PREFACE

The early stages of dementia can be difficult to recognise because the changes that an individual experiences may be attributed to other factors, such as family or work induced stress, physical health problems, depression, or other mental health problems. However, our overall understanding of early dementia, and particularly the experiences of living with early dementia, has advanced. In particular we are now more aware of the information and support needs of people with early dementia and their families. Although services to meet their needs are not well developed, there are some examples of good practice and there is a limited, but growing, body of relevant research. Yet there is little guidance available for service managers or practitioners. This guide aims to address this gap. It provides an overview of what we know about current practice in early dementia support services and offers suggestions about setting up, running and developing services.

The focus of this guide

The focus on this guide is on the provision of information, and social and emotional support, post diagnosis, for people with dementia and their immediate supporters, particularly significant family members. Although the likelihood of dementia increases significantly with age, dementia does not just affect older people. This guide, therefore, is concerned with services for both older people and younger people who are living with the early stages of dementia. Younger people with dementia are often referred to as people with early onset dementia, which should not be confused with ‘early stage’ dementia. This guide specifically addresses the latter.

People with early stage dementia may use a wide range of health and social services. These services include early recognition, diagnostic and treatment services. Although this guide deals with the relationships between these broader services and early support services, the development of these other services is beyond its scope.

Who the guide is for

This guide is intended primarily for managers and senior practitioners in health and social care who are concerned with the setting up, operation and development of early dementia support services. It will be of interest to commissioners, to service providers in the statutory, voluntary and private sectors, and also to people with dementia and their relatives who are actively involved in service development.

What the guide is based on

In producing this guide, we have drawn on a review of the literature and research on early stage dementia services as well as a review of leading edge practice. In particular, we have drawn throughout on an evaluation\(^1\) of six pilot early dementia advice and support (DASS) projects that received funding and support for two years from the Mental Health Foundation as part of an initiative to promote new service responses. Five of the DASS pilot services were based in the voluntary sector and one in an NHS Trust. All offered the provision of information to people with early dementia and their families; one-to-one, or group, support and advice, and, befriending. Further information about the DASS projects and the pilot services is provided in Appendix 2.

We have also drawn on the experiences of other innovative or high quality early dementia support services that we identified from a trawl of websites, literature, conference proceedings and personal contacts. We visited seven services to discuss their approach to early dementia support and advice, three in statutory sector agencies and four in the voluntary sector. These services served very different geographical catchment areas with populations that, like the DASS pilot projects, also differed substantially in their socio-economic and ethnic composition. In addition, we had telephone contact with six statutory and nine voluntary sector services.

Early dementia support is a new and evolving area of service provision and the evidence base for practice is in many respects limited. There are therefore few aspects of service development or practice about which we can give a definitive view. We can, however, draw on the literature and service experiences to identify the main issues that need to be considered in service development and to provide a guide to current thinking about good practice.

How to use the guide

Chapter 1: Early dementia. This provides context for readers, especially for those who are unfamiliar with this field. We describe the characteristics of early dementia, the changes that occur for the person and their family, and their support needs.

Chapter 2: The policy and service context. There is a brief description of service provision for people with early stage dementia and their families, and a brief overview of the policy and service context for developing services.

Chapter 3: The nature of early dementia support services. This chapter discusses the aims and values of early support services, and potential service components, including information, support, befriending; advocacy; education and training; and counselling and psychosocial therapy. It also discusses the role of some early dementia support services in awareness-raising, and the emergence of peer support groups.

Chapter 4: Planning and setting up services. This deals with assessing the needs in an area, deciding on a service model, deciding on the location of the service and obtaining funding.

Chapter 5: Staffing issues. This chapter addresses issues about staffing, including the role of volunteers, and supervision and support.

Chapter 6: Providing a service. This focuses on managing activity, ensuring that services are underpinned by sound operational policies and procedures, and service monitoring and review. It also addresses practice issues in working with people with dementia and working with other agencies.

The Conclusion argues that various service models can work well, but that to be effective for people with dementia, early support services need to be part of a co-ordinated care pathway.

Terminology

Throughout this guide we use the terms ‘early dementia services’ interchangeably with ‘early dementia support services’. We use ‘relatives’, ‘family members’ and ‘supporters’ rather than ‘carers’ to refer to the people who play a significant part in the lives of people with early stage dementia. This more accurately reflects the feelings and experiences of those involved who, in contrast to commonly held assumptions amongst professional service providers, do not necessarily perceive themselves to be in the role of carer, co-client, or co-worker.

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EXECUTIVE SUMMARY

This is a summary of a service development guide that is intended primarily for managers and senior practitioners, in statutory and voluntary health and social care, who are concerned with the planning, setting up, operation and development of early dementia support services. The guide is based on a review of the literature and research on early stage dementia services, as well as a review of practice. Central to this practice review was an evaluation of six pilot early dementia support (DASS) projects that received funding and support for two years from the Mental Health Foundation as part of an initiative to promote new service responses. The guide also draws on the experiences of other innovative early dementia support services that we identified from a trawl of websites, literature, conference proceedings and personal contacts.

People with early dementia

We estimate that there are over 200,000 people with mild dementia in the UK. Increasingly, people with dementia are being identified at an earlier stage of the disease. Diagnosis is a crucial step for most people with dementia and their families but recognising and adjusting to the onset and diagnosis of early dementia takes place over a period of time. The essential challenge for people with early dementia is to 'get on with living'. 'Getting on with living' is made difficult for people with early dementia not only by the impact of the disease but also by the impact of social exclusion that many experience in a variety of ways. For some this is their first experience of a mental health problem, or of social exclusion; for others it exacerbates existing problems. People with early dementia need support that enables them to retain their sense of identity when things within them and around them are changing. They need to be enabled to express their views and retain choice and control in their lives.

Context for service development

Until recently, the development of early dementia support services was generally limited and patchy, with service providers attaching priority to meeting the needs of people with more advanced dementia. Responding to the needs of people with early dementia can require inter-agency and inter-professional collaboration and care pathways through services were often poorly developed and unclear. These limitations have been identified and addressed in the National Service Framework (NSF) for Older People, which sets standards for the early identification and diagnosis of dementia, and in the service development guide Everybody's Business, which sets out recommendations for memory assessment and follow-up support services.

Early dementia support services

There is no single agreed model of what constitutes a good early support service and services often provide several types of support. There is a need for services that work jointly with people with dementia and their supporters. However, it is also important that services enable people with dementia and their families to receive support independently if they wish. Services may be provided on both an individual and a group basis.

The components of early dementia support services include:

- Information provision
- Emotional and social support
- Befriending
- Advocacy
- Education and training in coping with early dementia
- Counselling and psychosocial therapy
Some services also include awareness raising about early stage dementia as one of their functions. Peer support or self help groups of people are emerging.

Services may be provided by statutory or voluntary sector agencies. However, some types of provision, including independent advocacy, befriending and other social support activities, are generally provided by voluntary sector organisations.

**Key tasks in setting up new services**

- Involve people with early stage dementia and their relatives from the outset in planning any new services
- Ensure that the service is based on valuing the uniqueness of each individual and their relationships as well as their shared citizenship
- Tailor any new services to the needs of the local population and to existing service configurations
- Ensure new services are well linked with diagnostic pathways through primary care, especially general practice and old age psychiatry services as well as with other health and social care services
- Identify and involve all key service stakeholders (service commissioners, service providers and dementia organisations in the area)
- Clarify how ‘early stage’ will be defined for purposes of access to the service and for managing transitions to other forms of service support as the individual's dementia develops
- Ensure that the service provider organisation, at all levels, has understanding and expertise specifically in early stage dementia
- Decide on the physical location of the service, taking particular account of acceptability to, and access for, service users.

**Staffing**

**Composition of staff group**

Most services that we looked include at least some paid staff and some also have input from volunteers. One way in which services can ensure a good response to the varied needs of people with early dementia, is by ensuring that the composition of the staff group reflects the social and cultural diversity of the local population.

Paid staff may have relevant professional backgrounds or have skills and experience acquired through other support worker posts in the voluntary sector. Volunteers can bring a wide range of interests, commitment and skills to the service. However, it is important to consider very carefully the roles that volunteers take on to ensure that they are not used for work that should be undertaken by fully trained, paid staff.

**Working with volunteers**

Services that decide to use volunteers need to be realistic about the management commitment needed for recruitment, training, working with and retaining volunteers. The success of volunteering is dependent on having either a dedicated volunteer co-ordinator or a clearly designated paid worker with the responsibility, experience and skills to manage volunteers. Effective working with volunteers is based on understanding each person’s motivations and the aspects of the work that they find rewarding. It is essential to match volunteers and the people they support very carefully to ensure that they are compatible and have shared interests. Volunteers, like paid staff, need to be properly supported and developed.
Staff development and support

Even those staff with extensive prior experience of dementia care may have limited experience of working with people with early dementia. Good induction and training is therefore necessary. Volunteers also generally welcome and benefit from training. It is important to pace training inputs to meet the needs and capacity of individual staff and volunteers. Supervision and support is essential for paid staff and volunteers to ensure the quality of the service and to help them to deal with the emotional demands of the work.

Services need to encourage a culture of reflective practice and encourage staff to learn from others within the organisation and by networking with other early dementia support services.

Key tasks in providing a service

Involvement

- Provide opportunities for people with dementia, their families and front line staff to influence the operation and development of the service.

Referrals

- Identify factors in the broader service system that can either promote or hinder uptake of the services and tailor the 'marketing' accordingly
- Work with key people in other services to promote referrals
- Provide referrers with clear information about when to refer, the method of referral, the information needed and the type of response that they and their clients can expect
- Be careful that numbers are not pursued at the expense of quality of service

Practice

- Have a sound code of ethical practice and ensure that potential and actual ethical issues are identified and discussed with staff, including volunteers, in training and in supervision
- Ensure that staff have the skills, time, patience and commitment to engage with each person with dementia in ways that are suited to their personality, interests and circumstances
- Ensure people with dementia have the option of using services independently of their families if they wish and, when necessary, undertake advocacy work to enable this to happen
- Ensure that when groups are set up to work with people with dementia who are accompanied by a family member, there are alternative opportunities for people with dementia who have no relatives to receive the same type of benefits
- Ensure that staff recognise the limitations of the service and when it is necessary to refer people to more specialist support
- Ensure staff have strategies and support to manage endings and transitions to other services
- Ensure staff are clear about the boundaries of their role
- Have policies and procedures for dealing with case closure and referral on to other services.
Service development

There is still much to learn about how we can best provide support services for people with early dementia and their families. Service providers need to have a commitment to:

- Work jointly with other local statutory and voluntary sector organisations to ensure that the early dementia service and its development are embedded as a core component of the wider service system
- Ensure senior managers and first-line managers have dedicated time for promoting and developing the service
- Monitor, review and evaluate their work in ways that inform practice, operational management and service development
- Network with other early support services to share experiences and learning
- Adapt the service as experience of early support grows and new needs and potential service responses are identified.

It is now clear that service commissioners and providers must pay more attention to the early stages of dementia, not least because of the growing body of people with early dementia and their supporters who are articulating their needs and aspirations in campaigning for better services.
1. EARLY DEMENTIA

Key points about early dementia

- It is estimated that there are over 200,000 people with mild dementia in the UK
- More people with dementia are being identified at an early stage
- It can be difficult to pinpoint the beginning of the onset of early dementia and to define the point at which there is a transition to later stages of dementia
- We need to understand how our responses to people with dementia can affect them emotionally and can result in them being socially excluded
- Recognition of dementia and adjustment to the diagnosis takes place over a period of time
- Diagnosis is a crucial step for most people with dementia and their families
- The extent to which people with early dementia are aware of the changes associated with dementia varies and an individual's awareness may fluctuate over time and in different situations
- The essential challenge for people with early dementia is to 'get on with living'
- People with early dementia need support that enables them to express their views and retain choice and control in their lives. People with early dementia need support in relation to understanding the changes affecting them, maintaining their 'self' and dealing with services
- Family members often do not think of themselves as, or want to be treated as, 'carers'
- Family members' needs are for information, emotional support and support in developing coping strategies
- The needs of people with early dementia and their relatives vary with individual circumstances and at different times during their lives with early dementia.

Understanding early dementia

Until recently, thinking about dementia was dominated by biomedical ideas and there was little attention paid to the emotional and social experiences of people with dementia and their families. However, our understanding of the interplay between the person with dementia and their environment has now advanced substantially. We have arguments for a 'new culture of dementia care' that seeks to ensure a social and psychological environment in which the human worth and 'personhood' of each individual with dementia is maintained and enhanced. Alongside this approach, there has been a movement to understand dementia as a disability and to learn from the social model of disability about how the social and service environment needs to change if it is to avoid disabling and disempowering people with dementia, and contributing to their social exclusion.

Much of this new thinking about dementia has developed in relation to people with moderate or advanced dementia, and it is only recently that the situation of people with early dementia has begun to be considered in depth. This change has been influenced by the growing numbers of people with early dementia who are speaking out about their experiences and the nature of the support that they want in order to enable them to live their lives to the full. For people with early dementia the 'symptoms' of dementia are not always important; sometimes

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they are vague, or forgotten. The essential challenge for them is to 'get on with life' and to develop strategies to do this.

There are risks that as an individual begins to develop dementia other people increasingly take over in 'telling their story' for them. The extent to which this happens, and to which the person with dementia is comfortable with it, depends on the people involved and their pre-existing relationships.

Box 1 provides an extract from one personal account of the experience of early dementia.

### Box 1 The experience of early dementia

‘...this condition does more than rob one of short-term memory, inconvenient and aggravating though that is; it robs one of dignity and the respect of others... For this person is now transformed and one is never looked at in the same way again... nobody wants to be rude; nobody wants to be mean or unkind; but neither do they want to be uncomfortable... I have seen withdrawal on the part of many people, many old friends who just could not handle this disease comfortably ... Yet people [with dementia] can cope with this disease. But you need time - a period of adjustment. You need to realise what is important. And given the will, and supported by medications ... and the support of people, people like your spouse, children and few friends who are not afraid or uncomfortable, all are a tremendous help in the adjustment. You can reframe this disease. See it as a challenge ... a project instead of a disease.'

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**Definitions and numbers**

Dementia refers to progressive deterioration in cognitive functioning accompanied by significant decline in personal and social functioning. Different types of dementia are associated with different pathological changes in the brain. The chances of being affected by dementia increase substantially with age. There is no cure for dementia but there have been recent significant advances in diagnostic techniques and in the development of anti-dementia drugs for use in the earlier stages of some forms of dementia. Although many people with dementia, their relatives and clinicians have been very positive about the effectiveness of these drugs, there has been controversy about the guidelines for their use.

One of the consequences of these biomedical developments, alongside the growing number of people with dementia as the population ages, and growing public awareness of dementia, has been the identification of more people with early dementia. There are approximately 775,200 people in the UK affected by dementia, about 18,000 of whom are aged under 65 years. By 2010 the total number of people with dementia will rise to approximately 870,000. It is estimated that at any time 30% of people with dementia have mild dementia. This suggests that there may be around 230,000 people with mild dementia, with the figure

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expected to rise to over 250,000 by 2010. The rate at which new cases are identified in a population is heavily dependent on the extent to which services are proactive about early recognition and diagnosis, and on the general level of public awareness of dementia and attitudes towards diagnosis. The guidance issued by the National Institute for Health and Clinical Excellence (NICE)\textsuperscript{15} on the use of anti-dementia drugs potentially has major implications for early support services because the availability of these drugs provides one of the incentives for early identification and diagnosis.

Identifying early stage dementia

The onset of early dementia can be difficult to identify. Mild brain changes and memory symptoms, sometimes referred to as CIND (cognitive impairment, no dementia) or MCI (minimal, or mild, cognitive impairment) may be the earliest stages of dementia, but in most cases do not progress to dementia. MCI is ‘a term in evolution’ and there is no consensus on how to define it. Many people are reluctant to use MCI as a diagnostic term because of the ethical and legal implications for the individual involved and a reluctance to medicalise what some regard as a normal part of the ageing process\textsuperscript{16}. Distinguishing between MCI and early stage dementia requires specialist diagnostic assessment, which may be provided through memory clinics, neurology or old age psychiatry services.

As well as difficulties in defining and diagnosing the onset of dementia, there are difficulties in determining when dementia has progressed beyond the ‘early stage’. More detailed information and guidance is available for clinicians on diagnostic criteria, assessment tools and processes, including differentiating dementia from MCI and other conditions\textsuperscript{17}.

