

The Debenham Project: carers' experiences in rural Suffolk

Timothy Mason and **Gordon Slack** report on an in-depth research project that sought to capture the experience of carers of people living with dementia in rural Suffolk

Between July 2012 and August 2013, we carried out an independent in-depth research project in partnership with the Debenham Project in Suffolk. We were trying to capture the experiences of carers of people living with dementia within a single community and to investigate what encourages or discourages families to seek early diagnosis and support. As far as we know, this is the first time that a particular local community has been the subject of such an in-depth analysis.

The Debenham Project centres on the large village of Debenham and its surrounding area in Mid-Suffolk, which has a total population of between 6,500–7,500. Community-inspired and led, the project has developed a comprehensive range of local services aimed at supporting carers of people with dementia. It has managed to achieve a high level of awareness throughout the local community and has provided some level of support to more than 65 per cent of the estimated number of families living with dementia. It is in the vanguard of the development of dementia-friendly communities, as championed by the Prime Minister's Challenge of 2012.

The research was funded by the Norfolk & Suffolk Dementia Alliance with the aim of informing the Debenham Project, the Norfolk and Suffolk Dementia Alliance and others in their decisions concerning the provision of dementia support services in this region.

Methodology

We developed a methodology intended to capture as full a picture of the dementia journey as possible, with a particular focus on the views of family carers. At the outset, the Chair of the Debenham Project alerted us to the fact that the majority of people with dementia and their carers would be in the 70+ age group and many might be frail and, in the case of carers, very stressed by their role. Consequently, they would be unlikely to respond effectively to a standard online or postal survey.

We used the following process. First, we

identified the key questions that would provide appropriate data and facilitate subsequent analysis and used these to form the basis of a draft questionnaire.

We then transformed the questionnaire – in terms of language, style and freedom of expression – into one that was suitable for the target population. We included open-ended questions, encouraging as full responses as possible.

We sent this questionnaire (with prior contact) to 42 family carers of people with memory loss/dementia living in the area covered by the Debenham GP practices – and 37 responded (88 per cent).

We then conducted follow-up structured interviews with 32 (86 per cent) of the responding carers. These discussions deepened and broadened the picture, using a conversational approach that built trust and openness, and invited anecdotal evidence.

We sent a separate questionnaire to 37 Debenham Project volunteers to obtain views of a wider, informed group supporting people with dementia and their family carers. We also interviewed 12 professionals directly involved with the client group to learn about their knowledge, experience and views. They are all employed in the locality within health, social care and voluntary organisations.

Finally, we mapped the responses back into the initial survey format and analysed these in order not only to answer the original questions objectively, but also to add the informal evidence which resulted from using open questions followed up by empathetic interviews.

Names were obtained from the Debenham Project's database, with permission. The number of family carers on this database coping with symptoms consistent with memory loss or dementia – with or without a formal diagnosis – compared accurately with the official estimates for the area. In the course of the project, we made first-hand contact with virtually every family who understood that the symptoms they faced constituted dementia, whether diagnosed at that point or not (and note of course that as many as



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perhaps 25 per cent of the estimated population of people living with dementia may not be knowable since they or their families are not yet at the point where the symptoms have reached a critical level to impact on their lives).

We had very high response rates from the sample group, as well as significant depth and openness from carers both through the questionnaires and the face-to-face interviews. Its key concepts lie in recognising that the form of the interaction with the participant is critical to getting a positive and accurate response. We were able to gather insights that cannot be obtained by using online, postal or telephone surveys. The methodology is appropriate for replication by other groups, since the data obtained from its open-ended approach can be both reverse translated for quantitative analysis, yet also yields a wealth of anecdotal and subjective information.

Key findings

All this quantitative, qualitative and anecdotal information was captured in two reports (see Mason & Slack 2013a, b). The first reported mainly on statistical data. The second focused more on the collective and individual stories to emerge from the study. What follows are some of the highlights from the findings:

- 71 per cent of carers were over the age of 60 and all of the people with dementia were over 70 years of age. Just over half of the carers (52 per cent) lived with the person they were supporting; 48 per cent lived elsewhere.
- 35 per cent of carers reported that the



Clockwise from top left: a lunch club outing; different faces of Debenham; the project crest

services among professionals, and excessive form-filling)

- the issues causing or stemming from isolation.

