

Training Resources on Dementia for Informal Carers In the Thames Valley Area



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Training Resources on Dementia for Informal Carers In the Thames Valley Area – April 2106

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Acknowledgements

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Introduction

Aim:

a carer's pack were suggested as potential resources." (p145)

To get an overview of:

- What information and educational resources are made available to informal carers and families of people living with dementia in the Thames Valley
- What information and educational resources informal carers want
- What's works well
- Areas for potential development

Together with the driver from the Prime Minister's 2020 Challenge on Dementia (DH, 2015) and the Government's Mandate to HEE to work with health and social care organisations and other key stakeholders to promote resources available for training informal carers of people living with dementia, this led to the establishment of a Dementia Fellowship post to undertake this work. The first phase of the work was to get a more in depth picture of what education and training resources were currently available.

Rational:

In 2014 the Dementia Academic Action Group (DAAG), a collaboration of partners commissioned by Health Education England: Thames Valley (HEE: TV), published a scoping report on the extent of Tier 1 training in the region. Whilst mostly focused on training the workforce, the group also explored support offered to carers and people with dementia. Two focus group discussions were held with a total of nine carers. The report stated;

"There was a need to offer more signposting to information, provide greater clarity and depth of information, particularly in the early stages after diagnosis. The carers would have welcomed a one-stop shop or carers pack which they could refer to. Additionally, the development of greater support for the wider family and friends would be welcomed so that relationships could be better enabled and sustained." (p. 139)

It concluded that;

"Developing information resources for carers and family members, or providing signposts to this information would be valuable. For example, a one stop shop for information or

Methodology:

1. Literature review on providing information to caregivers of people with dementia.
2. Overview of information provided on the local NHS Trust websites.
3. Talking to health professionals working in dementia services.
4. Questionnaire distributed at a Health Education England: Thames Valley conference on dementia.
5. Identifying literature provided to carers, i.e. handbooks, and local free courses.
6. Internet search on other national courses available.

The caring role

It is estimated that there are 670,000 family members/friends in the UK acting as primary carers for people with dementia (Deloitte, 2015). In "Valuing Carers 2015" Carers UK and University of Sheffield reported that unpaid carers in general save the UK £132

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billion a year, the cost of a second NHS. The figure has dramatically increased, almost doubling since 2001. Researchers attribute this rise to the increased number of hours people are providing care for and the increase cost of replacement care. Whilst many people can find caring a rewarding experience that strengthens family bonds, there is strong evidence that it can also be challenging and have a detrimental impact on people's own wellbeing and family relationships (Alzheimer's Research UK, 2015). The State of Caring Report (2015) to which 4,500 people shared their views, found that 78% of carers were concerned about the impact of caring on their health. Interventions to support the needs of carers in their role are therefore essential.

One commonly cited need of carers is the provision of information to assist them in their role. As part of this scoping exercise 25 delegates from a variety of roles attending a 2016 HEE: TV conference on dementia overwhelmingly identified the benefits of providing information in a questionnaire given to them. Responses were that information had the power to:

- Improve the quality of care people with dementia receive.
- Improve carer well-being.
- Improve the dignity, respect and confidence of people living with dementia.
- Improve knowledge and understanding, increase awareness, hope, compassion and acceptance and reduce fear.
- Empower carers and the person with dementia, enhancing their ability to make informed decisions, plan ahead and raise concerns.

- Enable people with dementia to be able to stay at home longer.
- Create a more dementia friendly society.
- Reduce stigma.

What information do people need?

The Alzheimer's Society report, "Information Needs of People with Dementia and Carers" (2010) found in common with other reviews that there is limited published information on this topic. They found that the need for information is complex and individual. It is influenced by the individual presentation of dementia, which changes over time and the preference of individuals, for example the amount of information someone wants and in what format.

The report found a variation in what people most wanted information on, but the most commonly needed topics were;

Table 1

Findings taken from the Alzheimer's Society Report (2010) on what information carers most wanted.
--

- | |
|---|
| <ul style="list-style-type: none">• What dementia is and the types.• Progression of the condition.• Financial and legal information, including information on benefits.• Local services and how to access them.• Advice on how to care for a person with dementia, particularly in coping with behavioural and psychological symptoms.• Medication and treatment for dementia. |
|---|

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Carers taking part in the DAAG focus groups also identified what information they thought should be provided;

Table 2

Findings from the DAAG focus groups on what information carers most wanted.