The experience of early dementia

Seeking diagnosis

There is a great deal of fear and anxiety about dementia and people have varied views about the benefits of seeking a diagnosis. Some people prefer to continue for as long as possible with their own explanations for changes that they are experiencing (for example, that their memory problems are an aspect of normal ageing) and will not therefore seek or easily accept a diagnosis. Others want the relief of a diagnosis to end their uncertainty about the nature of their problems\textsuperscript{18}. A range of factors affects the time, on average 30 months, between people first noting symptoms and seeking help\textsuperscript{19}. These factors include: age, socio-economic and ethnic background, assumptions about normal ageing, negative attitudes to ageing, and feelings of shame, guilt and incompetence.

Diagnosis

Diagnosis is a crucial step for most people with dementia and their families. However, diagnosis is often not a single event but a process over time. For some people the process is long drawn out, even over a number of years\textsuperscript{20}. This delay is often a result of unavoidable diagnostic uncertainties although service limitations also contribute in some cases. In addition some people experience the assessment and diagnostic process as upsetting and distressing. It is also important to note that in some cases the diagnosis process is not initiated until dementia has advanced beyond the early stages.

Many family members do not think people with dementia should be told their diagnosis. Although the impact of disclosure is not well understood, research on people's reaction to receiving diagnostic information suggests that there is no general justification for withholding the diagnosis. The negative feelings reported by people with dementia are less about the disclosure per se and more about the impact of disease, for example, about loss of a driving licence or self confidence. People with dementia often argue that learning about their diagnosis is mostly positive as it enables them to plan, to make financial and legal arrangements, to get access to memory aids, to increase their social support and to 'make the most of their time'.

**Adjustment**

Adjusting to the onset and diagnosis of early dementia takes place over a period of time. An individual's approach may be different at different times and in different circumstances, as they adapt to their situation in complex ways that are meaningful to them and consistent with their beliefs and values.

People's feelings and coping strategies are affected by how the processes of diagnosis and disclosure of diagnosis are handled by professionals. They are also affected by a range of social factors including: family or carer attitudes, experiences of social stigma and access to information, service support and opportunities to talk.

The negative aspects of people's emotional reactions to living with dementia include anxiety, depression, grief, despair and terror. However, people go through different stages of adjustment and the process is by no means linear. Stages may overlap and some people may miss out some stages. It can be useful to think about two aspects of how people deal with the processes of adjusting. First, their use of 'self maintaining' responses that focus on maintaining continuity in how they think about themselves. Second, their use of 'self-adjusting' responses that recognise the full extent of the changes that are taking place and integrate this knowledge into the ways that they think about themselves. How individuals manage varies depending on their personality, past preferences and so on. People often struggle to find a balance between these processes for example, hope and despair, optimism and realism.

**Awareness**

The extent to which people with early dementia are aware of the changes associated with dementia varies and may fluctuate over time and in different situations. How individuals describe themselves reflects what they know about dementia generally and their own condition, and also how they make sense of the way that other people are relating to them.

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Sometimes other people may, in effect, force awareness upon the person with dementia\textsuperscript{30}. Lack of awareness may be a symptom of neurological damage but it is argued that it can also be an adaptive psychological response\textsuperscript{31}.

**Experiences of family members**

Although we know a great deal about the families of people with dementia, much of this work has been related to physical aspects of caring and the later stages of dementia. It is only recently that studies have begun to explore family members’ experiences of early dementia. Although family members may not at this stage be involved in providing personal care, they are involved in a complex process of emotional adjustment, role negotiation and developing practical coping strategies\textsuperscript{32}. In many ways relatives’ experiences of recognising and adjusting to early dementia mirror those that we described above for people with dementia themselves\textsuperscript{33}.

**Support needs**

Services need to ensure that they understand each person with dementia in the context of their social and family relationships. It is essential to take into account factors such as age, gender, sexuality, family composition, living arrangements, socio-economic position, occupation, ethnicity, cultural background, values and beliefs.

**People with dementia**

People with dementia vary with regard to what is most important to them. Some people will be most concerned with the impact of the condition on their self-esteem and sense of self while others will be more concerned with putting their affairs in order.

Support services need to understand the meaning of a particular situation for an individual in terms of continuity of their life and its underpinning values. It is particularly important to understand how cultural perceptions of dementia and family life may affect people’s experiences. Services also need to recognise that there is a tension between continuity and change. Understanding how individuals with dementia use self protection and adjustment can help inform how services can best offer support\textsuperscript{34}. Personal spirituality may be important in providing meaning and purpose in coping and in how people perceive their quality of life. Sometimes, but not necessarily, this may be related to a specific religious affiliation. Beliefs and religious practice may be affected by early dementia. For example people may experience increasing awareness of a need for faith, or they may experience doubts about their faith, or they may feel embarrassed by changes within themselves, leading to decreased attendance at their place of worship. Support in this area may therefore be important.

\textsuperscript{33} Clare, L. (2002) *We’ll fight it as long as we can: coping with the onset of Alzheimer’s disease*. Aging and Mental Health Vol. 6(2), pp. 139-148.
Some areas in which people with dementia may need support are summarised in Box 2 and support needs of relatives are set out in Box 3.

**Box 2 Some support needs of people with early dementia**

**Understanding changes:**
- Understanding the condition and how it affects them
- Managing the impact of dementia, especially how to cope with memory problems
- Understanding and coping with changes in personal relationships
- Understanding their own and others' emotional reactions to coping with dementia.

**Maintaining self:**
- Maintaining confidence in retained skills
- Maintaining self esteem, self worth
- Managing social and personal relationships
- Being enabled to continue to 'make a contribution'
- Looking after personal care
- Maintaining leisure interests and activities
- Managing occupation
- Ensuring companionship and avoiding isolation through social contacts and support
- Planning for the future.

**Dealing with services:**
- Getting access to information
- Obtaining advocacy if needed
- Managing treatment and medication
- Getting access to benefits and support services.

**Relatives**

The needs of the families of people with early dementia are very diverse depending upon, for example, family composition, socio-economic circumstances, geographical proximity, ethnic and cultural backgrounds. Services need to recognise that a wide range of family and friends will be affected when a person develops early dementia and that the reactions of individual members are affected by their relationship to the person with dementia (for example, whether they are a spouse, a sibling or an adult child). Relatives' reactions are also affected by the quality of their prior relationship with the person with dementia. When relationships have been less positive, family members are more likely to react negatively to the prospect of the person with dementia's growing need for support. Services need to base their work with relatives on a sound understanding of the complexity of people's attitudes and responses in early stage dementia and to their varied roles and relationships with the person with dementia. In particular they must recognise that many relatives of people with early stage dementia do not think of themselves as carers.

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Early stage services can be informed by the experiences of work with carers of people with dementia more generally and by the positive coping strategies that have been found to be useful. In particular the role of early dementia services is crucial in ensuring that relatives are well informed and supported in understanding the changes taking place in the person with dementia.

Some support needs of relatives are summarised in Box 3

<table>
<thead>
<tr>
<th>Box 3 Some support needs of relatives</th>
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<tbody>
<tr>
<td><strong>Information:</strong></td>
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<tr>
<td>• Obtaining information, knowledge and understanding about dementia and its implications for the future</td>
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<tr>
<td>• Obtaining information and advice about benefits and services.</td>
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<tr>
<td><strong>Emotional Support:</strong></td>
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<tr>
<td>• Having someone to talk to, a “listening ear”</td>
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<tr>
<td>• Managing their feelings and making decisions about how they will respond to the person with dementia’s anticipated growing need for support and care</td>
</tr>
<tr>
<td>• Managing changes in relationships</td>
</tr>
<tr>
<td>• Dealing with fears for the future.</td>
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<tr>
<td><strong>Strategies:</strong></td>
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<tr>
<td>• Managing memory difficulties and behaviour that challenge them and others</td>
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<tr>
<td>• Developing strategies for avoiding distressing situations</td>
</tr>
<tr>
<td>• Planning for the future</td>
</tr>
<tr>
<td>• Juggling the needs of the person with dementia with their own needs and those of the home and the family.</td>
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</tbody>
</table>
2. THE POLICY AND SERVICE CONTEXT

Key points about the policy and service context

- Early dementia support has been a low priority for service providers
- The development of early dementia support services is limited and patchy and often not well integrated with broader service systems
- Care pathways through early recognition, diagnosis, treatment and support are often unclear
- Early identification and diagnosis of dementia is a central tenet of service development guidance
- Disclosure should not be treated as a one-off event but rather seen as part of an ongoing process of care
- Any development of early dementia support services must be well linked with diagnostic pathways through general practice and old age psychiatry services
- There is no single agreed model of what constitutes a good early dementia support service. Service developments need to be tailored to the needs of local populations and existing service configurations.

Current service provision

Until recently there was limited public and professional awareness of the need for support in the early stages of dementia, and some resistance to addressing the issues. The priorities for statutory sector health and social care services were largely concerned with meeting the needs of people with later stages of dementia, for example responding to people who make high levels of demands on community services and managing demand for long-term care places. Voluntary sector organisations have also faced similar issues about prioritisation.

Professional service providers have tended to assume that the Alzheimer’s Society’s local branches provide what is needed for people with early dementia and that there are few limitations or gaps in the information and support that is available\(^37\). However, people with early dementia often have considerable unmet needs for information and support.

Care pathways

The development of early dementia support services is limited and patchy and often not well integrated with broader service systems. Often, there are no clear or standardised approaches to the care pathway that people follow in identifying a problem, obtaining a diagnosis and acquiring appropriate treatment and support.

General practitioners

For many people experiencing memory problems, the first point of contact for the individual or their relatives is a General Practitioner (GP). However, there are problems with GPs recognising and diagnosing dementia and referring people on to appropriate specialist clinical or social support services\(^38\)\(^39\). More recently, the Audit Commission found 40% of GPs to be reluctant to diagnose dementia early and concerns amongst other services that GP referrals for support are often delayed until a crisis occurs. The reasons for this include limited skills, lack of training to diagnose and manage dementia, diagnostic uncertainty and fear of false


positive diagnoses, negative attitudes to ageing and dementia and a lack of knowledge about support services. Memory clinics

The most extensive service developments associated with, but not exclusively dealing with, early stage dementia have been memory clinics. Memory clinics increase the identification of dementia at an earlier stage, potentially involving people who are on average younger and with lower levels of cognitive impairment than usually occurs in traditional old age psychiatry services. However, clinics are not available in all areas they may still require referral by a GP or other medical practitioner.

Memory clinics have mostly been set up in old age psychiatry departments and one survey shows that most include specialist assessment, providing a second opinion, advice and information provision to patients and carers, initiating and monitoring treatment and providing advice on management. Over half offer memory training and anxiety management and a small number of other interventions such as psychoeducational programmes for carers. A very high proportion of clinics refer people on to other services including social care services and voluntary organisations. However, it has been argued that ‘What happens at the clinic and what happens afterwards are often very separate processes’.

Although memory clinics will increasingly become an integral part of specialist mental health services, it is likely that different models will continue to be developed to suit different service contexts. It is essential that the development of memory clinics takes into account the integration of these services with broader community support services.

Disclosure of diagnosis

Once a diagnosis of dementia is established, there are different views and practices regarding whether it is disclosed to the person with dementia and/or their family. One study has suggested that only about half of memory clinics have an explicit policy or procedure regarding informing patients of their diagnosis. The reasons for professional reluctance to share diagnostic information include professed feelings of hopelessness and...
helplessness, a desire to protect the individual, and uncertainties about what the person wants or what is best for them.

**Support services**

The service development guide *Everybody’s Business* suggests that early intervention and support services should be provided as part of a specialist resource such as a memory clinic or as part of an extended role for community mental health teams (CMHTs) or through other local organisations. Our service review identified examples of a range of different types of early dementia support services.

**Policy and clinical guidance**

**Policy context**

The development of early support services for people with dementia needs to be informed by policies and guidance on the provision of older people's mental services. However, developments also need to be consistent with broader policy initiatives in health and social care. These initiatives include promoting choice in services, greater user control, direct and individual payments, more preventative services, and social inclusion as well as more specific initiatives such as the Expert Patient programme.

**Early identification and diagnosis**

The early identification and diagnosis of dementia is a central tenet of service development. The *National Service Framework for Older People* argues the case for this as follows:

...early diagnosis gives access to treatment, allows planning for future care, and helps individuals and their families come to terms with the prognosis. Diagnosis also aids better understanding of any changes in memory, behaviour and personality. If dementia is not diagnosed early carers can become demoralised due to lack of support and having to cope with apparently unexplained behavioural changes.’ (p97)

Other arguments include giving people more opportunity to understand their illness, to be involved in treatment decisions, to plan for their future, and to make choices in the present. The issue of access to treatment has become particularly important since the advent of, and some controversy about, the use of a number of anti-dementia drugs.

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Sharing the diagnosis

The decision to share a diagnosis should be made on an individual basis taking into account the social context and the individual's wishes and ability at a particular time. Generally, disclosure should take place as soon as possible once the diagnosis is made but it is important to guard against inappropriate disclosure to people who prefer not to know. Relatives may welcome professional advice about what they should tell the person with dementia. Disclosure should not be treated as a one off event. It should be seen as part of an ongoing process of care provision, including one of establishing relationships with services which the individual may wish to use in future.

Given the complexity of the implications of knowing the diagnosis of dementia at an early stage, the potential value of pre-diagnostic counselling, as happens with other conditions where there are similarly complex implications, has been recognised. However, counselling services of this kind have not yet been widely tested in dementia practice.

Care pathways

Any development of early dementia support services must be well linked with diagnostic pathways through general practice and old age psychiatry services and, where relevant, with memory clinics. This issue should be addressed through the requirements in the National Service Framework for Older People, Standard Seven.

If the role of general practice in early identification and diagnosis of dementia is to be developed, then services need to address GP attitudes and to invest in resources that will support and facilitate good practice.

Developing support services

The need for improved services to provide people with early dementia and their families with better information and emotional and social support has been well made. The NSF requires that health services and local authorities in England should develop plans for an integrated mental health service for older people including arrangements for early detection and diagnosis, assessment, care and treatment, and provision of specialist services for people with dementia. And Everybody's Business makes it clear that early dementia support services are a requirement of any comprehensive and integrated older peoples mental health service system. A service framework is being developed in Wales and a recent report sets out recommendations for service improvement in Scotland.

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There is wide variation in the structure and practices of old age psychiatry services as well as in existing voluntary sector support. This means that it is impossible to design an early dementia support service model that can be widely applied. Rather, the need is to identify the values and components of a service response and the processes by which managers and practitioners can tailor their implementation to the needs of their particular population and existing service configurations.

3. THE NATURE OF EARLY DEMENTIA SUPPORT SERVICES

Key points about the nature of early support services

- There is no single agreed model for the components of a good early support service and services often provide several types of support
- Early support provision may include:
  - Information support
  - Befriending
  - Advocacy
  - Education and training
  - Counselling and psychosocial therapy
- Services may be provided on both an individual and a group basis
- The information needs of people with dementia are often not entirely the same as the needs of their relatives and services need to respond to this
- One model of providing support is to use support workers or outreach workers, usually based in voluntary agencies
- Independent advocacy is most appropriately provided by an organisation that is independent of mainstream health and social services
- Befriending can make a contribution that is distinctive from other services and is to be valued in its own right
- Education and training programmes, usually provided in groups, are increasingly being developed as a way of supporting people with early dementia and their relatives
- Counselling and psychotherapy, both individual and group, can be of value to some people with dementia and their relatives
- Some services include awareness-raising about early stage dementia as one of their functions
- Peer support groups of people with early dementia are beginning to emerge.

Aims and values

Early dementia services need to be underpinned by clear and agreed values and principles. The values and principles that may be important for early dementia services include:

- Valuing personhood, based on a holistic appreciation of and respect for the emotional, social, spiritual and creative dimensions of the individual rather than a narrow focus on their cognitive abilities
- Valuing relationships with people with dementia and recognising the importance of interdependence and reciprocity
- Valuing citizenship and having a commitment to social inclusion based on securing people’s rights, promoting ordinary living and ensuring that people are empowered and have as much choice as possible.

Services will vary in their specific aims and objectives depending on the local context. They may incorporate several or all of the following aims:

- To promote individual well being, and maintain and improve quality of life
- To enable people to play a full part in decisions about everyday matters affecting their lives
- To facilitate access to, and use of, a range of services
- To enable people to play a full part in planning for their future
- To enable people to achieve the immediate outcomes that they want for themselves and their relatives and friends
- To assist people in protecting their rights and securing their entitlements
Early support service initiatives often also have aims relating to the operation of the service system, for example:

- To promote awareness of early dementia, for example amongst GP's and the general public
- To promote earlier identification and diagnosis
- To provide support and advice to other services
- To influence the practice of other services, for example, in achieving better inter-service communication.

**Individual and/or group work**

Much early dementia support is provided on an individual basis. This has obvious potential benefits in enabling the service input to be tailored to the needs, circumstances and wishes of each person with dementia and their relatives.

