



# 'Hear what I say'

**Developing dementia  
advocacy services**

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# CONTENTS

<b>Acknowledgements</b>	<b>3</b>
<b>1. SETTING THE SCENE</b>	<b>4</b>
Introduction	4
People with dementia	4
The policy context	5
Dementia advocacy	5
Developing a picture of dementia advocacy services in the UK	10
<b>2. DEMENTIA ADVOCACY IN PRACTICE</b>	<b>13</b>
Introduction	13
Responding to referrals	13
Working with people with dementia	13
Ethical issues	15
Representing the person with dementia	17
Working with family members	18
Working with other service providers	19
Boundaries	20
Completion/endings	23
Practice review and development	23
<b>3. SETTING UP A SERVICE</b>	<b>24</b>
Introduction	24
Getting started	24
The need for advocacy	25
Models of advocacy	25
Organisational location	25
Funding	27
Parameters of the service	28
Key steps	31
<b>4. PEOPLE AND STRUCTURES</b>	<b>32</b>
Introduction	32
Organisational management arrangements	32
Service management arrangements	33
Staffing	34
<b>5. MANAGING AND DEVELOPING A SERVICE</b>	<b>40</b>
Introduction	40
Managing activity	40
Policies and procedures	43
Developing the service	43
Working with other agencies	45
Monitoring and review	45
<b>6. CONCLUSION</b>	<b>49</b>
<b>References</b>	<b>50</b>
<b>Appendix 1 Further reading</b>	<b>52</b>
<b>Appendix 2 Useful resources</b>	<b>55</b>

## LIST OF BOXES AND EXAMPLES

<b>Box 1.1</b>	Models of advocacy and the benefits and limitations of different models for dementia advocacy
<b>Box 1.2</b>	Characteristics of case study advocacy services
<b>Box 2.1</b>	Suggestions and advice for advocates on working with people with dementia
<b>Box 2.2</b>	Suggestions about dealing with consent and other ethical issues
<b>Box 2.3</b>	Representing a person with dementia
<b>Box 2.4</b>	Working with families and carers
<b>Box 2.5</b>	Working with practitioners in other services
<b>Box 2.6</b>	Handling boundary issues
<b>Box 2.7</b>	Managing endings
<b>Box 2.8</b>	Developing a reflective diary
<b>Box 3.1</b>	Some key features that funders look for in assessing proposals for dementia advocacy services
<b>Box 3.2</b>	Key steps in setting up a service
<b>Box 4.1</b>	Organisational management arrangements
<b>Box 4.2</b>	Typical management functions of a service co-ordinator
<b>Box 4.3</b>	Skills and personal attributes of good dementia advocates
<b>Box 4.4</b>	Initial training programme for volunteer dementia advocates
<b>Box 5.1</b>	Information for referrers and other service providers
<b>Box 5.2</b>	Promoting referrals
<b>Box 5.3</b>	Some policies and procedures for dementia advocacy services
<b>Box 5.4</b>	Joint working with health and social care agencies to support and develop dementia advocacy
<b>Box 5.5</b>	Suggested routine data for service monitoring and review
<b>Example 1.1</b>	Independent dementia advocacy
<b>Example 2.1</b>	Perspectives on dementia advocacy
<b>Example 3.1</b>	Setting up a dementia advocacy service
<b>Example 4.1</b>	The value of supervision for dementia advocates
<b>Example 4.2</b>	The value of support for dementia advocates
<b>Example 5.1</b>	An example of a service caseload management system
<b>Example 5.2</b>	Influencing other services
<b>Example 5.3</b>	An approach to service self evaluation

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# CHAPTER 1.

## SETTING THE SCENE

### INTRODUCTION

The foundations of dementia advocacy lie in the distinct and developing fields of dementia care and advocacy. These fields are relatively new and evolving. Both fields have growing bodies of practice-based knowledge and experience but limited research-based evidence about what works and what constitutes good practice.

#### This report

This report provides an overview of what we know about current practice in dementia advocacy and makes suggestions about how to establish new services and develop existing services. We draw on a review of existing dementia advocacy practice, the limited available literature and research on dementia advocacy, and some of the wider literature on advocacy more generally.

Other fields of advocacy have reached the stage of having standards or consensus statements about good practice<sup>1,2,3</sup>. However in this report on dementia advocacy, there are very few areas in which we give a definitive view of ‘best practice’ or prescriptions for service development. The field has not yet developed its research or practice base sufficiently to allow this. Rather we try to set out the issues that current or new services need to tackle alongside a picture of what is currently happening in practice and what practitioners, managers and other commentators suggest should be happening.

We hope that this report will be of immediate practical help to service commissioners, managers and advocates who are involved in providing, or who are interested in developing, dementia advocacy services. We also hope that this report will contribute to identifying and clarifying the areas in which we need further research and knowledge development about dementia advocacy.

The report is in six chapters. In Chapter 1, we set the scene on advocacy and on the policy context in which dementia advocacy schemes operate. We also describe the work underpinning this report. Chapter 2 discusses the practice of dementia advocacy highlighting the ethical and operational challenges. In Chapter 3, the focus is on how to set

up an advocacy service from the initial identification of need, through the early stages of generating support and determining the parameters of the service. Chapter 4 focuses on management structures and staffing matters and Chapter 5 addresses some key management tasks and issues in ongoing service development. Chapter 6 provides a brief conclusion.

### PEOPLE WITH DEMENTIA

In recent years there have been significant advances in our understanding of dementia, the experiences of living with dementia and the experiences of caring for a person with dementia.

Approximately 750,000 people in the UK are affected by dementia, about 17,000 of whom are aged under 65 years<sup>4</sup>. Dementia refers to progressive deterioration in cognitive functioning accompanied by significant decline in personal and social functioning. It arises from a variety of brain diseases and is age related. There is no cure for dementia but there have been recent significant advances in diagnostic techniques and in the development of anti-dementia drugs that are effective in slowing progression in the earlier stages of some forms of dementia<sup>5</sup>. One of the consequences of these developments has been the identification of growing numbers of people with early dementia who expect to have a strong voice in the decisions that affect their lives.

Until recently, thinking about dementia was dominated by biomedical ideas and there was little attention to the psychosocial context in which the individual lives. However, our understanding of the interplay between the person with dementia and their social and psychological environment has now advanced substantially. We have ideas about a ‘new culture of dementia care’<sup>6</sup> that provides a psychosocial environment in which the human worth and ‘personhood’ of each individual with dementia is maintained and enhanced. Alongside this psychosocial approach, the social model of disability is increasingly being applied to understanding dementia care. This model alerts us to how the

disabling and disempowering aspects of the social and service environment<sup>7,8</sup> affects the experiences of people with dementia and their caregivers.

In parallel with these advances in our understanding of dementia, there has been growing interest in how we can better 'hear the voice of the person with dementia' and understand their experiences, views and wishes. Previously, rather than seek the views of people with dementia directly, services and researchers tended to rely on proxy views, usually provided by family carers. Now researchers and practitioners are finding ways to listen to, and communicate with, people with dementia in order that their voices are heard in shaping their lives and the services that they receive<sup>9,10,11,12,13</sup>. Work of this kind has demonstrated that when people with dementia are enabled to communicate, they have important things to say about how dementia affects them, about what they consider important about their present and future lives, including how their health and social care needs should be met.

Concern that people with dementia can, and should, have a greater voice is gradually having an impact on the way services are organised and the way people with dementia are organising themselves. There is growing recognition that advocacy, hitherto largely unavailable to people with dementia, is one important means of enabling people with dementia to have much more self-determination.

## THE POLICY CONTEXT

The recent growing interest in dementia advocacy has arisen in a sympathetic policy context. For some years now, health and social care policies have recognised the need to redress the imbalance in power between service providers and service users:

"Instead of users and carers being subordinate to the wishes of service-providers, the roles will be progressively adjusted. In this way, users and carers will be enabled to exercise the same power as consumers of other services..." (DHSSI,1991, p 9)<sup>14</sup>

More recently, the NHS Plan<sup>15</sup> emphasises shifting the balance of power further towards the patient and the public through increased user involvement, public participation and advocacy.

In the field of older people's mental health, service guidance has highlighted the importance of

encouraging empowerment, and maximising the independence and autonomy, of people with dementia<sup>16,17,18</sup>. Advocacy has for some time been recognised as having the potential to make a valuable contribution to achieving greater empowerment of vulnerable older people, particularly those with mental health needs:

"... [Advocacy] can be invaluable in helping a patient to express his or her views if there are difficulties in communication. As the advocates are neither a relative nor associated with the health care facility, they can offer assistance without being influenced by conflicting interests". (BMA and RCN, 1995, p 38)<sup>19</sup>

"Many older people with mental health problems have difficulty representing their own interests. They can feel powerless, unable to put forward their own views, or to state clearly what it is they want. They may need help in making key decisions, which will affect their lives, such as moving into permanent care, or they may need support asking for a particular service, or in managing a complaint against treatment they have experienced. An advocate can help with all such situations and through advocacy partnerships, older mentally ill people can: achieve what they want; receive emotional support; find friendship; feel some control and improved self-esteem." (DHSSI, 1997 p 31)<sup>20</sup>

The potential value of advocacy, specifically citizen advocacy, has also been recognised in the Lord Chancellor's Department guidance on mental incapacity and helping people to make decisions<sup>21</sup>.

Alongside this general support for advocacy, there have been specific policy developments in advocacy for children<sup>3</sup> and people with learning disabilities<sup>22</sup> and in the establishment of the Advocacy Safeguards Agency in Scotland (see Appendix 2). However, the UK unlike some other countries, has no comprehensive policy or legislative framework for the development of advocacy for vulnerable adults<sup>23,24</sup> or, more specifically, for people with dementia.

## DEMENTIA ADVOCACY

Example 1.1 provides a brief practical illustration of the nature of independent dementia advocacy.

### Example 1.1 Independent dementia advocacy

Bruce is 62 years old and a retired G.P. He was diagnosed as having dementia 12 months ago. He is married to Lorna who still works full-time.

Recently Bruce has become more forgetful. In the last few weeks Lorna has returned home twice to find the kitchen floor flooded and on one occasion Bruce invited a stranger into the house. Bruce insists he is managing fine.

Lorna contacts social services and asks for help to plan Bruce's future care. The care manager establishes that there is considerable tension between Lorna and Bruce and finds that Lorna does all the talking. Lorna makes it clear to the care manager and Bruce that it is time for him to move into a residential home. Given the conflict, the care manager decides to refer Bruce to the local independent advocacy service to ensure his views are heard.

The advocate spends time with Bruce in order to understand what he wants. The advocate finds out that Bruce is keen to stay at home and that he is not ready to look at residential homes. Lorna regularly phones the advocate to tell her that Bruce would be much better off in a specialist home. Lorna sometimes tries to find out what Bruce is telling the advocate. The advocate listens to Lorna but explains that she is there for Bruce and that their conversations are confidential.

The advocate supports Bruce for over a year. In that time the advocate speaks on Bruce's behalf to Lorna and to health and social services, making it clear that Bruce wants to remain in his own home until he feels ready to move into a residential home.

#### The nature of advocacy

"... it's not my job to decide what is best for that person, it's to stand by that person, and to ensure that we get what we can that will carry them on the way they want to carry on." (A dementia advocate)

Advocacy is about speaking out about people's views, wishes and rights. There are a variety of models and approaches to advocacy. At one end of the spectrum there is advocacy based on formal relationships and with a strong instrumental or task focus, such as legal advocacy. At the other end of the spectrum there is advocacy in which there is greater emphasis on supporting people in expressing their views and feelings, and on representation, or support for self advocacy in the context of a befriending relationship. In individual cases, the nature of the advocacy task and relationship may change over time.

There is general consensus about what advocacy is not. Advocacy does not involve making decisions in the 'best interests' of other people, making decisions on behalf of other people (substitute decision making), or acting on behalf of other people. Thus, for example, an advocate cannot give consent, sign forms or carry out legally effective acts on behalf of a client, whether that person has the capacity to make decisions or not<sup>24</sup>.

#### Models of advocacy

The original model of advocacy introduced to this country was citizen advocacy. Citizen advocacy services usually involve having someone employed as a service co-ordinator with the responsibility of recruiting, training and supporting volunteer advocates, often known as citizen advocates. Today, however, there are a variety of models of advocacy<sup>23,24,25,26</sup> and considerable debate about whether advocates should be paid or volunteer. Box 1.1 provides definitions of some common forms of advocacy. The models listed, with the exception of professional advocacy, would usually be regarded as forms of independent advocacy.

There is substantial literature on the general principles and practice of advocacy that is highly relevant to the development of dementia advocacy. Here, we draw on a range of advocacy experience and literature<sup>1,23,26,28,29</sup> to highlight common aims, values and principles, processes and models as they apply to dementia advocacy.

#### Dementia advocacy aims

The ability of people with dementia to understand issues, make decisions and speak up for themselves varies enormously depending on their circumstances and the degree of dementia that they are

experiencing. Many people with dementia face serious disadvantage and are vulnerable to discrimination and abuse. Advocacy for people with dementia aims to redress this disadvantage and discrimination by supporting people with dementia, for example, to:

- play a full part in decisions about everyday matters affecting their lives;
- play a full part in major life decisions, for example, about moving home;
- obtain outcomes that they want;
- prevent outcomes that they do not want;
- ensure their needs are met;
- protect their rights and secure their entitlements;
- promote their well being;
- improve their quality of life.

### Dementia advocacy values and principles

The values and principles that underpin dementia advocacy include:

- autonomy;
- empowerment;
- consent;
- acceptance and respect;
- choice;
- citizenship;
- inclusion;
- confidentiality;
- loyalty to the person with dementia;
- independence from other interests.

### Dementia advocacy processes

The processes of dementia advocacy typically involve some or all of the following:

- building a relationship with the person with dementia;
- ascertaining their views and wishes;
- enabling them to exercise choice;
- supporting them in having their views heard;
- representing their interests;
- influencing, often powerful, others;
- resolving conflicts.

### Models of independent advocacy for working with people with dementia

People with dementia vary enormously depending upon their age, gender, social and ethnic backgrounds, education, type of dementia, degree of dementia and so on. Responding to their diverse needs and circumstances requires a range of advocacy approaches and skills.

Individuals with dementia also have varying needs as the dementia progresses and their personal circumstances and their use of services change. This means that an individual may require different types of advocacy responses at different times and in relation to different issues<sup>23, 24</sup>.

“Over the long course of an illness, people with dementia may need different types of advocacy at different times. Self-advocacy especially in the early stages; continuing advocacy by informal carers; independent advocacy to provide representation in specific situations, or for longer term support.” (Killeen, 1996, p 29)<sup>23</sup>

In Box 1.1 we see some of the main benefits and limitations of different types of independent advocacy for people with dementia. Many existing services combine volunteer and independent professional advocacy. This means that they have advocates with different types and levels of skill. Services argue that they can therefore use resources more effectively. They can match advocates to the needs of people with dementia and focus highly skilled, paid advocates on more demanding and intensive work.

### Issues in dementia advocacy

The nature of dementia means that advocacy services confront questions about whether or not their clients have the mental capacity to understand issues, make decisions, instruct advocates and give informed consent to any action on their behalf. Further discussion and guidance on the ethical and legal principles related to mental incapacity is available from a range of sources (see Appendix 1).

Dementia advocacy services, like advocacy services more generally, operate on the basis that they represent the person’s case to decision makers but do not make decisions on behalf of the person with dementia. This approach is relatively straightforward for advocates working with those people with dementia who at the time a) have a good enough understanding of the specific issue to have a view about what they want and b) have the ability to convey their views to the advocate, albeit at their own pace and perhaps with some assistance with communication.