- The progression of dementia.
- Legal issues, such as Lasting Power of Attorney.
- Strategies to cope with behaviours such as mood changes, “wandering,” and communication difficulties.
- Where to get help.
- Importance of looking after yourself.

Information which should be provided to carers was also identified by the 25 delegates at the HEE: TV conference and is shown in Table 3.

Additional comments were that training should be for the local community and reflect the local community, and that it should be evidence-based, accurate, up to date and relevant.

Table 3

Findings from the conference questionnaire on what carers need information on.

- Signposting.
- Local updates of service provision.
- Causes of dementia, presentation and progression, including how the person might change.
- Coping with behavioural and psychological symptoms of dementia.
- Practical caring skills, such as how to get someone's shoes on safely.
- Communication (suggested several times).
- Oral care.
- How carers can care for themselves.
- The impact of other co-morbidities, such as sensory impairments, pain and other long-term conditions.

The Memory Services National Accreditation Programme standards (2014) also provide guidance on what information should be provided to carers (**Table 4**). They recommend information is provided in appropriate formats to meet the range of language, cognitive, sensory and learning difficulties patients and their carers’ may experience. The majority of memory services in the three NHS Trusts in the Thames Valley have accreditation, and the remaining few are in the process of getting it.

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Table 4

List of subjects carers need information on adapted from the MSNA recommendations (2014)

- Signs and symptoms.
- Course and prognosis.
- Options for care and treatment, including coping methods and strategies.
- Local care and support services.
- Sources of financial and legal advice, and advocacy.
- Medico-legal issues, including driving.
- Local and national information sources.
- Improving general health, living positively and maximising quality of life after diagnosis.
- Pharmacological, non-pharmacological or psychosocial interventions that the person and/or their carer has been offered.
- How to contact the service for advice after discharge.

There is a clear overlap between the above lists of what information carers want and the subjects covered in the Skills for Health Training Framework, which was produced in 2015 to guide the training of staff working with people with dementia (Table 5). Feedback from health professionals suggested that carers often need to feel confident that health and social care staff have the right knowledge and skills. Informing carers of training that staff have received could be useful in building trust and

in letting carers know what information staff should be able to provide to them with.

Table 5

List of Subjects the workforce need training on, take from the Skills for Health Framework (2015)

- Dementia awareness (tier 1).
- Dementia identification, assessment and diagnosis (tier2 & 3).
- Dementia risk reduction and prevention (tier2 & 3).
- Person-centred dementia care (tier2 & 3).
- Communication, interaction and behaviour in dementia care (tier2 & 3).
- Health and well-being in dementia care (tier2 & 3).
- Pharmacological interventions in dementia care (tier2 & 3).
- Living well with dementia and promoting independence (tier2 & 3).
- Families and carers as partners in dementia care (tier2 & 3).
- Equality diversity and inclusion in dementia care (tier2 & 3).
- Law, ethics and safeguarding in dementia care (tier2 & 3).
- End of life dementia care (tier2 & 3).
- Research and evidence-based (tier2 & 3).
- Leadership (tier 3)

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Interestingly, the Alzheimer's Society report (2010) found that little research had been done to explore the different information needs between carers and people with dementia. However, their study indicated that carers were more likely to be interested in learning about;

- Genetic aspects of Alzheimer's Disease
- Dealing with family and friends
- Long term planning.

A You.Gov survey of 2070 adults in the UK found two thirds believed a diagnosis of dementia would mean their life was over, with many people putting off seeking a diagnosis for a year or more (Alzheimer's Society, 2016) . Therefore, providing information on how to live well with dementia could be beneficial both to the general public and post diagnosis. Based on findings from the survey subjects worth including could be;

- Maintaining independence, positive relationships, interests and a sense of identity
- Informing friends and family
- Legislation around driving

Information on the emotional impact of coping and coming to terms with the condition was often missing in resources provided. The need to include emotional support highlights the overlap between information provision and the implementation of supportive interventions. Experiencing feelings of guilt generated through difficult decision-making was identified in the DAAG focus groups. There is a risk that burdensome feelings created by ethical dilemmas may be inadvertently over-looked by health and social care professionals witnessing this kind of decision making on a regular basis. Hughes et al (2002) suggest that there may be a

need for health professionals to include value-based discussions with informal carers as well as fact-based ones. This may reduce some of the burden and guilt carers can experience when making difficult decisions.