However, group work is also frequently used in early dementia support services. Group work for people living with early dementia may be time limited or open ended, and may variously involve people with dementia only, family members only, or people with dementia and family members together. Sometimes group members also receive support individually or as family pairs. Voluntary sector based services are more likely to provide more informal information, social support and social activities as compared with NHS services where the emphasis is more often on professionally-led intervention and/or therapy.

The aims of group work with people with early dementia mirror the aims of individual work, but group work has the added aim of providing the opportunity for participants to benefit from shared experiences and mutual support, while also engaging in social activities, acquiring information and coping strategies. The ways in which group work is used in early dementia are summarised overleaf in Box 4.

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Box 4  Uses of group work in early dementia services

- Informal support from others in similar circumstances
- Opportunities to share experiences in a safe and supportive environment without fear of upsetting others
- Help in making sense of living with dementia
- Memory management techniques
- Practical coping strategies
- Information
- Relaxation techniques
- Health promotion
- New friendships and social activities
- Therapeutic support in expressing and dealing with emotions
- Empowerment and helping people feel a sense of control over their lives.

Groups are not suitable for everyone. Some people want more individual, personal contact and some people, for a variety of practical reasons, cannot attend group meetings. The experience of some of the services in our review was that groups that are designed for people with dementia and relatives need to have flexible referral criteria that allow either the service user or the carer to attend if the other is unwilling or unable to take part.

Information

Information may be provided on a one-to-one basis or as part of a group activity. Groups may provide an opportunity to have expert speakers, for example, a representative from the local Alzheimer’s Society branch, a consultant psychiatrist, a manager from a mental health trust, or a solicitor. The information needs of people with dementia are not entirely the same as the needs of their relatives and services need to respond to this.
Box 5 summarises some of the common information needs of both people with dementia and their relatives.

<table>
<thead>
<tr>
<th>Box 5 Information needs of people with dementia and their relatives</th>
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<tbody>
<tr>
<td><strong>For people with dementia and relatives:</strong></td>
</tr>
<tr>
<td>• Technical information about what is happening to the brain</td>
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<tr>
<td>• The causes of dementia</td>
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<tr>
<td>• Nature of dementia and treatments</td>
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<tr>
<td>• Different types dementia and what it means for people with dementia</td>
</tr>
<tr>
<td>• The diagnostic process (if that is not yet complete)</td>
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<tr>
<td>• Medication</td>
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<tr>
<td>• Prognosis</td>
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<tr>
<td>• Practical information about support services and benefits</td>
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<tr>
<td>• Driving</td>
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<tr>
<td>• Financial planning</td>
</tr>
<tr>
<td>• Legal issues</td>
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<tr>
<td>• New technologies, including computer based aids.</td>
</tr>
<tr>
<td><strong>Particularly for people with dementia:</strong></td>
</tr>
<tr>
<td>• Advice about changing relationships with family members</td>
</tr>
<tr>
<td>• Dementia self management and coping strategies</td>
</tr>
<tr>
<td>• Self care</td>
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<tr>
<td>• Health and social care services that can help them.</td>
</tr>
<tr>
<td><strong>Particularly for relatives:</strong></td>
</tr>
<tr>
<td>• Management of the impact of dementia.</td>
</tr>
<tr>
<td>• Behavioural and psychiatric symptoms.</td>
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<tr>
<td>• Practical implications.</td>
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<tr>
<td>• What to expect.</td>
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<tr>
<td>• How to address their own needs.</td>
</tr>
<tr>
<td>• What to do in a crisis.</td>
</tr>
<tr>
<td>• Health and social services that can help them.</td>
</tr>
<tr>
<td>• Support groups.</td>
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</tbody>
</table>


How much information and when?

It is particularly important to ensure that people with dementia are not overloaded with information and that information is provided in forms that are accessible for them. There are some information resources specifically designed for this purpose but it is likely that services will also have to produce some locally relevant material.

Relatives generally want as much information as possible\(^1\). Good information is generally associated with carers having lower rates of depression and more positive coping strategies (although also higher levels of anxiety). One survey found that most relatives want a wide range of information as early as possible to help them to be able to plan ahead. However, few of the relatives at a very early stage wanted detailed information about future stress and likely future constraints on their lives. A minority of relatives more generally preferred to receive information as the need arose as they thought that too much information could be overwhelming.

Meeting different needs

Services may need to develop strategies to meet the information needs of different types of supporter. They need to be able to provide information for a range of family members (not just the immediate supporters), including children. They need to be aware of diversity issues in information provision including the needs of people with lower levels of education, the needs of relatives from black and minority ethnic communities, especially those for whom English is not a first language, and the needs of those who have disabilities, including visual and hearing impairment. Services particularly need strategies to meet the information needs of relatives who live at a distance as many such relatives experience similar levels of distress to those located closer by while having less satisfactory information provision.

Support

Support is an overarching term to include emotional, social and practical support. Support can be provided individually or in groups and at different levels of intensity and frequency. It can be provided by professionally qualified staff, by other paid staff, or by volunteers.

Individual support

One model of providing support is to use support workers or outreach workers. Most posts of this kind are based in voluntary agencies. The support workers, often staff without professional qualifications, maintain contact with people with dementia and their relatives usually by visiting them at home, and sometimes by telephone.

Not everyone needs, or wants, to be put in touch with services. People who are lonely and isolated may be suspicious of any services for fear of losing control, or fear of new experiences. Equally, relatives can be reluctant to recognise that services, might be beneficial to them, and/or to the person with dementia. Workers sometimes have to think creatively about ways of meeting needs other than by fitting people into the services that happen to be available. For example, someone who is lonely or unoccupied may gain greater pleasure from going out for a walk with a befriender than from being persuaded to attend a day centre.

Some of the roles of support workers with people with dementia and with relatives are summarised in Box 6

### Box 6 Some support worker roles with people with early dementia and their Relatives

- Advising on how to obtain a diagnosis or about how to disclose a diagnosis
- Giving, or directing people to, information and advice about dementia and other topics, such as legal and financial issues
- Providing a listening ear
- Giving emotional support
- Giving advice about coping strategies
- Tutoring, about memory management through use of prompts and aides memoire and about avoiding difficult situations
- Helping the person with dementia with personal care by monitoring and prompting personal hygiene and domestic activities such as laundry
- Liaising with other services regarding any changes in the situation of the person with dementia or their home circumstances
- Referring on for other services such as home care support, carer support, support groups, volunteer befriending and counselling
- Supporting relatives in adjusting to changes in their own life situation
- Helping resolve conflicts between different members of a family concerning the person with dementia
- Providing a 'sounding board' about difficult decisions and planning for the future
- Providing regular reassurance of regular visits

### Group support

The value of support groups for people with dementia and relatives can include reassurance, meeting others, communication, new friendships, opportunity to share experiences, emotional support, reduction in anxiety, increasing confidence, decreasing levels of depression, sense of common identity, reduction of stigma, showing fears openly, reduced embarrassment, sharing coping strategies, and help with the identification and expression of emotions. When groups have a primarily social function it can be important for members to have some interests in common to facilitate social interaction and activities. Social support groups are therefore sometimes run as single sex groups and some services also provide groups specifically for younger people with dementia. However, there is no reason for group work for people with dementia to be confined to younger people because older people can also participate and benefit.

Examples 1, 2 and 3 in Appendix 3 provide illustrations of the provision of support, individually and in groups.

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Advocacy

People with early dementia and their relatives sometimes need advocacy services. They may want an advocate to help them to obtain services or to get their views across to family members who have a different perspective. Advocacy may be part of the role of a broader early support service. For example, in some DASS services, staff sometimes accompanied, or helped the person with dementia, or their family, to represent their case to other service providers. However, early support services are not always able to provide a specialist independent advocacy function. Independent advocacy is most appropriately provided by an organisation that is independent of mainstream health and social care services, and early support services are often part of wider provider organisation. It is therefore important that staff understand the type of circumstances in which independent advocacy can be of value and that early support services ensure that they are well linked with local advocacy services to refer people on as necessary.

Befriending

The positive effects of friendships on the quality of life, and more specifically on the health and wellbeing, of older people are well established. There is considerable experience of the value of befriending for people with dementia through the work of organisations such as the Alzheimer's Society. Befrienders can have a particularly valuable role with people with early dementia in extending their opportunities to engage in individual and stimulating conversation.

The experience of the DASS projects suggests that befriending can play a part in providing ongoing support in cases that would be deemed a low priority for support from statutory sector services. But befriending services are not simply a substitute for statutory sector services; befrienders can make a contribution that is distinctive from other services and one to be valued in own right.

Befriending is sometimes provided by paid staff, usually from voluntary agencies. However, befriending may be best provided by volunteers, as their motivation is more consistent with the notion of friendship.

Befriending schemes need to be clear about their boundaries and the differences between the relationships offered by befrienders and the relationships provided by relatives, friends and neighbours. The aim of befriending services is generally to complement, not replace, these other people.

Services offering befriending need to ensure that the interests of the befriended and befrienders are protected.

Education and training

Education and training programmes are increasingly being developed as a way of supporting people with early dementia and their relatives. Education and training is sometimes provided in groups. The work is often based, on the principles of cognitive behavioural therapy and includes, but is not limited to, cognitive training and cognitive rehabilitation.

Appendix 3, Examples 4 and 5 illustrates this type of approach in working with people with early dementia and Example 6 provides an illustration of its application with relatives.

Counselling and psychosocial therapy

The boundaries between counselling or psychotherapy and more general support are often not clearly defined. For our present purposes we define counselling and psychotherapeutic work as activities that are undertaken by practitioners who are qualified to provide these more specialised forms of support. Practitioners from a variety of professional backgrounds who have contact with people with dementia and their relatives around the time of diagnosis often regard some counselling as part of their role. However, the provision of specific counselling or psychosocial therapy services, around the time of diagnosis and thereafter, is currently limited. Although the evidence for the benefits of qualified counselling compared with befriending is as yet limited arguments are increasingly being made for counselling and psychosocial therapy to be more widely available for people with dementia.

Counselling techniques can be modified to cope with memory impairment and other difficulties. Counselling for people with dementia is distinctive particularly in the more proactive role of the counsellor and often the involvement of a family member (with the consent of the person with dementia). Dementia counselling services may also need to address a range of practical issues, including memory problems, in order to work well.

Although not everyone with early dementia will want counselling support, there is the potential for some people to benefit from being able to discuss their experiences and feelings with a counsellor who, not being a relative or friend, does not need to protect, or be protected from the person with dementia’s feelings.

A range of the issues that may be addressed by counselling and psychotherapy are summarised in Box 7.

<table>
<thead>
<tr>
<th>Box 7 Some issues addressed in counselling/psychotherapy for people with dementia and their relatives</th>
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<tbody>
<tr>
<td>• Addressing fears arising from people’s prior experiences (for example negative experiences of the diagnostic process)</td>
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<tr>
<td>• Dealing with changing relationships within the family</td>
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<tr>
<td>• Accepting the reality of the condition</td>
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<tr>
<td>• Maintaining a social life</td>
</tr>
<tr>
<td>• Managing dependency and inter-dependency</td>
</tr>
<tr>
<td>• Keeping control over their lives and future</td>
</tr>
<tr>
<td>• Finding and using coping strategies, for example denial, humour, avoidance</td>
</tr>
<tr>
<td>• Coping with loss in areas such as memory, intellectual ability, reduced ability to communicate, reduced independence</td>
</tr>
<tr>
<td>• Maintaining self esteem.</td>
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</table>
Psychosocial group work

Groups are often used as a means of providing psychosocial therapy. Themes in psychosocial therapy group discussions typically include: loneliness, sex, relationships, optimism, diagnosis and acceptance of it, treatment, communication, fears of dependency, expression of feelings, disempowerment, attitudes of others including stigma and lack of respect, and service and legal issues\textsuperscript{91, 92}.

See Appendix 3 about a counselling/psychotherapy group for people with dementia.

Awareness raising

Early dementia services can raise awareness in the general public and amongst service providers about the condition. Awareness raising may involve services in giving talks to local groups, distributing information leaflets in libraries, community centres and GP surgeries and so on.

Peer support

There is a small but growing number of examples of groups of people with early dementia coming together for peer support, often combined with work on changing attitudes to dementia and campaigning for social and service change. Some of this work is outlined in Appendix 3.

4. PLANNING AND SETTING UP SERVICES

Key points about planning and setting up services

- Involve people with early stage dementia and their relatives in service planning and development from the outset
- Identify and involve all key service stakeholders, including commissioners, service providers and organisations concerned with dementia, mental health and older people
- Consider setting up a steering group made up of people with a strong commitment to early stage dementia services. Ensure that all interested local organisations are represented including potential referrers
- Obtain information from other early support services about their experiences
- Assess the level of demand in the area
- Consider how the new service will fit within the service system and dementia care pathways
- Clarify the parameters of the service in terms of access and eligibility criteria
- Decide on the range of provision to be included in the service
- Decide on the organisational location for the service
- Decide on the management structure for the service
- Ensure that the service provider organisation has the necessary understanding and expertise specifically in early stage dementia
- Seek funding
- Be prepared to review/amend proposals in the light of funders' responses
- Decide on the physical location of the service, taking particular account of acceptability to service users
- Appoint an operational service co-ordinator/manager with a clear role definition, responsibilities and accountability arrangements
- Develop policies and procedures before accepting referrals
- Before accepting referrals, ensure arrangements are in place to provide cover for absences at management and practice levels
- Consider how service monitoring and evaluation will be carried out
- If the service has time-limited funding, consider how sustainability will be addressed.

Getting started

The initiative to establish an early stage dementia service may arise in a variety of ways. For example, practitioners in health or social care services may recognise that they are not meeting the needs of people in the early stages of dementia and set out to develop a more appropriate response; a voluntary organisation may respond to requests for support from people in the early stages of dementia by setting up their own service response or pressing statutory services to respond; or, managers in health or social care services may act in response to policy imperatives, needs assessments or service reviews, or service user demand. The early stage support may be developed as a specific new service or as an extension or adaptation of an existing service, such as a memory clinic or CMHT\textsuperscript{93}.

Whatever the origins of the initiative to develop early stage services, key people in the locality need to be engaged from the outset: commissioners, service managers and front line practitioners, a wide range of professional disciplines and people with dementia and their families. From the experience of the services we reviewed, the establishment of a steering group with broad stakeholder representation can be a useful first step.

Involvement of people with dementia and families

The planning and management of services should be informed by the perspectives of local people with early stage dementia and by the perspectives of their families. The involvement of family carers is already well accepted in statutory and voluntary sector organisations. We might therefore expect to find relatives serving as members of steering groups. However, the experience of some early support services is that they are more likely to attract relatives of people in the mid to later stages of dementia, or former carers who feel strongly that services should be improved. This lack of involvement of supporters of people with early stage dementia may arise because these people do not define themselves as ‘service users’ or because it is difficult for them to find the time and energy to become active in influencing the policy direction of new and developing services. It is nonetheless important that services do make every effort to involve relatives as experience suggests that they can make a very significant impact on the development of services.

Although the involvement of relatives is well accepted, the involvement of people with dementia in planning and developing services is embryonic. However, it is now well established that people with dementia have views to contribute and are often keen to have the opportunity to be involved. They can provide a unique perspective on what is needed and can themselves benefit from their views being valued and respected.

What people want from services

The following features are important to, and valued by, people with early dementia and their relatives:

- Follow up after diagnosis
- Holistic assistance in managing their lives
- Consistency in information and advice
- Staff who are warm, informal, supportive and caring
- Social contact
- Help in using services
- Comfort and reassurance
- Help in understanding their experiences and reactions
- Opportunities to talk about their experiences and feelings
- Co-ordinated services that do not overload them with too many inputs.

It is also clearly important for people with dementia to feel that they are receiving individual attention and that their views and needs are not eclipsed by attention being paid to their relatives.

What is needed in the area?

Assessing the extent of need

A new service must be based on a good estimate of local need. This estimate may take into account the number of already identified people with early stage dementia and the rate at which new cases will be identified. An overall estimate of these numbers can be obtained by applying general estimates of prevalence and incidence of dementia to local population figures, supplemented by local information on unmet need from both the statutory and voluntary sectors.

Service commissioners need to consider how they will address the diversity of people with dementia in their local communities, including socioeconomic diversity, the urban / rural population distribution and the ethnic and cultural communities in the locality. The needs of

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marginalised groups including younger people with dementia, people from black and minority ethnic communities, people who have a learning disability and dementia, and people with co-existing mental health needs such as depression or psychosis, should be given particular consideration. 95 96

Understanding the current care pathway

The configuration and operation of services locally affects the extent, and the stage at which people's problems surface and are diagnosed. Routes into services vary and even within an area there may be a range of possible pathways to early identification and diagnosis, including through GPs, old age psychiatry services, memory clinics, old age medicine and neurology. Protocols should be in place for early identification and diagnosis 97.