In addition, many carers reported having physical health problems that can make their caring role more difficult. Many carers also report financial difficulties. The main reasons potentially encouraging family carers to seek help were:

- emotional responses to the situation (for example desperation or dealing with fears)
- greater publicity and awareness
- interaction with skilled frontline staff including GPs and volunteers
- increased peer support, knowledge and education of carers.

Overall, half said in different ways that they wished they had acted sooner and/or had been more assertive.

However, to obtain results and action (for appropriate support) takes energy, assertiveness and tenacity, while carers were frequently exhausted, depressed or demotivated.

Accessibility, usefulness & timeliness

There was significant disquiet among carers about professional service provision – knowledge, availability, person-centredness and quality.

As a result of a diagnosis, 50 per cent of families were offered a service (but for 2 out of 5 it was insufficient or late), while 40 per cent reported they were not. One-third of the services were provided by the voluntary sector, a quarter from health and less than a fifth from social services (16 per cent). This is of concern, not least since an assessment from social services should have included a benefits check, a community care assessment and a carer's assessment.

While half the carers were positive in some way about the help or service offered as a result of the diagnosis, just under half said it was not helpful in at least some way. For example, carers reported not being listened to, having to wait a long time for an assessment, having case responsibility passed from one professional to another, and being given only minimal support (just information or a meals on wheels service).

The most frequent service offered from the point of diagnosis was a list of organisations to contact. It was noted that in many instances a diagnosis of dementia was only precipitated when other health conditions caused a hospital admission. ➤



emotional or psychological aspects of caring for a loved one with dementia had the most significant impact on their lives.

- While most carers considered themselves to be in good or fairly good health, many had physical conditions that could significantly affect their caring role.
- 1 in 3 carers report that financially they are "vulnerable" and a further 16 per cent are "ok for the moment" or can only manage if they are careful.
- Respondents identified almost three times as many things that might *discourage* families seeking help/diagnosis as those that would encourage them.
- 42 per cent of carers reported that the diagnosis had made a positive and overall difference; 31 per cent felt it had been a negative influence, and 33 per cent were undecided. However, when asked how the diagnosis made a difference, almost 60 per cent of the reasons given were positive.
- Carers expressed significant concern about professional service provision; 1 in 5 carers reported that their difficulties had been directly exacerbated by a perceived shortcoming of the statutory health and/or care agencies. Examples of shortcomings included time spent trying to make contact with social services, lack of coordination within social services, lack of knowledge among professionals about services available, excessive number of forms to be completed to access a service, and disinterest from services if the family were identified as self-funding.
- 88 per cent of the carers felt that the Debenham Project was a key source of help and support: social contact/friendship (22 per cent), reassurance/understanding (20 per cent), and advice/information (11 per cent) were key areas.

What encourages or discourages seeking help

Family carers reported a wide range of difficulties. They reported feeling:

- poorly supported by the statutory agencies (with the possible exception of their local GPs)
- perplexed and ignorant about what was happening to the person they were caring for, about dementia and its likely progression, and its impact on themselves as carer
- isolated due to the overwhelming needs of the person they were caring for
- lacking knowledge of the services that might be available.

Some fell back on their own resources (such as wider family support) or had to wait for a crisis. A high proportion of carers reported that – particularly during the early months and years of supporting their loved one with memory loss/dementia – they had little or no idea what was happening to their relative. One said: "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."

Overall, three times more reasons were given which discourage, rather than encourage, seeking help. The main impediments were:

- emotional responses to the situation (for example guilt, pride, fear, denial)
- problems between the person with dementia and their carer or other family members
- problems with services (such as time spent trying to make contact with social services, lack of knowledge about

➤ A large majority of carers – 69 per cent – saw clear benefits in early support. Prime responses to what early support would have helped were: greater knowledge of who to ask and what is available, peer support and training (including in understanding the condition). Most of the reasons why early support was seen as not beneficial stemmed from the person with dementia being reluctant about accepting it.