Finally, the Alzheimer's Society report (2010) found that more information for carers was available than information designed specifically for people with dementia. This may reflect a perceived challenge of designing information for people with a range of cognitive difficulties and a historical bias towards disempowering people with dementia as passive recipients of care. However, as people are being diagnosed earlier it would seem imperative that a range of appropriate information is made available, particularly to people in the earlier stages of dementia.

What format is preferred?

There are likely to be variations in format preferences and one questionnaire respondent suggested that information should be provided in a variety of formats. The Alzheimer's report, "Information Needs of People with Dementia and Carers" (2010) found the preference of carers was for printed information, which was backed up by a face to face conversation. People liked to be able to relate their own experiences to the information and the face to face contact provided an opportunity to receive emotional support to help with beginning to come to terms with the information received. In response to public and patient preference for face to face contact acute hospitals in the Thames Valley with third sector organisations have recently introduced outreach workers to actively seek out informal carers and provide information and support.

A potentially cost-effective method of delivering psycho-education to a large audience is through internet-based programmes. Kieren et al (2015) conducted a systematic review and meta-analysis of internet-based interventions for carers of people with dementia and concluded that

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there was a lack of quality randomised control studies on this format of intervention. McKechnie et al.'s (2014) systematic review found mixed, but positive results of internet-based programmes. They suggested the delivery model would benefit from being explored more in line with the mainstreaming of information technology use across all age ranges, although an assumption should not be made that all carers either have easy access to the internet or are confident in information technology.

Currently, an on-line psychoeducation and cognitive-behavioural therapy for carers of people with dementia, Caring for Me and You, is being evaluated in a national randomised control trial being run in a partnership between Alzheimer's Society and Oxford NHS Foundation Trust (OHFT). If this proves to be effective making it available as part of service provision will add to the pool of educational resources carers can make use of.

An evaluated on-line information programme called Caring with Confidence designed for informal carers in general is available through NHS Choices (Arksey, 2012).

Where should information come from?

A participant in the DAAG focus groups shared that despite also being a health professional she had experienced difficulty navigating the system as a carer. The Prime Minister's Dementia Challenge (2012) described Dementia Advisors (DAs) as a being an effective component of post diagnostic care for people with dementia and their families. The role of a DA is to be a single identifiable point of contact approachable at any stage following diagnosis and providing information and access to a range of local services. An Age UK and Department of Health survey (2016) on the provision of DA services had a low response rate, but found from those who

responded that the role is well established. 99% of DAs were providing support to carers, 67% running support groups for carers, 91% having face to face contact with people living with dementia and carers and 89% telephone contact. Figures on caseloads were harder to obtain, with an approximate range of 75-170 per DA being suggested. Memory services in the Thames Valley either refer or signpost on to third sector organisations which have people either working as DA's or in similar roles. The challenge is ensuring the continuity of these services and reducing any barriers which can deter carers from engaging with them.

The One Stop Shop is commonly recommended as a helpful way of reducing the need for carers to have to seek out specific information from what can be a frustrating minefield of different sources. A complementary idea is that local communities become more socially inclusive of people with dementia and that everyone in the neighbourhood has information to share and support to give. Across the Thames Valley local Dementia Action Alliance groups promote this vision, despite losses in funding, and their continued work needs to be recognised and supported.

The Department of Health requires all of the workforce who have regular contact with people living with dementia to undertake Tier 2 training, and those in leadership roles to undertake Tier 3 training. This includes understanding and meeting the needs of informal carers meaning that everyone should be in a position to be able to provide information and signpost.

Do demographic groups have different needs?