Difficulties arise for advocates, however, when the person with dementia is unable to express their wishes clearly or when the advocate has doubts about the person’s ability to understand and form a view about the matter in hand. In these cases, dementia advocacy services may operate on the

## Box 1.1 Models of advocacy and the benefits and limitations of different models for dementia advocacy

Advocacy model	Description of model	Use in dementia advocacy
<b>Self advocacy</b>	Involves speaking up for oneself.	<p>With a few exceptions (for example, the Dementia Advocacy and Support Network International, listed in Appendix 2), dementia self-advocacy support is poorly developed<sup>23</sup>. Self advocacy has most potential for use with people with dementia in the earlier stages of development. Improvements in diagnostic techniques, and services such as memory clinics, mean that many more people with dementia are being identified who are well able to speak up for themselves. The need for self advocacy support services is therefore likely to grow.</p>
<b>Peer advocacy</b>	Involves one person advocating for another who has experienced similar difficulties and discrimination.	<p>Peer advocacy has been little used in dementia care but its potential is seen in organisations such as Dementia Advocacy and Support Network International (Appendix 2). The group of people with dementia who contributed to our project felt that they could advocate for each other. For example, they suggested that if a member of their group had not seen a community psychiatric nurse for a while, but wanted a visit, then someone else in the group would ask on their behalf. Peer advocacy, like self advocacy, has most potential with people whose dementia is in the earlier stages of development. However, it does not naturally follow that all peers have the necessary skills to act as advocates<sup>27</sup>.</p>
<b>Volunteer (citizen) advocacy</b>	Involves an independent, unpaid volunteer, or citizen advocate, working in a one-to-one relationship with a person who needs support to achieve what they want or to exercise their rights.	<p>Many dementia advocacy services use this model. There are mixed views about the role of volunteers in advocacy for people with dementia. People variously think that volunteers:</p> <ul style="list-style-type: none"> <li>– are very independent and less likely than professional advocates to experience conflicts of interest as no payment is involved;</li> <li>– can spend more time with the person with dementia than is usually possible for a paid advocate and hence can advocate more effectively;</li> <li>– can effectively build relationships with a wide range of people with dementia and can work effectively with people with advanced dementia providing the volunteers are well supervised and supported;</li> <li>– are less likely than professional advocates to sustain the focus on advocacy and more likely to drift into a befriending relationship;</li> <li>– do not have the skills to work with people with more advanced dementia and should only be used with people in the early stages of dementia;</li> <li>– should be used only to do less complex advocacy work;</li> <li>– are less likely than paid workers to be able to provide the consistent, long-term service that many people with dementia need.</li> </ul>

**Box 1.1 cont. Models of advocacy and the benefits and limitations of different models for dementia advocacy**

**Advocacy model**  
**Independent, or professional, or paid, advocacy**

**Description of model**  
 Involves the use of paid advocates. Advocates working in these projects usually support people in dealing with a specific issue or problem and work with them until that issue is resolved.

**Professional advocacy**

Involves professionals in health and social services advocating for their clients' rights, encouraging self determination and protecting them from abuse.

**Use in dementia advocacy**

Many dementia advocacy services use this model. The advantages identified of having paid advocacy include:

- having staff with a clearer focus on advocacy tasks and on maintaining a time-limited advocacy relationship;
- having staff with higher levels of training and expertise;
- having staff with more credibility and 'clout' than volunteers in negotiating with other professionals;
- having a staff resource that can be managed to provide a consistent, responsive service with more predictable long-term support for people with dementia.

The main potential disadvantage identified is the risk that independence is compromised as a result of advocates being on an agency payroll.

Professionals can be powerful advocates for their clients. However, their occupational interests and their employment by a service providing organisation, can seriously constrain them in pursuing their clients' interests<sup>23,24,25</sup>. Professionals need to develop a clear understanding of the scope and limitations of their advocacy role.

basis of ‘substituted judgement’<sup>28,30</sup> and ‘passive consent’<sup>31</sup>. This means that advocates use a variety of information (for example, about the person’s values and beliefs as demonstrated in their life history) to form a view about what the person with dementia would want in their current situation. Sometimes advocates have to base the views they represent more tenuously on the basis of asking themselves the question ‘if I were in their shoes what would I want?’ Having formed views to represent, and having tried to explain or demonstrate these views to the person with dementia, the advocate then assumes that their actions are acceptable to the person with dementia unless they receive some indication to the contrary (either verbally or through careful observation of non-verbal communication).

Some people would argue that advocacy on the basis of ‘substituted judgement’ and ‘passive consent’ is unacceptable as it runs counter to some of the key principles of advocacy being based on autonomy and consent. Others justify advocacy for people with dementia who are unable to actively express their views, on a number of counts. First, the advocate can pursue a ‘protective’<sup>23,32</sup> or ‘safeguarding’<sup>26</sup> function in relation to ensuring human rights, needs, decency and service standards. Second, the advocate may be the only person who can offer a perspective that is concerned entirely with the person with dementia and is free of other financial, practical, emotional, professional or organisational pressures or interests. Third:

“...it may be ...morally wrong to pass over someone who is vulnerable and apparently unable to agree to the appointment of an advocate but whose quality of life might be vastly improved by the attention of such a person.” (Killeen, 1996, p 32)<sup>23</sup>

Dementia advocacy services grapple with complex ethical issues on a day-to-day basis, for example:

“Only in situations where the person is unable to communicate their opinions would an advocate act on an ‘as if it were me’ way, based on other information gathered about the person as an individual. Although this is not entirely satisfactory, or failsafe, it does, at least, give a view of that person’s situation and their needs and preferences, by someone who has no conflict of interest in the situation.” (Fife Advocacy Project, undated)<sup>33</sup>

There are no simple answers for advocacy services in dealing with these issues. (See Chapter 2 for some examples of how such issues can be handled in practice).

The most fundamental requirement for all services is that they:

“...meet ethical obligations and good practice considerations in being clear about whether the older person with dementia is being honestly represented on the basis of what the person is saying and ‘telling it as it is’, ‘best interests’ or ‘if it were thee or me’. Otherwise they risk disempowering those they seek to represent, albeit through a kind of ‘myopia of good intention’.” (Dunning, 1997, p 99–100)<sup>24</sup>

### DEVELOPING A PICTURE OF DEMENTIA ADVOCACY SERVICES IN THE UK

The work underpinning this report began with a mapping exercise to locate, as comprehensively as possible, dementia advocacy services in the UK. This involved an initial postal questionnaire ‘trawl’ of around 500 organisations in the UK including: advocacy networks; generic, mental health, older people and learning disability advocacy service providers; and, a range of older people’s and dementia voluntary sector organisations. This ‘trawl’ resulted in 300 responses of which around 200 reported some interest in advocacy for people with dementia. We identified 61 of the 200 as providing some advocacy to people with dementia as a core part of their service. We sent a more detailed questionnaire to these organisations. We received 55 returns from which we identified 35 organisations that were providing dementia advocacy either as a stand alone service or by using specialist dementia advocates working in the context of a broader advocacy service. We have drawn on the information provided by these 35 services throughout this report.

We also undertook case studies of seven dementia advocacy services. In selecting the services we tried to ensure that we reflected the diversity of existing dementia advocacy provision on the following counts:

- host organisations;
- geography of catchment areas;
- social and ethnic composition of catchment populations;
- advocacy models;
- service settings;
- number and types of advocate.

### Box 1.2 Characteristics of case study advocacy services

Service	Advocacy model	Organisation	Service setting	Catchment area/population	Number of paid advocates	Number of volunteer advocates	Advocacy service established
<b>A</b>	Citizen and paid	Advocacy – voluntary sector	Community and hospital	Urban and rural	1 part-time	2	1998
<b>B</b>	Paid	Dementia services – voluntary sector	Hospital	Urban/ethnically mixed	1 full-time	0	2000
<b>C</b>	Citizen and paid	Advocacy – voluntary sector	Hospital	Urban and rural	2 full-time	7	1992
<b>D</b>	Citizen and paid	Dementia services – voluntary sector	Community	Urban	1 full-time	2	1994
<b>E</b>	Paid	Advocacy – voluntary sector	Community and hospital	Urban/ethnically mixed	1 part-time	0	1998
<b>F</b>	Paid	Advocacy – voluntary sector	Community and hospital	Urban and rural	1 part-time	0	2000
<b>G</b>	Paid	Older people services – voluntary sector	Community and hospital	Rural	1 part-time	0	2000

The main features of these services are summarised in Box 1.2 above.

For each of the case study services we undertook field visits, usually of about four days, during which we variously interviewed:

- chairs of steering/management groups;
- the manager responsible for the service;
- advocacy co-ordinators;
- paid and volunteer advocates;
- referrers;
- carers;
- key personnel in linked services.

Some interviews that could not be undertaken in person were completed by telephone. We also obtained from the case study services a range of policy and procedures documentation, funding proposals, annual reports and service monitoring and evaluation reports. Each case study site also provided us with some standardised data about their activity levels and information about their users, referrals, interventions and outcomes.

To get an 'external' perspective on the advocacy services, we used postal questionnaires in each locality. One questionnaire asked health and social services referrers about their experience of the service; the other questionnaire to carers of former advocacy service users asked about their views of the service.

From the outset we wanted to include people with dementia in our review but we recognised that it

would be difficult to do this. In practice, we did not have the time or the resources necessary to build up a trusting relationship to ensure that the person with dementia felt at ease to be interviewed. Similar difficulties have been encountered in other studies of dementia advocacy<sup>34</sup>. We therefore decided to adopt three approaches to obtaining some insight into people with dementia's perspectives on dementia advocacy.

First, we sent a simple postal questionnaire to people whom the service co-ordinators had identified as being appropriate recipients and as having used the service between March 2001 and December 2001. The case study services had reservations about this approach and we knew that responses would be limited. In the event we had a nil response rate – but we nonetheless think it important to have tried. Second, our project worker observed an advocate working with some people with dementia. The focus of the observation was on the advocacy – what the advocate did, how she did it and how the person with dementia responded. Third, our project worker met with a group of seven younger people with dementia at a day centre unconnected with the advocacy case study services. She told them about our work and discussed their views about dementia advocacy. All of the people in the group had good communication skills and we obtained some useful insights, although limited by the fact that no one in the group had personal experience of working with an advocate.

## CHAPTER 2.

# DEMENTIA ADVOCACY IN PRACTICE

### INTRODUCTION

This chapter concentrates on practice issues in advocacy with people with dementia from the point of referral to completion. It highlights the complexities of dementia advocacy casework and draws attention to the challenges of communicating with people with dementia. It discusses the ethical dilemmas that are raised in dementia advocacy work, considering in particular issues of consent and conflicts of interests between the wishes of the person with dementia and the wishes and values of others, including carers. It makes some suggestions about how to represent the views of the person with dementia. It discusses working with carers and other service providers and highlights the challenges in retaining clarity around the boundaries of advocacy work. Example 2.1, below, introduces Tom and his advocate, James, and illustrates many of the issues discussed in this chapter.

### RESPONDING TO REFERRALS

There are many reasons for referral to dementia advocacy and our case studies highlighted the following as common:

- a person with dementia having difficulty obtaining services;
- a conflict or difference of opinion between a person with dementia and a carer;
- different service providers having different views about the care of a person with dementia;
- a person with dementia being sectioned under the Mental Health Act 1983;
- a professional seeking a 'third party' to help diffuse a stalemate or difference of opinion between them and a carer about the wishes of a person with dementia;
- a professional seeking support to enable a person with dementia to live with an element of risk in the face of opposition from family, neighbours or other services;
- a professional wanting someone to independently assess the views of a person with dementia whom the professional thinks may be being 'bulldozed' by others into an action they do not want.

Cases referred for advocacy are usually complex, involving a number of people and issues. The referrer

may cite one reason for making a referral but, as the advocate spends time with the person with dementia, other issues may emerge. It is important that advocates are open to this possibility. It is also important that advocates are aware that while the referrer may have discussed the advocacy process with the advocate, they may not have explained the referral to the person with dementia. Advocates should therefore not make assumptions about the person with dementia's expectations of their first encounter but should go along prepared to explain their role and why and how they have become involved.

### WORKING WITH PEOPLE WITH DEMENTIA

Experience in current services is that advocates can be involved in an individual case for a short time (no more than a few weeks) or for periods of over a year. The quality of the relationship, whether short or long-term, that the advocate forms with the person with dementia is crucial to the success of the advocacy. And good relationships are in turn dependent on good communication.

Communication with clients is central to the advocacy process. Good communication can be difficult in dementia advocacy because the communication skills of people with dementia are profoundly affected as the dementia develops. Thus, it can be difficult for the advocate to be clear about what the person with dementia wants, whether they understand who the advocate is and what they are doing, and whether they are happy with the process and outcomes.

Dementia advocates need to spend a lot of time with their clients to optimise communication and gradually build up a picture of what the person with dementia wants. In one of our hospital-based case study services, the advocate does not generally initially introduce himself as an advocate. Instead, he approaches the person with dementia on the basis that he has come to see if there are any ways in which he might be able to help them. The issue of whether advocacy is needed is clarified as he spends time with the person with dementia and learns about their circumstances.

## Example 2.1 Perspectives on dementia advocacy

### Tom, a dementia advocacy service user

A man visited me today. I thought I recognised him – he said he’s called James and he’s visited me a few times. I don’t really remember exactly. He’s very nice. He chats to me about Glasgow – we were both born there. We support the same football team.

I told James that I am fed up being in hospital. The doctor, and a woman who comes to see me, keep trying to get me to move into a home. I feel like they are all against me. I want to go back to my own house but since that fall and coming into hospital I don’t think I’ll feel safe there. My friend George, he moved somewhere after he was in hospital – a place where there are people around if he needs them. I asked James about that – if I could go there too.

James wrote a letter to the hospital staff for me, but I wouldn’t sign it – I don’t like signing things. I went to a meeting – it was really confusing and I got upset. They wanted to put me in a home. James was with me and he told them that I want to live like my friend. I don’t mean to be a nuisance. The other day I visited a place, it’s great – reminds me of my friend’s place. People are there to help but you get to do your own thing – like watching your football team. James said the hospital will let me go there.

### Susan, care manager

I chaired the case conference for Tom. I was under pressure to get Tom off the ward. Tom had told me he didn’t want to go home but I found it difficult to get him to discuss other options. In my view Tom needed a placement in a residential care home. When I said that at the meeting Tom started to cry. Everyone in the meeting apart from Tom and the advocate said that he needed the full-time support of residential care. The atmosphere was awful.

The next thing I received a letter from the advocate saying that he is very concerned about what happened at the meeting. He feels that Tom was not given enough opportunity to express his wishes and that he is being denied choices and access to appropriate services. At the meeting he said that Tom might be interested in sheltered accommodation. I’ve never had an advocate involved in a case before. I didn’t know how to take him really. However, I thought he had a point about the meeting, so I’ve talked to Tom again and arranged for him to go on a visit to an extra-care housing scheme.

### James, dementia advocate

I’ve visited Tom several times but it has been hard to be entirely sure what he wants. The hospital staff wanted him to go into a care home. I knew Tom didn’t feel happy about managing at home – but also that he didn’t want to go into a care home. My job was to try to make sure that Tom had time to look at options and to have his views taken seriously. From bits and pieces of what Tom said I realised that he had a friend in sheltered housing and liked the idea of living there. So I suggested that at the case conference and then followed it up in a letter afterwards. Advocacy isn’t a perfect science but being an advocate allows me to try to get as close as possible to what the person with dementia wants. Other service providers have other factors to consider – but in Tom’s case it looks as if his wishes will prevail.

### Derek, ward manager

James has an unusual perspective – he is independent, so he hears and sees things differently. He doesn’t get locked into organisational or staff agendas. His only agenda is the patient’s. It took me and my staff a while to understand that and not to feel threatened by his advocacy.

Tom’s case was a bit of a turning point for us. Having James intervene made us realise that if we’d spent a bit more time listening to what Tom was saying and his reasons for saying it, then maybe we would all have achieved what we wanted more quickly and with less upset. Tom is one of the quiet ones and we often miss what they say and need. It’s not right, but the staff have a lot to juggle and prioritise.

In dementia advocacy in general, a number of visits may be necessary before the advocate feels they know enough about the views of the person with dementia to advocate for them.

Advocates need to find ways to keep the person with dementia as actively involved as possible throughout the process. This requires continual reviewing of events with the person, explaining what is happening again and again, and repeatedly checking their reactions.

Where the person with dementia has limited communication skills, advocates usually spend time with friends and family to build up a consistent picture of what the key issues are for that individual. They also usually talk to service providers who have been involved in the care of the person with dementia, particularly workers in care homes, day centres or home care services who have had longer-term and more intensive contact with the person with dementia. By talking to a range of people involved in caring for the person with dementia, the advocate can obtain a more rounded picture of the person with dementia with less risk of being over influenced by individual bias.

A number of studies<sup>10,11,35</sup> have shown that communication with people with dementia can be much more effective than is often assumed. There are a variety of resources and guides available on communication skills and techniques that advocates will find useful (see Appendix 1). One common message about communication with people with dementia, is that while skills and techniques play an important part, there is no substitute for having plenty of time, patience and a commitment to engaging with each individual in ways that are suited to their personality, interests and circumstances. Advocates often feel that the time they have available for each person with dementia is too limited. However, they usually have more time than many of the professionals involved in assessment and care planning, and they are, therefore, relatively well placed to enable people with dementia to have their voice heard.