The vast majority of respondents highlighted the crucial role of the Debenham Project. Most of the carers reported that their journey with dementia began both before the Debenham Project was developed (indeed it was developed in response to unmet local needs), and before many of the local authority/NHS services became available over the last year or so (for example the Dementia Advisory Service, the Dementia Intensive Support Team, the Suffolk Dementia Helpline). It was often the only place for carers to turn in the absence (at the time) of person-centred professional services. The Project offered (and continues to offer) high levels of personal and responsive support in ways that it was/is felt the statutory or voluntary services could not/cannot easily provide. These were through facilitating and providing peer support, regular social events, and a range of other practical help and services, information and advice. These helped greatly to reduce the isolation, perplexity and lack of knowledge or support.

Carers' views about potential improvements

Carers reported there were too many agencies to deal with and they saw significant scope for improvement in the services offered by professionals, mostly in the statutory sector. The encouragements and discouragements (above) to seeking help point very directly to areas expressed by family carers as needing development – publicity and awareness, improved services, greater education. Carers' responses to what improvements could be made to actual services provided can be grouped thus:

- more information (20 per cent)
- improved inter-agency working/ intra-agency working (16 per cent)
- improved support (32 per cent)
- greater person-centredness in services (24 per cent)
- nothing to be done (4 per cent)

The existence of a clear care pathway for dementia understanding, diagnosis and support (comparable to that for cancer) could have eased the frustration, feelings of inadequacy, isolation, unsupportedness and bleakness reported by carers.

The Carers Trust's *A road less rocky* was also undertaken in 2012/2013. Both this and our project (and our final report *In at the deep end*) examined the dementia journey for the family carer and the person with dementia/memory loss and the challenges they face. The fact that there is much in common between the results of both studies suggests that each has achieved significant representativeness and accuracy and at the same time, perhaps, going some way towards validating the others' findings.

Carers' views regarding early diagnosis

While more respondents saw an early diagnosis as making a positive rather than a negative difference, a very significant minority saw it as having a negative impact on their quality of life and some saw it as a mixed blessing. The main benefits reported were the ability to plan for the future; confirmation of what the problem is; early medical and other intervention; and the delaying effect medication can have. The main drawbacks seen were that it changed nothing or made no difference; confirmed worst fears/suspensions; encouraged a sense of the pointlessness of having a diagnosis; and reinforced a sense of ignorance or helplessness about dementia.

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.

Conclusion

When we embarked on the study it was with the concern that accurately gathering the perceptions and views of a predominantly older (and frail) group would be difficult, and perhaps impossible, considering their emotional/stressful situation. However, we obtained both high response rates and significant depth of quantitative, qualitative and anecdotal information. The findings have illuminated the dementia journey of the family carers and people with dementia in this community, and fulfilled the aim of identifying the pros and cons of early diagnosis and early engagement with services.

The results have confirmed much that was already felt about the needs of family carers and those they care for. Over recent years positive developments in new dementia services and organisations are evolving in ways that are consistent with

areas of concern highlighted in this study. However, there still appear to be significant gaps in the provision of a seamless service to people with memory loss/dementia and their family carers. The authors believe that the experiences, perceptions and views captured by the study represent a significant body of data against which the local delivery of dementia health and social care services should be tested.

The Debenham Project has fulfilled an important role in terms of its comprehensive range of community-based services and these are already in line with many of the local needs expressed in the survey. The results were published at the beginning of 2014, so it is too early to assess the overall impact they will have on strategic planning. However, The Debenham Project's model and good practice are being taken notice of for example by central government, the Joseph Rowntree Foundation and the funders. The study's findings are already being included in the upcoming Suffolk Dementia Needs Strategy.

Are the results of this work applicable to other communities? Since the quality and quantity of dementia support services varies greatly across the UK, the results would need to be considered in the light of such variations. However, the authors believe that the study provides at least a good starting point.

In the light of the unpreparedness of family carers and the sheer burden of caring, perhaps the overarching message that emerges from this study is the need for greater person-centredness, quality and depth of support and services – and effective training across services to achieve this. In the words of one carer:

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. ■

References

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For more information on the Debenham Project, go to www.the-debenham-project.org.uk