It is likely that while information needs may be based on personal preference and experience, there may also be a need to tailor it to specific demographic groups. Respondents to the conference

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questionnaire identified that information and educational resources needed to be made available to;

- Extended family members
- The Asian community
- Children
- People living in rural locations

Needs according to age

With the trend towards having children later in life and a growing number of younger people being given a diagnosis of dementia, there is an increase in the number of young people providing care. “Young People Caring for Adults with Dementia in England” (Children’s Bureau, 2016) describes the age and situation appropriate support that young people caring for a parent with dementia require. Tailored literature, for example, would refer to “a parent with dementia” as opposed to a grandparent. The report also highlights the support and information needs of older young people who provide support to a parent with dementia from a distance, whilst perhaps, working, studying or a raising a family in another part of the country. These findings suggest that it would be beneficial;

- To have signposting to information on dementia available from all health and social care services, and not just from services for older people.
- For educational programmes to be accessible to family members beyond the immediate carer.

Age UK’s report, *Invisible but Invaluable* (2016) highlighted the growing number of informal carers over retirement age. 47,882 carers are aged 85 and over. As age is the strongest risk factor for dementia (Alzheimer’s Society, 2016) it is likely that many older carers provide care for someone

living with dementia. The report identifies that older carers are more likely to be providing intimate personal care and heavy nursing type tasks than younger carers and described older carers as a “*sub-group of carers with special needs that are not necessarily met by present service provision*” (p5). It found older carers were often unclear about what services were available to them and often had to take the lead in finding and asking for help, rather than it being provided proactively. Age UK urges health professionals to consider how they can identify older carers and provide information and support to them.

Needs according to gender

Erol et al (2015) identified that men and women approach and react differently to the need to take on caregiving tasks, and subsequent changes in their roles and identities. They suggest that this is something which needs to be recognised by health professionals. They found globally two thirds of primary care givers are women. In traditional extended family structures there is more likely to be an expectation that women will take on the caring role. However, as these familial structures change over time this may become more difficult to achieve, leading to a conflict between family expectations, individual preferences and what is realistically possible. It can be important for health and social care practitioners to understand the practical and emotional difficulties family members may face regarding the extent to which they can take on a caring role. Erol et al (2015) found female care givers are more likely to report increased levels of stress, burden and depressive symptoms and are more likely to reduce their paid working hours, potentially leading to financial strains. The authors stress the importance of informing women of what support is available and of supporting them to overcome reluctance to seek help which can be seen as a sign of weakness.

Grigorovich et al (2016) and Greenwood and Raymond (2016) explored the role and

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experience of male informal carers stating it was an under-developed area of research. This highlights the need for health and social care practitioners to be open to exploring what the education and information needs of male informal carers are and to consider these needs when setting up educational programmes.

Needs according to ethnicity

It has been suggested that lack of knowledge about dementia and stigma in Black and Minority Ethnic communities contributes to people from these communities being less likely to present to memory services for diagnosis in the early stages of the condition (All Party Review, 2014). The review stresses that with these barriers in place it is important that cultural and language needs are taken into account in post-diagnostic support. In Slough a protected Punjabi speaking post has been created. The team now run a cognitive-stimulation therapy group and an information session in Punjabi in response to the needs of the local population. Speaker of other languages in the team are able to offer individualised tailored sessions.

Central and North West London (CNWL) responsible for the Milton Keynes memory service, provide a useful downloadable handbook “Dementia Information for Black and Asian Minority Ethnic Communities” (Truswell and Tavera, 2016). This information resource is designed to help clinicians and support staff signpost people from Black and Asian Minority Ethnic communities. Whilst mostly focused on the London area it could potentially be adapted for use in other areas of the Thames Valley, if nothing similar already exists.

The Children’s Bureau (2016) reported on the significant proportion of young carers from Black and Minority Ethnic groups. Educational literature for this group of young people is being developed at Sheffield University, which would be useful to follow up.

Barriers to accessing information

In the Alzheimer’s 2010 report a barrier to receiving information was that people didn’t always know what they didn’t know and therefore didn’t always know what information to ask for. As a result information was often received reactively and too late, for example rather than receiving information on reducing the risks of pressure injury, information was given after a pressure injury had developed. A similar example was given in the DAAG focus groups. These kinds of scenario are likely to have a detrimental impact on both the physical and psychological health of the person with dementia and the informal carer, in addition to having a health cost implication. A further barrier identified was uncertainty over the roles of different health and social care professionals, which resulted in people not knowing who to ask for particular information.

