FINAL REPORT:

A PROJECT TO VALIDATE GUIDELINES WHICH SEEK TO INVOLVE LAY CARERS OF PEOPLE WITH DEMENTIA IN CARE PLANNING PROCESSES

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The Project Team
CHAPTER 1

INTRODUCTION

1.1. Summary of the project

This project was carried out by members of staff in the Department of Health and Nursing at Queen Margaret University College (QMUC) and completes the first phase of a comprehensive study which plans to facilitate involvement of carers in the processes of care planning for people with dementia.

The present project, which began in April 2000, has developed and refined previously generated guidelines (Walker et al. 1999). Walker et al.’s qualitative research study identified factors that inhibit carer involvement in care planning for people with dementia admitted to hospital. Resulting guidelines (Appendix 1) aimed to facilitate better involvement of carers in care planning processes for people with dementia when in hospital. The present project has involved carers in validation processes to ensure that these guidelines are relevant and appropriate for use in hospital and community settings.

Involving carers in this project has been essential, as this has enabled their expertise to influence validation processes and ensure resulting guidelines
are fit for their purpose in a variety of settings – home, day care, respite, and hospital. Building on carers’ in-depth and personal perceptions of their situation has informed a more person-centred approach to inquiry which we believe has been mutually beneficial for carers as well as the project team. Working alongside carers has reflected a developing partnership that has enabled carers to assert their needs. Articulation of these needs are reflected in the refined guidelines which, when implemented in various care settings, will have an impact on the decision making processes undertaken when planning care for the person with dementia.

Validity of the guidelines was further enhanced through dissemination processes. These dissemination meetings with different health care representatives, confirmed the importance and relevance of the guidelines, but highlighted issues regarding the ease with which they could be implemented. Dissemination of these guidelines is still ongoing, as political and educational organisations still need to be targeted. This report will outline dissemination work still outstanding in this area.

Further work is now needed to evaluate implementation of the guidelines in various care areas. Funding is currently being sought for this final phase of the study, which addresses implementation of these guidelines in practice through a programme of Work Based Learning (Dewar & Walker 1999). The outcome of this final phase of the project will further validate the guidelines by triangulating carers’ and health care professionals’ perspectives.
This final validation process will also increase current knowledge relating to complex processes inherent in implementing research in practice through collaboration. This secondary benefit to knowledge development was initiated by Walker et al.’s (1999) experiences of promoting collaborative inquiry, and is further highlighted in this report by reflecting on our experience of working alongside carers.

1.2. The project’s aims:

The primary purpose of this recently completed project, funded by the Foundation of Nursing Studies, was to:

• emphasise the importance of collaboration in care planning between lay carers and health professionals;

• inform policy at local and potentially national level to directly influence principles of good practice;

• generate further knowledge to augment debate surrounding qualitative processes of inquiry.

The specific objectives were:

• To evaluate the relevance of the guidelines to carers of people with dementia.
• To differentiate between the degrees of relevance of guidelines for carers at different stages of the caring continuum.
• To explore the guidelines fitness for purpose in various community and hospital settings
• To disseminate together with core groups of carers revised guidelines to carer organisations, local education institutions and local Trusts

1.3. Justification for guidelines

These guidelines which are consistent with Government initiatives, such as those outlined in ‘Designed to Care’ (Scottish Office 1998), emphasise the importance of stakeholders’ involvement in decisions regarding the provision of health care services

However, traditional ways in which decisions about care for people in society are made reveal how power and prestige is socially constructed through the conferring of titles such as ‘professional’. Professionals are recognised as possessing specialised expertise derived from education, training and experience. Their specialist knowledge underpins the authority which legitimises their decision making powers, delineating them from other groups in society.

However, current thinking challenges this perspective by questioning:
• Who is best placed to really know the person with dementia: professional workers or lay carers?
• How can health and social care professionals use carer expertise more effectively to achieve a more ‘person centred’ approach to care giving?

Promoting a partnership of carer and professional expertise enables better communication of care that will directly impact on the quality of care the person with dementia receives. It also ensures that decisions made in care planning are shared. This process of inclusion, it is envisaged, enhances the care given to the individual with dementia, as it is founded on person-centered principles. This project is underpinned by this perspective.