It is important that managers developing new support services understand the routes through diagnostic services and how any new service will fit in with, and affect, other care pathways 98 99. A useful step is to map existing services in the locality and in particular the service pathways that people follow through early identification, diagnosis and both the immediate and the longer-term, post-diagnosis stages of the process. It is particularly important that this service mapping is not just based on agreed protocols, operational policy statements or agreed care pathways. Rather this mapping needs to be based on the realities of people's individual experiences and reflect the diversity of their experiences. This involves consulting people with dementia and their supporters. It is also important to consider how any new development will complement, or add to, existing statutory and other voluntary sector services.

What type of service should be developed?

Parameters of the service

A range of factors may play a part in determining the scope and parameters of a new service including:

- The views and wishes of the people with dementia and their relatives
- The history, experiences and views of existing service staff
- An assessment of local need and current service provision
- Commissioners' and funders' views about the scope of the service that they are prepared to support
- The level of demand that will be generated and the capacity of the service needed to respond
- Lessons learned from the experience of other projects and from the dementia literature
- The skills and resources available within potential providing organisations
- The advantages of being coterminous with other important related services such as old age psychiatry service boundaries.

The aim in planning the service may be to extend existing provision or fill a gap in provision. In either case it is important to ensure that the new service does not duplicate existing provision or lead to difficult service boundary issues. Ideally the plan will be to develop a comprehensive, coordinated range of support, which may be provided by one or several agencies.

It is important to reach a clear local agreement about the scope and parameters of the proposed development to enable existing service providers to understand the projects’ objectives and see how services fit together on the ground. Decisions that are made in the planning stages may need to be reviewed in the light of experience or as circumstances change.

**Open access or referral**

A range of approaches can be taken to ensure service access according to the nature of the new service, existing services, available resources, and the anticipated level of demand. For example, it may be appropriate for access to a memory training group to be restricted to patients of a memory clinic, but more general information services may be provided on an open access basis for anyone who has a concern about their memory or is concerned about a relative. More generally, open access services can have potential advantages in promoting earlier service contact, in being less threatening and less stigmatising, and in allowing the person with early dementia and their relatives to feel more in control.

**Eligibility criteria**

Planners need to consider whether the service will deal with people pre-diagnosis or will be restricted to people who have a confirmed diagnosis of dementia. Some services define their role as including work with people with suspected dementia pre-diagnosis and providing support through the diagnostic process. Unsurprisingly, most services focus on people who have a diagnosis. If these services are contacted by people who do not have a diagnosis, they generally provide them with information and direct them to their GP with advice to ask to be referred to a consultant or a memory clinic. In cases where the person with suspected dementia has had prior difficulty in gaining access to diagnostic services, some early support services will intervene on their behalf with health professionals to try to ensure that a diagnosis is provided.

If a service intends to accept clients pre-diagnosis, managers must consider the name and presentation of the service and establish referral procedures that confirm what the person has been told about their possible diagnosis. The importance of this clarity is demonstrated in some existing services where staff have had to deal with individuals and their families who are surprised or distressed to find themselves in contact with a ‘dementia’ service, having been referred by a GP who has not disclosed the actual or suspected diagnosis.

It is important to consider the criteria to be used to determine when the service can no longer meet the needs of a person for whom dementia has progressed beyond the early stages. Clear service pathways need to be established to ensure that there will be a smooth transition to other services that are better placed to provide an ongoing response (see Box 8).
### Box 8 Questions to consider about the parameters of the service

#### Type of development

Will the proposed development:

- Be a stand alone support service or part of a comprehensive diagnostic, treatment and support service?
- Be a time-limited pilot project or an established service?
- Seek to influence the service system, for example by:
  - raising awareness of early dementia?
  - promoting early identification and diagnosis?
  - promoting improved communication or other improvements?

#### Users and access

Will the service be:

- For people pre-diagnosis or post-diagnosis, or both?
- For people with dementia, their families or both?
- Restricted by age, to the population of a particular locality, or to the users of a related service (for example particular GP practices)?
- Provided to individuals or groups or both?
- Provided indefinitely, for a specified time period, or based on an assessment of the level of dementia remaining ‘early stage’?
- Available by open access or referral only?

#### Components

Which of the following will be provided?

- Information?
- Emotional and social support?
- Advocacy?
- Education and training?
- Counselling and psychotherapy
- Befriending?
- Peer support?

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### Where will the service be located organisationally?

Early dementia services may be provided by new, specialist organisations. More often, however, early stage services are developed in an existing organisation, for example, a voluntary sector service provider or an NHS Trust usually as part of a memory clinic or CMHT.

The benefits of being part of a larger service organisation include:

- Opportunities to capitalise on the organisation’s established reputation and credibility as a service provider
- Staff having access to substantial dementia expertise and support
- Staff being able to be part of a larger, possibly multi-disciplinary, team
- Opportunities for staff to extend their experience and skills by working with clients with other needs.
There are, however, potential disadvantages that include:

- The early stage service being 'just another project' and not receiving enough dedicated management attention
- Early stage dementia staff feeling isolated and unsupported if others in the organisation continue to view early stage work as a luxury and as marginal to the organisation's mainstream activities
- Potential conflicts and difficulties in maintaining the focus of the early stage service if its priorities differ in significant ways from that of the host organisation (for example, having a predominantly carer focussed organisation provide the base for a service that prioritises the interests of the person with dementia rather than their relatives).

In choosing an organisational location, service commissioners need to take into account the nature of the potential providing organisation and its reasons for moving into early stage services. Sometimes early stage services are hosted by one organisation but managed through a multi-agency management group. There are considerable advantages in having multi-agency involvement in securing commitment to the new service. However, there are some risks of added complexity and the potential for lack of clarity about accountabilities and responsibilities. It is important for managers and staff in the new service, the host organisation and the management group to be clear about lines of accountability in this type of management structure.

**Voluntary sector**

Many early support services are located in the voluntary sector, often in Alzheimer's Society branches or, in Scotland, with Alzheimer Scotland. The independence of voluntary agencies has to be weighed against possible issues about establishing the credibility of the service and selling it to other agencies and service users. Endorsement by significant local service 'stakeholders' can help add credibility.

The advantages of a base in a dementia specialist voluntary sector agency may include the service:

- Having knowledge of the lived experience of dementia based on the involvement of people with dementia and/or their relatives in the organisation's management or operation
- Having knowledge of the local community and its social resources based on the involvement of local people in the organisation's management or operation
- Having a more informal approach than is typical of statutory services
- Being more acceptable to users, particularly in not carrying the stigma of either psychiatry or social care services
- Being well placed to link people informally with others on the same journey.

However, it is important to note that dementia specific organisations do have some disadvantages for service users who are not comfortable with the use of the word 'dementia' and who perceive it as stigmatising.
How will the service be managed?

A management or steering group can bring about ownership and support in the local health and social care system. It is important to be clear whether it is expected to have a more strategic role or more operational involvement. It is also important to be explicit about whether members of the group are there to represent their organisations or to bring specific personal skills and inputs. Also, it is necessary to decide:

- Which commissioning/funding organisations need to be represented?
- Which related service providing organisations need to be represented?
- What management levels are needed to ensure the necessary influence?
- What practice/professional expertise needs to be represented?
- What professional groups need to be involved to ensure ownership by their colleagues?
- What management skills and expertise are needed (for example supervision, human resources, finance)?
- How will people with dementia and family members be able to contribute?
- How will the service’s managers and staff be involved? Will potential members have the commitment and time available?
- What size will the group be?
- How will the group ensure continuity and consistency of support from its membership?

Operational management

Operational management is usually the responsibility of a service manager. This type of post is often held by someone who has a relevant professional background, for example in social work or nursing. However, posts in voluntary organisations are also sometimes held by people with other relevant qualifications combined with skills and experience gained in voluntary sector roles.

Key aspects of the manager’s role include:

- Promoting the service
- Interagency liaison
- Working with any steering group
- Staff management and supervision
- Activity monitoring
- Quality management
- Staff and/or volunteer training
- Ensuring sound office administration, including IT.

The line of accountability of the manager may be simply to the agency that employs them to provide the early stage service. However, if services operate on the basis of partnerships between agencies, management arrangements can be more complex. For example, the individual may be line managed on a day-to-day basis by one organisation but receive professional support from senior staff in another agency and strategic advice from a steering group.

Policies and procedures

Early stage dementia services require the usual range of statutory and ‘good practice’ policies and procedures that would be expected of any service employing staff or using volunteers. There are a number of specific additional considerations in early support services.

First, given that many people who come into contact with the service will have had no prior experience of early dementia support, it is particularly important to develop public and service user information, for example in the form of leaflets and posters, about the role of the service,
the way it works, the standards to which it adheres, and the nature of its relationships with other providers.

Second, it is essential that there is clarity about the service's boundaries in dealing with clinical, financial and legal matters that need to be handled by suitably qualified professionals.

Third, it is essential that services have appropriate codes of conduct, staff education and training, and supervision arrangements to ensure sound ethical practice and the protection of clients who may be vulnerable. Policies and procedures such as CRB checks are needed to ensure that people taken on to work with clients are suitable. Policies and procedures are also needed for handling any instances of service malpractice or any suspected or actual cases of abuse.

Fourth, there are some specific health and safety issues for staff who are likely to work on their own and in clients' homes. Staff can find themselves working in highly emotive situations. Services need to develop appropriate policies covering practical arrangements (for example, logging location, time and place of appointments and of the staff's return to base). They need also to have policies about joint working in difficult situations, and about debriefing and support for staff who have been involved in stressful encounters.

Fifth, policies and procedures may need to include agreed protocols with other services to ensure that individuals and their families can move on smoothly to other more appropriate forms of support. They also need to cover supervision and support for staff in dealing with people with dementia and relatives whose needs can no longer be met by the early support service.

A list of some of the policies and procedures that early dementia services need to develop is provided in Box 9.

**Box 9 Some policies and procedures for early dementia services**

- Clear job descriptions and practice briefs for service co-ordinators, staff, volunteers, management group and steering group members
- Protocol and information sheets on the service approach to working with people with dementia and their relatives
- Service standards including, for example, response time to referrals
- Policies setting out referral criteria and procedures, arrangements for regular case review (who is responsible for this, how it is recorded, who is involved and so on), procedures for managing difficult decisions, and case closure criteria and procedures
- Protocols covering relationships with other service provider agencies and how staff work together
- Protocols on managing consent, including how capacity to consent will be kept under review
- Protocols covering confidentiality and other ethical issues. Policies and procedures for the selection and support of volunteers
- Policies and procedures for the selection and support of paid staff
- Policies and procedures for dealing with malpractice or potential, suspected, or actual abuse of clients
- Equal opportunities policies
- Health and safety policies
- Policies and procedures to ensure service user feedback and involvement in shaping the service.
How will the service be funded?

Existing services are commissioned and funded in a wide range of ways. Some are commissioned by health or local authorities as part of strategically planned development in the area. Some are not planned strategically but are funded by health or local authorities in response to voluntary sector bids to establish new services. Often commissioning draws upon pump-priming or short-term funding and in many areas the voluntary sector also has a role in contributing part of the funding package. Often services are established with multiple funding sources, with some or all of these sources time-limited. Many services start up as pilot projects with pressure to demonstrate value and make a case for longer term funding.

Ideally the development of early stage services in future should be an integral part of the commissioning of comprehensive dementia care provision. However, since many areas will want to explore what early stage service configuration works most effectively within their service system, it is likely that, in the short-term at least, some services will be set up on a pilot basis with time-limited funding.

Sustainability

The DASS projects’ experience suggests that short-term pilot projects often experience difficulties in establishing themselves and generating sufficient support to sustain their services. Services that are built into the mainstream service structure form the outset, rather than being ‘add ons’ or pilot services, are likely to have less difficulty with sustainability.

Planners need to aim to ensure that funding is secure enough for the service to become sufficiently well established to demonstrate its worth and make a case for inclusion in local service strategies and service development budgets. Building in robust monitoring and evaluation systems from the start enables a service to present its case more effectively.

When services are funded on a time-limited basis, depending on the original funding sources and whether the service is located in the statutory or voluntary sector, planning for sustainability may involve working with initial funders or preparing a strong case to convince new funders that they should ‘pick up the tab’ and sustain the development. It is important that managers/steering groups begin very early to plan their strategy for sustaining the original service or an alternative, improved, option. For example, in a three year funded project, service commissioning timetables may be such that bids need to be prepared in the second year in order to have continuation funding by the end of the third year. This will require time and energy, which may move the priority and focus from other activities.

Different commissioning and funding organisations have different priorities and concerns when considering proposals. Thus, local statutory sector service commissioners are likely to be particularly concerned about evidence of need and effectiveness, how the development fits within their priorities and how it will help them to deliver on their local, and nationally set, policy agendas. They are also likely to be concerned about how the new development will work in the local service system. Charity funders are more likely to be interested in funding innovative and experimental projects and may therefore be more open to an evolutionary and organic approach to developing the service. These funders may be more likely to be prepared to support dementia services in new or small organisations that can demonstrate that they are robust and ethically sound, even if they do not have an extensive track record in service provision.

Box 10 summarises some of the key factors that commissioners and funders are concerned to see prospective service providers address clearly in their proposals.

**Box 10 Key components of proposals for early dementia services**

- A description of the target user group and the settings in which the service will operate
- Evidence of demand
- An outline of the problems that the service will tackle
- The type and level of case work that will be provided
- A demonstration that the service has the practice skills to work sensitively in dementia care
- A demonstration that the service has clear management accountability
- Evidence of ability to work with key stakeholder agencies
- Evidence of good ethical standards
- The availability of training, support and networking for staff and any volunteers
- Sound financial management arrangements
- Clear and reasonable costings and budgets
- Plans for monitoring and evaluation
- Clear arguments as to why the service is worthy of support.
5. STAFFING ISSUES

Key points about staffing

- Most services include at least some paid staff and some also have input from volunteers.
- Paid staff may have relevant professional backgrounds or have skills and experience acquired through other support worker posts in the voluntary sector.
- Volunteers can bring a wide range of interests, commitment and skills to the service.
- It is important to consider very carefully the roles that volunteers take on.
- The composition of the staff group needs to reflect the social and cultural diversity of the local population.
- Good induction and training is important for paid staff. Even those staff with extensive experience of dementia care, may have limited experience of working with people with early dementia.
- Services that decide to use volunteers need to be realistic about the management commitment needed for recruitment, working with, and retaining volunteers.
- The success of volunteering is dependent on having either a dedicated volunteer co-ordinator or a clearly designated paid worker with the responsibility, experience and skills to manage volunteers.
- Effective working with volunteers is based on understanding each person's motivations and the aspects of the work that they find rewarding.
- It is essential to match volunteers and the people they support very carefully to ensure that they are compatible and have shared interests.
- Volunteers generally welcome, and benefit from, training.
- It is important to pace training inputs to meet the needs and capacity of individual volunteers.
- Supervision and support is essential for paid staff and volunteers to ensure the quality of the service and to help them to deal with the emotional demands of the work.
- Services need to encourage a culture of reflective practice and encourage staff to learn from others, within the organisation and by networking with other early dementia support services.

General issues

Services may use a range of staff, including paid staff and volunteers. In some services (particularly in statutory agencies), paid staff will be professionally qualified in health or social care. Often, their required skills are shared by a range of professionals in community-based dementia services, e.g. social workers, psychologists or nurses. Other specific input may sometimes be required, for example, a psychologist may be required to run certain groups. In the voluntary sector, paid staff may have a professional qualification or another relevant professional background or skills.

Some early dementia services use volunteers, usually to provide befriending services or other social support. Some services, such as the provision of information or counselling, might potentially be provided either by volunteers or by professionally qualified staff. It is important to use volunteers appropriately, reflecting their skills, while not using them for work that should be carried out by trained, paid staff. The role of volunteers should be clearly defined. The experience of the DASS projects suggests that the success of volunteering is dependent on having either a dedicated volunteer co-ordinator or a clearly designated paid worker with the responsibility, experience and skills to manage volunteers.

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The staff group – both paid staff and volunteers – should, where possible, reflect the diversity of the community served.

Box 11 summarises some key questions about staffing that service planners and managers need to consider.