One of the challenges of longer-term dementia advocacy is responding to changes in the person with dementia and ensuring that the advocate continues to represent their client's wishes as the dementia progresses (see also Chapter 1). There is no simple solution to this; success is dependent on the strength of the advocacy relationship and the advocates' skills in flexibly tailoring their ways of working with each individual to match their changing abilities, needs and wishes.

Finally, it is important that advocates bear in mind that people with dementia are often very dependent on their families and on care providers and that this can make them vulnerable to abuse. Advocates should therefore be familiar with good practice guidance in relation to abuse of vulnerable adults<sup>36,37</sup> and with the relevant inter-agency procedures in their locality<sup>38</sup>.

Box 2.1 summarises suggestions and advice for advocates on working with people with dementia.

## ETHICAL ISSUES

Crucial questions from the outset of any dementia advocacy relationship concern whether the person with dementia is able to indicate that they want an advocate, whether they are able to understand the advocate's role, whether they are able to express their views clearly and whether they understand the consequences of the advocate representing their views.

Dementia advocates in practice often experience doubts about whether they are accurately and appropriately representing the person with dementia's wishes. They often cannot be entirely confident that the person with dementia knows that they are an advocate or fully understands what they are doing. The position is further complicated for advocates who are working with people with dementia whose cognitive abilities appear to fluctuate. For further information and guidance about issues of capacity and consent in relation to dementia see Appendix 1.

Dementia advocacy services generally resist narrow definitions and views of mental capacity<sup>31</sup>. In practice dementia advocates usually deal with issues of consent by treating consent as an ongoing process and not a 'one off' action. Advocates seldom think it is appropriate to get a person with dementia to sign a consent form. They instead usually rely on regularly checking with the person with dementia, verbally and by observing their body language, that they are happy with the advocate being present and that they are happy about any action being taken.

In practice, however, both paid and volunteer advocates sometimes work with people with dementia who have little or no understanding of the advocacy role. 'Consent' in such cases may be no more than the person with dementia indicating recognition of the advocate and agreeing to the process by smiling and continuing to engage with them. Advocates in these cases generally work on the basis of spending a lot of time with the person

### Box 2.1 Suggestions and advice for advocates on working with people with dementia

- Begin work at the earliest possible opportunity to build up rapport with the person with dementia.
- Check that the environment for meeting is suitable (noise levels, privacy and so on).
- Check in advance if the client has any vision or hearing difficulties and, if needed, that they are wearing their glasses and any hearing aids are working properly.
- Check in advance if a client is a member of a minority ethnic or cultural community and particularly whether an interpreter is needed.
- Ensure that the person with dementia feels safe and orientated.
- Check what, if anything, the referrer has explained to the person with dementia and arrange an appropriate introduction accordingly.
- Treat the person with dementia with respect and ensure that they can maintain their dignity.
- Talk clearly and use simple, straightforward language.
- Explain as much about your role as is appropriate for the individual.
- Establish that the person with dementia is consenting to the process (see below).
- Be sensitive to the individual circumstances of the person with dementia.
- 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 community organisations) to do this.
- Do not assume that the issue identified in the referral is the only, or the most important, issue to the person with dementia.
- Take time to get to know the person with dementia. It may take several visits of varying length to establish a rapport; reminiscence about early life may provide a useful point of contact.
- Build up trust.
- On each visit spend time prompting and reminding the person with dementia who you are and what you discussed at the last visit.
- Take time to talk around the situation, be unhurried.
- Explain the options and the consequences of any choices.
- Explain the course of action and what might change.
- Be alert to non-verbal communication such as facial expressions and body language.
- Use touch sensitively.
- Be aware that you will not always get a response.
- Adopt a 'softly softly' approach.
- Do not be too intense.
- Use your instincts.
- Visit at regular times and regular days.
- Take care that you do not overly 'guide' what the person with dementia is saying.
- Try to find out what is behind what the person with dementia is saying.
- Try a range of communication tools and techniques, for example, writing things down, visual images.
- Check that you have understood what the person with dementia is communicating.
- Do not try to move people on at a faster pace than they are able to cope with.
- Recognise that the views of the person with dementia may change in the course of a meeting, or from day to day, as well as over longer periods.
- Be aware that there is the possibility that some people with dementia will be subject to abuse and be prepared to deal with this.
- Be alert to cues as to when to leave. It is better to have 10 minutes quality time than an hour with nothing happening.

with dementia, and with others who know them well, to build as full as possible an understanding of their wishes. Some advocates in these circumstances will ‘interpret’ what the person with dementia is saying. If they do this, they should be explicit with professionals, families and carers that this is the case. If the advocate reaches a point where they feel it is impossible to know, and therefore represent, the views of the person with dementia then they should be explicit about that too.

There are, clearly, grave risks that advocates working with people with limited mental capacity may misrepresent their wishes or exert undue influence on them. This may happen inadvertently, with the very best of intentions, or in pursuit of other interests. Although advocates are generally very clear that they should not impose their own ideas, the realities of practice mean that they do not always adhere rigidly to this approach. For example, one advocate explained her thinking about her advocacy intervention with a woman who wanted to remain living in her own home.

“I am sure she wants to live in her own house... in order to continue to do that, because she really can’t prepare her own food, she has to be accepting some services. She initially didn’t want to be accepting any services and I did convince her to accept services. But I felt for the ultimate goal of getting what she wanted, which was staying in her own house. That’s how I justified that. We [the service] did say we wouldn’t talk people into doing anything, so there are grey areas, and there are times when you have to reconcile what you’re doing, and you have to keep checking what you are doing, and checking it all the time.”

Dementia advocates individually, and dementia advocacy agencies (see Chapter 5), need to take steps to ensure that the boundaries of acceptable practice are clearly defined and that vulnerable people with dementia are protected from the potential for advocates to abuse their position and influence.

Another major area of ethical concern identified by advocates is in relation to conflicts of interest. Advocates expect to deal with conflicts between the wishes and views of their client and those of other people. Clearly there are circumstances in which fulfilling the client’s wishes may be detrimental to others. The advocate is faced with an ethical problem if the other people affected are unable to fully represent their own views and interests. This is

most likely to occur in relation to family carers (see below for suggestions about working with families).

Advocates may also face dilemmas if they find themselves in the position of promoting the rights of the person with dementia, and what the person with dementia wants, when this conflicts with the advocate’s own values or their views about what is in the person with dementia’s best interests. Supervision for advocates is an important means of identifying and dealing with dilemmas of this kind (see Chapter 4).

Finally, advocates are often in a privileged position in that they will be given information from a wide range of people who would not necessarily wish that information to be shared with others (the person with dementia, perhaps a number of family members with different views and interests, a range of service providers). Advocates, therefore, need to be constantly mindful of issues of confidentiality and to ensure that they have consent before they share information that may have been given in confidence.

Box 2.2 provides some ideas about how dementia advocates and their services can deal with ethical issues.

## REPRESENTING THE PERSON WITH DEMENTIA

Having reached a view about what the person with dementia wants, the advocate’s task is to represent that view to others and to assist the person with dementia to achieve their wishes. The way that the advocate pursues this will depend upon the retained skills and abilities of the person with dementia. When people have less advanced dementia the advocate’s task may be to support them in self-advocacy. More often, however, advocates are working with people with dementia who are unable to effectively voice their wishes.

Dementia advocates may have to represent the views of people with dementia to a range of ‘audiences’ (for example, relatives, doctors, care managers). These audiences inevitably vary in the extent to which they are open to hearing and acting on what the advocate has to say. Whether or not the advocate expects the reaction from others to be sympathetic or resistant, it is important for advocates to maintain a consistent, professional approach. Experience suggests some key elements of good practice that are outlined in Box 2.3.

### Box 2.2 Suggestions about dealing with consent and other ethical issues

- Treat consent as an ongoing process not a one-off decision.
- Record how consent is obtained at the beginning and throughout the advocacy process.
- Record the basis on which you form your views about what the person with dementia wants.
- Explain to the person with dementia what you are recording and how this information will be used.
- Try to establish the issue(s) that are important to the person with dementia and agree which to prioritise.
- Continually reflect on what you are doing, why and in whose interests.
- Ensure that confidentiality is maintained and that you have consent to share information with others in the family or the service system.
- Ensure that you receive regular supervision in which potential and actual ethical issues are identified and discussed with clear recording of agreed action and the reasoning underpinning those actions.
- Ensure you have received appropriate training/education on issues of capacity, consent, human rights and other ethical issues.

### Box 2.3 Representing a person with dementia

- Be prepared to explain and justify the range of approaches you have taken to communicating with the person with dementia and to understanding their perspective.
- Be prepared to explain how you have handled issues of consent.
- Keep written notes on your interactions with the person with dementia, particularly documenting 'evidence' of their views and wishes.
- Only speak on issues discussed with the client or on which you have good evidence about the client's wishes.
- Present what the person with dementia wants based on what you know about them and what they have communicated – not by second guessing their views.
- Make it clear how you have established the views that you present.
- Be clear about when you are 'interpreting' what the person with dementia wants.
- Present the case clearly and concisely whether within meetings, for example, the care-planning meeting, in individual discussions or in writing.

We now look in more detail at some broader aspects of working with families and with other service providers.

#### WORKING WITH FAMILY MEMBERS

Families and carers are often thought to be the natural advocates for people with dementia<sup>23</sup>. Sometimes family members can be very effective advocates: when they know the person with dementia and their wishes very well; when they care strongly about the person with dementia having their needs and wishes met; and when representing the person with dementia presents them with no

conflicts of interest. However, sometimes the emotional, practical and financial complexities of family life make it very difficult for family members or carers to be an advocate for a relative with dementia. One advocate summarised the view generally taken by dementia advocacy services about their role in working with families and carers:

"I would work with the carer, but my viewpoint has got to come from the person with dementia."

Advocates may undertake a variety of tasks in working with carers and other family members. They may:

- Obtain information from relatives that can help them in understanding the person with dementia and in advocating for them.
- Represent the person with dementia's views and wishes to relatives.
- Guide carers about where to obtain support services as a means of enabling them to continue to care and hence enabling the person with dementia to fulfil their wish to remain at home.
- Advocate for carers in obtaining support services as a means to enabling them to continue to care and hence enabling the person with dementia to fulfil their wish to remain at home.
- Support relatives in advocating for the person with dementia.
- Help resolve conflicts between different members of a family concerning the person with dementia.

Advocates sometimes find that carers make it difficult for them to meet with the person with dementia in private and that they have to work very sensitively with carers to persuade them to allow this. When the person with dementia is a member of a minority ethnic or cultural community, advocates should ensure that they understand how that culture's perceptions of dementia and family life may impact on the issues and processes of advocacy.

Service providers generally recognise that relatives have a lot of influence and that sometimes what the relatives want conflicts with what the person with dementia wants. When there is conflict between

relatives and a person with dementia there is a potential role for the advocate in trying to find a degree of compromise within the family. Advocates may achieve this by representing the client's view, explaining to family members why the client wants something and trying to find common ground amongst those involved. In some cases, particularly if a carer is not able to fully represent their own interests, it may be more appropriate for the advocate to refer the carer for their own independent advocacy support.

There are sometimes circumstances in which the advocate's personal views and sympathies will be as much, or more, with relatives than with the person with dementia. Supervision is particularly important in such cases to ensure that the advocate is able to work effectively with the person with dementia and to identify when it may be more appropriate for the case to be transferred to another worker.

Box 2.4 provides suggestions and advice for dementia advocates in working with families and carers.

### WORKING WITH OTHER SERVICE PROVIDERS

We note in Chapters 3 and 5 that dementia advocacy often involves working closely with other services but that it is important that the independence of the advocacy service is maintained. At an individual case level, practitioners in other services often recognise that their role places limitations on their ability to advocate for people with dementia and they value

#### Box 2.4 Working with families and carers

- Provide relatives with clear information about the advocacy role to prevent them having misconceptions, particularly about the advocate being there to further their wishes.
- Respect the views and feelings of the relatives.
- Be clear about the areas in which the wishes of the relative(s) and the person with dementia are in agreement or conflict.
- Ensure that the emotional aspects of the past and future relationship between the relative(s) and person with dementia are considered when exploring the wishes of the person with dementia and the life options they want to pursue.
- Try to 'take relatives with you' rather than being confrontational.
- Follow explicit service criteria about when advocates should, and when they should not, advocate for carers (see also Chapters 3 and 5).
- Be clear about who you are advocating for – the carer or the person with dementia.
- Where possible and appropriate, support the relative(s) in advocating for the person with dementia.
- Where necessary refer relatives to other agencies for support or advocacy in their own right.

the contribution that an independent advocate can make. Although practitioners in other services sometimes view advocacy as an unwelcome challenge to their practice, most are positive about the role of advocacy and how it can influence their decisions in the interests of their clients.

The quality of working relationships that advocates have with other service providers varies. An individual advocate may even have different experiences with different agencies and different practitioners within these agencies. One advocate described the spectrum of his experiences as ranging from 'being allies', through 'having some differences but still good working relationships', to feeling as if he and the person with dementia are 'up against the whole world'.

Dementia advocates can be very dependent on other professionals on a number of counts: for practical information (for example, a person with dementia will rarely telephone the advocate to tell them the time of a meeting); in understanding problem areas and possible risks; and, in achieving the wishes of the person with dementia. Advocates need to make alliances with other professionals and need to have an understanding of the professionals' roles and responsibilities. However, the advocate is there to get the best for the person with dementia by representing their views and where necessary arguing and negotiating for them. This can inevitably lead to tensions.

It is important for advocates to recognise that other practitioners may bring a range of assumptions, expectations and motivations to their relationship with the advocate. The experiences of our case study sites suggest the following may be important for other practitioners in working with advocates:

- desire to ensure that the person with dementia's wishes are at the centre of the assessment process;
- concern that a person with dementia is at risk of getting 'lost in the system';
- assumptions that the advocate has more time to work with individuals than statutory service providers;
- perceptions that advocates can provide a different, 'neutral' perspective when family, carers and services are in conflict;
- expectations that advocacy will reinforce or complement an existing commitment to service user empowerment;
- hopes that the advocate will support the referrer's viewpoint in the context of multidisciplinary care planning;

- hopes that the advocate as an 'outsider' can put pressure on other professionals without jeopardising established good multidisciplinary relationships;
- anxiety about criticism of their practice.

It is also important for advocates to understand the ideas and responsibilities of other practitioners and how the day-to-day concerns and pressures of their agencies may impact on working relationships. For example, advocates are sometimes aware of staff and resource shortages in local health and social services. They may find that this affects practitioners' willingness to work with them, particularly if the other service providers think that the advocacy involvement might, for example, slow up the assessment process or delay a hospital discharge. In such instances advocates sometimes find other practitioners 'obstructive', for example, in not returning telephone calls or informing them about important meetings.

Finally, it is important for advocates to understand different care models and how they affect the practice of other professionals. For example, a practitioner with a strong traditional medical background may be inclined to 'advise' and 'prescribe' for the 'patient' whereas a practitioner with a social care background may be more familiar with an approach based on service user empowerment. Such different backgrounds and orientations are likely to affect the way different practitioners respond to the involvement of an advocate.

Box 2.5 provides an overview of suggestions and advice for advocates in working with practitioners from other services.

### **BOUNDARIES**

The nature, and the generally limited resources, of advocacy services make it important that practitioners maintain clear boundaries. Advocates in practice frequently encounter dilemmas about the boundaries of their role, including:

- The level of practical support that they should provide (for example, whether it is appropriate to collect toiletries for a person in hospital who has no family available).
- The level of general emotional support or befriending that they should provide.
- Whether they should 'help out' another service provider by undertaking some of their tasks in order to expedite an outcome for the client.

- When it is appropriate to challenge another practitioner about their practice or responsibilities.
- When to take an issue to another practitioner's line manager.
- The limits that they should apply in relation to handling money or financial matters.
- The limits that they should apply in relation to giving information on legal issues, for example, in relation to Enduring Power of Attorney or Court of Protection matters.

In accepting referrals and undertaking casework, advocates need to be clear about the boundaries of what is appropriate to their role. Without this there is a risk that the advocacy resource will be dissipated

in more general support and befriending work or that advocates will become involved in areas in which they are not competent to practice. Some advocates maintain very clear boundaries in their practice. Others argue the need for a flexible approach and if they think it necessary in a particular case they will, at least in the short term, take on befriending or practical work that is not strictly 'advocacy'.