1.4. Background to the project

Walker et al.’s study (1999) identified factors that inhibit carer involvement in care planning: for example, lack of communication, lack of agreed agendas, and lack of recognition of carers’ expertise. The carers who were interviewed in Walker et al.’s study suggested four markers of satisfactory involvement:

1. feeling that information is shared
2. feeling included in the decision making process
3. feeling that there is a contact person available
4. feeling that the service is responsive to their needs.
What constitutes a satisfactory level of involvement will vary from individual to individual. Therefore, a fundamental way of facilitating carer involvement, is for nurses and carers to openly discuss and negotiate a framework within which involvement can operate firstly in a way that they both feel comfortable with, and secondly in a way that endorses the principles of good practice already established (see Callery & Smith 1991, Kenny 1990). This process needs to be supported by the organisational and professional structures within which nurses practice (Kirk 1998).

Importantly, if there are no agreed objectives for carer involvement (as is currently the case), then there is no basis on which it can be evaluated, either by the carers themselves or by nursing staff and management. Such evaluation provides opportunities for practice and service development as well as for assuring the quality of care (see Nolan & Grant 1993).

Since the early eighties, researchers, carers’ organisations and other interested groups have argued for the need for change within the NHS and community care services to value and provide adequate support for carers. By investigating the concept of carer involvement in one hospital setting, Walker et al.’s study enabled a deeper exploration of some of the main issues highlighted repeatedly in the literature, in particular, the lack of information given to carers and their exclusion from the decision-making
process. A greater understanding of the barriers to involvement provided Walker et al. with the means to begin to develop some very practical and realistic strategies to improve and extend carers’ involvement – namely, generation of guidelines to facilitate carer involvement.

This project is directly related to the Walker et al.’s (1999) research, and as such, emphasises the team’s belief in the importance of implementing research findings into practice.

1.5. The project team’s philosophy

It was important in this project to hear the voices of carers since this was consistent with the general philosophy of valuing differing perspectives in the care planning process. In practice, this entailed carers reviewing original guidelines, feeding back their subsequent opinions through focus group discussions, checking out the newly reconstructed guidelines for personal relevance and getting involved in dissemination activities. Figure One (page 9) shows the development of the process of collaboration and the ongoing inclusion of feedback from the various groups of carers allowing the development of the final guidelines. Analysis of the information and feedback gained from the focus groups in workshop 1 was included in the second workshop as a way of confirming the data. Similarly, feedback from workshop 2 fed into the dissemination meetings allowing for verification by the health care professionals.
Each set of feedback situations directly linked into the amendment of guidelines and confirmation by carers of the validity of those guidelines for their own situations as well as the global reality for carers. These double loop mechanisms ensured the reflexivity of the process of devising the guidelines and placed value on all contributions throughout the project in the production of the final guidelines.
Figure 1: Diagrammatic representation of the collaborative process.

- Development of draft guidelines
- Carers workshop 1
  - Focus Group
  - Focus Group
  - *Reflexive commentaries*
- Carers workshop 2
  - Focus Group
  - Focus Group
  - *Reflexive summary*
- Amended guidelines
- Individual Carer review for validity of guidelines
- Dissemination meeting 1
- Dissemination meeting 2
- Refinement of guidelines
- Final guidelines agreed
This process of validating the guidelines required a collaborative approach. Encouraging and sustaining collaboration was not a straightforward process. Describing in a clear and concise way what we did and how we did it does not capture the complexities inherent in collaborative inquiry. Challenges we had in establishing and maintaining partnerships are addressed in detail in Chapter 4, and reflect our concerns regarding carers' high expectations of the project, and the team’s belief and trust in qualitative processes (particularly in focus group discussions). We have given detailed descriptions of these challenges and outlined how we overcame them. This is done for several reasons.

1. To demonstrate our commitment to working with rather than on people.
2. To reveal to others interested in this way of working complexities inherent in this process.
3. To ensure that the processes of collaboration and validation are transparent to others.