Brodaty et al (2005) found the main reason why caregivers of people with dementia don’t always seek information was because they considered they didn’t need it despite struggling. They also identified the barriers of lack of knowledge of services and reluctance to ask for help. The Alzheimer’s report, (2010) found that the reasons carers sometimes do not want information are linked to limited time, energy and appetite for it, and a perception that it would provide an unhappy vision for the future and lead to an increase in anxiety. Time was also identified as a barrier by people completing the questionnaire, which has implications for programme design. Sommerlad (2014) reported that NHS services gave a lot of information at diagnosis and often too much negative information at once. Similarly, one questionnaire respondent said it is often difficult for carers, particularly when under stress, to take in all the information given.

In a study evaluating the effectiveness of a befriending scheme for carers of people with dementia, Charlesworth et al (2008) found that despite isolation being a common

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experience for carers, they were often too busy to set time aside on a regular basis to spend time with a befriender matched to them. The preference of carers was often for day to day practical support, which suggests carers may place practical needs before their own emotional needs. Another respondent to the questionnaire said carers may be unable to leave the person they provide care for to attend information sessions.

Informal discussions with healthcare staff with experience of supporting informal carers and from people with experience of providing care to a family member provided the reasons below why information may not always be sought;

- People don't always see themselves as a carer, instead identifying themselves as wives, husbands, daughters, sons, friends etc. People spoken with suggested overcoming this by discussing the word, "carer" in order to break down any barriers it presents. With earlier diagnosis it is likely that the person with dementia is less likely to see themselves as someone needing care and more as someone needing information for them self to enhance understanding and enable informed decision making. Equally, their family members are less likely to see themselves as carers, although information to aid understanding and planning could still be beneficial.
- Carers sometimes feel they don't need information as they currently aren't experiencing any difficulties. People spoken with suggested it can be useful to acknowledge this, whilst also encouraging information to be taken proactively. This can enable the person with dementia and the carer to plan ahead and

develop an awareness of what might help and the support they can access in the future should it be needed. Similarly, people spoke about carers sometimes needing help to recognise the impact of their role on their lives. It was also suggested that carers could benefit from having someone experienced to help them draw out the real impact of caring when completing a Carer's Assessment, to ensure that needs are met.

- Carers will often try something once if they think it could help, but are unlikely to continue if it does not appear helpful. Word of mouth within the carers' community is often influential. Designing information and educational resources in collaboration with carers, following guidelines, such those provided by The Dementia Engagement and Empowerment Project (DEEP), seeking feedback and using evaluation methods should help to ensure resources are successful in achieving what they are intend to achieve.

The above highlights the importance of addressing the factors which deter carers from accessing information and provides a useful insight into how information and educational resources might need to be designed to enable carers to make informed choices about using them. Table 6 summaries the factors which can deter carers from accessing them.

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Table 6

Summary of factors that can deter informal carers from accessing information

- Carers don't know what they didn't know and therefore don't always know what to ask.
- Awareness of issues is not always raised with carers proactively by the workforce.
- Practitioner roles are not always clear.
- Not knowing services exist.
- Carers not recognising the impact their caring role is having.
- Being put off by the word "carer."
- Everything being okay at that time information is offered.
- Limited time.
- Being too tired.
- Perception that information will be negative and likely to raise anxiety.
- The need to prioritise practical day to day care.
- Overload of information, particularly when under stress.
- Information not meeting needs in terms of content, format, time.
- Unable to leave the person care is being provided for.
- Feeling too stressed.

Current Provision of Information and Training Resources in the Thames Valley:

Current provision of training resources across Oxfordshire, Berkshire, Buckinghamshire and Milton Keynes was looked at. As a practical starting point information offered from referral to memory services was explored. A summary of what was found is described below. It should be born in mind that the picture is a brief snapshot in time, April 2016. It is a large geographical area, which is difficult to comprehensively reflect and services and information provision frequently changes.

Websites

An assumption was made that at the time of referral to a memory service, patients and carers may look on the NHS Trust website to seek further information. At the time of looking, the NHS Trust websites for the region all provided information on what to expect at the memory service, with OHFT providing a short reassuring film to watch. OHFT and Berkshire Healthcare Foundation Trust (BHFT) provided downloadable information leaflets on dementia, links to support groups and carer organisations and to the Alzheimer's Society website.