<table>
<thead>
<tr>
<th>Box 11 Some key questions about staffing</th>
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</thead>
<tbody>
<tr>
<td>• Does the service require any staff with specific professional qualifications?</td>
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<tr>
<td>• What type of non-professionally qualified paid staff are required?</td>
</tr>
<tr>
<td>• Will paid staff have generic support roles or will there be a requirement for any specialist staff, for example a volunteer coordinator or someone to work with minority ethnic communities?</td>
</tr>
<tr>
<td>• What are the prior training and experience requirements for paid staff?</td>
</tr>
<tr>
<td>• What combination of full-time, part-time or sessional staff will fit best with the hours of service delivery?</td>
</tr>
<tr>
<td>• Could volunteers be used to provide some aspects of the service?</td>
</tr>
<tr>
<td>• How will any volunteers be managed?</td>
</tr>
<tr>
<td>• Does the staff group reflect the social and cultural diversity of the local population?</td>
</tr>
<tr>
<td>• What administrative support will be required?</td>
</tr>
<tr>
<td>• How many staff will be required to meet the estimated demand, taking into account the size of the catchment area?</td>
</tr>
</tbody>
</table>

**Paid staff**

Good induction and training is important for all because even those staff with professional qualifications, or with extensive experience of dementia care, may have limited experience of working with people with early dementia. For all staff who have had limited prior experience of dementia services, it may be useful to spend time with other dementia services to learn about the type of assistance that will be available for the people they support as their dementia progresses.

**Volunteers**

Services in our review that used volunteers variously suggested that volunteering should be fun, volunteers should not be asked to do anything too complex, volunteers’ responsibilities should be consistent with the unpaid nature of their work, volunteers should be considered to be important members of the service team and volunteers should be helped to feel part of the organisation, for example, by being included in social events.

Volunteers can bring a wide range of interests, commitment and skills to the service and their unpaid contribution can add substantially to the resources available. However, the experience of the services we reviewed suggests that managers who decide to use volunteers need to be realistic about the undertaking on a number of counts.

First, it is important to understand existing volunteering patterns in the area and to consider the pool of volunteers likely to be available. Some early dementia services, having experimented with volunteering, have concluded that in their area it is not a viable option.

Second, services have found that establishing a relationship with a person with dementia often requires substantial time commitment from a volunteer. It is essential that both the potential volunteers and the organisation ensure that they are being realistic about the level of commitment that the volunteer is able to make.
Third, some work with people with early dementia requires a long-term commitment. Although most services have no specified minimum commitment for volunteers, some ask volunteers to commit themselves initially for perhaps six months or one year.

Fourth, it is important that organisations are clear with potential volunteers about the challenging and emotionally demanding nature of the work

Fifth, the recruitment, management and support of volunteers requires considerable time, expertise and supervision. The resources required to manage volunteers should not be underestimated.

**Recruiting volunteers**

The recruitment of volunteers to work directly with people with dementia can be quite difficult. Suggested barriers to volunteering with people with dementia include: fear of dementia\textsuperscript{102} fears that 'that could be me in a few years time', and perceptions that people with dementia are unresponsive and that the work is therefore unrewarding.

In seeking volunteers, services need to be prepared to counter these negative perceptions. They also need to consider how they can recruit volunteers from the range of ethnic and cultural communities that they serve. Managers need to consider carefully the likely supply of volunteers in their area and whether they are in 'competition' with other volunteering opportunities. Existing voluntary sector support organisations, such as volunteer bureaux, may be able to provide assistance with recruitment and advice on practical issues such as how to manage the process of obtaining clearance for potential volunteers from the Criminal Records Bureau.

In some instances volunteers may already know the people with dementia whom they 'befriend' because they live nearby. Legitimising their contact through a volunteering role can give some structure to the relationship and protection for the volunteer by enabling them to become involved with supporting people with dementia but with less risk of being drawn into difficult situations. Being a volunteer also means that some of the costs are covered. But there are also potential disadvantages in that being a formal volunteer is likely to entail having to accept some rules and regulations, for example about time commitments and not giving home telephone numbers.

The amount and duration of contact that volunteers offer varies from a few hours occasionally up to one day per week. Volunteers need to be prepared to reassess the commitment that they are making as and when their circumstances change.

**Working with volunteers**

Many volunteers are likely to have been family carers or to have had family experience of dementia and some will have current or past work experience of people with dementia. Their motivations may include: seeking ongoing contact with someone with dementia because they find this enjoyable and rewarding, helping others and alleviating their stress, gaining experience and learning, including through formal training, that can lead to paid employment, sharing personal experience and making worthwhile use of their spare time.

It is important to try to understand each volunteer’s motivation, and what aspects of the work they find rewarding, matching each person with an activity that suits them. Some people are more comfortable working in groups and some happier with one-to-one contacts. Some people will prefer a quiet discussion while others like to be more energetic and gregarious. When the volunteer’s role is to work individually with a person with dementia and their family, there is also a crucial task of matching people to ensure that they are compatible and have shared interests.

Appendix 3 provides an illustration of this matching process as undertaken in one service.

Retaining volunteers

The experience of the DASS projects suggests the new services often underestimate the drop out rate for volunteers but that those volunteers who do stay tend to stay for a considerable time. Volunteers are more likely to stay when they feel appreciated and supported, and feel included as members of the team.

Staff development

Paid staff development

The training and development needs of paid staff in early dementia services will vary depending on their prior experience, education and training. Therefore training, whether provided 'in-house' or arranged through external trainers, often has to be tailored individually.

Different types of staff in different settings will have specific supervision requirements. They will benefit from different approaches, for example: formal monthly supervision; ad hoc support and supervision from colleagues; peer support\(^\text{103}\) as well as external support networks. Providing support for people with early dementia and their relatives can be very emotionally demanding for staff. All staff need opportunities to receive clear and appropriate feedback about their practice and to be supported in dealing with the emotional aspects of the work.

Ongoing practice review and development is particularly important in early dementia support services because staff are in many ways 'pioneers' who are able to draw on a relatively limited bank of established good practice advice or training programmes.

One way to encourage practice review is for services to adopt the principles of reflective practice\(^ {104 105 106}\). The use of reflective diaries and links with staff in other dementia service can enhance reflective practice.

Volunteer development

In addition to topics that also apply to paid staff, volunteers need training on their role as a volunteer, including working within the boundaries of their competence and responsibility.

It is important to pace training inputs to meet the needs and capacity of individual volunteers. Box 12 provides some ideas about how to approach training for volunteers. Services might also consider introducing volunteers to the opportunity to study aspects of volunteering on distance accredited courses.

Box 12 - Suggestions for training and support for volunteers

- Ensure training is specific to the volunteers’ role and activities
- Include contact and interaction with people with dementia, especially in induction sessions
- Pilot new training programmes with a known volunteer
- Consider having a pattern of a few initial training sessions followed by regular ongoing training
- Provide the programme flexibly to fit in with volunteer needs, circumstances and numbers
- Consider group based training, which makes good use of the trainer’s time and has some advantages in facilitating learning from peers, as well as individual training, which is particularly useful to meet individual needs, geographical constraints or a slow flow of new volunteers
- Draw on the advice of other trainers and make use of existing well tried materials where possible
- View training as one component of broader, ongoing support for volunteers to share problems and reinforce good practice.

It is essential to have good supervision and monitoring of volunteers’ work. This may be done in a variety of ways, for example: through regular meetings, with volunteers individually or in groups; through regular telephone discussions with volunteers; or, by asking volunteers to complete short monitoring returns that record what has happened on each contact. Volunteers should be encouraged to bring all issues of concern to the co-ordinator without delay.

Volunteers generally like to feel included as part of the service. They like to be contacted by staff and also appreciate knowing that there is someone to call if they need to. They also welcome feedback on how the person with dementia may have benefited from their input. Supervision and support can help a volunteer to clarify whether or not the person with dementia is benefiting, to deal with the volunteer’s feelings about how the person is reacting, and to decide whether to maintain their efforts or discontinue visits without feelings of failure on their part.

Supervision of volunteers is also very important in providing an opportunity for staff to identify any client unmet needs or other issues that they need to address or that need to be taken up by the service at a general rather than individual level.
6. PROVIDING A SERVICE

Key points about providing a service

- Identify factors in the broader service system that can promote and hinder uptake of the services and tailor the ‘marketing’ accordingly
- Provide opportunities for people with dementia, their families and front-line staff to influence the operation of the service
- Good relationships with key people in other services are crucial in promoting referrals
- Be careful that numbers are not pursued at the expense of the quality of the service
- Provide referrers with clear information about when to refer, the method of referral, the information needed and the type of response that they and their clients can expect
- Have clear criteria for responding to, and if necessary prioritising, referrals
- Have policies and procedures for dealing with case closure and referral on to other services
- Ensure staff are clear about the boundaries of their role
- Ensure that staff have the skills, time, patience and commitment to engage with each person with dementia in ways that are suited to their personality, interests and circumstances
- Ensure people with dementia have the option of using support services independently of their families if they wish and when necessary undertake advocacy work to enable this to happen
- When groups are set up to work with people with dementia who are accompanied by a family member, ensure that there are alternative opportunities for people with dementia who have no relatives to receive the same type of benefits
- Work jointly with other local statutory and voluntary sector organisations to ensure that the early dementia service and its development are embedded as a core component of the wider service system
- Ensure that staff recognise the limitations of the service and when it is necessary to refer people to more specialist support
- Ensure staff have strategies and support to manage endings and transfer to other services
- Have a sound code of ethical practice and ensure that potential and actual ethical issues are identified and discussed with staff in supervision
- Monitor, review and evaluate the service in ways that inform practice, operational management and service development
- Ensure senior managers and first-line managers have dedicated time for promoting and developing the service
- Be prepared to adapt the service as experience of early support grows and new needs and potential service responses are identified.

Involvement

Chapter Four emphasised the importance of involving people with early dementia and their families in setting up services. This involvement needs to be maintained in shaping the operation of the service. People with dementia have influenced early dementia support services in a number of ways, including general awareness raising and influencing the direction of policy. This is developing through groups such as the Scottish Dementia Working Group, and, at an international level, the Dementia Advocacy Support Network (DASNI).

It is also important that front-line staff have opportunities to contribute to the operation and ongoing development of services.
Managing activity

Referrals

Promoting uptake of early support services is generally easier when a partnership of local agencies has been involved in establishing the service. If this type of partnership is not put in place, then new services need to give early consideration to how best to foster support for their work. Good relationships with key people in other services are crucial in promoting referrals. Once professionals have experience of working with staff and seeing clients benefit, then referrals are likely to flow more easily, particularly if the service is promoted as a positive aid to practitioners, such as GPs, in supporting their patients or clients and their families.

A number of early stage services have put a great deal of effort into working with GPs as they are assumed to be in a particularly good position to refer people not only to diagnostic and treatment services but also to support services. However, the experience of the DASS services in attracting referrals from GPs was variable. Some people argue that GPs do not refer - they pass on to others to refer - and that a focus on GPs may be at the expense of other service providers (e.g. community nurses) who may be more sensitive to the early signs of dementia and to people's support needs.

Potential referrers need clear information about when to refer, the method of referral, the information to supply, and the timing and type of response that they and their clients can expect. Alongside formal referral procedures, it may be useful to ensure that there are opportunities for practitioners in related services to have informal discussions with early support service staff about the suitability of cases and the support that can be provided.

The topics that might be included in promotional material are summarised in Box 13.

<table>
<thead>
<tr>
<th>Box 13 - Information for referrers and other service providers</th>
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<tbody>
<tr>
<td>• A clear definition of the service's role</td>
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<tr>
<td>• The values and rationale underpinning the service</td>
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<tr>
<td>• The level and type of support available to the person with dementia and to their relative</td>
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<tr>
<td>• Examples of what the service can provide</td>
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<tr>
<td>• Eligibility criteria for access to the service</td>
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<tr>
<td>• Guidance on when, where and how to refer and arrangements for informal discussion of potential referrals.</td>
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</table>

If the early stage dementia service operates on an open, self-referral basis, it needs to consider how it can be as directly accessible as possible to potential service users. One option is for services to actively promote their work in settings used by people who may benefit from their services, for example in GP practices, community centres and libraries as well as in specialist settings such as memory clinics. Services must also consider issues of equity of access, particularly for users from minority ethnic or cultural communities.
Box 14 summarises suggestions for promoting referrals and uptake of the service.

<table>
<thead>
<tr>
<th>Box 14 Promoting referrals</th>
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<tbody>
<tr>
<td>• Undertake preparatory work to build good relationships with referring agencies</td>
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<tr>
<td>• Capitalise on any pre-existing good relationships with staff in referring agencies</td>
</tr>
<tr>
<td>• Provide good quality information to staff in other agencies about the process and benefits of early stage dementia services</td>
</tr>
<tr>
<td>• Provide good quality, user friendly information to promote the service with potential users in a variety of community and hospital settings</td>
</tr>
<tr>
<td>• Be prepared to ‘sell’ the service and make numerous presentations and individual contacts</td>
</tr>
<tr>
<td>• Collaborate with other service providers to increase general awareness of dementia amongst service practitioners and the local community</td>
</tr>
<tr>
<td>• Link with relevant services and community groups to ensure equity of access for users from minority ethnic or cultural communities</td>
</tr>
<tr>
<td>• Ensure that a high quality, timely, professional response is given to referrals at all times.</td>
</tr>
</tbody>
</table>

Some referrals may be made through personal contact with staff if the service has a presence at a memory clinic. Otherwise a high proportion of referrals are likely to be received by telephone rather than letter. Most services seek basic information about the potential client that includes, gender, age, living arrangements and contact details as well as diagnostic status. Practice in the use of locally devised referral forms varies, but the rate of electronic referral, using a standardised referral form, is likely to increase as new technologies become more widely available.

**Workload management**

It can take some time for an organisation to establish the size of workload that it can manage with its existing resources. Since it is crucial to establish the quality and reputation of the service, it is generally better to build up gradually and to be cautious about taking on too many cases in the early months.

It is important to be careful that numbers are not pursued at the expense of quality of service and that staff are not placed under pressure. This is particularly important since a very clear message from some users of early support services is that they value the ability of staff to spend much more time with them than is typical of other service providers.

Referrals, once received, have to be assessed and the outcome of the assessment communicated to the client and referrer. It is often valuable for staff to discuss the reason for referral with the referrer prior to making contact with the potential client.

Criteria, and a process for responding to, and if necessary prioritising, referrals may be required. If services have to turn referrals away, they need to explain clearly why they are doing this and, where appropriate, direct people to other services. Waiting lists are clearly undesirable but they sometimes arise because of the difficulty of balancing supply and demand in services. If services have a waiting list, they need to provide users, families and other service providers with clear information about how their referral will be handled.

Some early support services are provided on a time-limited basis. However, many services are more open-ended and intended to support people until their needs are better met by other services. Regular review is important, with clear criteria for when a transition should be instigated.
The progressive nature of dementia means that staff can find it difficult to withdraw their support and close cases. This can be difficult in areas where there is a lack of appropriate services to which referrals can be made for ongoing support. As a result, early support services may find themselves retaining contact with a core group of clients who have needs that they are not well placed to meet, but for whom no other services are available. If services are to maintain their ability to accept new referrals, they need a throughput of cases and hence policies and procedures for dealing with case closure and referral on to other services.

**Practice matters**

**Boundaries**

Staff in early support services need to be clear about the boundaries of their role, including:

- The level of practical support that they should provide (for example, where does a befriending service end and a home care service begin?)
- The limits that they should apply in relation to providing information or giving advice on clinical, financial or legal matters, for example, relating to the use of provisions in the Mental Capacity Act 2005 (or in Scotland the Adults with Incapacity (Scotland) Act 2000)
- The extent to which they should 'help out' other services by undertaking some of their tasks in order to expedite an outcome for the client.

**Communication with people with dementia**

Good communication with people with dementia is central to an early support service. Many people using early support services will retain good verbal communication skills but many will be experiencing difficulties. It is therefore important that staff have the skills, time, patience and commitment to ensure that the service engages with each individual in ways that are suited to their personality, interests and circumstances. It is important to understand how each person understands and speaks about their condition and, more specifically, what terms are familiar and acceptable to them. Workers need to know whether or not the person acknowledges that they have a memory difficulty or cognitive impairment, how the person refers to their dementia and how they refer to services. Some people may not know their diagnosis or have forgotten it and people may have limited recall or understanding of the nature of the service support they receive.

**Working with individuals**

Services may work with individuals with dementia, sometimes with relatives and sometimes separately. Sometimes, relatives are reluctant to let them meet with the person with dementia on their own. It is very important that people with early dementia have the opportunity of using support services as they choose, and some people with dementia may wish staff to provide some advocacy support to enable this to happen. It is sometimes difficult to establish working relationships with people who are not aware that they have dementia. Addressing this requires great sensitivity from staff.
Box 15 summarises some practical suggestions for working individually with people with early dementia.