Advocates' practice boundaries should be informed by clear agency policies (see Chapter 5) but they also need individually, and in the context of supervision, to reflect carefully on the boundaries of their role. Some suggestions for practice are provided in Box 2.6.

### Box 2.5 Working with practitioners in other services

- Ensure that other practitioners are clear about your role and that you understand their roles and responsibilities.
- Be clear with others that you are working to represent the views of the person with dementia.
- 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 you work.
- Work sensitively with other professionals, respect their perspectives but avoid collusion.
- Invest time in 'getting to know' key professionals and building a rapport with them.
- Consider regular drop-ins or visits to remind other service providers about your role and to develop good working relationships.
- Be proactive and establish alliances with other practitioners to encourage information sharing.
- Keep the referrer and other key service providers informed of progress as appropriate within the bounds of confidentiality.
- Challenge where you need to challenge, either on an individual or organisational level.
- Remember that antagonising other practitioners will not help the person with dementia.

### Box 2.6 Handling boundary issues

- Be prepared to explain your role to the person with dementia, carer, family and other practitioners.
- Discuss timescales and other parameters of your involvement at the beginning of the advocacy relationship.
- Agree the nature of your involvement explicitly with key people and keep this under review.
- Do not get over-involved in financial or legal matters – the advocacy role is to help people voice their views and concerns and to guide them to appropriate, expert advice.
- Use supervision to clarify boundary issues.
- Be clear about when you cannot advocate for an individual – do not be afraid to say no!

### Box 2.7 Managing endings

- Recognise that carers and people with dementia often become dependent on you as an advocate (and vice versa).
- Ensure that you have clear criteria underpinning your involvement and individual decisions about ending contact.
- Ensure that your plans for intervention from the beginning include plans for the withdrawal of the advocacy service.
- Once other services are in place withdraw but check at predefined intervals to see that everything is working out as planned.
- Give carers and the person with dementia details of key names and telephone numbers to enable them to re-contact the service if they need it. This information should be provided in writing with appropriate visual prompts (for example, photographs) as necessary.
- Encourage other practitioners to regularly review the individual's needs for advocacy and to refer back as necessary.
- 'Switch off' after you have done the work.
- Seek supervision and support to help in withdrawing from contact and to deal with issues related to loss or bereavement.

### Box 2.8 Developing a reflective diary

Reflect and write up in detail one case a month. Consider questions such as:

- What were the issues on which the person with dementia needed advocacy?
- What were the issues on which you provided advocacy?
- What other issues did you find yourself taking on?
- What changed for the person with dementia?
- What changed for other people?
- What contributed to making change happen?
- What, if anything, prevented change happening or made it difficult?
- How do you feel about this case and how have you coped with your feelings?
- What were the ethical issues and how were they handled?
- Were there any issues in this case that keep coming up in your work?
- What have you learned from your successes and mistakes?
- Is it time to address any issues at service level, for example, by lobbying service providers for changes or developments?
- Do you need managerial support to address the issues?

## COMPLETION / ENDINGS

A dementia advocate spends a lot of time with the person with dementia and finds out a lot about them and their needs. Advocates in many cases become very attached to the person with dementia and find it difficult to end the advocacy relationship. Advocates may be concerned about what happens to the person with dementia once the advocacy has ended, particularly when the person with dementia is socially isolated and where the advocate is aware that service provision is inadequate or inconsistent. Advocates may also feel guilty about ending contact with someone who has not achieved their wishes (for example, to remain in their own home). And, advocates may have to cope with serious deterioration in the health of their client, or even their death.

Advocates need to be able to accept that they cannot always ensure that the wishes of the person with dementia are secured. Sometimes the service resources are not available and sometimes the advocate may not be able to overcome all of the well-recognised problems of fragmented and uncoordinated services<sup>17,18</sup>. Some advocates experience a good deal of frustration in their work, particularly if they are advocating on the same issues repeatedly with limited success, for example, advocating for people to remain at home but finding that they are nonetheless admitted to care homes. This generates stress for advocates and they need to

develop strategies for managing this stress. Advocates need to have exit strategies and support to manage endings in individual cases. Some suggestions to help manage endings are provided in Box 2.7.

## PRACTICE REVIEW AND DEVELOPMENT

Dementia advocates are working in a field in which there is relatively little in the way of established 'best practice' guidance. Advocates, not surprisingly, often find it difficult to assess their own practice. However, it is important that they do so in order to learn and develop. Advocates may say that they are too busy to spend time on reviewing their work or that they find it difficult to quantify the nature of what they achieve. One way to encourage practice review is for services to adopt the principles of reflective practice<sup>39,40,41</sup>. Reflective practice can be undertaken individually by each advocate, for example, by developing an individual reflective diary (see Box 2.8). However, advocates generally value learning with, and from, other advocates. So, a useful approach may be to encourage advocates to spend time together reflecting on practice issues and assessing the value of what they are doing. Services can encourage such processes of mutual review either amongst advocates within the organisation or by linking advocates with the staff of other dementia advocacy providers. See also Chapter 4 for discussion of support and supervision.

## CHAPTER 3.

# SETTING UP A SERVICE

### INTRODUCTION

This chapter discusses the issues that any group or organisation must consider before setting up a dementia advocacy service including identifying need, preferred advocacy model, location of the service and funding. The stages and issues discussed in this chapter are illustrated in Example 3.1.

### GETTING STARTED

The initiative to establish a dementia advocacy service can come about in a number of ways. The idea may come, for example, from an existing organisation that is already providing generic advocacy or advocacy for other specific client groups. Or, practitioners or managers in health or social services may identify that there are conflicts of

### Example 3.1 Setting up a dementia advocacy service

The need for a dementia advocacy service in City was identified by a number of social workers working in a specialist elderly care team. They found that many of the people with dementia with whom they were working were unable to raise issues that were clearly important for them. The social workers were concerned that their role, and the organisational pressures on them, prevented them from speaking clearly on behalf of their clients.

The social workers raised their concerns with their service manager who in turn approached a local voluntary sector organisation (City Age Care) to discuss the possibility of setting up a dementia advocacy service. The manager approached City Age Care because this organisation had in the past provided a general advocacy service for older people.

The chief executive of City Age Care was keen to revive the organisation's prior commitment to advocacy services but recognised that dementia advocacy demands specialist skills and knowledge of dementia. A steering group was therefore formed that included, in addition to the City Age Care chief executive and development manager, a local solicitor with experience of Court of Protection work, and a social service manager with experience of dementia care. A manager in the local NHS Trust who showed interest in the proposed project also joined the group.

The steering group agreed that the City Age Care organisation could provide a suitable management infrastructure for the service and that its independence from statutory service provision was particularly valuable.

The steering group decided to adopt a combined paid and citizen advocacy model. This was because they were aware of the need to support volunteer advocates and because they felt that the skills of trained paid advocates would be needed for more complex cases.

Social services agreed to provide some modest start-up funding for the service. The steering group made an application to a national charity for the balance of funding required for the service and received three years funding from the charity. The second and third year's funds were conditional on the service producing a clear strategy for development and for securing longer-term funding.

With initial funding in place City Age Care was able to appoint a dementia advocacy co-ordinator with responsibility to promote referrals, provide paid advocacy and recruit and support volunteer advocates.

interests in their work that they cannot address and they may take the first steps in stimulating local discussions about setting up an advocacy service.

Experience suggests that where the concept and early development of dementia advocacy are owned by key people in the locality, the service is more likely to flourish. Both service commissioners and providers have a role to play in the successful establishment of an advocacy project. The early establishment of a 'steering group' with broad stakeholder representation is therefore a usual and useful first step. In one of our case study sites, for example, the group hoped from the outset to involve someone from the health service but in the event this did not happen. The group felt that this subsequently adversely affected referrals and the way the service was used by health service practitioners.

## THE NEED FOR ADVOCACY

It is difficult to provide estimates of the need for advocacy<sup>42</sup>. In considering need, steering groups should be mindful of the groups of people with dementia whose needs are often marginalised in mainstream services, including younger people with dementia, people from minority ethnic communities and people who have a learning disability and dementia. Steering groups, for example, should from the outset consider how they will ensure that their pool of advocates includes people with the range of ethnic, cultural and linguistic backgrounds to be able to respond to the diversity of people with dementia in their local communities<sup>43</sup>.

Demand for the new service will be heavily influenced by the success of the service in 'marketing' itself by raising awareness of its existence and benefits amongst potential referrers. In practice, new dementia advocacy services usually aim to 'start small and build up'. In part the small scale origins of most services are also a function of the funding available usually being limited until the new service has 'proven itself'.

## MODELS OF ADVOCACY

The philosophy and features of different models of advocacy are outlined in Chapter 1 and summarised in Box 1.1. One of the first tasks of a steering group is to clarify the extent and type of advocacy that they want to have provided in their locality. Based on current experience, the main types of advocacy that steering groups need to consider are: independent professional or paid advocacy; and citizen or volunteer advocacy. Most existing dementia advocacy services have at least some paid advocacy

and almost two-thirds of all services involve some citizen/volunteer advocacy.

Other types of advocacy that steering groups might consider are currently provided in very small numbers of services, sometimes in combination with paid and/or citizen advocacy. The most common alternative models are self advocacy (around 5 services report providing this) and peer advocacy (3 services report providing this although in one this meant 'chronological peer' rather than peer as 'also living with dementia'). Other models reported by individual services include crisis advocacy and 'situational advocacy' (an ad hoc term used by one service).

## ORGANISATIONAL LOCATION

### Independence

It is widely accepted that in order to avoid conflicts of interest, advocacy services should be independent of service providers<sup>2,23,24,26</sup>. The voluntary sector is often perceived as having that independence and therefore as offering the best organisational location for dementia advocacy services. Certainly the vast majority of existing dementia advocacy services are organisationally located in the voluntary sector. The organisations involved include the Alzheimer's Society, Alzheimer Scotland – Action on Dementia, Age Concern, MIND, advocacy provider organisations and other voluntary sector service provider organisations. Only a very small proportion of existing dementia advocacy services are organisationally located in statutory sector organisations and a similarly small proportion jointly in voluntary and statutory sector organisations.

However, in deciding on the organisational location for a dementia advocacy service, steering groups should remember that organisational location in the voluntary sector does not in itself guarantee independence. We note below that much of the funding for dementia advocacy comes from statutory health and social services organisations. This means there is the potential for these organisations to have undue influence on the operation of the advocacy service. It is, therefore, important that contracts for the provision of advocacy services are explicit about the service being independent and about the nature of the relationship between the funding organisation and the service provider.

Steering groups should also be aware of the potential for internal conflicts when a dementia advocacy service is located within a voluntary sector

organisation<sup>24</sup>. There may be conflicts of interest related to the internal allocation of resources or to different client groups involved in the organisation. More specifically difficulties may arise if the organisation provides other services for people with dementia. In these circumstances advocates may feel compromised if their client's wishes are in conflict with those of their employer. Contracts with voluntary organisations to provide advocacy should therefore make it explicit that the advocacy service within these organisations must be free of any undue management pressure. Independence and potential conflicts of interest need to be taken into account in determining the membership of management groups (see Chapter 4). They must also be considered at a practical level, for example, in ensuring that advocates have office space and filing systems that are separate from other staff involved in service provision.

### Developing dementia advocacy in an established organisation

In choosing an organisational location, steering groups need to take into account the nature of the potential providing organisation, its reasons for moving into the dementia advocacy field and its development plans. Dementia advocacy could be provided by a new, specialist organisation. More often, however, dementia advocacy is taken on by an existing organisation. The range of possible organisations is large, and we therefore can consider only the key issues in some of the most common organisational locations.

Some potential provider organisations will have prior experience in developing and providing advocacy services for other client groups and there are some obvious advantages in this. These organisations offer the prospect of substantial transfer of skills and expertise into dementia advocacy. The benefits of being part of a larger advocacy organisation can include:

- capitalising on the organisation's established reputation and credibility as a advocacy provider;
- staff having access to substantial advocacy expertise and support;
- staff feeling they are part of a larger advocacy team;
- opportunities for dementia advocates to extend their experience and skills by working with other types of advocacy client.

There are, however, potential disadvantages that include:

- the organisation's management not having the level of knowledge or expertise in dementia required to develop the new service;
- the dementia advocacy service being 'just another project' and not receiving enough dedicated management attention;
- the dementia service being overly influenced by existing ideas and practices in the organisation, for example, a strong commitment to a particular model of advocacy, and being inhibited from developing its own dementia advocacy approach;
- staff needing to devote resources to educating other people in the organisation about dementia;
- dementia advocacy staff feeling rather isolated and unsupported if others in the organisation continue to view dementia work as marginal to the organisation's mainstream activities.

Given these potential disadvantages, it is important that providers who have previously worked with other client groups, understand the particular challenges of providing advocacy for people with dementia. They need to ensure that their existing staff and stakeholders appreciate the distinctive nature of the new service. If they plan to transfer existing advocates into the dementia service, they need to ensure that any education and skills gaps are addressed. They also need to review current policy and procedures and identify those that are transferable to dementia advocacy and those that need to be revised or replaced.

Some potential provider organisations will have no prior experience of advocacy but will have experience of working with people with dementia and/or their carers. Where potential providers have a strong tradition of providing more general advice, information and support for people with dementia, it is important that they are clear about, and fully committed to advocacy as a different form of service. Without this clarity and commitment it is likely either that the advocacy role will not be properly developed or that the organisation will encounter conflicts of interest for which they are ill prepared. To avoid these problems, the potential provider needs to show that they have plans to develop a sound understanding of the principles of advocacy and to provide staff across the organisation with training about the new service.

Where potential provider organisations have a strong tradition of working with carers, it is particularly important that these organisations consider how they will manage advocacy involving conflicts of interest between carers and people with dementia,

especially in circumstances where the carer is receiving services from another part of the organisation.

The benefits of locating dementia advocacy in a non-advocacy organisation depend on the nature of that organisation, but can include:

- opportunities for dementia advocates to extend their experience and skills by doing some non-advocacy work;
- staff having access to colleagues with a broader range of expertise and specialist information, for example, on social security benefits or legal issues;
- the possibility of cross-referrals between the organisation's different services.

The disadvantages of such a location can include:

- potential conflicts of interest if the organisation is a service provider;
- advocacy staff having to devote resources to educating other staff about advocacy;
- staff lacking peer support from advocacy specialists;
- the organisation's management lacking specialist knowledge and expertise in advocacy provision.

## FUNDING

One of the early questions that a dementia advocacy steering group is likely to face is: 'How can we get funding to develop a service?'

### What are the sources of funding?

The experience of existing dementia advocacy services suggests that new services are likely to have to put together funding packages involving grants from a variety of sources. Over two-thirds of existing services have some funding from either a local authority, a health authority or both. A similar proportion have some voluntary sector funding from charitable trust grants or from the National Lotteries Charities Board. Less than a quarter of existing services rely solely on charitable funding. In seeking funding, dementia advocacy services need to consider whether the aims and values of any potential funder are in accord with the mission, aims and values of the proposed service.

At the outset, steering groups are likely to be most concerned to secure 'start up' funding. One of the risks in the early stages of a dementia advocacy service, as with many new developments, is that funding will 'dry up' after the initial project grant covering perhaps the first two or three years of the service. It is therefore important that steering groups

begin very early to plan their strategy for obtaining long-term funding. This may involve building a strong relationship with initial funders as a basis for a longer-term funding partnership. It may also involve preparing a strong case about the value of the service to convince new funders that they should 'pick up the tab' and sustain the development.

### What do service commissioners and funders want?

Since dementia advocacy is relatively new, service commissioners and other funders often have very little knowledge, or prior experience of the field on which to base their decisions about whether a project merits their support. Service commissioners and funders will want reassurance about many of the issues that are covered in this report. So, steering groups and prospective service providers need to be prepared to provide answers to a very wide range of questions, for example, about the nature of dementia advocacy, why a service is needed, who will use the service, how the service will fit within the existing service system, what training and skills the advocates will have and, how the service will be managed.

Different commissioning and funding organisations have different motivations and concerns when considering grant applications. 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 agenda. They are also likely to be concerned about the specifics of service operation and 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 are more likely to be prepared to support dementia advocacy 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.

