal complaint to xxxx Hospital about the standard of dementia care...for example when I took him to the WC I discovered he was caked hard with excrement, so I cleaned him but this was repeated over three consecutive days. He wasn’t attended to the WC, and he also fell and injured his head. Staff didn’t learn even small ways of understanding him.”*

### 2.1.8. Coping with practical & emotional problems – carer and cared-for

On this issue, The Volunteers Questionnaire enhanced the findings in the Final Report, indicating overridingly that the greatest positive help for the **carer** would be more localised, sensitive support. The greatest perceived issues militating against carers coping were isolation/loneliness (38%) and difficulties and inconsistencies with services/agencies.

Likewise, the volunteers observed that the greatest positive help for the **cared-for** in coping with the practical and emotional problems of their dementia would be: acceptance, kindness and understanding (31%); good listening/respect (25%); stimulation, eg hobbies, music, photos, reminiscing (20%). The least helpful factors in this area for the cared-for were reported by volunteers as being: communication by *others* towards the cared-for 48%; communication by the cared-for *towards* others 15%.

This was helpful in adding breadth to the picture here. A further point arising from the structured interviews was how the carer (mostly the spouse of the cared-for) had usually to take on tasks that previously were their partner’s. Typically, given the older profile, for a carer who was the wife this meant taking on managing the couple’s finances and perhaps

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DIY tasks. For a carer who was the husband, this meant learning cooking and housework skills. As one female carer put it, it was *“Role reversal; he doesn’t now say or do a thing. He used to take the lead in everything and I didn’t say boo to a goose. But now I’ve had to take the lead”*.

This carer went on to point to another issue that was alluded to by a number of others: *“I couldn’t manage him [physically eg lifting]. We got superb care for six weeks after he came out of hospital. They built rapport and he responded very well. But then agency carers came and made him go back into his shell. They had a huge turnover of staff – and less training”*.

### 2.1.9. Diagnosis

This subject was covered extensively in the Final Report. But some comments from the structured interviews are worth quoting since they reveal some aspects in more breadth or perhaps more starkly.

A number of carers commented during the structured interviews just what a gradual process the emergence of dementia was, several highlighting that it could be over as long as five years or more. Some went further, highlighting the vital need to notice, then address what is happening, act quickly and not deny it. One carer summarised: *“The most important thing when you see it coming is to prepare yourself.”* And another carer expanded:

*“[My husband] ‘died’ five years ago. It looks like him but it’s not his personality. It’s a shell of him. He’s just existing – he hasn’t had a life worth living for three years. By the time you realise what they’ve got, they’re not in a state to do (eg) a living will. Had I realised sooner we could have done things together.”*

One professional interviewed admitted that diagnosis can be ‘pot luck’, and other professionals intimated that accuracy of diagnosis was sometimes open to debate. Frequently carers (and volunteers) additionally felt that in getting a diagnosis, there was insufficient recognition of the individuality of the person and hence the need for person-centred, flexible responses. The same carer said:

*“So much depends on individual circumstances. Officialdom seems unable to differentiate between situations; they have a set of rules that seem sacrosanct – you need to be able to bend the rules.”*

A professional commented that typically, people only hear or absorb a third of what they are told when given the diagnosis. Thus they saw it as vital that the diagnosis is given in the most appropriate environment and allowing sufficient time to help maximise their receptiveness.

70% of responding volunteers believe it makes a difference if treatment/support is received early after symptoms recognised or diagnosed. Information or advice, and help/guidance from someone in a mentor or advocate role are seen as the main routes to

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allaying concerns about seeking a diagnosis and being a single gateway post-diagnosis (40% in each case).

### 2.1.10. How much should diagnosis be the key to services

As detailed in the Final Report, the researchers noted a debate over the issue of needing a diagnosis to get services, given that there is very frequently a need for services including help, advice and/or assistance prior to the diagnosis.