Information given at Memory Services

The main information booklets given out at the memory services are;

1. The Dementia Guide, Living well after diagnosis (2013, updated 2015), Alzheimer's Society (to be updated again in 2016)
2. Oxfordshire Dementia Guide (2013), Oxfordshire Dementia Action Alliance
3. Berkshire Carers Handbook

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Table 7 List of contents of the main information books used

1.The Dementia Guide	2. Oxfordshire Dementia Guide	3. Berkshire Carers Handbook
About dementia	Understanding dementia	Understanding dementia
Treatments	Who can I talk to	Day-to-day living
Planning ahead	Living with dementia	Support
Services for people with dementia	Help for carers	Legal and money matters
Support for carers	Practical help for family and friends	A-Z of symptoms and behaviours
Research	Legal help	Record keeping
Alzheimer's Society services and support	Money matters	
Other useful organisations	Resources	
Checklist (of things to do)		

All of these books have been compiled through a collaboration between organisations involved in dementia care, people living with dementia and informal carers. The Berkshire Carer's Handbook for example, was a result of local carers deciding information would be more manageable if it were presented in a single book, rather than multiple leaflets. There was a preference for the book to contain a large volume of information to enable carers to self-manage, picking and choosing what was relevant to them at a specific time, as opposed to health professionals and support workers deciding what information people should have. As well as being given out at the memory clinics where support is provided to familiarise people with it, it is available to download from the Trust website and distributed to GP surgeries. The format enables information to be updated as necessary. Such development of a resource book within and by a locality is

likely to create a sense of ownership and relevancy, increasing the likelihood of its use.

An e-book based on the Berkshire Handbook has a recently been produced for national use in collaboration with HEE: TV and University of Reading as an outcome of the DAAG report.

Courses offered

There are a range of free courses offered to carers, with each region following a slightly different model. An outline of each is given below.

Berkshire

Berkshire have a very established six week programme for carers in six localities across the county. People given a diagnosis of dementia at the memory services are invited to attend. Sessions last for 2.5 hours, with an optimal 20 attendees per group. The programme content is delivered in conjunction with the Berkshire Handbook. Some programmes are run in the evenings. The sessions are led by a pool of facilitators from the Trust's local community teams. Support with transport and providing care for the person with dementia can be provided, although the later appears to be less in demand with the increase in earlier diagnosis. Evaluation is collected at the end of each programme through the use of rating scales measuring the usefulness of the training. To date feedback has been positive. The communication session is often particularly well-received, with the usefulness of sessions often appearing to be related to what individual carers are experiencing in their role at the time. Facilitators meet a couple of times a year to share feedback. Local adaptations to the programme are made according to need, for example, the Newbury group has taken out the physical care session which focuses on mobility and falls prevention, as it is not so relevant to the increased number of younger people being diagnosed with dementia. An adapted programme is run a couple of times a year for carers of younger people

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with dementia, and another for younger people diagnosed with dementia. Additionally, a short information and experience sharing session has recently been included at the end of Cognitive Stimulation sessions for people diagnosed with dementia. Information sheets are provided which can be taken home to share with family members. Attendees have requested that this is continued.

A 12 week Cognitive Behavioural Therapy (CBT) for Carers programme is run by a psychologist in Windsor and Maidenhead, using the Oxfordshire and Buckinghamshire model, described below. Outcome measures are pooled and a large scale analysis is currently being undertaken. The programme is held in local facilities, such as a town centre community centre.

Milton Keynes

Milton Keynes memory service run fortnightly single post diagnostic support sessions for people given a diagnosis of dementia and family carers. Approximately 15 pairs of people attend. Basic information about dementia is given, and attendees are given access to an information room to collect supplementary written information. Everyone is invited to attend one of 3 longer programmes that the service offers. Each programme is tailored to the stage of dementia the person is experiencing. These programmes run from 5 to 14 weeks. For each therapeutic group run for people diagnosed with dementia, a psychoeducation group for their carer is run in tandem. This enables the person with dementia and their family member to both attend a session at the same time, as opposed to coming on separate days. Feedback is collected from all the groups. In addition, Assistant Psychologists are able to offer the Strategies for Relatives programme (START) on an individual basis to family carers. This is a manualised eight week programme delivered by trained facilitators. In a randomised control trial the use of the programme resulted in significantly less cases of depression in

carers and improved quality of life eight months after the programme (Livingstone, 2013). Facilitators use the Hospital Anxiety and Depression Scale and the Burden of Care Scale to evaluate the effectiveness of programmes.