<table>
<thead>
<tr>
<th>Box 15 Suggestions about working individually with people with early stage dementia</th>
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<tbody>
<tr>
<td><strong>Preparing:</strong></td>
</tr>
<tr>
<td>• Check what, if anything, the referrer has explained to the person with dementia</td>
</tr>
<tr>
<td>and arrange an appropriate introduction accordingly</td>
</tr>
<tr>
<td>• Check in advance if a client is a member of a minority ethnic or cultural community</td>
</tr>
<tr>
<td>and particularly whether an interpreter is needed.</td>
</tr>
<tr>
<td><strong>Meeting:</strong></td>
</tr>
<tr>
<td>• Give people the opportunity to meet in the office or another neutral venue</td>
</tr>
<tr>
<td>• If you are visiting at home, let people know when with a telephone reminder on the day</td>
</tr>
<tr>
<td>• Explain as much about your role and service as is appropriate for the individual</td>
</tr>
<tr>
<td>• Establish that the person with dementia is consenting to the contact (and continues to consent)</td>
</tr>
<tr>
<td>• Be sensitive to the individual circumstances of the person with dementia</td>
</tr>
<tr>
<td>• Ensure that you take full account of the ethnic and cultural background of the person with dementia and where appropriate enlist the help of others (for example, a member of their community or a community organisation) to do this</td>
</tr>
<tr>
<td>• Do not assume that the need identified in the referral is the only, or the most important, one to the person with dementia</td>
</tr>
<tr>
<td>• At each meeting be prepared to spend time prompting and reminding the person with dementia who you are and what you discussed at the last meeting or visit</td>
</tr>
<tr>
<td>• Be alert to cues as to when to leave - it is better to have 10 minutes quality time than an hour with nothing happening.</td>
</tr>
<tr>
<td><strong>Communicating and building a relationship:</strong></td>
</tr>
<tr>
<td>• Treat the person with dementia with respect and ensure that they can maintain their dignity</td>
</tr>
<tr>
<td>• Ensure that the person with dementia feels safe and orientated</td>
</tr>
<tr>
<td>• Take time to get to know the person and build up trust</td>
</tr>
<tr>
<td>• Talk clearly and use straightforward language</td>
</tr>
<tr>
<td>• Be alert to non-verbal communication such as facial expressions and body language</td>
</tr>
<tr>
<td>• Use touch sensitively</td>
</tr>
<tr>
<td>• Do not be too intense</td>
</tr>
<tr>
<td>• If verbal communication is difficult, try, for example, writing things down or using visual images as prompts</td>
</tr>
<tr>
<td>• Pace conversation to suit the person with dementia and take time to talk around issues</td>
</tr>
<tr>
<td>• Check that you have understood what the person with dementia is communicating, for example, by summarising, reflecting back, and checking that the person agrees.</td>
</tr>
</tbody>
</table>
Working with groups

In group working, particularly in time-limited group work, the ‘recruitment’ of appropriate members at the required time can be challenging. Services need to be prepared to develop groups to meet the needs of the current cohort of their service users. Services need to be clear about their membership and ‘moving on’ criteria.

Groups may be set up solely for people with dementia, solely for relatives, or for both together. There are advantages and disadvantages of running groups for people with dementia and their relatives together. The advantages include: having ‘no secrets’ in families about what is being discussed; and relatives being able to provide ongoing reminders to the person with dementia of some of the messages of the group work. The main disadvantage is the risk of the group being dominated by relatives and this detracting from the people with dementia.

When groups are set up to work with people with dementia who are accompanied by a family member, it is important that services also take steps to ensure that people with dementia who have no relatives have alternative opportunities to receive the same type of benefits.

Often members of time-limited groups wish to continue contact at the end of the programme and there is a need to make provision for a follow-on social support group or a peer support group.

Working with other services

The nature of early dementia means that early support services cannot meet all of the needs of their clients. This makes it important that practitioners work well with colleagues in a range of other agencies and service settings. For example, the need for the prescription and monitoring of anti-dementia drugs makes relationships with memory clinics, old age psychiatrists, community psychiatric nurses (CPNs) and GPs important. The risk of role overlap more often exists in expectation than reality. For example, social care services do not generally have the capacity to work with people who have the ‘low level’ needs of those using early support services, and support services can fit very neatly with memory clinics:

Often practitioners in other services are cautious, or even defensive, about working with new early support services. These reactions generally arise from a lack of understanding of the relationship between their own role and that of the early support staff, or doubts about a service which has no established ‘track record’. When services are established on time-limited funding other practitioners are sometimes reluctant to risk their clients coming to rely on support that may be withdrawn. Also, with services based in the voluntary sector, other professionals sometimes have reservations based on stereotyped perceptions of voluntary work.

New services have to work to overcome other services’ reservations about working with them by demonstrating their expertise in understanding people with early dementia, the good outcomes they can achieve for clients and the way in which they can complement existing services. Joint visits can be a good way of ensuring that other services have a complete picture of what the new service can offer and thus consider it for a wider range of their clients. It is also important that the staff of the new service demonstrate that they recognise their limitations and when it is necessary to refer people to more specialist support. If they do not do this they are likely to find that practitioners, such as CPNs, are reluctant to involve them because of a perceived risk to their professional accountability for their patients.


Effective new early support services are likely to find that they became known as ‘experts’ in early stage dementia and that other professionals progressively seek their advice.

One of the frustrations for workers in early support services can be identifying their client’s needs but finding that other agencies are not able to address these needs. It is important for staff to understand the responsibilities of other practitioners and how the day-to-day concerns and pressures of their agencies may impact on working relationships and the way in which they are able to respond to needs. Some early services mentioned that it is particularly important that staff in non-NHS organisations are comfortable around clinical people and understand their way of working. It is also important that staff understand any agreed care pathways in their area and how their service fits in that context.

Some illustrations of cross service and cross agency working with early support services are provided in Example 12 in Appendix 3.

Box 16 provides an overview of suggestions and advice for early dementia service staff in working with practitioners from other services.

<table>
<thead>
<tr>
<th>Box 16 Working with other services</th>
</tr>
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<tbody>
<tr>
<td>• Ensure there is understanding of, and respect for, the roles and responsibilities of other practitioners</td>
</tr>
<tr>
<td>• Ensure that others are clear about the role of the early support service</td>
</tr>
<tr>
<td>• Develop knowledge about different approaches to understanding and responding to dementia (for example, medical and social) and how these inform the practice of the professionals with whom they work</td>
</tr>
<tr>
<td>• Invest time in 'getting to know' key professionals and building a rapport with them. Consider regular drop-ins or visits to other service providers to develop good working relationships</td>
</tr>
<tr>
<td>• Be proactive and establish alliances with other practitioners to encourage information sharing and sharing of decision making especially about risk management</td>
</tr>
<tr>
<td>• Consider making joint visits with other professionals, particularly at the point of referral from other agencies</td>
</tr>
<tr>
<td>• Keep the referrer and other key service providers informed of progress as appropriate within the bounds of confidentiality</td>
</tr>
<tr>
<td>• Challenge where they need to challenge, either on an individual or organisational level</td>
</tr>
<tr>
<td>• Gain respect by providing an efficient response to requests from other service providers.</td>
</tr>
</tbody>
</table>

Completion/endings

If early support services are committed to ensuring continuity of support for clients, it can make completion of work and 'endings' difficult to manage. This is further complicated by the progressive nature of dementia and the fact that the service often involves staff spending a lot of time with the person with dementia. Staff necessarily find out a lot about people and their needs. They may become concerned about what happens to the person with dementia once the person’s condition develops beyond the early stages, particularly when the person with dementia is socially isolated. They may also have concerns that other service support is likely to be inadequate or inconsistent. In these circumstances staff may become very attached to the person with dementia and find it difficult to end the relationship. Staff therefore need to have exit strategies and support to manage endings in individual cases.

Ethical issues

Any service needs a sound code of ethical practice. For dementia services one of the main ethical complications arises in relation to the ability of clients to give informed consent to any
activity undertaken with them, or on their behalf. Many people with early dementia will be well able to provide informed consent to all aspects of service involvement. However, the position is complicated as people’s cognitive abilities change and it is important that services have arrangements in place to deal with such changes.

Another common ethical issue for services relates to the disclosure of a diagnosis of dementia. Sometimes services receive referrals in which the client has not been told their diagnosis, although it may sometimes be known to their relatives. Some services operate on the basis of only accepting clients who know their diagnosis of dementia. However, in practice many services find that, for a variety of reasons concerned with family responses and local service practices, an individual’s diagnostic status is less clear than this. Services therefore often decide to operate more flexibly in relation to diagnosis and, before working with a client, will engage in prior discussion with family members about what the person with dementia knows and the terms used to describe the problems.

Box 17 provides some ideas about how early stage services can deal with ethical issues.

<table>
<thead>
<tr>
<th>Box 17  Suggestions about dealing with ethical issues in relation to people with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Treat consent as an ongoing process not a one off decision</td>
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<tr>
<td>• Record the basis of consent</td>
</tr>
<tr>
<td>• Explain to the person with dementia what information about them is recorded and how this information will be used</td>
</tr>
<tr>
<td>• Respect the person with dementia's rights and wishes in relation to being given information about their condition</td>
</tr>
<tr>
<td>• Ensure that confidentiality is maintained and that individuals consent to any sharing of information with others in the family or the service system</td>
</tr>
<tr>
<td>• Consider using ‘shared information records’ to facilitate communication of details that have been agreed by the client</td>
</tr>
<tr>
<td>• Ensure that potential and actual ethical issues are identified and discussed with staff in supervision and that there is clear recording of agreed action and decisions and the reasoning underpinning those actions and decisions</td>
</tr>
<tr>
<td>• Ensure that staff have received appropriate training/education on issues of capacity, consent, human rights and other ethical issues</td>
</tr>
<tr>
<td>• Ensure that staff understand how to manage conflicts in views between people with dementia and their relative(s) or other professionals</td>
</tr>
<tr>
<td>• Encourage staff to continually reflect on what they are doing, why and in whose interests.</td>
</tr>
</tbody>
</table>

Monitoring and review

Monitoring and review arrangements are important for services in assessing their performance and in planning developments. They are also important for service commissioners and funders. It is generally considered good practice for services to have ongoing systematic monitoring. Some services monitor their performance against a range of activity, quality and management targets that they set for themselves and some produce an accessible annual report.

The experience of the DASS services, and other services, suggests that many early stage dementia commissioners and funders recognise the importance of working in depth with people with dementia. They are therefore not just concerned about case numbers, but are keen to see services demonstrate the quality of their work. Services may find it useful to produce short reports containing examples to illustrate the nature of the problems they are working with, how they go about providing support, the nature of their achievements and the challenges and difficulties that they encounter.
Box 18 provides a list of some of the core areas that services need to consider including in their monitoring and review arrangements.

**Box 18  Suggested routine data for service monitoring and review**

<table>
<thead>
<tr>
<th>Service activity:</th>
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<tbody>
<tr>
<td>• Number and sources of referrals</td>
</tr>
<tr>
<td>• Uptake of referrals</td>
</tr>
<tr>
<td>• Characteristics of user population (for example, age, gender, ethnicity)</td>
</tr>
<tr>
<td>• Reasons for referral</td>
</tr>
<tr>
<td>• Response time</td>
</tr>
<tr>
<td>• Nature of service provided</td>
</tr>
<tr>
<td>• Duration of intervention</td>
</tr>
<tr>
<td>• Referrals on to other services</td>
</tr>
<tr>
<td>• Outcomes</td>
</tr>
<tr>
<td>• Reasons for case closure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service quality:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Consistency, completeness and quality of case records</td>
</tr>
<tr>
<td>• The views of users</td>
</tr>
<tr>
<td>• The views of families and carers</td>
</tr>
<tr>
<td>• The views of referrers and other related service providers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Management:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Staff numbers and changes</td>
</tr>
<tr>
<td>• Volunteer numbers and changes</td>
</tr>
<tr>
<td>• Staff training</td>
</tr>
<tr>
<td>• Training inputs to other agencies</td>
</tr>
<tr>
<td>• Publicity and information providing activities</td>
</tr>
<tr>
<td>• Development and implementation of standards and codes of practice.</td>
</tr>
</tbody>
</table>

With increasing policy emphasis on services being evidence-based, there is a need for research that investigates the processes and outcomes of early stage services and for formal service evaluations that provide a more rigorous assessment of outcomes than is possible in routine service monitoring and review. For evaluation to be most useful to service funders and providers, it needs to:

- Examine services that have been established long enough to demonstrate their worth
- Include a range of perspectives and views
- Include both qualitative and quantitative assessment of the services
- Be timed to allow learning to inform practice and service developments
- Be adequately resourced, taking into account the demands of data collection on staff and management time.

In order to ensure that evaluation can be carried out effectively, it can be useful for services to involve evaluators from an early stage in considering the goals and outcomes of the service and how its achievements can be assessed.

**Developing the service**

Development may involve expanding the capacity of the service or developing new approaches to provision. One of the messages from a number of existing services is that managers need to be prepared to adapt services as experience of early support grows and new needs and potential service responses are identified.
The development of the service may be primarily the responsibility of a management group, although in practice it often falls to the service manager to take on many of the operational tasks of service development. A pre-requisite of successful service development is ensuring that senior staff and first-line managers have sufficient dedicated time for this work.

Management groups and service co-ordinators who are involved in service development often find it useful to make links with other similar services to share experiences and learn from each other. Some obtain advice and support from being part of a larger provider organisation, such as the Alzheimer’s Society, Alzheimer Scotland or Age Concern, whose philosophy, resources and members’ collective experience can be crucial to the development of the early support service.

Appendix 3 has several examples of the ongoing development of some new early support services.
CONCLUSION

This guide has drawn on a review of the literature and leading services, including the DASS pilot projects that were initiated, funded and supported by the Mental Health Foundation, to provide ideas and suggestions for developing services that people find accessible, relevant and supportive. It has messages for both managers and practitioners.

We have argued that the experience of early stage dementia is complex, as are the support needs of people diagnosed with dementia and their families. Meeting these needs requires services with a range of components including: information provision, emotional and social support, befriending, advocacy, education and training in coping with early dementia and counselling and psychosocial therapy. From the perspective of service users it is essential that support is flexible, person focussed and provided by people who are sensitive and knowledgeable. There is no one service model that is clearly more effective than others in providing this type of support. The different components of support need not necessarily be provided by one agency and both statutory and voluntary agencies may have a part to play. Whatever the types of early support services that are provided, it is essential that they are an integrated part of a co-ordinated care pathway with early identification, treatment and ongoing care services that can provide individuals with a comprehensive response to their needs both immediately following diagnosis and in the longer-term.

There is still much service development work and research to be done to inform the delivery of services for people who have been recently diagnosed with dementia and their families. However, it is now clear that service commissioners and providers must pay more attention to the early stages of dementia, not least because of the growing body of people with early dementia and their supporters who are articulating their needs and aspirations in campaigning for better services.
APPENDIX 1: SERVICES VISITED OR CONTACTED

'Changes Programme': Priestley Day Unit, Mid Yorkshire Hospitals NHS Trust
'Space' Project: Alzheimer's Society Lowestoft and Waveney Branch
'Time to Listen' Befriending Project: Alzheimer's Society Bradford Branch
'Voices for Choices' Volunteer Befriending Project and the 'Deep Thinkers' Project:
Alzheimer's Society North Tyneside Branch
Carers' support groups: Alzheimer's Society Croydon Branch
Carers' Support Service and Information Service: Alzheimer's Society Newcastle Branch
Community Day Service: Isle of Wight Healthcare NHS Community Trust
Dementia Service: Age Concern Havering
Community Memory Screening Clinic: The Research Institute for the Care of the Elderly, Bath
Croydon Memory Service: South London and Maudsley NHS Trust
Dementia Counselling Service: Alzheimer's Society Salisbury Branch
Dementia Link Project: Alzheimer's Society Woking Branch
Early Memory Group: Holderness Older People's Community Mental Health Team, The
Humber Mental Health Teaching NHS Trust
Early stage dementia groups: Alzheimer's Society Peterborough Branch
Early Stage Dementia Service: Alzheimer's Society Penrith Branch
Information and support groups: Alzheimer's Society Norwich and District Branch
Living with Memory Loss Program: Alzheimer's Australia
Memory Clinic Link Worker Service: Alzheimer's Scotland-Action on Dementia, Dumfries and
Galloway Services
Memory Clinic: Department of Old Age Psychiatry, Avon and Wiltshire Mental Health
Partnership NHS Trust
Memory Club for early stage dementia: Becton Centre Community Mental Health Team
Hampshire Partnership NHS Trust
Memory Management Service: South of Tyne and Wearside Mental Health NHS Trust
Memory Remediation Group: Newcastle Memory Clinic, Newcastle, North Tyneside and
Northumberland Mental Health NHS Trust
Support groups for people in the early stages of dementia: Alzheimer's Society Huddersfield
Branch
APPENDIX 2: THE DASS PILOT PROJECTS

The DASS initiative

As part of a wider programme of work on older people and mental health\textsuperscript{109, 110, 111} the Mental Health Foundation funded six projects for two years to pilot the provision of services to people in the early stages of dementia and their families and friends. The Foundation described the aims of the DASS initiative, in summary as:

- To provide those with dementia and their carers with ready access to a personal home based support service offering information and support
- To provide a befriending service via a network of volunteers
- To promote the maximisation of physical and mental functioning of both the person with dementia and their carers. This will include accessing more intensive services as is needed
- To enhance carers’ coping skills and physical and emotional support
- To provide advice and help in accessing existing support, treatment and care
- To identify gaps in local home support services and develop plans to extend provision
- To maximise local voluntary support.