One professional stated that for him and his teams, 'dementia-like symptoms' would be enough – i.e. in his view services cannot be prescriptive about the diagnosis being the sole gateway to services. The volunteers (reporting in their questionnaire) also appear clear that there are needs before the diagnosis. To the question 'Should a formal diagnosis be required?', 48% said 'no'; 24% said 'yes & no' (i.e. there are pros and cons). Only 28% said 'Yes'. Four out of the seven 'yes' answers were because it is the gateway to services. The majority of 'no's' indicated there are issues needing support prior to reaching a tipping point which leads to diagnosis. They understand the statutory organisations' need for diagnosis prior to acting, but see it as important that help available as soon as is needed.

One other point made by a great majority of carers (both in the questionnaire and structured interviews) in some form, was expressed thus by one carer: *"I'd never dealt with [dementia] before and was just dropped in at the deep end. I didn't know what to do, or who to turn to when we left the clinic."* Another carer put this possibly even more bleakly: *"Everything is unknown and the unknown is terrifying at times"*.

### 2.1.11. Medication

A professional viewpoint reported to the researchers was that 60% of cases of dementia are treatable with medication (which is considerably higher than the public perception). However, more than one professional felt that some GPs are negative or lack understanding about the differences that medication can make.

A proportion of carers reported medication such as Aricept was prescribed following diagnosis, with mixed results. For some it helped delay further decline, while others reacted badly to it and/or caused it side-effects (eg nausea) which made it intolerable, as confirmed by a professional who stated that these effects can be grave or unsafe.

It was noticeable too from the structured interviews that in a significant number of situations, the GP had given anti-depressants when the cared-for first saw them about memory issues. The researchers certainly heard from some professionals about the importance of screening out depression at the beginning of the process. However many carers were reporting that the GP did not appear to be considering that the presenting signs might constitute what they (the carer) believed, i.e. that it was already clearly the beginnings of memory loss/dementia. Sometimes also the carer had to battle to be allowed to be present with the cared-for, and thus to get the GP fully to understand the circumstances and to consider other possibilities than depression.

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### 2.1.12. Support & support services

The answers given by the volunteers to the question, ‘What information, advice, support, care or other service is offered to the cared-for person and the family carer?’ showed (with the exception of the Alzheimer’s Society and the NHS including GP practices) noticeably higher awareness/recall than was the case in the Final Report, despite the experience of the carers. However, there was a common theme in both sources about the lack of help from the statutory agencies, and an astonishingly high 89% of volunteers commented that services’ lack of person-centredness and unhelpfulness of workers were the least helpful aspects of support.

The research evidenced where health and social care have been of great and timely service, but there were many cases among carers interviewed where the reverse is true – and at a critical time. As was stated in the Final Report, the most prevalent help, advice or support offered was a list of organisations to contact, or literature. Also, as noted in the Final Report, the voluntary sector came out better than the statutory.

During one structured interview, and by no means untypical, a carer articulated a clear description of how he had had to find out about/procure help and support, and which was the most and least helpful:

*“With Social Services, we saw different people each time; they came when it suited them, at different times. My wife said she wasn’t going to accept this so I bathed her and so on. She would bite and scratch but once in the bath she relaxed. Then she became incontinent. I found a nurse through the pharmacy – the surgery never told me. This nurse provided pads and absorbent sheets: I had been washing them once or twice daily and my wife insisted on me ironing them! The most helpful thing was a woman who came once a week which enabled me to do the shopping. She was very positive with my wife and my wife felt she had done something each time. I feel I wasn’t very good at that side of things but it’s difficult to change your habits or personality. The least helpful was the psychiatrist – I expected help but they were totally negative”.*

Another carer during a structured interview commented that there were:

*“Far too many people asking questions – also too many organisations providing services.”*

Sources of help & support listed by volunteers were principally: Age UK Suffolk 27%; Alzheimer’s Society 5%; Social Services 14%; GP Practices 11%; and other NHS services 8%.

Family & friends were seen by the volunteers as providing emotional support (40% of responses) and practical support (27%).

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### 2.2. THE DEBENHAM PROJECT

As recorded in the Final Report, the Debenham Project was seen by most as extremely helpful and of great benefit to carers and cared-for. Its advice, lunch clubs and peer support stood out above all in the structured interviews. One carer said *“I wouldn’t have minded moving to Debenham five or six years ago because of what it’s got now”*.