Oxfordshire

Psychologists, joined by care co-ordinators, have been piloting an eight week programme of 1.5 hours for people with dementia and a carer. Approximately six pairs of people attend. Referrals come from memory services, Age UK and the Community Mental Health teams, and have been greater in the north of the county. Whether this is due to the population or promotional strategies is unknown. The programme content and structure is based on the research carried out by Cheston (2016). The first 20 minutes of the session focuses on a specific topic and is attended both by people with dementia and their carers. The group then splits to continue to talk about the topic or other relevant issues, before re-joining to round up. Content is focused on coping strategies and tries to give a positive perspective. A range of standardised assessments measuring psychological distress, quality of life, apathy, anxiety and depression are being used pre and post group to evaluate the effectiveness of the programme. When sufficient data has been collected it will be analysed to enable a decision to be made on whether to continue the programme. There are also provisional plans to develop a shorter 3 session programme, which would clearly address the barrier of time commitment which carers can face.

A 12 week CBT for carers, which has a psychoeducational component is also available to carers through a joint partnership between OHFT Psychological Pathways and Talking Space, the local Increasing Access to Psychological Therapies service (IAPT). Active promotion of the course is carried out by an Assistant Psychologist and carers can self-refer. Funding to provide care for the person with

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dementia during the course has recently been withdrawn by Social Services. Attendees complete a range of standardised assessments pre and post course. Analysis of data collected over the years is currently being analysed, as mentioned earlier.

Until recently Oxfordshire County Council subsidised Carers Oxfordshire to run the Dementia Essential Core Knowledge (DESK) programme. The funding has now ceased and the programme has become the Oxford Dementia Programme. This consists of a foundation session and a more in-depth family programme. Until a sponsor can be found there is a charge of £30 and £90 respectively, with a discount for three people who support the same person attending. The impact of this change on attendance has not been explored by this scoping exercise, but clearly the introduction of a charge has the potential to impact on equity of access. Another programme incurring a charge is SPECAL, which promotes a specific approach to dementia care and is based in Oxfordshire, but also accessible to people outside the county.

Buckinghamshire

Carers Bucks are offering a 2 hour workshop called, “Caring for Someone with Dementia.” The organisation is also offering for the first time in the UK, a pilot clinician – led online support service for carers of people living with dementia. The six 1 hour sessions are staffed by Healios, a company offering a similar service to support people with a range of mental health conditions.

An established programme of workshops for carers in general on practical issues, help available and how to look after yourself is also run by Carers Bucks called “Caring for You”.

As in Oxfordshire the 12 week CBT for carers programme is also offered in partnership with OHFT and the Buckinghamshire IAPT Service, Healthy Minds.

Course organisers from across the Thames Valley commented that although carers who attend the programmes generally find them useful, the number of carers attending is far lower than the number of people offered post-diagnosis support. Questionnaire respondents from the HEE:TV suggested that more needs to be done to engage with carers to understand why many do not take up the training course available.

Role of Third Sector and Local Councils

In Oxfordshire and Buckinghamshire third sector organisations have the contract to provide information and support to people with dementia and informal carers given a diagnosis at the memory services. In Berkshire and Milton Keynes people are signposted to local support.

Across the area a wide range of locally-based information, support, social and leisure -based groups for people with dementia and informal carers are listed on the websites of third sector organisations, in addition to the individual support they offer.

The Alzheimer’s Society Carers Information and Support Programmes (CrISP) 1 & 2 are currently not running across the Thames Valley, but there are plans to deliver them again. CrISP 1 is designed to be run over 3 sessions and CrISP 2 over 4 sessions.

Table 8 Contents of the Alzheimer’s Society CrISP programmes

CrISP 1	CrISP 2
Understanding dementia	Understanding change
Money & legal matters	Living well as dementia progresses
Providing support and care and coping on a day to day basis	

The Alzheimer’s Society has recently also nationally evaluated a version of CrISP for South Asian carers, the Information Programme for South Asian Families

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(IPSAF). Plans to offer this in the Thames Valley are unknown.

Information for carers and courses for carers in general are listed on local council websites.