The DASS pilot projects

The Foundation selected pilot sites to reflect a range of socio-economic, ethnic and geographical settings and different provider agencies, including the voluntary and statutory sectors. The pilot projects evolved in different ways, reflecting local needs and existing services. All projects were hosted by a service provider agency. Each of the six local projects was staffed by a co-ordinator and in five projects additional part-time staff carried out varied roles as information officer, befriending co-ordinator or development worker. All projects promoted their services extensively within their local communities and endeavoured to work closely with other service providers.

Over 400 people with dementia, and in many cases also a spouse, daughter or other relative, were supported by the six projects over the two years of the DASS initiative.

The services provided by each of the pilot projects, and the staffing of the projects, are summarised in Table 1 and described in more detail below.

Rural projects

Two of the DASS projects were located in small towns (Bangor\textsuperscript{112} and Kendal) serving largely rural populations. These populations include stable, long-established communities as well as substantial numbers of older people who have recently retired to the area from other parts of the country. Both projects were based in local branches of the Alzheimer’s Society that had prior experience of providing general information and support for carers of people with dementia and, to a lesser extent, for people with dementia themselves.

Both rural projects provided information, support and advice on a one-to-one basis to help people and their families address the anxieties and problems resulting from the impact of

\textsuperscript{111} Alzheimer Scotland - Action on Dementia (2003) Making the journey brighter: early diagnosis and support services for people with dementia and their carers. Edinburgh: Alzheimer Scotland - Action on Dementia. (see pp.48-56)
dementia on day-to-day living and relationships. The project based in Kendal created two separate but linked services: a family support service and a befriending service. Specific initiatives included an education group and a support group/lunch club for people with dementia and their relatives. The family support worker worked jointly with other services in the area, for example, with a local memory clinic to provide newly diagnosed patients and their families with information and personal support at home.

Both of the rural projects attempted to extend the support provided through the use of volunteer befrienders. The project based in Bangor, working within a close-knit bilingual Welsh/English community, recruited 19 befrienders by approaching local community groups for volunteers to support particular individuals. The befrienders were able to link people with dementia into broader social support networks and to re-introduce some people with dementia to members of the local community whom they had known earlier in their life, through a church or other social activity. In contrast, the project based in Kendal had very little success in recruiting volunteers, despite extensive promotion of the need for befrienders. This project subsequently appointed a paid home support worker to befriend people with dementia.

Urban projects

Four of the DASS projects were located in urban areas. Two were based within Alzheimer's organisations in large cities, Nottingham and Glasgow. One was based within Age Concern in Calderdale with offices in Halifax and covered an industrial town with a rural hinterland. And one was based in an NHS Trust in Winchester, a small and relatively affluent city with rural surroundings. Nottingham and Halifax, in particular, have an ethnically mixed population and the DASS projects employed support/outreach workers, who as members of South Asian communities, were better able to encourage uptake of services by people in the local minority ethnic communities.

Like the rural projects, the urban DASS projects offered individuals with dementia and their families a listening ear, emotional support, information about dementia and services, and guidance about managing the impact of dementia on their lives. They variously offered additional services (see Table 1) including counselling, volunteer befriending and support groups.

The variation between the urban projects arose from their scale, the capacity of their host agencies, and their links with existing services. Winchester DASS, for example, operating with one worker, focused on providing one-to-one support and developing awareness of early stage dementia amongst the wider community and other service providers. The Glasgow project, based in Alzheimer Scotland, with more staff and an established project prior to funding from the Mental Health Foundation, offered a range of help, counselling and support services which were promoted widely with a number of service agencies and within local communities. The project focussed particular attention on GPs and their primary healthcare colleagues. The main source of referrals to the project, however, was an outpatient/memory clinic, where the co-ordinator of the Glasgow project, a qualified counsellor, was introduced to clients immediately after a diagnosis had been given.

The support groups run by these projects, sometimes in collaboration with other services, ranged from information groups for people with dementia through stress management and education groups for carers, to social groups for people with dementia and their partners. In its second year, Calderdale DASS collaborated in a multi-agency initiative to provide time-limited group support, help and advice to people in the early stages of dementia and the Glasgow project provided an education programme for newly diagnosed people with dementia in collaboration with community based psychiatric nurses.

In Glasgow the DASS project matched some people who needed ongoing social support with a befriender from a pool of volunteer befrienders that they recruited and supervised. Later this proved an untenable service, because of a lack of volunteers, and instead outreach was provided by staff. Calderdale DASS recruited and supported volunteers who were able to sustain a limited but valued befriending service. In Winchester, despite extensive promotion of the service and its need for volunteers, including local press coverage and liaison with existing voluntary agencies and volunteer groups, only one volunteer was recruited. Nottingham DASS project did not attempt to provide a volunteer befriending scheme, advocacy, or specific support for carers as it took the view that this would duplicate existing dementia services that could be used by people with early stage dementia.

The six projects had varied success in securing funding to sustain the services beyond the pilot phase funded by the Foundation, but a similar service continued to be provided in North Wales, South Lakes, Nottingham and Winchester.\footnote{Mental Health Foundation (2004) \textit{First Signs. Celebrating the achievements of the Dementia Advice and Support Service: a project for people in the early stages of dementia}. London: The Mental Health Foundation. Available from: http://www.mentalhealth.org.uk/html/contentfirstsigns.pdf}
### TABLE 1 THE DASS PILOT PROJECT SERVICES AND STAFF

<table>
<thead>
<tr>
<th>North West Wales</th>
<th>Calderdale</th>
<th>Glasgow</th>
<th>South Lakes</th>
<th>Nottingham</th>
<th>Winchester</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DASS Services</strong></td>
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<tr>
<td>Advice</td>
<td>Advice</td>
<td>Information</td>
<td>Advice</td>
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<tr>
<td>Support</td>
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<td>Support</td>
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<td>Information</td>
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<td>Volunteer</td>
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<td>Volunteering</td>
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<td>Support groups</td>
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<td>with statutory</td>
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<td>provider</td>
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<td>Outreach</td>
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<td>dementia</td>
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</table>

| **Staff**         |            |         |            |            |            |
| Co-ordinator     | Co-ordinator | Counsellor/| Manager   | Co-ordinator | Co-ordinator |
| (p/t)             | (p/t)       | co-ordinator| (f/t)     | (f/t)       | (f/t)       |
|                  | Development | Assistant  | Family     | Support     |            |
|                  | worker (p/t)| co-ordinator| support   | worker (p/t)|            |
|                  | Development | Volunteer  |            | Volunteer   |            |
|                  | worker (p/t)| co-ordinator|            | co-ordinator|            |
|                  | (p/t)       | (p/t)     |            | (p/t)       |            |
|                  |            | Administrator|            | Administrator|            |
|                  |            | (p/t)     |            | (p/t)       |            |
|                  |            | Home      |            | Home        |            |
|                  |            | support   |            | support     |            |
|                  |            | worker (p/t)|            | worker (p/t)|            |
|                  |            | short term|            | short term  |            |
|                  |            |           |            |            |            |
APPENDIX 3: EXAMPLES FROM PROJECTS

Example 1: Individual support – Lowestoft and Waveney Alzheimer’s Society

Lowestoft and Waveney branch of the Alzheimer’s Society has support workers who provide a flexible, activities based project that extends support to people with dementia and enables them to become involved in decisions in their lives, pursue hobbies and go on outings. ‘Programmes’ are individually planned with the person with dementia and the support worker then visits on a regular basis. The service is reviewed after 6-8 weeks but experience suggests that this is too short a time for benefits to be assessed as time is needed to establish rapport. Referrals are via statutory sector professionals, self referral or from relatives. The project was initially funded by the Primary Care Trust and then through the Carers Grant. Respite for carers is seen as one of its beneficial outcomes. Moving people on from this service is difficult because of a lack of other suitable services. The service benefits from having two workers, with different skills and interests, enabling clients to be moved between workers if they appear to become too dependent on a relationship. Volunteers have not been used because they would have specific training and support needs and would need close supervision beyond the capacity of the branch.

Example 2: Support groups - Huddersfield Alzheimer’s Society

The format for one group, run by the Huddersfield Alzheimer’s Society branch, was determined by consulting with four people with dementia who attended an initial meeting. They wanted to be able to ask questions, to meet others with the same problems, and to meet frequently.

The group aims: to put people in touch with others living with memory problems, to provide a safe, confidential environment where people can share feelings and coping strategies, to foster mutual support, to provide an opportunity for people to become informed about the illness, to provide a social setting where trusting friendships can grow, to provide mutual encouragement, to organise events and outings for members and carers and to give relatives a break. The group is facilitated by an experienced support worker who has counselling skills.

Following a referral to the service, the support worker visits people at home. Membership criteria are explained, as is the fact that people will not always benefit from the group and will move on to other services. The criteria for membership are that people are aware that they have a memory problem and have been told a diagnosis, want to learn about the illness and how to live with it, want to meet others in a similar situation and, want to encourage others and be encouraged. Membership is limited to eight. A second group was started when numbers outgrew the first group.

Meetings are held weekly. Groups do not have a pre-determined programme. Talk is about whatever crops up. It can be something serious about the illness and at other times it might be ‘having a laugh’. However the group is focused on the illness - it is not a purely social group. If a topic such as driving comes up in the conversation, the facilitator can provide information and discuss the issues.

Members are ‘learning to live with the illness’. The outcome is that members are preserving a sense of worth and significance’ and that they ‘...feel a positive and loving experience’ even if they do not remember the detail of the activity. Personal information shared in the group is confidential to the group.

Four original members were still attending after two-and-a-half years. They have been able to maintain their function within the group, although it is likely that some deterioration in functioning, which they acknowledge, is more apparent outside the group. Some have
difficulty, for example, with word finding. But the group is familiar territory and this familiarity helps them to function well.

Example 3: Support groups - Norwich Alzheimer’s Society

Norwich Alzheimer’s Society branch runs fortnightly support groups for younger people with dementia and their relatives that include lunch and offer a range of activities including quizzes, games and reminiscence. During part of each meeting people with dementia spend time engaged in activities in a room separate from their relatives. Speakers are invited and outings and trips are arranged. Participants have the chance to decide how the groups should develop.

Peer support is emphasised as a key gain by participants who stress the limited opportunities they have to meet similar people. Members also report valuing the sharing of experiences, opportunities for social interaction and friendship, information, a good lunch, increased confidence and knowledge, increased happiness and self assurance, practical advice, satisfying social events and learning from others.

The group activity runs alongside one-to-one support from the branch support worker. The group is also open to people with dementia who live alone. The support group has close links with the local Memory Clinic and support workers from the clinic attend group sessions as helpers.

A group with a similar format group is offered to people over the age of 65 and their relatives on a monthly basis.

Example 4: Education and support group for people with dementia - The Becton Memory Club

The Becton Memory club runs a seven-week programme of weekly groups of approximately two hours including a lengthy coffee break. The meetings are facilitated by a psychologist and cover a programme that included topics such as understanding how the brain works and driving. However, members of the group decide on the sequence of topics and what to repeat. There is a strong ‘training element’ that is based on a memory manual. The group covers only basic strategies for memory management because people do not remember a great deal. A major element of the work is validating how people feel and allowing opportunities for peer support.

The first part of each session is principally ‘educational’ and the second part is more about validating feelings. The facilitator tries to meet the needs of all members taking into account that some have a preference or need for formal instruction and discussion around specific topics, whilst others’ needs are primarily for validation and support.

The benefits for participants are knowing that they are not on their own, sharing and mutual support.

Example 5: Education and support group for people with dementia - Memory Remediation Group from the Memory Clinic in Newcastle

A CPN and a psychologist run the Memory Remediation Group from the Memory Clinic in Newcastle. It is a time limited group for people experiencing memory difficulties and is not confined to people with a diagnosis of dementia. The group aims to provide practical solutions to everyday memory problems for people with mild memory problems, and an opportunity to discuss these with others with similar difficulties. The group also provides information about reasons for memory difficulties. Handouts are provided for each session and are illustrated with coloured pictures. The group uses a problem solving approach to common problems.
such as taking telephone messages. Members are given 'homework' exercises between sessions.

Example 6: Education and support group for relatives - ‘Changes’ Carer Education and Support Programme, Priestley Day Unit, Mid Yorkshire NHS Trust

The 'Changes' Carer Education and Support Programme is an established 6-week course for relatives run from the Priestley Day Unit, Mid Yorkshire NHS Trust. The person with dementia can attend the unit and take part in recreational activities whilst the relatives' training is taking place.

The programme covers diagnosis, behaviour management, carer stress and burden, medication, the role of the memory clinic and the voluntary sector. Speakers from various disciplines contribute, for example pharmacy, nursing, occupational therapy (OT) and medical staff. Sessions last for four hours and include lunch.

Relatives who attend the 'Changes' programme can go on to join a monthly support group 'Connections', which enables social and informal support to be maintained. 'Connections' is facilitated by NHS staff but held in a variety of community settings.

Example 7: A counselling/psychotherapy group for people with dementia, Salisbury Alzheimer’s Society

People are referred to a group provided by the Salisbury Alzheimer’s Society from a variety of professional and voluntary sector sources. All members of the group must have a diagnosis of dementia. Two qualified counsellors run the group. One counsellor visits all clients at home, if they so wish, prior to first coming to the group. This is an important phase of getting to know the clients and establishing trust and some understanding of the person's history and their home circumstances, relationship with spouse, family members and others. If the person is then interested in joining the group, the counsellor has background knowledge that can enable them to support the person to integrate by, for example, picking up on topics or activities that the person might like to pursue. The counsellor is also able to share this with the second counsellor.

Groups have around 8 or 9 members and meetings last around 90 minutes. During the meetings the counsellors sit opposite each other. One counsellor usually sits close by anyone who is either new to the group or needs some help to express themselves.

The format for each group meeting is the same at the start and finish, but there is no set agenda. The meetings start with the relatives, who have brought people along, enjoying a cup of tea while one of the group members plays the piano. The meeting ends with the same pianist playing again for a few minutes. People discuss feelings and share coping strategies. Some of the time the conversation is very light hearted. But the group also discusses difficult topics such as driving or drugs and people are encouraged to share their feelings, for example about how other people treat them.

The emphasis of the group is that people share together and that 'people support each other’. If there is a particular issue that people wish to explore further, a guest speaker, for example a consultant psychiatrist, is invited. The counsellors try to reinforce retained skills and make the meetings positive. They use prompts for discussion such as knowledge that someone has just been on holiday, but also occasionally memorabilia and other physical prompts. One counsellor writes up what has been discussed and, at the end of each meeting, gives a verbal review of the session comprising a summary of what has been discussed and the views of each member. This gives members confidence that what they have said has value. The counsellors do not give members a written summary.
Overall the counsellors draw on a variety of approaches and feel that there is no one approach that is best. They have found a memory guide useful as it gives group members something to refer back to.

Example 8: Peer support group - Dementia Advocacy and Support Network International (DASNI)

This is a not-for-profit, internet-based, and member run organisation. Its membership is international including people with dementia in the UK, Canada, USA, Australia, New Zealand and Brazil. DASNI states its Principles, Beliefs and Values as follows:

- We are autonomous and competent people diagnosed with dementia, and our loyal allies
- We believe that shared knowledge is empowerment
- We believe our strengths provide a supportive network
- We are a voice and a helping hand
- Our purpose is to promote respect and dignity for persons with dementia, provide a forum for the exchange of information, encourage support mechanisms such as local groups, counselling, and Internet linkages, and to advocate for services.

Example 9: Peer support group - The People Relying on People Group (PROP)

In 1999, a new NHS post was established, in Doncaster, with the remit to develop services that would be responsive to the views and needs of younger people with dementia and their supporters. The worker who was appointed encouraged service users and carers to set up a group. This resulted in the PROP (People Relying on People) Group, an independent group that is self-managed by a committee and in which the role of vice chairperson has been held by a person with dementia. The Group has a written constitution (important in obtaining funding) but meetings are conducted informally to enable full participation for all members. The Group has had an impact in a range of ways in influencing local service providers and service developments. Members also enjoy a great deal of mutual support through social contact and shared activities. They have their own premises for meeting informally, leased to the group by their local NHS Trust.