#### 2.2.1. Key existing functions

The responses to the Debenham Project volunteer questionnaire built a useful albeit anecdotal overview of its main activities: 56% reported information & advice as a key function; 24% saw activities & social support likewise; 13% saw respite similarly; while 8% reported emotional & peer support.

Other positive factors seen through the structured interviews included its trustworthiness; just being there (24/7) even when not actively needed; the ability for the carer to ‘offload’; the social element; connecting carers with services and help; helping carers to understand what to expect.

#### 2.2.2. New services for The Debenham Project

Volunteers felt the following could assist and help develop the Debenham Project further: better premises for carers club and meetings; develop existing activities further; singing groups; more outings (with disabled transport); a buddying service; local professionally trained carers; local residential care; and a local Debenham Project charity shop with carers/cared-for volunteers. Future developments envisaged by carers included home visits; ongoing support/visits for cared-for who have moved to residential or nursing homes; activities for male carers; likewise for people now on their own; help for working families (though it was acknowledged that this was less of a problem in the Debenham area);

#### 2.2.3. New services by other orgs

Overwhelmingly, responses here (from structured interviews and volunteer questionnaire) were building a picture of the positive impact more local and cohesive services would provide – eg local dementia-trained GPs, local housing, greater (local) joint working among agencies, regular local respite.

#### 2.2.4. Debenham Project Volunteers

Of the 25 volunteers responding to the researchers’ questionnaire, half had experience as immediate family carers, and a further quarter had other caring experience either personally or professionally. In their volunteer role, 75% had direct face to face contact with the cared-for, and 80% with the carer.

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### 3. THE CHANGING CONTEXT OF SERVICE PLANNING & DELIVERY

#### 3.1. Overview

Services across the board are in a state of restructuring and transition, partly due to an acknowledgement that systems have not been working effectively, particularly (in this field) due to the significant growth of the older population, their increased/increasing frailty and consequent increased demand on services and hence cost implications, at a time of financial constraints. The researchers' meetings with professionals highlighted also that the restructured services are experiencing a much higher level of response which according to some threatens to overwhelm them – due in part to the raised profile of dementia and thus increased awareness.

The researchers noted changes being put into place that start to address these issues, and some very positive outcomes but also some areas still of concern.

Thus this section of this Supplementary Report lays out the researchers' understanding/overview of the new system now in place since the primary research in 2012, based on discussions with professionals and others involved.

#### 3.2. GP Service

The structured interviews confirmed how when first signs of memory loss or dementia like symptoms were noticed by the main family carer, they often spoke with family and close friends. From that point the GP was then seen as the first point of professional contact in seeking help and support.

This is confirmed by meetings with professionals. People approaching other services will be advised of the importance of making contact with the GP in order that the symptoms being presented are properly investigated. Thus, the first point of contact with Suffolk County Council Customer First or the advice from voluntary agencies (such as the Alzheimer's Society Helpline or the Suffolk Dementia Partnership's helpline provided by Sue Ryder) directs people to seek the advice of the GP.

In order for services and support to be provided, a diagnosis is essential, and thus the GP, as initiator of the assessment process and referral on, sets things in motion to access services and support. This all emphasises the key role of the GP, including the identification of whether the apparent symptoms of memory loss is in fact a dementia or whether there are other causes which need to be addressed.

The interviews with professionals confirmed the importance of the role of the GP as the key single point of contact, able to undertake initial assessments, to provide preliminary diagnosis and being paramount in providing consistency and continuity of care.

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GPs reported that screening for dementia is seen as an important function for many services, including GPs. The DES (Directly Enhanced Services) contract requires GPs to screen those over 60 for certain conditions eg arteriosclerotic, diabetes, Parkinson's, and whether the person has had any memory problems over the last year.

GP Hubs are being developed to provide a regular, localised focus for dementia diagnosis, advice and support.

### **3.3. Specialist Assessment and Diagnosis.**

At the time of this research the Norfolk and Suffolk Partnership NHS Foundation Trust was implementing its strategy 2012-16 which included 'complexity in later life' (i.e. covering dementia) and the restructuring of the Memory Clinics into Integrated Delivery Teams (IDTs), with the emphasis on local assessment. All mental health assessments will be carried out by the Trust.