The experience of existing dementia advocacy services suggests that service commissioners and funders in general value the following features in advocacy services:

- independence;
- objectivity;

- clearly articulated boundaries between meeting the needs of the person with dementia and those of the carer(s);
- good and innovative practice using a range of techniques for working with people with dementia;
- skilled staff with expertise in communicating and forming relationships with people with dementia;
- attentiveness to issues such as staff support and user safety;
- sound management;
- accountability;
- value for money.

Funders vary in their approaches to assessing proposals. Few have established processes or criteria specific to dementia advocacy. Box 3.1 summarises some of the key factors that commissioners and funders are concerned to see prospective service providers address clearly in their proposals.

### PARAMETERS OF THE SERVICE

One of the first steps in setting up dementia advocacy is to clarify the scope and broad parameters of the service. This clarity is important for any funding applications as well as in the first operational stages of the service. Some of the

important questions that need to be considered about the scope of the service include:

- **How should the service define its target user group?**

Most dementia advocacy services do not require their clients to have a formal diagnosis of dementia but accept referrals of anyone who appears to have dementia related needs. Some services that focus on dementia adopt a more inclusive approach and accept referrals of people aged over 65 years who have other mental health needs. One of their reasons for doing this is that problems of dementia and depression often co-exist.

Age is a criterion that many dementia services use to define their user population; about one-third of dementia advocacy services require users to be over 60/65 years or retirement age. However, there is the issue that dementia also affects younger people, albeit in smaller numbers, and that their needs for advocacy should be considered. This is particularly important as advocates in other advocacy services for younger people, for example, advocacy for working age adults with mental health needs, may not have the skills and experience needed to work with people with early onset dementia.

### Box 3.1 Some key features that funders look for in assessing proposals for dementia advocacy services

- a description of the target user group and 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 and in the designated settings;
- a demonstration that the service has clear management accountability and the capacity to cope with the complexities of dementia advocacy;
- evidence of ability to work with key stakeholder agencies;
- defined advocacy principles;
- evidence of high ethical standards and arrangements to ensure the safety and security of service users;
- the availability of training, support and networking for advocates;
- sound financial management arrangements;
- clear and reasonable costings and budgets;
- plans for monitoring and evaluation;
- a clear argument as to why the service is worthy of their support.

A related issue is the need for the service to be clear about how it will define its boundaries in relation to advocating for carers and relatives of people with dementia. Most dementia advocacy services are clear that their focus is on people with dementia and that if carers or other family members have a need for advocacy they will refer them on to other services.

- **Should the service be limited to the population of a particular locality or to the users of other specific services?**

Some dementia advocacy services, for example, have been established to provide for people in specific service settings, usually care homes or hospital wards. Most services, however, are open to anyone within a defined geographical or administrative catchment area. As noted above, it is therefore very important that services are equipped to respond to the full range of needs within the social, ethnic and cultural diversity of their local population<sup>43</sup>.

- **Should the service be time limited or open-ended?**

Dementia advocacy is not generally viewed as something that can be undertaken within a short, predetermined period; only a small number of existing services have time limits and they generally apply these limits flexibly. Nor, however, is dementia advocacy an indefinite, long-term support service. Most dementia advocacy providers are in broad agreement that the duration of contact should be determined by the issue to be resolved. As one service explained:

“The advocacy we provide is based on issues presented, not time limited. It is focused on the problem and once resolved it is closed.”

- **Should the service advocate for individuals or should it advocate for groups?**

Some dementia advocacy services are set up specifically to advocate for particular groups, for example, people in a hospital facility or care home that is being relocated. Most services, however, are set up primarily to work with individuals but some are prepared to take on this type of group advocacy should the need arise.

- **What range of individual advocacy issues should the service be prepared to handle?**

Dementia advocacy services generally need to be prepared to deal with a wide range of issues. Existing services, with very few exceptions, provide advocacy in relation to:

- information about services;
- complaints about services;
- moving from home into a care home or hospital;
- hospital discharge planning;
- community care assessments;
- medical assessment and treatment;
- use of legal provisions (for example, related to the Mental Health Act 1983 or Court of Protection);
- finance and social security benefits;
- abuse;
- conflicts of interest (for example, between people with dementia and their relatives, carers or service providers).

- **In what settings should the service operate?**

Unless the service is dedicated to work with a particular user population (for example, people in a specific hospital facility), it should be prepared to be flexible about where advocacy is provided. Just over half of existing services use their own offices for service provision; but it is clearly possible to operate without this facility. Most existing services work with people in their own home and the majority also work with people in care homes or hospital inpatient facilities. Some services work in outpatients facilities and smaller numbers in other community settings such as day care.

- **Where should dementia advocates be based?**

The independence of advocacy is crucial (see Chapter 1). In general advocates have an office base within their employing organisation and this is deemed to be important in reinforcing their independence from other service providers. However, some advocacy services opt to have an office on the site of other services. This most often happens in hospital-based advocacy schemes.

Advocates who work in hospital settings have to draw a fine line between maintaining the distance necessary for independence, and establishing the strong ‘presence’ that is necessary to gain access and work effectively in this environment. It is not unusual for advocates in hospital advocacy schemes to have a desk ‘on site’. However, in order to help avoid becoming over influenced by hospital staff and organisational interests, some advocates working in this context find it valuable to be able to ‘escape’ back to a desk in their employing organisation. See Appendix 1 for further information on hospital-based advocacy services.

A range of factors may play a part in influencing how a service decides to define its scope and the broad parameters of its operation:

- funders' views about the scope of the service that they are prepared to support;
- the level of demand that will be generated and the ability of the service to respond;
- the local service context and the availability of other advocacy provision;
- lessons learned from the experience of other projects and from the advocacy literature;
- the skills and resources available (within the providing organisation or from other sources), for example, whether there is access to specialist advice on legal matters or social security benefits.

### Box 3.2 Key steps in setting up a service

- Bring together key people in the area to identify the need and consider how to address it.
- Ensure that the needs of minority ethnic and cultural communities are addressed as well as those of other groups with particular needs, such as younger people with dementia and people with learning disabilities and dementia.
- Identify all key stakeholders (service commissioners, service providers and other advocacy organisations in the area).
- Set up a steering group made up of people with a strong commitment to dementia advocacy. Ensure all interested local organisations are represented including potential referrers.
- Obtain information from other services about their experiences of dementia advocacy and of setting up advocacy services more generally.
- Clarify the aims of any proposed service development.
- Establish the centrality of the concept of independence for the advocacy service.
- Decide on the model of advocacy.
- Decide on the scope of the service.
- Decide on the organisational location for the service.
- Decide on the management structure for the service.
- Apply for and secure funding.
- Ensure that the service provider organisation's management group has a clear understanding of the specialist nature of dementia advocacy and how it differs from other types of advocacy.
- Establish clear written agreements between the dementia advocacy providers, service commissioners and other key service providers in the area; do not rely on personal relationships and communications as people can move on leaving the project having to re-establish its position.
- Establish clear lines of operational communication with front-line managers in the key agencies with which the advocacy service will be working.
- Avoid setting up a service that will be spread too thinly.
- Set clear operational parameters for the service (for example, geographical boundaries) and stick to them.
- Consider piloting the dementia advocacy in one area.
- Develop an initial strategy for promoting the service and referrals to it.
- Develop policies and procedures before accepting referrals.
- Appoint a co-ordinator/manager with a clear role definition, responsibilities and accountability arrangements.
- Before accepting referrals, ensure arrangements are in place to provide cover for absences at management and practice levels.
- Consider how service monitoring will be carried out.

Decisions about the scope of the service that are made at the outset may need to be reviewed in the light of experience of operating the service or as circumstances change.

### **KEY STEPS**

Example 3.1 above, illustrates how the need for advocacy can be identified and eventually developed into the establishment of a funded specialist dementia advocacy service. Box 3.2 more specifically, summarises some key steps in setting up a dementia advocacy service.

## CHAPTER 4.

# PEOPLE AND STRUCTURES

### INTRODUCTION

This chapter explores some of the main organisational management and staffing issues for dementia advocacy services. The chapter gives guidance on the key functions and qualities of managers. It discusses the skills and personal attributes of good dementia advocates and it highlights the importance of supervision for advocates, and of multi-agency support for advocacy services.

### ORGANISATIONAL MANAGEMENT ARRANGEMENTS

Chapter 3 notes that the majority of dementia advocacy services are organisationally located in the voluntary sector. However, no matter where the services are located, experience suggests that it is useful for services to have multi-agency involvement in their management arrangements. Almost two-thirds of existing services report having a combination of voluntary and statutory sector (often NHS and social services) involvement in some form of management committee or steering group. This multi-agency involvement reflects the complex nature of dementia care and the recognition that the issues dealt with in dementia advocacy often have multi-agency implications or require multi-agency action. Multi-agency involvement in some services is sometimes also related to the statutory agency funding of the service.

If new services are to maintain appropriate independence (see Chapter 3) they must consider carefully the nature of the involvement of statutory sector funders, or indeed other funders, on management groups. One option, which accords with more general recommendations for good practice in advocacy services<sup>1</sup>, is that commissioners and funders become co-opted members of management groups with no voting rights. This ensures that they can support and advise the service about making best use of their funding without undermining the independence of the service. Commissioners and funders themselves can also potentially benefit from this type of arrangement by, for example: learning more about the service user's experience; gaining ideas for service

improvement; and, promoting effective monitoring and evaluation.

It is important that services ensure that their management groups include people with knowledge and expertise in dementia care. For example, in one of our case study sites where the 'parent' organisation was not a dementia specialist organisation, arrangements were made to co-opt a dementia expert to advise and educate the management group and support the dementia advocacy service. Legal expertise is another area that a small number of services have decided to address through having a solicitor on their management group.

Services should also consider what front-line input they will have to their management group from the staff and users, direct and indirect, of the service. Thus about 40% of existing services include dementia advocates in their management groups.

Ideas about the involvement of people with dementia in service management and development are changing. There are growing numbers of examples of how this involvement can be effectively achieved<sup>11,44</sup>. Amongst existing dementia advocacy services, only about 15% have a person with dementia on their management group. Views about the appropriateness of involving people with dementia differ often within, as well as between, management groups. For example, in our case study sites there were some management group members who thought that people with dementia could not contribute and that family carer involvement was more appropriate. Most of our case study management groups, however, had decided that people with dementia could be involved, providing they had the ability and mental capacity to cope with the role. New dementia advocacy services should, as a matter of principle, endeavour to enable people with dementia to have a voice in service management. In doing so, they need to ensure that appropriate support is available to the person with dementia and that management groups are properly prepared for working with people with dementia.

New services should also consider the involvement of family carers in management groups.

As compared with people with dementia, the involvement of family carers is more common amongst existing services (it happens in about 30% of services). It is important that services remember that carers' perspectives are different to those of people with dementia. Some existing services, for example, caution that it is important that management groups, particularly those with strong carer or former carer representation, do not fall prey to the over-simplified assumption that carers always 'know best'.

Finally, and more generally, experience suggests that it is beneficial for the development of dementia advocacy services if management groups have members who have known each other for some time, who can work well as a group and who have well established links with the local community.

Box 4.1 summarises some key suggestions about organisational management arrangements.

### SERVICE MANAGEMENT ARRANGEMENTS

Management groups need to ensure good service management arrangements and, particularly, good first-line management as this role is crucial in determining the quality and success of any new development. Most existing services have adopted the structure of having a first-line service manager,

often called a co-ordinator, who is also a paid advocate. This co-ordinator is usually responsible for the work of volunteer advocates, and occasionally other paid advocates, alongside a more general role in promoting and developing the service.

It is essential that the accountability of the service co-ordinator is clear and allows for them to be effectively supported in operating and developing the service. Current opinion appears to be fairly evenly split between two main structures. One structure, which exists in about 40% of services, involves the co-ordinator being accountable to a line manager in the service's 'parent' organisation. The other structure, used in about 45% of services, involves the service co-ordinator being directly accountable to the management group, which as we have noted, may be a multi-agency group. A third option, adopted in about 15% of services, involves the co-ordinator having joint accountability to a line manager and a management group.

### The service co-ordinator

As the first-line manager of the service, service co-ordinators fulfil a range of functions that vary depending on the organisational structure and service operations within which they work. As noted above, some co-ordinators undertake some practical advocacy work alongside their management

## Box 4.1 Organisational management arrangements

- Dementia advocacy is best provided by voluntary sector organisations that can operate 'independently' of other service providers.
- Management arrangements should allow for the involvement of the main stakeholder agencies in the locality.
- It can be valuable to have funders contributing to management groups but their role should be clearly delineated to avoid any risk of compromising the independence of the service.
- Management groups with responsibility for dementia advocacy should include people who have expertise in dementia care.
- Management groups should consider whether their members would benefit from some specialist educational inputs on dementia and dementia advocacy.
- There should be opportunities for advocates to be represented in service management.
- There should be opportunities for people with dementia to be represented in service management.
- There should be opportunities for carers to be represented in service management.
- Services should consider whether they would benefit from having a solicitor involved in their management committee.
- Management committees need to pay attention to working well as a group and to developing good links with their local communities.

responsibilities. Box 4.2 lists some of the typical management functions of service co-ordinators. Aspects of the co-ordinator's role are discussed throughout this section and in Chapter 5.

There is no definitive view about the qualifications or prior experience that should be held by co-ordinators of dementia advocacy services. Clearly requirements will depend on the job description for the specific service. Many co-ordinators will have to combine good general management skills and abilities with those of a practising advocate (see below).

Co-ordinators of existing services come from a wide variety of backgrounds and have varied levels of qualifications. Current practice suggests that services find it advantageous to have a service co-ordinator with a background in health, social care or education. Most services have co-ordinators who have qualifications in areas such as social work, nursing, teaching, counselling, psychotherapy or community education. Although management skills are essential for co-ordinators, only a small proportion have a formal management qualification. There is a small, but significant, proportion of services in which co-ordinators have no formal qualifications.

Our case studies suggest that services should seek co-ordinators who have good management skills, a strong sense of social justice and a passionate belief in the rights of the people with dementia to have a

say in the decisions that affect their lives. Services also need co-ordinators whose drive to do their utmost for people with dementia will help them to stay motivated, and to motivate others, in doing a difficult job with limited resources.

### STAFFING

Dementia advocacy services may be staffed by paid advocates, volunteers or both.

#### Paid advocates

It is very likely that new dementia advocacy services will want to employ one or more paid advocates. Around 80% of existing specialist dementia services employ paid advocates. Just over half of the services with paid advocates have one, or occasionally two, full-time workers. Most of the rest have between one and three part-time workers. Sessional paid advocates are seldom used.

The role of paid advocates varies with some taking on the responsibilities of service co-ordinator, some focusing solely on individual advocacy work, and some combining individual advocacy with supervision of some volunteers. The skills and experience that a service should look for in employing paid advocates therefore depends on the specifics of the job description. The skills and experience required for paid advocates to take on the role of service co-ordinator are discussed above and those for individual advocacy work are discussed below.

### Box 4.2 Typical management functions of a service co-ordinator

- Recruiting and selecting volunteers and any other paid advocates.
- Providing initial background information to other advocates about the people referred to the service.
- Introducing volunteers to the people referred to the service.
- Being available to accompany volunteers on visits as required.
- Being available for ad hoc discussion and support as required by volunteers and any other paid advocates.
- Providing formal supervision for volunteers and any other paid advocates.
- Organising training for volunteers and any other paid advocates.
- Contributing to the development of policies and procedures.
- Ensuring implementation of policies and procedures.
- Liaising with other agencies.
- Monitoring activity.
- Reporting to a service manager and/or management group.

Current experience suggests that paid advocates may come from a wide range of backgrounds. Having said that, qualifications and experience in relevant caring occupations is a common route into paid advocacy. For example, people from a nursing or social work background often find that the knowledge and experience that they gained in their previous work provides a useful background for their advocacy work. Some direct experience of relating to people with dementia, whether gained professionally or personally, is also valuable.

### Recruitment and Retention

There is considerable variation in how easy dementia services find the recruitment of paid advocates: just under half of the services surveyed reported recruitment to be easy or very easy and just over half reported it to be difficult or very difficult. The reasons for this variation are not clear; but the existence of such varied experiences suggests that services need to be prepared to investigate their local employment market carefully and to tailor their recruitment strategy accordingly. Services with several advocates should endeavour to include people from a range of ethnic and cultural backgrounds to reflect the diversity of people with dementia in their local communities. They also need to ensure that their advocacy posts are attractive in their remuneration, flexibility of working hours and the availability of good support and supervision.