Information from the Acute Hospitals to Support Carers

Dementia Leads and teams have been employed by Trusts to work in the hospitals actively seeking out and providing support to carers of people living with dementia. From speaking to people in roles offering support to informal carers visiting the hospitals, once rapport is formed carers very often get back in touch when they require more assistance. This highlights the importance of forming positive relationships to engage carers. Issues people in these roles spoke about included the following points in italics;

- *The need for more people to know their GP can register them as a carer or a person being cared for. This information will be picked up on admission to hospital and enable appropriate actions to be put in place. The importance of GPs registering patients as carers to raise awareness of their potential health needs is stressed in Invaluable, but not Invisible (2016).*
- *The variation in levels of support and information relatives receive when a decision is made that someone should be discharged into a care home, with those families self-funding likely to receive less support than those who are eligible for funding. The process of a relative moving into care is an example of the stressful ethical-based decision making informal carers can experience, and therefore a time when support is likely to be needed.*
- *Relatives not being clear on the role of different health and social care*

professionals. Confusion can be created by the existence of the same roles in-patient and community-based settings, but with different functions.

Summary

Providing information and educational resources effectively to informal carers of people with dementia is clearly important. This exploratory exercise into current provision of information to informal carers has shown that a wide range of information exists in terms of handbooks, online downloadable handouts, person to person contact and group opportunities. Psychoeducational courses are running in all of the four localities. There is some variability in the frequency, structure, content and evaluation used in each locality. Courses tend to be offered to the closest carer. All of the NHS course providers were aware that the number of people attending was substantially less than the number of people given a diagnosis.

Provision is a moving picture and likely to be continually influenced by the needs of the patient and relative group, measured effectiveness, funding and capacity of services to deliver.

A limitation of the exercise is that only the memory service pathway has been considered. People who received a diagnosis before memory services and associated post diagnostic support was established may not have received the same level of information and signposting, but may still be providing care. Relatives who have a family member living in a care home may still benefit from information on understanding dementia, supporting someone with dementia and maintaining positive relationships. Some care homes in the region do facilitate information sessions on dementia to families and the public and a minority have staff in dedicated family liaison roles, but there is potentially scope to do more.

Table 9

Summary of factors to consider on providing information;

- Value the role and expertise of the carer.
- Provide information proactively, i.e. actively identify carers who may benefit, supplement written materials with discussion, avoid making assumptions about what people know without being condescending and readily offer information which could be helpful.
- Include factual and practical information.
- Consider the emotional impact of the carers experience and provide information with sensitivity.
- Tailor information to individual needs.
- Consider the implications of demographic needs.
- Provide in a range of formats to provide choice.
- Offer information to people beyond the immediate carer.
- Measure effectiveness.
- Support everyone the workforce to feel confident to share information.
- Include signposting for further information.
- Get the balance right between the real difficulties people are likely to face and the potential to live well with dementia.
- Address the barriers to accessing information

Providing information and educational resources well to informal carers of people living with dementia across a large geographical area is complex. In a systematic review on information and support given to caregivers of people with dementia Thompson et al (2007) suggest that the fundamental questions to ask are; which carers are most likely to benefit, in what circumstances will the package be most effective and at what stage of the caring journey. Table 9 summaries the factors to consider when providing information.

Scope for the Dementia Fellowship post

Workforce training

- Work with colleagues developing Tier 2 and 3 training to provide opportunities for learners to develop knowledge and skills in understanding the needs of informal carers and to be able to provide information effectively.

Extending Accessibility of Information

- Explore the adaptability of the Tier 1 training for informal carers and extended families.
- Promotion of the E-book to the workforce, informal carers and GP.
- Explore opportunities for collaborative working with third sector organisations to promote and support their training programmes.
- Explore opportunities for collaborative working with Trust facilitators to develop further delivery of their programmes.

Beyond scope of the Dementia Fellowship post

- Scoping and developing information and educational resources specifically for people living with

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dementia in collaboration with people living with dementia.

- Explore if an equivalent handbook to the CNWL book designed to help clinicians and support staff in signposting people from Black and Asian Minority Ethnic communities exists in the Thames Valley. Develop a resource based on this if a gap is identified.
- Explore the information needs of specific groups locally, such as older carers and male carers.

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