The researchers were informed that the seven memory clinics have been restructured into five IDTs in Suffolk: two in West Suffolk and three in East Suffolk with boundaries coterminous with the CCGs. The IDTs for people with a dementia will be comprised of consultant, medical registrar, nurse support, support workers and access to psychology and OT. The IDTs are community based rather than hospital based and the researchers were told how they should facilitate people not having to travel distances to be supported by IDTs. Staff who had been previously based in Community Mental Health Teams would form part of the IDTs.

Referral to the IDT service is through the GP and via the acute hospital (CQUINS – Commissioning for Quality and Innovation), and not through Suffolk County Council Customer First. There is an expectation that the GP will undertake a baseline cognition test, provide a full medical history, and undertake the appropriate blood screening. A clinician at the IDT will then carry out further tests leading to a diagnosis.

IDTs provide pre-diagnosis counselling and see the patient and the family carer separately.

The service will support and advise on (for example) diet, physical ailments; brain stimulation; referrals to other agencies; cognitive stimulation; "adjustment" clinics; referral to a psychologist; ensuring benefits check; establishment of compliance systems by pharmacists; liaison with assistive technology; referral to Suffolk Adult and Community Services; Alzheimer's Society; fire safety checks; ID bracelets; infection advice; management advice. 24 hour cover is intended.

What was also stated was that most GPs do not know about sub-typing and that there are different medications which affect and benefit people differently - GPs are not necessarily aware of these differences. Thus the importance of referral for specialist assessment and diagnosis is seen as critical.

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### 3.4. Acute Hospitals

The structured interviews confirmed that the diagnosis of dementia can follow a hospital admission for a condition not necessarily related to dementia.

The researchers' Final Report referred to the introduction of CQUINS (Commissioning for Quality and Innovation) in Acute Hospitals to aid the "identification of patients with dementia and other causes of cognitive impairment alongside their other medical conditions". People over the age of 75 whose stay in hospital is more than 72 hours are now screened by being asked whether in the last 12 months they have had a significant memory problem. If this is the case then they can be referred directly to the Integrated Delivery Team. Additionally the GP will be informed that this assessment has occurred prompting their awareness at any future GP appointment.

While in hospital for other health conditions, a patient may display signs of confusion, disorientation and memory loss. The patient might be identified as having delirium. This provides for assessment and referral to the IDT. However, this could prompt a referral to another specialist who might diagnose a dementia and provide treatment but not offer the range of support available through the IDT.

The issues of delayed transfer of care was identified which could result in the involvement of the hospital social work team or the Dementia Intensive Support Team (DIST). The criteria for this service include being over 65 years with suspected dementia or delirium. Thus there is a further route for professional involvement in the provision of support services for people with a dementia. This team aims to prevent unnecessary acute hospital admissions; to expedite discharge from the acute hospital; and to prevent premature admission to 24 hour care upon discharge from acute hospital.

### 3.5. Adult Social Care

Again, at the time of the research, changes were being introduced in the provision of support services from Suffolk County Council Adult and Community Services. Under the banner of '*Supporting Lives, Connecting Communities*' (SLCC), a three tiered system of support is being implemented.

- a) **Tier 1** is to help people help themselves to keep independent without formal care, through providing information about support available in local communities
- b) **Tier 2** is addressing the issue of people at risk of losing their independence which might include short term or crisis situations
- c) **Tier 3** is for people requiring ongoing support, tailored to people's individual needs.

ACS professionals interviewed stated that behind their new way of working is the aspiration that this will be a preventative methodology.

The researchers were told that Suffolk Adult & Community Services is returning to the "cluster model". There are 4 localities which will have neighbourhood clusters which will be mainly social work driven and comprise of social workers, community care practitioners

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and occupational therapists. There will also be a dementia cluster which will work with older people, many who will have dementia or dementia like symptoms.

The researchers were informed by Adult and Community Services about a Flexible Dementia Service (FDS) where across the county a contract with domiciliary care agencies will provide a specialist domiciliary care service, able to advise and obtain support in a crisis, preventing hospital admission which could include round the clock care. The carers are specially trained and able to respond to agitation, aggression and other behavioural problems.