### Volunteer advocates

Volunteer advocates are used in almost two-thirds of dementia advocacy services. The number of volunteers in most existing services ranges between one and twenty. The average number of volunteers is around six and our case studies demonstrate that even small numbers of volunteers can be valuable.

Services that decide to use volunteers need to be realistic on a number of counts. First, establishing a relationship with a person with dementia often requires substantial time commitment from a volunteer within a relatively short period. 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. The experience of our case study services suggests that volunteers generally recognise that it is important to give a reasonable time commitment. In practice, volunteer time commitments are very varied, for example, from a few hours every fortnight to up to 6 hours a week.

Second, some advocacy with people with dementia requires a long-term commitment; and developing dementia advocacy skills and experience certainly requires this. Organisations need to ensure that volunteers understand this. They must also be realistic about the commitments that people will be able to make. Although most services have no specified minimum commitment for volunteers some do ask volunteers to commit themselves initially for perhaps six months or one year. It is not clear what effect such requirements have in practice. Current services have found, however, that there are volunteers who are prepared to be involved in dementia advocacy for several years.

Third, it is important that organisations are clear with potential volunteers about the challenges of the work. In particular, as one service explained:

“...volunteers need to know that the person with dementia is going to get worse and that interventions may not appear to make much difference.”

Fourth, if services are to work effectively with volunteers they must try to understand each person's motivations and the aspects of the work that they find rewarding. Experience suggests that volunteers' backgrounds and motivations vary and include for example:

- former carers seeking ongoing contact with someone with dementia because this is enjoyable and rewarding;
- former carers or family members of people with dementia wanting to ensure that others have a better experience than their relative with dementia;
- people who feel that it is important that a person with dementia has someone to speak up for them;
- people seeking work experience to help in securing paid employment;
- people following an interest first developed during professional training;
- people who are 'time rich' and see dementia advocacy as an interesting opportunity because they enjoy working with people;
- people seeking to extend a prior positive experience of working in the voluntary sector;
- people with a commitment to a service ethos of working holistically.

Volunteer dementia advocates describe some of the rewards as follows:

- being recognised by the person with dementia;

- receiving the gratitude of the person with dementia;
- meeting ‘fascinating’ people with dementia.

As one volunteer explained:

“... if I can talk to the person with dementia for an hour and make them feel better, I feel as though I have done something.”

### Recruitment and retention

Most services that use volunteers report that it is difficult or very difficult to recruit them. About two-thirds of services also report that it is difficult or very difficult to retain volunteers. Suggested barriers to volunteers working with people with dementia were: fear of dementia; stigma; 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. Services also need to consider carefully the likely supply of volunteers in their areas and whether they are in ‘competition’ with other volunteering opportunities. They should aim to recruit volunteers from the range of ethnic and cultural communities that they serve. As with paid advocates, services can make volunteering more attractive if they offer flexibility of involvement and good support and supervision.

### What makes a good dementia advocate?

Advocates, whether paid or volunteers, need to be highly skilled individuals. Some people argue that: “...advocates are like teachers, they need to be born not made...”. There are undoubtedly personal attributes that make some people more suited to advocacy work than others. These attributes are important in the initial selection of potential advocates. However, there is much about being a good dementia advocate that can be learned if opportunities are provided for people to develop their knowledge and skills.

People with dementia who contributed to our work identified the following as the important attributes for advocates: good listening skills, knowledge about where to get information and knowledge about how to access the support and the services that people need. Box 4.3 summarises a wide range of views about the knowledge, skills and personal qualities needed by dementia advocates.

### Staff development

The training and development needs of dementia advocates vary depending on their prior experience,

education and training, and whether they are paid or volunteer workers.

### Training

Paid advocates, depending upon their qualifications and prior experience, may benefit from both initial and ongoing training. However, there are few training programmes available to assist new or established advocates in developing general advocacy skills or skills geared more specifically to dementia advocacy.

Volunteer advocates also generally welcome, and benefit from training. Most dementia advocacy services that use volunteers provide them with advocacy training including specialist input on working with people with dementia. One advocate commented that the nature of the work means that training is often necessarily intense. It is therefore important to pace training inputs to meet the needs and capacity of individual advocates, especially volunteers. Box 4.4 provides some ideas for an initial training programme for volunteer advocates. Such programmes may be provided ‘in house’ or by bringing in external trainers.

### Support and supervision

Dementia advocacy is a developing area and because advocates are in many ways ‘pioneers’ there is often a limited bank of established good practice knowledge on which they can draw. As one advocate explained:

“I don’t know if that’s the right way to do things – it’s uncomfortable, because I always feel I am trying to balance, go by the seat of my pants, just go with the flow.”

The uncertain and evolving nature of practice, makes it particularly important that time is allocated for advocates to have supervision and the opportunity to reflect on their work (see also Chapter 2). Supervision is important for other reasons too. First, in a context in which the ‘client’ may have limited ability to express views about the advocate’s work, it provides a mechanism of accountability<sup>23</sup>. Second, it helps advocates to deal with the stress that they can experience as a result of so often dealing with conflicts and distressing situations. Third, it helps counter the risk that advocates may become personally over involved in individual cases.

About two thirds of current services provide supervision for paid advocates at least monthly. Three quarters of services with volunteers provide supervision for these advocates. However, given that a volunteer will generally undertake much less

### Box 4.3 Skills and personal attributes of good dementia advocates

#### Knowledge/Understanding

- the nature of dementia;
- availability of local services and other resources;
- the operation and management of other services;
- the rights and entitlements of people with dementia;
- advocacy process;
- relevant health and social care policies and legislation;
- relevant service protocols;
- sources of information and advice and how to access them;
- family dynamics;
- social, cultural and ethnic diversity in the local community.

#### Skills

- ability to relate to people with dementia;
- ability 'to speak the client's language as well as the professionals';
- communication, including the ability to communicate at an emotional level, for example, through touch or smile;
- listening;
- insight and creativity in situations that can be very emotive;
- assertiveness to break into a professional culture in which it is often assumed that the professionals 'know best';
- diplomacy;
- ability to give feedback;
- ability to challenge;
- ability to negotiate;
- networking;
- ability to use humour to good effect;
- ability to maintain good relationships with professionals;
- ability to work for a client with dementia despite disagreeing with what the client wants;

- ability to recognise and act appropriately in relation to personal and professional 'boundaries';
- ability to maintain appropriate confidentiality and ethical practice;
- ability to gain the confidence and consent of the person with dementia;
- ability to handle conflict;
- ability to handle risk;
- ability to make written and oral presentations.

#### Personal Attributes

- holds the belief that with patience and determination it is possible to communicate with anyone with dementia;
- warm;
- tolerant;
- patient;
- sensitive;
- sense of humour;
- open and honest;
- committed to social justice;
- committed to empowerment of people with dementia;
- drive and energy;
- tenacious in the face of challenges;
- aware of own temperament;
- not unduly worried about how regarded by other people;
- no 'hang ups' about dementia;
- respects people with dementia as individuals;
- wants to work with people at all levels;
- strength of character;
- friendly;
- accepts criticism;
- tactful;
- flexible but clear where to 'draw the line'.

### Box 4.4 Initial training programme for volunteer dementia advocates

All volunteers would be required to complete the training programme, which might take around 4 days, and would generally be spread over a period of several weeks.

Topics covered would include:

- the principles and processes of advocacy;
- general communication skills;
- communication with people with dementia;
- the nature of dementia (including the progression of dementia and issues of mental capacity);
- understanding the experience of people with dementia and of living in different settings (for example, at home, in a care home or a hospital);
- understanding the experience of families and carers;
- understanding the experiences of people from ethnic and cultural minority communities;
- working effectively with other professionals and other service organisations;
- policies and procedures (national, local and own organisation);
- local services and resources;
- legal issues (including, for example, Court of Protection, Enduring Power of Attorney, relevant sections of the Mental Health Act 1983, the NHS and Community Care Act 1990 and the Human Rights Act 1998);
- ethical issues;
- boundary issues (including how to work constructively with service providers while enabling the person with dementia to make their own decisions; how to manage the advocacy role in working with family carers and other service providers; how to identify when advocacy should end).

The training programme would have to be made available flexibly to fit in with volunteer needs, circumstances and numbers. The programme should be viewed as the first step in an ongoing process of training and supported development.

advocacy than a paid worker, it is not surprising that in about half of these services supervision takes place less than monthly.

Supervision provides an opportunity for advocates to discuss cases and plan their work. It is important that advocates receive clear and appropriate feedback about their practice. This may be achieved in various ways, for example, by the supervisor discussing case notes with the advocate or by the advocate occasionally producing written accounts of the advocacy process for discussion with the supervisor. The supervisor's advice and comments may simply be made verbally, or may be confirmed in an agreed written checklist of follow up action.

Supervision is also very important in providing an opportunity to identify when it is necessary for the advocate, service co-ordinator or agency management to take up an issue at a general rather than individual level, perhaps by involving a higher authority in their own or other organisations (see Chapter 5).

Example 4.1 highlights the value of supervision in complex cases and Example 4.2 shows the importance of support for advocates working in stressful situations.

Advocates in different settings may have rather different supervision and support needs. For example, advocates who spend a lot of time working in isolation from peers, such as those based in hospital schemes, may need more support. It is therefore important that supervision and support is provided flexibly. One of the issues for advocacy services is who should provide the supervision. If an organisation does not internally have the required combined specialist skills in dementia care and in advocacy, it should consider making arrangements for externally provided supervision. One of our case study services, for example, used a manager to provide formal monthly supervision for advocates but also encouraged ad hoc support and supervision from colleagues and external support networks such as the Dementia Advocacy Network (see Appendix 2).

### Example 4.1 The value of supervision for dementia advocates

A dementia advocate is asked by a care manager to work with Mrs Chivers. The care manager is concerned that as Mr Chivers is becoming physically frailer, the couple are not able to care for themselves properly.

The couple's son and daughter-in-law live nearby but they resent the time that they have to spend visiting and sorting out practical problems for his parents. They are pressing for Mrs Chivers to be admitted to a care home after several incidents when she has been found by neighbours some distance from her home and unable to find her way back.

Mrs Chivers wants to stay in her own home. Her husband is not sure what to do for the best but is reluctant to disagree with his son. Relationships all round have become tense and the advocate's intervention is not welcomed by Mrs Chivers' son who considers that his mother cannot be adequately cared for by his father.

The advocate makes the point to the family that Mrs Chivers clearly wants to go out walking and that options should be considered to enable her to do this. After several fraught visits to the family during which the conflicting wishes of each member become more entrenched, the advocate finds it difficult to see how Mrs Chivers' wish to remain at home can be met and takes the problem to her supervisor. The supervisor suggests various approaches. Based on her discussion with her supervisor, the advocate talks to the care manager to see how Mr Chivers could be better supported with services to enable him to continue to care; and proposes use of a volunteer to accompany Mrs Chivers and prevent her getting lost when out walking.

### Example 4.2 The value of support for dementia advocates

A dementia advocate has been working with Mrs Adams, a resident in a care home, for some time. She feels she has come to know Mrs Adams well and is developing a good understanding of the issues on which she should be advocating on her behalf. Many of these issues are about Mrs Adams' finances and how she wants to leave her money when she dies.

Without any warning, Mrs Adams makes it clear that she has changed her mind about wanting advocacy. The advocate feels very discouraged and disappointed particularly since she has spent a long time working with Mrs Adams and has grown to like her very much. The advocate finds it useful to discuss how she feels about what had happened with her supervisor.

The supervisor is able to assess the advocate's practice and reassure her that there was nothing more that she could have done to sustain the advocacy relationship. The advocate manages to continue to visit other people in the home. She later learns that Mrs Adams has died. The advocate is very upset and in further discussion with her supervisor agrees that she would like some counselling on dealing with her strong feelings of loss. The counselling is provided by an external organisation as part of a standing arrangement with the advocacy service.

Other services have used group meetings and newsletters to help advocates to share experiences and ideas<sup>45</sup>. These examples highlight the

importance of peer support and external expert advice as means of developing practice in dementia advocacy services.

## CHAPTER 5.

# MANAGING AND DEVELOPING A SERVICE

### INTRODUCTION

This chapter addresses the tasks of managing activity and ensuring that services are underpinned by sound policies and procedures. It then considers some of the issues involved in developing dementia advocacy services, particularly the importance of working with other agencies. The chapter ends by outlining ideas about how services can undertake effective monitoring and review.

### MANAGING ACTIVITY

#### Access to the service

Most existing services are available all weekday office hours with small numbers also being open on some weekday evenings and occasionally at weekends. Since much advocacy takes place away from the advocacy office base (see Chapter 3) managers need to ensure that the pool of advocates available can realistically cover the geographical catchment area for the service.

Managers must also consider issues of equity of access for users in different service settings and for users from minority ethnic or cultural communities (see also discussion of referrals below).

#### Referrals

Dementia advocacy services generally have very open referral policies (see also Chapter 3). Almost all

existing services receive referrals from social services and from the NHS, and the vast majority of services also receive referrals from the private sector and from other voluntary sector organisations. Most services accept referrals from carers, relatives or friends of people with dementia. A high proportion of services, around 80%, accept self-referrals by people with dementia although we know that in practice this happens infrequently. Such an open referral policy needs to run alongside clear acceptance criteria. As one service explained:

“We accept referrals from anyone but there needs to be an issue to be addressed. It is not a befriending service. The worker uses casework procedures recording all meetings plus telephone conversations. Once the issue is resolved the case is closed.”

Referrals to dementia advocacy are often from professionals in other services, many of whom have little or no prior experience of advocacy services. They need clear information about when to refer to dementia advocacy and about the type of response that they and their clients can expect. Dementia advocacy services should have written information that they distribute to ‘advertise’ their services to local practitioners and that they provide in response to specific enquiries from prospective referrers. The topics that might be included are summarised in Box 5.1.

### Box 5.1 Information for referrers and other service providers

- A clear definition of the advocate’s role.
- Eligibility criteria for accessing the service.
- The hours of availability of advocates.
- The level and type of support available to the person with dementia.
- Guidance on when, where and how to refer and arrangements for informal discussion of potential referrals.
- The advocacy service’s code of conduct.
- The values and rationale underpinning the service.
- Examples of the type of circumstances in which advocacy can make an effective contribution.

Alongside formal referral procedures, it is useful to ensure that there are opportunities for professionals to have informal discussions with an advocate about the suitability of cases and the services that will be provided. Dementia advocacy services might also consider providing potential referrers with examples of successful advocacy to illustrate what can be achieved.

Experience suggests that good personal relationships with key people in other services are crucial in promoting referrals. For example, sometimes service co-ordinators and advocates are already known to potential referrers because they have previously worked with them or have been known to them in their role as a family carer. The existence of relationships of trust based on prior contact of this kind often make it easier to overcome any suspicions that might otherwise inhibit the uptake and development of the advocacy service. Services can capitalise on the opportunities provided by such relationships but also need to have other strategies to build up trust and rapport with potential referrers.

For hospital-based services there are often well established avenues by which to develop working relationships with other service providers and to pick up referrals from staff, carers and patients (for example, through attendance at ward rounds). Community-based advocacy services can also work proactively. Some services have found that preparatory contacts can be useful, for example, going into care homes to get to know the staff and residents and only gradually, when the time feels right, introducing the idea of advocacy for residents with dementia. Once professionals have experience of working with advocates and seeing clients benefit, then referrals are likely to flow more easily.

Since dementia advocacy services in practice rarely receive self-referrals of people with dementia, they need to take steps to avoid access to advocacy being effectively controlled by other services. In particular, they need to consider how they can make themselves as directly accessible as possible to potential service users. One option is for advocacy services to actively promote their work in settings where there are people with dementia who may benefit from their services.

Approaches that have been used to promote uptake of advocacy by people with dementia include providing ‘user friendly’ information leaflets (including leaflets in minority ethnic languages), informal talks or routine ‘social visits’ to day centres, memory clinics, old age psychiatry assessment wards and so on. One of our case study services, for example, has volunteer advocates visiting people in residential homes and the paid advocate doing a ‘drop in’ session at the local hospital. Service providers and users appreciate these regular visits and the advocate taking the time to explain the advocacy process. As a result the advocacy service is made more accessible to service users and the service itself benefits from having its referrals on a more secure and predictable basis.

Box 5.2 summarises suggestions for promoting referrals and uptake of the service.

### Caseloads

The service caseload in existing dementia advocacy organisations is generally quite modest; around three quarters of services have a current caseload of less than 20 and only a small number have an annual caseload of more than 100.