Example 10: Peer support group - The Scottish Dementia Working Group

This is an independent group, formally constituted within Alzheimer Scotland, run by people with dementia with the support of a co-ordinator. The group members support each other and campaign to improve services for people with dementia and attitudes towards people with dementia.

This Group was established when one person with dementia took the initiative inviting others to become involved. He was convinced that people with dementia in Scotland needed a voice to question and influence services and government, and to improve public perceptions of dementia. Members who are willing to lead and chair the Group have been a significant factor in its success, as has been the support of Alzheimer Scotland. Members have been involved in speaking at conferences and in giving interviews to the media, in commenting on policy consultations and in producing a range of information and publications for other people who have dementia.

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Example 11: Matching volunteer befrienders with people with dementia in North Tyneside

In the North Tyneside Alzheimer’s Society branch volunteer befriending project, the volunteer coordinator:

- takes into account the specific needs of both parties based on as much information about the volunteer and client as possible, including information about client likes/dislikes
- Checks that client and volunteer have some similar interests and/or hobbies
- ensures that the frequency of visits needed is compatible with the availability of the volunteer
- ensures geographical proximity of client and volunteer
- provides the person with dementia with an information booklet about the volunteer including a photograph.

If a good one-to-one volunteer match for a person with dementia cannot be made, the coordinator offers that person with dementia alternative support until a good match can be made.

Example 12: Working with other services – examples from the DASS projects

The Calderdale DASS support workers collaborated closely with members of a CMHT to develop and jointly run support groups for couples. The group benefited from an emphasis on social involvement and activities that was introduced through the support workers.

Support workers in three of the DASS projects (Glasgow, South Lakes and to some extent Winchester) were involved as partners with professionals in health and social care services in developing information groups for people with dementia and/or their carers. Support workers shared the responsibility for developing the programme, contributed a session on their services and participated in other sessions as facilitators.

Example 13: Ongoing development of new early support services, Peterborough Alzheimer’s Society

The Peterborough Alzheimer’s Society branch developed, jointly with the local memory clinic, groups for people with early stage dementia that ran alongside groups for carers. These groups functioned for about two years until referrals stalled. Six week ‘memory strategy groups’, for people with early stage dementia and their partners, were then introduced, run by the Alzheimer’s Society branch and a psychologist from the memory clinic. Couples attending these groups remained together in the group. Members were asked what else they needed and they identified a need for training. The services responded by commissioning a trainer to run one group for people with dementia and one for carers. However, the participants in these groups felt that they could learn more from a shared experience and this led to a pilot of joint training sessions on ‘being together with dementia’.

Example 14: Ongoing development of new early support services, Penrith drop-in service

In Penrith, CPNs encouraged the branch manager of the Alzheimer’s Society to obtain funding for a drop-in service. The CPNs initially provided input to the service but were not able to sustain this commitment. The drop-in service initially operated as a group activity but this was subsequently changed to one-to-one support as people who attended the drop-in did
not cohere as a group. The drop-in service was eventually disbanded. In its place, the CPNs identified a group of men to form the core of an ongoing support group. Funding was subsequently obtained for an early stage support worker, an assistant and a carer support worker. Two groups (a men's group and a ladies' group) are supported as well as an occasional lunch club and social activities. This comprehensive service offers a mix of one-to-one and group work (with groups mainly being used to meet social needs and one-to-one work being used for information provision). Latterly the staff have come to recognise that they probably need to provide a follow-on service for people who can no longer benefit from the groups.
APPENDIX 4: FURTHER READING

Dementia

Personal accounts of people with dementia


Understanding dementia and its impact


**Recognition, diagnosis and disclosure**


**Processes of adjustment**


**Marginalised groups of people with dementia**


**Practice issues**

**Anti-dementia drugs**


For current national guidance on the use of these drugs see website: http://www.nice.org.uk

**Assistive Technology**


See also websites:

http://www.astridguide.org/

http://www.enableproject.org/
Communication with people with dementia


Ethical and legal


Adults with Incapacity (Scotland) Act 2000. (Information can be found on Scottish Executive site: http://www.scotland.gov.uk/Topics/Justice/Civil/16360/4927 ).

*Mental Capacity Act 2005* (Information can be found on the Department for Constitutional Affairs site: http://www.dca.gov.uk/menincap/legis.htm)

For information about driving, see the information sheets produced by the Alzheimer's Society or Alzheimer's Scotland.

Services

General


**Improving primary care response**


**Information and advice for people with dementia and their relatives**


Alzheimer Scotland - Action on Dementia (undated) *Don't make the journey alone: a message to fellow travellers*. Edinburgh: Alzheimer Scotland - Action on Dementia.

Counselling and psychosocial therapy


Groupwork


Befriending and volunteer support


Dementia Advocacy
Involving people with dementia


## APPENDIX 5: USEFUL RESOURCES

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| Mental Health Foundation | 9th Floor  
9th Floor  
Sea Containers House  
20 Upper Ground  
London SE1 9QB  
Tel: 020 7803 1100  
http://www.mentalhealth.org.uk | The leading UK charity working in mental health and learning difficulties. Brings together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. Uses the findings to promote survival, recovery and prevention.  
Links to information on the Dementia Advice and Support Project and other dementia related research initiatives funded by the Foundation.  
See http://www.mhili.org/ for information and support for people in later life. |

### DEMENTIA SPECIFIC ORGANISATIONS

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<th>Organisation</th>
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| Alzheimer’s Society | Gordon House  
10 Greencoat Place  
London  
SW1P 1PH  
Tel: 020 7306 0606  
http://www.alzheimers.org.uk | Main care and research charity for people with dementia, their families and carers in England, Wales and Northern Ireland. |

*Links to:*  
Alzheimer’s Talking Point  
A web based discussion forum for people with dementia. |

| Alzheimer Scotland - Action on Dementia | 22 Drumsheugh Gardens  
Edinburgh  
EH3 7RN  
Tel: 0131 243 1453  
http://www.alzscot.org/pages/sdwg.htm | Provides services and campaigns to help people with dementia, their families and carers.  
An independent group run by people with dementia who meet to support each other and campaign on behalf of others with dementia. |

*Links to:*  
Scottish Dementia Working Group (SDWG) |
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<th>Organisation</th>
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| Alzheimer's Society of Ireland | National Office  
The Alzheimer Society of Ireland  
Alzheimer House  
43 Northumberland Avenue  
Dun Laoghaire  
Dublin  
Tel: 00 353 1 284 6616  
E-mail: info@alzheimer.ie  
http://www.alzheimer.ie/ | Provides support to families and information on dementia |
| Dementia Advocacy and Support Network International | http://www.dasninternational.org | An organisation run for and by people with dementia and their trusted supporters |
| Dementia Services Development Centres | Each centre provides support and information in a specified geographical area in the United Kingdom on all aspects of dementia service provision to commissioners, service providers and policy makers. |
| England | Details of the English Centres can be found, with links to all sites, on http://www.dsdcengland.org.uk/ | Links to the Dementia Services Collaborative http://www.dementianorth.org.uk see below for details of the DSC |
| Dementia North | Northumbria University  
Coach Lane  
Newcastle upon Tyne  
NE7 7XA  
Tel: 0191 215 6110  
Email: hs.dementianorth@northumbria.ac.uk  
http://www.dementianorth.org.uk | |
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| Trent Dementia Services Development Centre | Department of Psychiatry for the Elderly
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| Oxford Dementia Centre | Institute of Public Care  
Roosevelt Drive  
Oxford  
OX3 7XR  
Tel: 01865 761815  
Fax: 01865 762015  
Email: ipc@brookes.ac.uk  
http://ipc.brookes.ac.uk |
|-----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| London Centre for Dementia Care | Department of Mental Health Sciences  
University College London  
Wolfson Building  
48 Riding House street  
London  
W1W 7EY  
Tel: 020 7679 9588/9  
Fax: 020 7679 9426  
Email: margot.lindsay@ucl.ac.uk  
http://www.ucl.ac.uk/~rejumli |
| Dementia Services Development Centre  
South East | Canterbury Christ Church University College  
Canterbury  
CT1 1QU  
Tel: 01227 782702  
Email: dsdcse@canterbury.ac.uk  
http://dementiacentre.cant.ac.uk |
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| Scotland                              | Iris Murdoch Building    |
|                                       | Applied Social Science Department |
|                                       | Faculty of Human Sciences |
|                                       | University of Stirling    |
|                                       | Stirling                  |
|                                       | FK9 4LA                   |
|                                       | Tel: 01786 467740         |
|                                       | Email: dement1@stir.ac.uk |
|                                       | http://www.dementia.stir.ac.uk/ |

<p>| Wales                                  | Neuadd Arudwy             |
|                                       | University of Wales Bangor|
|                                       | Holyhead Road             |
|                                       | Bangor                    |
|                                       | LL57 2PX                  |
|                                       | Tel: 01248 383719         |
|                                       | Fax: 01248 382229         |
|                                       | Email:<a href="mailto:dsdc@bangor.ac.uk">dsdc@bangor.ac.uk</a>   |
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<td><a href="http://www.kingshill-research.org">http://www.kingshill-research.org</a></td>
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<td>Bradford Dementia Group</td>
<td>School of Health Studies</td>
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<td>Undertakes training and research to promote understanding of dementia care approaches that improve the quality of life and care for people with dementia and their families.</td>
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<td>University of Bradford</td>
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<td>25 Trinity Road</td>
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<td><a href="http://www.brad.ac.uk/acad/health/bdg">http://www.brad.ac.uk/acad/health/bdg</a></td>
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### OTHER USEFUL ORGANISATIONS – GENERAL

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Address</th>
<th>Phone/Toll Free</th>
<th>Website</th>
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<tbody>
<tr>
<td>Age Concern</td>
<td>Age Concern England&lt;br&gt;Astral House&lt;br&gt;1268 London Road&lt;br&gt;London SW16 4ER&lt;br&gt;Tel: 020 8765 7200&lt;br&gt;<a href="http://www.ageconcern.org.uk">http://www.ageconcern.org.uk</a></td>
<td>Provides a national information line for older people and their concerns, 0800 00 99 66</td>
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<td>Befriending Network (Scotland)</td>
<td>45 Queensferry Street Lane&lt;br&gt;Edinburgh&lt;br&gt;EH2 4PF&lt;br&gt;Tel: 0131 225 6156&lt;br&gt;Email: <a href="mailto:info@befriending.co.uk">info@befriending.co.uk</a>&lt;br&gt;<a href="http://www.befriending.co.uk">http://www.befriending.co.uk</a></td>
<td>Offers supportive, reliable relationships through volunteer befrienders to people who would otherwise be socially isolated.</td>
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<td>Carers National Association</td>
<td>Ruth Pitter House&lt;br&gt;20-25 Glasshouse Yard&lt;br&gt;London&lt;br&gt;EC1A 4JT&lt;br&gt;Tel: 0207 490 8818&lt;br&gt;<a href="http://www.londonhealth.co.uk/carersnationalassociation.asp">http://www.londonhealth.co.uk/carersnationalassociation.asp</a></td>
<td>Campaigns and raises awareness of carers’ needs and provides information and support to carers.</td>
<td>Links to Carers UK <a href="http://www.carersuk.org">http://www.carersuk.org</a>&lt;br&gt;Carers UK is a carers led campaigning organisation providing carers with information and delivering training and research.</td>
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<tr>
<td>Centre for Policy on Ageing</td>
<td>21-31 Ironmonger Row&lt;br&gt;London&lt;br&gt;EC1V 3QP&lt;br&gt;Tel: 020 7553 6500&lt;br&gt;<a href="http://www.cpa.org.uk">http://www.cpa.org.uk</a></td>
<td>Promotes awareness of the needs of older people through the spread of good practice, research and information.</td>
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<td>Organization</td>
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<tr>
<td>Department for Constitutional Affairs</td>
<td>Selbourne House</td>
<td>Government Department responsible for ensuring people's rights and responsibilities. Links to information about the Mental Capacity Act 2005.</td>
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<td>54-60 Victoria Street</td>
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<td>Tel: 020 7210 8500</td>
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<td><a href="http://www.dca.gov.uk">http://www.dca.gov.uk</a></td>
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<td>Department of Health</td>
<td><a href="http://www.dh.gov.uk">http://www.dh.gov.uk</a></td>
<td>Links to policy, guidelines and relevant publications</td>
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<td>Department of Health home page</td>
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<td>Help The Aged</td>
<td>207-221 Pentonville Road</td>
<td>Develops practical solutions in partnership with older people. Offers free advice through Senior Line 0808 800 6565.</td>
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<td>London N1 9UZ</td>
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<td>Tel: 0207 278 1114</td>
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<td><a href="http://www.helptheaged.org.uk">http://www.helptheaged.org.uk</a></td>
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<td>Joseph Rowntree Foundation</td>
<td>The Homestead</td>
<td>An independent development and social research charity. Website provides access to relevant publications.</td>
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<td>40 Water End</td>
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<td>Mental Health Act Commission</td>
<td>Maid Marian House</td>
<td>Safeguards the interests of all people detained under the Mental Health Act 1983.</td>
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<td>Tel: 0115 943 7100</td>
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<td><a href="http://www.mhac.org.uk">http://www.mhac.org.uk</a></td>
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<td>Mind (National Association for Mental Health)</td>
<td>15-19 Broadway</td>
<td>Provides information and support on mental health issues.</td>
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<td><a href="http://www.mind.org.uk">http://www.mind.org.uk</a></td>
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| National Council for Voluntary Organisations | Regent’s Wharf  
8 All Saints Street  
London  
N1 9RL  
Tel: 020 7713 6161  
http://www.ncvo-vol.org.uk/ | Umbrella body for the voluntary sector in England that represents views of members to Government, Charity Commission, etc and provides general advice for the voluntary sector, including approaches to fundraising. |
| National Institute for Health and Clinical Excellence (NICE) | MidCity Place  
71 High Holborn  
London  
WC1V 6NA  
Tel: 020 7060 5800  
http://www.nice.org.uk | Responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. Includes guidance on anti-dementia drugs. |
| National Institute for Mental Health in England | http://www.nimhe.org.uk/ | Through regional development centres NIMHE provides practical support to mental health service development including older people’s mental health services. |
| Princess Royal Trust for Carers | 142 Minories  
London  
EC3N 1LB  
Tel: 020 7480 7788  
help@carers.org  
http://www.carers.org/ | The Princess Royal Trust for Carers provides comprehensive carers’ support services in the UK, through a network of independently managed Carers’ Centres and training support for Centres. |
| The Royal College of Psychiatrists | The Royal College of Psychiatrists  
17 Belgrave Square  
London SW1X 8PG  
Tel: 020 7235 2351  
Fax: 020 7245 1231  
http://www.rcpsych.ac.uk/index.htm | Produces useful leaflets on older people’s mental health issues including memory and dementia for practitioners, service users and relatives. Download from:  
http://www.rcpsych.ac.uk/info/oldhealth/htm |
### Scottish Development Centre for Mental Health

17a Graham Street  
Edinburgh  
EH6 5QN  
Tel: 0131 555 5959  
Email: sdc@sdcmh.org.uk

A not-for-profit organisation focused on the development and improvement of mental health services in Scotland.

### Social Care Institute for Excellence (SCIE)

Goldings House  
2 Hays Lane  
London  
SE1 2HB  
Tel: 020 7189 6840  
http://www.scie.org.uk/

Develops and promotes knowledge and good practice in social care. Includes gateway to eLSC (the electronic library for Social Care) and Caredata, which enable online access to extensive abstracts of relevant social work and social care literature.

### University of Wales Lampeter

http://www.volresource.org.uk/services/training.htm

For information about sources of training for volunteers.

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### DEMENTIA JOURNALS

**Dementia: The International journal of social research and practice**  
Sage Publications  
6 Bonhill Street  
London EC2A 4PU  
Tel: 020 7330 1266  
http://www.sagepub.co.uk

An academic journal that provides good multi-disciplinary cover of practice issues and developments.

**Signpost**  
Cardiff and Vale NHS Trust with Dementia Services Development Centre Wales  
Tel: 029 2033 6073  
http://www.signpostjournal.co.uk

A specialist quarterly journal aimed at those working with and caring for people with dementia, older people with mental health problems and their carers.
About the Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy, and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by services users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and to promote mental well-being.

We also work to influence policy, including Government at the highest levels. And we use our knowledge to raise awareness and to help tackle the stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services. We can only continue our work with the support of many individuals, charitable trusts and companies.

To support our work, please visit our website or call our fundraising team on 020 7803 1121.

If you would like to find out more about our work, please contact us.

Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
020 7803 1100

Scotland Office
Merchants House
30 George Square
Glasgow G2 1EG
0141 572 0125

www.mentalhealth.org.uk
registered charity no. 801130

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