Meeting with representatives of Adult and Community Services, the researchers were told of the importance of good quality early diagnosis and intervention. They also described the need for integrated commissioning of services and for sustainable funding to service providers. The need for workforce training targeted at general practice, domiciliary care, residential care and hospitals was also identified.

Also, assistive technology is being promoted by Adult and Community Services: it was identified by professionals as potentially greatly assisting remaining at home and in the community.

### 3.6. The voluntary sector

The researchers met with representatives of Age UK Suffolk, Sue Ryder, Suffolk Family Carers and the Alzheimer's Society – all members of the Suffolk Dementia Partnership.

Age UK Suffolk has the contract to provide Dementia Advisors and their work was acknowledged very positively by respondents of questionnaires and in the structured interviews. There are currently 3 part-time advisors working in localities in Suffolk. In essence their remit is to be an 'anchor person' for the cared-for/carer, providing an initial 2 hour visit; a follow-up visit or visits; be available at any time; and to signpost further.

Sue Ryder amongst other services provides specialist day care for people with dementia and operates the Suffolk Dementia Helpline. This is "caller led" – personal details not necessarily needed or given. It is a listening and signposting service and people who contact this service will not necessarily have a diagnosis. Sue Ryder also has funding to encourage the development of Dementia Friendly Communities elsewhere.

Suffolk Family Carers provide a range of services to family carers, many of whom will be supporting people with a dementia; and they will continue working with carers for up to two years after bereavement. They operate a small budget to help with carer respite, carry out carers assessments and most specifically Suffolk Family Carers run a '*Caring with Confidence*' course. This gets people together and discusses, amongst other things, general benefits, looking after oneself, difficult and challenging situations, communicating with person with dementia and communicating with professionals. The groups provide peer support. They also can provide (non means tested) innovative support.

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The Alzheimer's Society, as a national charity providing help, advice and information, provides a local helpline service, national internet chatline, local support workers, home visits, support groups for carers, branch activities, Alzheimer Society Cafés and carer education courses. They will also take on referrals from the Dementia Advisory Service where they are not able to provide specialist knowledge or information.

The services provided by the voluntary sector are seen as key elements in the Dementia Strategy, and accordingly tenders are bid for from statutory sources, but professionals commented that there is a strong tendency for key services to be funded on a short term basis.

In addition to all the services above, it should not be forgotten that in the research area, the Debenham Project also is already providing many locally-based advice, information, help and support services. Community based initiatives are also being developed in other locations including Wickham Market, Halesworth, Aldeburgh and Wells-next-the-Sea.

### 3.7. Clinical Commissioning Groups (CCGs)

Behind much of the above is of course the commissioning system which enables services to be provided. One of the major structural changes has been the move within health services to Clinical Commissioning Groups (CCGs) from Primary Care Trusts (PCTs): CCGs are formed of member GP practices, and they are responsible for commissioning local health services. *Living Well with Dementia* (the Suffolk dementia strategy) established a joint commissioning board, of which CCGs are a part, along with Suffolk County Council Adult & Community Services and others.

The East CCG (covering the research area) is aiming for 76% diagnosis of dementia by 2016.

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### 4. DISCUSSION ABOUT CHANGES TO SERVICES/SYSTEM

This section discusses the effect of service or system changes on carers and cared-for. It considers the extent to which the lives of those in the research sample would have been changed or will be changed henceforth by the alterations in the ways of working outlined above. It draws on the conclusions in the researchers' Final Report along with the further themes in Section 2 of this Supplementary Report.

#### 4.1. Clear benefits of new system

There is evidence from professionals of an increase in number of referrals to services. This appears to be due to increased media coverage and other awareness building (not least from the Debenham Project in the sample area) and more screening and identification of people potentially with dementia. Thus also the diagnosis of dementia may be less stigmatised and denied for those with concerns about immediate or future memory loss.

In turn, there is clear evidence that dementia is higher up the Government agenda and therefore is attracting resources – funding and services. The pathway for diagnosis, treatment and support appears to be more comprehensive. Services across agencies in Health, Social Care and the Voluntary Sector have been and are being improved and refined, with a view to meeting the needs of cared-for and carer.