It can take some time for an organisation to establish the size of caseload that they can manage with their

## Box 5.2 Promoting referrals

- Capitalise on any pre-existing good relationships as a route into referring agencies.
- Undertake preparatory work to build good relationships with referring agencies.
- Provide good quality information to staff in other agencies about the process and benefits of dementia advocacy.
- Provide good quality, user friendly information to promote the service with potential users in a variety of community, day care, care home and hospital settings.
- Collaborate with other advocacy providers to increase general awareness and openness to advocacy amongst service practitioners and the local community.
- Ensure that you provide a high quality, professional service at all times.

existing resources. Experience suggests that it is better to build up gradually and to be cautious about taking on too many cases in the early months when attention to the depth and quality of the work is crucial. If services have to turn referrals away at this stage, they should explain clearly why they are doing this and encourage people to re-refer at a later date.

We have already noted that dementia advocacy can be very time consuming (see Chapters 2, 3 and 4). It is therefore important that services ensure that advocates have a manageable caseload. It is difficult to be prescriptive about the size of caseload that is appropriate; this will depend on the service setting, the user group, the type of problems that arise and, the style and skills of the individual advocate. So for example, an advocate working in a hospital setting may be able to cope with a larger caseload than an advocate working across a range of service settings in a large rural area.

It is clearly important that services make good use of their resources and optimise the number of cases they can handle. However, one of our case study sites pointed out the risks of advocates 'being spread too thinly'. Managers, therefore, need to be careful that numbers are not pursued at the expense of quality of service and pressure on advocates. Criteria, and a process, for prioritising referrals may be required. However, in prioritising referrals services need to take into account that the presenting issue may, on further investigation, prove neither to be the main, nor the only issue to be addressed.

We noted in Chapter 3 that, for a variety of reasons, advocates can find it difficult to close cases<sup>31,34</sup>.

If services are to maintain their ability to accept new referrals, they need a throughput of cases and hence policies and procedures covering case closure. These policies and procedures should be backed up by supervision and support for advocates in dealing with difficult 'endings' (see Chapters 2 and 4).

### Waiting lists

Waiting lists are clearly undesirable but they are sometimes inevitable given the difficulty of balancing supply and demand in services of this kind which have for example, unpredictable volunteer recruitment and uneven referral rates. However, only a small proportion of existing services operate a waiting list. The number of people on these waiting lists is usually small (six or less) with estimated waiting times usually of between one month and three months. 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.

### Management systems

The experience of our case study services suggests that advocates may not always share a management perspective on how to handle caseloads. In particular, there can be tension between a management interest and an advocacy interest. It is therefore important that these issues are discussed explicitly within the service and that advocates are involved in formulating service policies and procedures that keep the interests of the user in the forefront. Example 5.1 shows one approach to caseload management.

## Example 5.1 An example of a service caseload management system

In one community-based advocacy service, a referral sheet is completed which records every identified advocacy issue. The service manager, not the advocate, then prioritises each issue. The service manager and advocate discuss each referral and agree the issues to be tackled in each case. Cases are subsequently kept under regular joint review by the advocate and manager.

The service manager argues that this process helps to ensure that everyone referred, or referring themselves, to the service has an equitable chance of accessing an advocate. The process also helps to ensure that the advocate's time is spent on priority issues and not taken up disproportionately by a small number of clients with multiple, but less pressing, needs. Moreover, this system of every advocacy issue being assessed by someone not directly involved with the case, helps to protect the advocate from taking on too great a workload and overstretching themselves.

## POLICIES AND PROCEDURES

Dementia advocacy services require the usual range of statutory and ‘good practice’ policies and procedures that would be expected of any agency employing staff or using volunteers to provide services. For advice about these general requirements see Appendix 2 (Other useful organisations – General). There are, however, issues that arise in dementia advocacy that require particular attention.

First, given the innovative nature of many dementia advocacy services and the fact that many people are unfamiliar with this type of work, it is particularly important to develop policies and procedures, and public information, 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, there are the practice issues that we identified in Chapter 2 in relation to: consent, confidentiality and other ethical issues. It is essential that services have appropriate codes of conduct, staff education and training, and supervision arrangements to ensure sound ethical practice. For further guidance see Appendix 1.

Third, there are a range of issues related to the protection of clients who are particularly vulnerable. Policies and procedures are needed to check that people taken on to work with clients are suitable. Policies and procedures are also needed for handling any instances of suspected or actual physical, sexual, financial or emotional abuse. For further guidance see Appendix 1.

Fourth, there are some specific health and safety issues. Advocates often work on their own. They can find themselves working in highly emotive situations and are occasionally subject to verbal abuse and threatening behaviour. Services need to develop appropriate policies covering:

- training for advocates (for example, in de-escalation techniques);
- practical arrangements (for example, logging location, time and place of appointments and of the advocate’s return to base; also accompanying advocates in situations of particular risk);
- debriefing and support for advocates who have been involved in difficult encounters.

Fifth, there are potentially employment and disciplinary issues that need to be addressed. For example, procedures on how to handle an employee (or volunteer) who exceeds their role by pursuing

issues and making complaints about problems that have not been raised by clients.

Sixth, there are issues about maintaining boundaries in relation to advocates’ involvement in financial and legal matters that should be dealt with by other suitably qualified professionals. Some dementia advocacy services have links with legal firms who have specialist expertise in this field and to whom they can ‘signpost’ people with dementia and carers. These services suggest that this can lead to very effective joint working in which the advocate focuses on care needs and the solicitor works on legal and financial arrangements.

A list of some of the policies and procedures that dementia advocacy services need to develop is provided in Box 5.3.

## DEVELOPING THE SERVICE

The development of the service is primarily the responsibility of the organisation’s management group although in practice it often falls to the service co-ordinator to take on many of the practical tasks of service promotion and development. A pre-requisite of successful service development is ensuring that senior staff and first-line managers have sufficient dedicated time for this work.

Advocacy projects need to be aware of the service context in which they are working and tailor their ‘marketing’ and service development accordingly. We note in Chapter 3 that promoting uptake of a dementia advocacy service is generally much easier when a partnership of local agencies has been involved in establishing the service. If this type of partnership was not put in place, then new services need to give early consideration to how best to foster multi-agency management support for the development of their work. This is discussed in more detail below.

At the level of practice, experience suggests that it is difficult to extend and develop a dementia advocacy service in areas where practitioners in other services are resistant, or disinterested. Even when there is, in principle, interest in working with an advocacy service, it is difficult to promote advocacy with other services where there are chronic staff shortages and services operating in a crisis mode. It is easier for dementia advocacy providers to develop their work in areas where there is already a well-established, person-centred approach to working with people with dementia and where the professional and organisational culture is open to innovation and change. On all of these counts there can be

### Box 5.3 Some policies and procedures for dementia advocacy services

- Clear job descriptions and practice briefs for service co-ordinators and advocates.
- Protocol and information sheets on the service approach to working with people with dementia and carers.
- 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.
- Protocols covering relationships with other service provider agencies and how advocates work with their staff.
- Protocols covering relationships with other agencies providing advocacy to people with dementia in the same locality, particularly covering cross-referral procedures.
- 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 potential or actual abuse of clients.
- Equal opportunities policies and procedures.
- Health and safety policies and procedures.
- Policies and procedures to ensure service user feedback and involvement in shaping the service.

### Example 5.2 Influencing other services

One dementia advocacy service became aware that advocates regularly encountered people with dementia who had been admitted to hospital for assessment and then wanted to return home against professional advice. Despite their best efforts, the advocates' experience was that many of these people ended up in a care home. Sometimes the advocates were left feeling that they had achieved very little on the person's behalf and that this might be due to their ineffective practice.

Their service co-ordinator was able to assess the advocacy practice. He concluded that it was usually pressures and problems in the service system, rather than inadequate advocacy, that was preventing people with dementia who could manage at home from doing so.

The supervisor's first step was to support an experienced advocate in discussing these pressures and problems with the multi-disciplinary service team. When this proved to be ineffective in addressing the pressures and problems, the supervisor raised the issues with his manager in the advocacy agency who was then able to take it up with health and social services managers at a more strategic level.

considerable variation within and between agencies in any geographical patch. Managers of dementia advocacy services therefore would do well to identify local variations in factors that can promote and hinder the development of their services and to tailor their development strategies accordingly.

Management groups and service co-ordinators who are involved in service development will often find it useful to make links with other similar services to share experiences and learn from each other. Some services obtain advice and support as a result of being part of a larger advocacy provider, some services gain support from other advocacy organisations working in their locality and many (about 80%) have links with local or national advocacy networks. See Appendix 2 for contact details for advocacy networks.

### WORKING WITH OTHER AGENCIES

Dementia advocacy services and other agencies in their locality need to work together and to share responsibility for ensuring that dementia advocacy flourishes as a core component of the service system. For example, agencies should together consider issues of ease and equity of access, particularly how to ensure that dementia advocacy is readily available to those who need it. When advocacy services are limited, they may also have to jointly consider how best to prioritise use of these services.

Dementia advocacy services and other local agencies also need to work together particularly to ensure that the use of advocacy is widely valued and supported organisationally. This might involve, for example, health and social services organisations introducing routine consideration of the need for advocacy in community care assessments and care planning<sup>23</sup>. It certainly involves all agencies ensuring that their staff know that their organisation accepts and values advocacy and that there is no need, as happened in some of our case study sites, for them to refer anonymously to 'protect their own back'.

Dementia advocacy services learn a great deal about how people with dementia experience services. They often identify issues that can be more effectively addressed at a general rather than an individual level. They are, therefore, often well placed to contribute to service planning and development in their locality by identifying gaps in services. This is described in Example 5.2. Service commissioners and service providers often appreciate that advocacy services can play a significant role in helping them to be more responsive to what users want.

Some advocacy services take the view that their role is to work solely at individual case level, some think it appropriate for advocacy agencies to lobby more generally for better services and some are happy to become involved in the development or the provision of other services. By working in partnership with statutory sector agencies, dementia advocacy services may serve as valuable change agents. In addition, the advocacy service itself may benefit as the links with other services help raise its profile and support its development. However, there is a risk that if the advocacy service becomes too closely linked with other services this will compromise its independence. Advocacy services must, therefore, strike a careful balance between independence and collaboration in working with other agencies to improve service standards or develop new services. Suggestions about ways in which dementia advocacy services and other agencies can work together are provided in Box 5.4.

### MONITORING AND REVIEW

Monitoring and review arrangements are important for advocates, and for advocacy providing organisations, in assessing their performance and planning service developments. They are also important for advocacy service commissioners and funders. It is generally considered good practice for services to have ongoing systematic monitoring, to produce an accessible annual report and to be open to external, independent scrutiny and evaluation<sup>2</sup>. Existing dementia advocacy services clearly recognise the importance of monitoring and self-evaluation with approximately 60% having routine arrangements for this. Some services monitor their performance against a range of activity, quality and management targets that they set for themselves.

The experience of the case study services suggests that many dementia advocacy 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. They are also often realistic about what can be achieved and will therefore assess dementia advocacy services against 'good enough' criteria, (for example, that the service has a sound reputation and provides reliable quality) rather than a 'gold standard'.

Many people involved in dementia advocacy would argue that it is as important to have advocated for the person with dementia as it is for the advocate to have secured what the individual wanted. If services

### Box 5.4 Joint working with health and social care agencies to support and develop dementia advocacy

- Ensure that practitioners and managers in health and social care agencies understand the advocacy role.
- Provide opportunities for staff in health and social care agencies to meet with advocates to discuss shared issues; staff need to learn about advocacy and advocates need to be aware of the pressures on other service providers.
- Work with key organisations, statutory and independent, to develop support for dementia advocacy at management as well as practice levels.
- Understand the pressures and constraints on other services that may affect how they respond to dementia advocacy.
- Promote good relationships between advocates and key personnel in other agencies who can 'champion' the advocacy service. This should include agencies that work with minority ethnic and cultural communities.
- Identify services that already have a person-centred approach to dementia care and work with them as 'demonstration sites'.
- Build advocacy into the culture of health and social care agencies, for example, by having policies that promote the use of advocacy and require practitioners to routinely consider whether advocacy is needed.
- Empower practitioners in health and social care agencies to use advocacy services, this includes ensuring that they know about when and how to make referrals.
- Encourage referrals for advocacy before cases reach the point of crisis.
- Consider the development of referral policies, for example, routine referral of all clients with dementia who are subject to the powers of the Mental Health Act 1983, or facing major life changes such as giving up their own home.
- Develop policies and procedures in health and social care agencies covering the involvement of advocates (for example, the recording of advocacy involvement in case files, the sharing of information with advocates and so on).
- Encourage managers in health and social care agencies to use supervision to help staff to identify potential advocacy issues and to encourage them to make referrals.
- Monitor how staff in health and social care agencies refer to, and work with, advocacy services to identify issues, such as areas of under-use, that should be addressed organisationally.
- Establish inter-agency mechanisms at senior management level to discuss any general issues identified in the course of individual advocacy and to ensure that advocacy service planning and development is considered in the context of health and social care strategic planning.

adopt this perspective then they will have to ensure that their monitoring and review captures information about their advocacy processes as much as their outcomes.

Box 5.5 provides a list of some of the core areas that services should consider including in their monitoring and review arrangements.

Services may also find it useful to undertake more extensive self evaluation exercises<sup>23</sup>. An example of the approach taken by one case study site is provided in Example 5.3.

In presenting service reviews and self-evaluations to external audiences, dementia advocacy services should bear in mind that some people will have little idea about what the service involves. Services may, therefore, find it useful to produce case study reports to illustrate the nature of the problems they are working with, how they go about providing advocacy, the nature of their achievements and the challenges and difficulties that they encounter.

#### External evaluation

There are as yet few formal external evaluations of dementia advocacy<sup>34,45</sup>. With increasing policy

### Box 5.5 Suggested routine data for service monitoring and review

- Service activity:
  - number and sources of referrals;
  - uptake of referrals;
  - characteristics of user population (for example, age, gender, ethnicity);
  - reasons for referral;
  - nature of service provided;
  - duration of intervention;
  - referrals on to other services;
  - outcomes.
- Service quality:
  - the views of users;
  - the views of families and carers;
  - the views of referrers and other related service providers.
- Management:
  - staff numbers and changes;
  - volunteer numbers and changes;
  - consistency, completeness and quality of case records;
  - staff training;
  - training and supervision provided for other agencies;
  - publicity and information providing activities;
  - financial accounts;
  - development and implementation of standards and codes of practice.

### Example 5.3 An approach to service self evaluation

A dementia advocacy service that wanted to evaluate its work sought help from a local advocacy network that had expertise and resources available for the independent evaluation of advocacy projects. Questionnaires were prepared by the advocacy service in consultation with the network. Questionnaires were sent to carers and professionals who provided support for people with dementia who had had contact with the advocacy project. The advocacy service sent out the questionnaires (70 in total) but they were returned to the advocacy network office to be collated. This approach helped to maintain the independence of the evaluation by ensuring anonymity for respondents.

The questionnaires asked for people's views about: awareness of the dementia advocacy service, understanding of service aims, access to the service, frequency of contact with the service, reliability of the service, the advocate's communication skills, the level of support from the advocate, the advocacy outcome, the impact of the service on the person with dementia, the impact of the service on the way professionals in other agencies work.

People with dementia were encouraged by the advocate to contribute to the evaluation process by participating in an interview with an independent evaluator. In the event, for various reasons all declined to do so.

The questionnaire response rate was fairly low (just over 30%). However, the advocacy service was able to use the information collected to inform changes in the way it publicised its services, worked with carers and promoted professionals' understanding of independent advocacy.

emphasis on services being evidence-based, there is a great need for research that investigates the processes and outcomes of advocacy.

Dementia advocates, advocacy service managers and other services are often aware of the difficulties of evaluation. Advocates in particular are very conscious that dementia advocacy is a new area of practice and that it is sometimes difficult to know what it achieves. Many think it would be useful to evaluate their work and to clarify what makes for successful dementia advocacy.

The difficulties of evaluation are not peculiar to dementia advocacy services. Advocacy services generally have found it difficult to agree on definitions of advocacy, models of advocacy and standards that can serve as a basis for evaluation<sup>29,45</sup>. However, the evaluation of dementia advocacy brings additional challenges particularly because the person with dementia, with whom the advocate works, is often able to give little, or no, direct feedback on their experience of the advocacy process. One of the challenges for future research in the dementia advocacy field is to develop the methodology for service evaluation.