Health, social care and the voluntary sectors all reported an increased local provision of services, along with some reduction, and are moving away from the historic centralised service base. The Debenham Project focuses exclusively on its community, as the sample group highlighted, and so there are obvious benefits to its population.

#### 4.2. Purposes of, and issues raised in, the research

The primary aims of this research project were to obtain information from family carers and cared-for about the memory loss/dementia journey; a profile of the carers and cared-for; their perceptions and experiences; and also views from them and others on the positive and negative aspects of early diagnosis and early intervention of/ by services. The researchers recorded many issues voiced by carers, and also by volunteers in the Debenham Project and relevant professionals in social care and health during the research project. These are laid out below, sourced from the conclusions to the researchers' Final Report, and from this Supplementary Report (Section 2 above), as recapped in 4.2.1 & 4.2.2.

These provide the background to the discussion from 4.2 onwards about if and how the lives of carers and cared-for in the research sample would have been changed or will be henceforth by the changes in the ways of working outlined.

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### 4.2.1. Final Report conclusions

The major areas of concern expressed were:

- Lack of knowledge and unpreparedness of carers
- Greater range and depth of person-centred support [required]
- [The need to] address 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
- [The ability to] obtain services before diagnosis
- [The need for] a single point of contact for carers and people with dementia/memory loss
- Training needs of GPs, other health and social care professionals

These issues are taken into account in the section below.

### 4.2.2. Part Two of this Supplementary Report

Further, specific points have been either newly identified or elaborated upon in Section 2 above in this report. The points covered do not represent every aspect of the issues, but reflect the findings of the research.

- **Burden of caring; Isolation**

The Debenham Project appears to be a lifeline for the research sample in helping to alleviate this issue, through for example its social events, peer and other support (including respite), advice, information and help. It demonstrates the positive effect of a local community-based project, and it appears that this is being taken on board by commissioners, eg in the Suffolk Joint Strategic Needs Assessment Executive Summary: *“By raising awareness and creating communities that are ‘dementia-friendly’, we can reduce fear, stigma and social isolation that people with dementia and their family carers experience”*.

Other services from the statutory and voluntary sectors also seek to address / alleviate these issues, such as the Dementia Advisory Service; Adjustment Clinics (at the IDTs); the Sue Ryder Suffolk Dementia Helpline to name but a few. However, there are many other services offered by agencies and the researchers heard from carers and professionals that they were not known about or used by the sample population, and that it was difficult to keep abreast of the changes and developments in services.

One particular area highlighted in both of the researchers’ reports was how the burden of caring is exacerbated by financial worries and problems, and the researchers are not aware of any developments in this specialist area.

- **Stigma**

There is some alleviation of this issue implicit in the awareness and profile-raising being carried out. Local initiatives (including the Debenham Project) perhaps develop greater

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familiarity in their community, which is also enhanced by increasing national media exposure. However it appears to still be an ongoing problem, as quoted above, *“Dementia has now almost replaced cancer as THE fear”*.

### ○ **Respite**

The researchers are not aware of any significant investment in additional respite since the research was carried out, especially any that is tailored to the person with dementia. However, the Debenham Project (including their ‘Carer’s Co-Operative’) is playing a part in helping to alleviate the problem locally to the sample group. The issue of transport can be a significant barrier to appropriate respite but the researchers are conscious that commissioners are aware that this requires attention.

### ○ **Church & Faith**

This is an area that appears to help a significant proportion the sample group and thus doubtless others in the local community too. There appears nonetheless to be more that could be done by church communities to add to their support corporately and individually. There is perhaps a question to be posed as to whether more could or would be provided by church groups were funding to be made available from statutory agencies, as with the rest of the voluntary sector.

### ○ **Perspectives of the Cared-for**

Communication with the cared-for was the underlying issue in 2.1.6 above. There is evidence of greater person-centred focus by services than previously, although considerably more training is required (as it is understood is being planned).

### ○ **Stimulation of the cared-for**

There are training programmes already established (eg Dementia Coaches) which aim to upskill care home and domiciliary care staff. High staff turnover and funding concerns remain issues though for the care sector, as evidenced throughout the research.

Professionals are saying that referral to care homes is not now the option of choice for people with dementia, but rather to promote care at home and in the community. This raises the question of the availability of appropriately trained (and available) staff, particularly in rural areas. There is evidence from the structured interviews that the amount of time currently available to (paid) domiciliary carers means that they often have insufficient time (or indeed training) to engage in stimulating activities with their clients.

Given that under-stimulation appears to have a major role in the rapid decline and death noted in the ‘care home effect’ detailed earlier, this whole issue needs raising up the agenda, and active steps taken to stimulate and maintain skills and interests. When and where it does take place successfully, there would of course typically be a cost implication.

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- **Coping with practical & emotional problems – carer & cared-for**

The research identified that there was a problem of the additional burden for the carer in having to take on practical, administrative and decision-making tasks which were unfamiliar and solitary.

Once again, locally, the Debenham Project provides a range of support, as do other community or voluntary sector groups.

- **Diagnosis**

Many of the research sample reported they did not know what was happening when the cared-for started to show signs of memory loss, and they did not know who or where to turn to. The researchers found that there remains a lack of clarity about this among the target population, volunteers and professionals interviewed or questioned.

The issue is still a priority for commissioning groups, and new important new initiatives have been established, such as GP hubs & IDTs (there are five which, however, replaced seven memory clinics. So they are not wholly new, and also incorporate the old CMHT dementia diagnosis function). Also, higher early diagnosis rates are a key priority.

It is also acknowledged by commissioners that an integrated, post-diagnosis support service is required that will provide a single point of contact for carer and cared-for.

- **How much should diagnosis be the key to services?**

The research highlighted the debate over the issue of needing a diagnosis to obtain services. Professionals, volunteers and carers do not have a uniform viewpoint on this, but there is professional support for eg ‘dementia-like symptoms’ being sufficient to access some services, and if there is to be person-centred service planning and delivery, the researchers believe there is enough evidence to mean that there needs to be flexibility on this issue.

- **Medication**

Notwithstanding the evident benefits of medication in many cases, a need was reported to ensure that what is prescribed is apposite not only to the recipient’s dementia but also that they can tolerate the drug. There appears also to be a need to ensure that the correct condition is identified (which may not necessarily be dementia), as a misdiagnosis may lead to the wrong medication being prescribed.

- **Support & support services**

The research showed a lack of person-centredness in many areas but particularly among statutory agencies. The need for training in this area has been identified (eg Suffolk Joint Strategic Needs Assessment Recommendation Nine – for GPs, domiciliary care providers, residential care services and hospitals). The particular pressure points appear to be frontline staff and carers, and hospital staff.

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### 5. CONCLUSIONS

- This supplementary report follows on from the Final Report which the researchers produced in October 2013. It fleshes out the findings of that report, bringing in narrative and additional data. It is based largely on information from professionals working in the field of dementia, volunteers from the Debenham Project and the structured interviews of carers
- There have been a number of changes to the structures of health, social care and some voluntary services which appear to assist potentially beneficial outcomes for cared-for and carers
- There is a very evident move to more community based services and recognition of the importance of projects like the Debenham Project and current & future attempts to replicate it
- There is a laudable methodology of early intervention/graded response/preventative being aimed at by policy makers and commissioners.
- However, despite the changes resulting in apparently positive outcomes, there still appear to be significant gaps in the provision of a seamless service to people with memory loss/dementia and their family carers as evidenced above.
- The major areas of continuing concern include person-centredness; where people go for help; quality of care home provision; training of frontline staff including GPs
- Also, from a carer's perspective, the issues raised in Section 2 above remain pertinent to a very great extent.

### 6. ACKNOWLEDGEMENTS

The researchers wish to thank most warmly all family carers and also the front-line staff, clinicians, GPs and managers in health, social care and the voluntary sector who participated in and contributed to this research with their time, expert knowledge, views and insight.

They are greatly indebted to the Debenham Project and in particular to Lynden Jackson, the Chair of the Debenham Project.

Sincere thanks also go to the Norfolk & Suffolk Dementia Alliance for funding the whole research project.

**Note: The anonymised raw data for this whole research project will be securely archived by the Debenham Project so that it may be used for further study if required.**



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