## CHAPTER 6.

# CONCLUSION

Dementia advocacy is in its infancy. However, changes in dementia care and more generally in user involvement in health and social care, are creating a favourable climate for substantial growth and development of dementia advocacy. We are now much more aware of the importance and the possibilities of people with dementia having a voice. It is therefore important that we learn all we can from the experiences of the people and organisations who have been innovators in this field.

This report has drawn on current experiences in dementia advocacy services and on related literature to provide many suggestions and some advice about good practice in dementia advocacy services. In summary, it suggests that those involved in setting up and providing dementia advocacy services need to:

- Start from a value base in which the individuality, dignity and self-determination of each person with dementia is central.
- Engage other local service stakeholders from the outset in setting up the dementia advocacy service.
- Recognise that it can take some time and considerable 'marketing' to establish dementia advocacy and promote its uptake amongst service providers, families and people with dementia, many of whom will be unfamiliar with its benefits.
- Have a clear philosophy and model of service that distinguishes advocacy from other forms of advice and support.
- Ensure that the service is equipped to address the needs of the diverse social, ethnic and cultural backgrounds of people with dementia in the locality.
- Invest in training advocates, paid and volunteer, to ensure they have the specialist knowledge and skills required for working with people with dementia.
- Demonstrate a robust value and ethical basis for practice underpinned by a framework of supporting policies and procedures.
- Work sensitively and constructively with the family members of people with dementia but be clear about the prime focus of the service being the person with dementia.
- Develop constructive relationships with other service providers based on mutual understanding and respect.
- Encourage a culture of reflective practice.
- Encourage advocates to learn from each other, within the organisation and by networking with other dementia advocacy services.
- Ensure that advocates, paid and volunteer, are well supported and supervised in dealing with the distress, conflicts and dilemmas that are integral to much dementia advocacy.
- Locate the service in organisational structures that provide management support without compromising the independence that advocates need.
- Provide opportunities for people with dementia, carers and advocates to contribute to the management of the service.
- Build on the strengths that the 'parent' organisation can provide but recognise, and act to address, any limitations or gaps in expertise in advocacy or dementia care.
- Ensure senior managers and first-line managers have dedicated time for promoting and developing the service.
- Work jointly with other local statutory and voluntary sector organisations to ensure that dementia advocacy and its development are embedded as a core component of the wider service system.
- Monitor, review and evaluate the service in ways that inform practice, operational management and service development.

This report noted at the outset that the evidence base for dementia advocacy is not well developed. If dementia advocacy is to flourish, we need to invest in research that advances dementia advocacy conceptually and practically. Thus, there is a need for research that will improve our understanding: of what people with dementia want from advocacy services and how they experience them; of the processes of advocacy; of the strengths and limitations of different models of advocacy; and, of the effectiveness of advocacy in giving people with dementia greater influence in the decisions that shape their lives.

It is only through improving our knowledge base in this way that we can ensure that we can aspire to develop the services that enable people with dementia to say "They hear what I say."

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## APPENDIX I

### FURTHER READING

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## APPENDIX 2 USEFUL RESOURCES ADVOCACY SUPPORT – GENERAL

Organisation	Contact	Comment
Advocacy Across London (AAL)	St Paul's Church Lorrimore Square London SE17 3QU ☎ 020 7820 7868 <a href="http://www.btinternet.com/~advocacyacrosslondon/index2.html">www.btinternet.com/~advocacyacrosslondon/index2.html</a>	A resource primarily for London. Supports existing advocacy groups and helps develop new ones. Website has useful information on advocacy in the United Kingdom and links to international projects. Publishes a quarterly magazine <i>Planet Advocacy</i> .
Advocacy Safeguards Agency	91 Hanover Street Edinburgh EH2 1DJ ☎ 0131 718 4373	Funded by the Scottish Executive Health Department to ensure that good quality and independent advocacy is available to anyone in Scotland who needs it.
Age Concern Advocacy Practitioners' Network	c/o Research and Development Unit Age Concern England Astral House 1268 London Road London SW16 4ER ☎ 020 8765 7200	Regular meetings for advocates working with older people.
Citizen Advocacy Information and Training	Unit 164 Lee Valley Technopark Ashley Road London N17 9LN ☎ 020 8880 4545 <a href="http://www.citizenadvocacy.org.uk">www.citizenadvocacy.org.uk</a>	Provides information and training on citizen advocacy.

**ADVOCACY SUPPORT – GENERAL cont.**

<b>Organisation</b>	<b>Contact</b>	<b>Comment</b>
Older People's Advocacy Alliance (OPAAL)	c/o The Beth Johnson Foundation Parkfield House 64 Princes Road Hartshill Stoke on Trent ST4 7JL ☎ 01782 844038 <a href="http://www.opaal.org.uk">www.opaal.org.uk</a>	Supports and promotes the development of independent advocacy for older people in the UK.
Scottish Human Services Trust	1a Washington Court Washington Lane EH11 2HA ☎ 0131 538 7718 <a href="http://www.shstrust.org.uk">www.shstrust.org.uk</a>	Works toward social inclusion. Site has a range of information about advocacy and a number of full text reports on advocacy in Scotland.
Scottish Independent Advocacy Alliance	138 Slateford Road Edinburgh EH14 1LR ☎ 0131 455 8183 <a href="http://www.siaa.org.uk">www.siaa.org.uk</a>	Replaced Advocacy 2000. Provides information, advice and support to local advocacy organisations; undertakes training on advocacy and related issues for agencies in the statutory and voluntary sectors; and ensures the 'voice' of the advocacy movement is heard at a national level to influence current and future practice and policy. Advocacy 2000 reports can be downloaded via the website.
National Advocacy Network	c/o Gateshead Advocacy and Information Network John Haswell House 8-9 Gladstone Terrace Gateshead NE8 4DY ☎ 0191 478 3130	Works with national, regional and local advocacy groups to establish and promote supportive and strategic networking.

## DEMENTIA ADVOCACY SUPPORT

Organisation	Contact	Comment
Dementia Advocacy Development Project	Dementia North Allendale House Northumbria University Coach Lane Campus Newcastle upon Tyne NE7 7XA ☎ 0191 215 6110 A specialist website will be launched in Summer 2003	New project providing tailored dementia advocacy practice, service commissioning and management support and advice to planned, developing and established projects. The project runs learning networks, training events and publishes regular newsletters on dementia advocacy.
Dementia Advocacy Network	Westminster Advocacy Service for Senior Residents 55 Dean Street London W1V 5HU ☎ 020 7439 3131	Meets regularly to share information on dementia advocacy.
Dementia Advocacy and Support Network International	DASN International P.O. Box 1645 Mariposa California USA 95338 <a href="http://www.dasninternational.org">www.dasninternational.org</a>	An organisation run for and by people with dementia and their trusted supporters.

**OTHER USEFUL ORGANISATIONS – GENERAL**

<b>Organisation</b>	<b>Contact</b>	<b>Comment</b>
Age Concern	Age Concern England Astral House 1268 London Road London SW16 4ER ☎ 020 8765 7200 <a href="http://www.ageconcern.org.uk">www.ageconcern.org.uk</a>	Provides a national information line for older people and their concerns.
Help the Aged	St. James's Walk Clerkenwell Green London EC1R 0BE ☎ 0207 278 1114 <a href="http://www.helptheaged.org.uk">www.helptheaged.org.uk</a>	Develops practical solutions in partnership with older people. Offers free advice through Senior Line 0808 800 6565 and via information leaflets.
Action on Elder Abuse	Astral House 1268 London Road London SW16 4ER ☎ 020 8765 7000 <a href="http://www.elderabuse.org.uk">www.elderabuse.org.uk</a>	Provides help and information to all concerned about the abuse of older people. Freephone Helpline 0880 8808 8042.
Centre for Policy on Ageing (CPA)	19–23 Ironmonger Row London EC1 3QP ☎ 020 7553 6500 <a href="http://www.cpa.org.uk">www.cpa.org.uk</a>	Promotes awareness of the needs of older people through the spread of good practice, research and information.

## OTHER USEFUL ORGANISATIONS – GENERAL cont.

Organisation	Contact	Comment
Ethicists and Practitioners in Collaboration on Capacity (EPICC)	Centre for the Study of Global Ethics School of Public Policy The University of Birmingham 13 Pritchatts Road Edgbaston Birmingham B15 2QU ☎ 0121 693 4678 <a href="http://www.globalethics.bham.ac.uk/epicc/">www.globalethics.bham.ac.uk/epicc/</a>	A project to develop new ethical approaches to the assessment of decision-making capacity in mental health practice. There are useful legal links from their website.
Institute of Mental Health Act Practitioners (IMHAP)	<a href="http://www.markwalton.net">http://www.markwalton.net</a>	Promotes good practice in the implementation of the Mental Health Act. Website has useful information and links on human rights and on consent and capacity.
Lord Chancellor's Department	Selbourne House 54–60 Victoria Street London SW1E 6QW ☎ 020 7210 8500 <a href="http://www.lcd.gov.uk">www.lcd.gov.uk</a> <a href="http://www.lcd.gov.uk/family/mi">http://www.lcd.gov.uk/family/mi</a>	Website section on 'Family and Individual' matters has up to date guidance on mental incapacity and good links to other resources.
Mind (National Association for Mental Health)	15–19 Broadway Stratford London E15 4BQ ☎ 020 8519 2122 <a href="http://www.mind.org.uk">www.mind.org.uk</a>	Provides information and support on mental health issues.

**OTHER USEFUL ORGANISATIONS – GENERAL cont.**

<b>Organisation</b>	<b>Contact</b>	<b>Comment</b>
Mental Health Foundation	83 Victoria Street London SW1H 0HW ☎ 020 7802 0300 <a href="http://www.mentalhealth.org.uk">www.mentalhealth.org.uk</a>	Uses research and practical projects to help people survive, recover from and prevent mental health problems. See <a href="http://www.mhills.org">www.mhills.org</a> for information and support on mental health in later life.
Mental Welfare Commission for Scotland	K Floor Argyll House 3 Lady Lawson Street Edinburgh EH3 9SH ☎ 0131 222 6111 <a href="http://www.mwscot.org.uk">www.mwscot.org.uk</a>	An independent organisation protecting the welfare of people with mental health needs, including dementia. Their website has information on current legislation and useful links to organizations and reports.
Mental Health Act Commission	Maid Marian House 56 Hounds Gate Nottingham NG1 6BG ☎ 0115 943 7100 Fax: 0115 943 7101 <a href="http://www.mhac.trent.nhs.uk/">http://www.mhac.trent.nhs.uk/</a>	Safeguards the interests of all people detained under the Mental Health Act 1983.
National Council for Voluntary Organisations (NCVO)	Regent's Wharf 8 All Saints Street London N1 9RL ☎ 020 7713 616 <a href="http://www.ncvo-vol.org.uk">http://www.ncvo-vol.org.uk</a>	Provides comprehensive information on voluntary sector issues including policy, funding, charity law and financial management.

## OTHER USEFUL ORGANISATIONS – GENERAL cont.

Organisation	Contact	Comment
Social Care Institute for Excellence (SCIE)	1st Floor Goldings House 2 Hay's Lane London SE1 2HB ☎ 020 7089 6840 <a href="http://www.scie.org.uk">http://www.scie.org.uk</a>	Includes gateway to eLSC (the electronic Library for Social Care) and Caredata which enable on line access to extensive abstracts of relevant social work and social care literature.

## OTHER USEFUL ORGANISATIONS – DEMENTIA

Organisation	Contact	Comment
Alzheimer Scotland – Action on Dementia	22 Drumsheugh Gardens Edinburgh EH3 7RN ☎ 0131 243 1453 <a href="http://www.alzscot.org.uk">www.alzscot.org.uk</a>	Provides services and campaigns to help people with dementia, their families and carers.
Alzheimer's Society	Gordon House 10 Greencoat Place London SW1P 1PH ☎ 020 7306 0606 <a href="http://www.alzheimers.org.uk">http://www.alzheimers.org.uk</a>	Main care and research charity for people with dementia, their families and carers in England, Wales and Northern Ireland.

**OTHER USEFUL ORGANISATIONS – DEMENTIA cont.**

<b>Organisation</b>	<b>Contact</b>	<b>Comment</b>
Bradford Dementia Group	School of Health Studies University of Bradford 25 Trinity Road Bradford BD5 0BB ☎ 01274 236367 <a href="http://www.brad.ac.uk/acad/health/bdg">www.brad.ac.uk/acad/health/bdg</a>	Undertakes training and research to promote understanding and care approaches that improve quality of life and care for people with dementia and their families.
Kingshill Research Centre	Victoria Hospital Okus Road Swindon SN1 4JN ☎ 01793 481 182 <a href="http://www.kingshill-research.org">www.kingshill-research.org</a>	Produces high quality research information for use in the development of new treatments.
<b>Dementia Services Development Centres Network</b>		<b>Each centre provides support and information in a specified geographical area on all aspects of dementia service provision to commissioners, service providers and policy makers.</b>
<b>England</b> Dementia North	Allendale House Northumbria University Coach Lane Newcastle upon Tyne NE7 7XA ☎ 0191 215 6110	

**Dementia Services Development Centres Network cont.**

North West Dementia Centre	<p>Dover Street Building University of Manchester Oxford Road Manchester M13 9PL ☎ 0161 275 5682</p>	
Trent DSDC	<p>Department of Psychiatry for the Elderly Leicester General Hospital Leicester LE5 4PW ☎ 0116 273 013</p>	
Dementia Plus (West Midlands)	<p>Warstones Resource Centre Warstones Drive Wolverhampton WV4 4PG ☎ 01902 575056 <a href="http://www.wmpmh.org.uk/dementiaplus/">http://www.wmpmh.org.uk/dementiaplus/</a></p>	
London Centre for Dementia Care	<p>Department of Psychiatry and Behavioural Sciences University College London Wolfson Building 48 Riding House Street London W1N 8AA ☎ 020 7679 9588 <a href="http://www.ucl.ac.uk/~rejumlj">http://www.ucl.ac.uk/~rejumlj</a></p>	

**Dementia Services Development Centres Network cont.**

<p>Dementia Services Development Centre South East</p>	<p>Canterbury Christ Church University College Canterbury Kent CT1 1QU ☎ 01227 782702</p>	
<p>Oxford Dementia Centre</p>	<p>Institute for Public Care Roosevelt Drive Headington Oxford OX3 7XR ☎ 01865 761815 <a href="http://www.brookes.ac.uk/schools/social/dementia/index.htm">http://www.brookes.ac.uk/schools/social/dementia/index.htm</a></p>	
<p>Dementia Voice</p>	<p>Blackberry Hill Hospital Manor Road Fishponds Bristol BS16 2EW ☎ 0117 975 4863 <a href="http://www.dementia-voice.org.uk">www.dementia-voice.org.uk</a></p>	
<p><b>Scotland</b> Stirling DSDC</p>	<p>University of Stirling Stirling FK9 4LA ☎ 01786 467740 <a href="http://www.stir.ac.uk">www.stir.ac.uk</a></p>	

**Dementia Services Development Centres Network cont.**

<p><b>Wales</b> Wales DSDC – South</p>	<p>Practice Development Unit Whitchurch Hospital Cardiff CF14 7XG ☎ 02920 336073 <a href="http://www.bangor.ac.uk/dsdc">www.bangor.ac.uk/dsdc</a></p>	
<p>Wales DSDC – North</p>	<p>Neuadd Arduwly University of Wales Bangor Holyhead Road Bangor LL57 2PX ☎ 01248 383719 <a href="http://www.bangor.ac.uk/dsdc">www.bangor.ac.uk/dsdc</a></p>	
<p>Ireland</p>	<p>Dementia Services Information and Development Centre Top Floor Hospital 4 St James's Hospital James's Street Dublin 8 Ireland ☎ 3531 4162035 <a href="http://www.dementia.ie">www.dementia.ie</a></p>	

**DEMENTIA JOURNALS**

<p>Journal of Dementia Care</p>	<p>Hawker Publications                  Culvert House                  Culvert Road                  Battersea                  SW11 5DH                  ☎ 020 7720 2108  <a href="http://dementia.careinfo.org">http://dementia.careinfo.org</a></p>	<p>A multi-disciplinary journal aimed at all people working with dementia.</p>
<p>Dementia: The international journal of social research and practice</p>	<p>Sage Publications                  6 Bonhill Street                  London EC2A 4PU                  ☎ 020 7330 1266  <a href="http://www.sagepub.co.uk">www.sagepub.co.uk</a></p>	<p>An academic journal that provides good multi-disciplinary cover of practice issues and developments.</p>