1.6. Structure of the report

This report will give a detailed description of how we validated and refined previously generated guidelines which we believe will facilitate carer involvement in decision making processes for people with dementia, irrespective of care setting or level of carer involvement in care delivery.
Chapter 2 sets the guidelines in the context of the current political and professional emphasis on user involvement. The literature reviewed in this chapter identifies the gap between policy and practice in relation to carer involvement.

Chapter 3 gives a detailed account of methods used, including how we carried it out, and the problems we encountered in accessing a sample group.

Chapter 4 explores the issues embedded in collaborative processes and demonstrates how our beliefs and values in qualitative approaches were put to the test. This chapter also reveals how the differing agendas between carers and project team members (in relation to the project’s purpose) were managed. Issues regarding dissemination are also addressed, with respect to accessing relevant health and social care workers, despite the fact that no comprehensive database exists.

A comprehensive description of each guideline, with an accompanying rationale is detailed in Chapter 5. The rationale was derived from discussion with the carers in focus groups and follow up telephone calls.

In Chapter 6 we summarise our experiences and findings from the project, and make recommendations for enabling implementation of each guideline.
Specific considerations are made for practitioners, policy makers, educators and managers.
CHAPTER 2

THE GUIDELINES IN CONTEXT

2.1. Political justification for user ‘involvement’

For the last fifteen years, a central theme of government health care policy has been to encourage the health service to change the way it relates to those who use it. Recent health policy documents (Our National Health: A Plan For Action, A Plan For Change, Scottish Executive 2000, Designed to Care, Scottish Office 1998: Making it Work Together, Scottish Executive 1999, Making a Difference, Department of Health 1999) emphasise a move away from competition to a more integrated way of working that reflects co-operative partnerships. The overall aim underpinning these changes is to implement clinically effective methods which improve the care patients, and their families, receive. The net effect should be the creation of a health service which is accountable to its users and is responsive to their needs. Implementing such initiatives on a day-to-day level means that users will retain greater control over what happens to them, reflecting user autonomy advocated by strategies such as ‘clinical governance’ and ‘clinical effectiveness’.
Good quality patient care resides in a health care system which actively involves service users both in policy development and in decisions relating to their own care (Scottish Executive 2000). As a result, there has been considerable change in the way that service users are perceived within the NHS and related health and social services. The role of ‘patient’ has been redefined from that of passive recipient of care to that of responsible and active participant in care. In part, this change was stimulated by a development within nursing philosophy away from the medical model towards holistic care which requires that patients be treated as individuals (Davies et al. 1997). An allied belief is that an empowered patient who is involved in decisions regarding their own care benefits physically and psychologically: thus, empowerment and involvement are linked to quality care (Sheppard 1994).

Involving service users in decision-making, then, fulfills two purposes: it benefits the users themselves by ensuring good quality care services that are responsive to their needs; it also benefits health services by enabling them to set and maintain high standards of care.

### 2.2. Problems with defining involvement

Numerous policy documents make reference to the concept ‘involvement’, for example the Patients Charter states that:
You are entitled to be involved so far as is practical in making decisions about your own care, and wherever possible given choices...From April 1992, all hospitals and other health care providers will be required to involve patients (Department of Health 1991: p. 6) (emphasis added).

Although the Patient’s Charter identifies involvement in decision-making and the provision of choice as an entitlement, it clearly indicates that this entitlement operates under certain conditions. Who is to determine whether it is practical and possible to meet this entitlement? Presumably, it is the health care professionals who should do so. What are the conditions under which they can legitimately withhold this entitlement? Can patients expect to be involved in all decisions relating to their care, or are there exceptions?

There are no guidelines to advise either health care professionals or service users on good practice relating to ‘involvement’.

An important consequence of this situation is that service users (be they patients or informal carers) are subject to health care professionals’ perceptions of how and when they should be involved. This undermines, rather than supports, the autonomy and empowerment of service users (Davies et al. 1997). For example, there is some evidence that older people tend to be more passive and dependent than their younger counterparts when it comes to receiving health care, preferring to leave decision-making to medical and nursing staff (Barder et al. 1994, Waterworth & Luker 1990). Such individuals may find themselves feeling pressurised into a greater
level of involvement than they are happy with because health care professionals consider it to be beneficial (Waterworth & Luker 1990).

Clearly, carers should have an opportunity to establish, in partnership with health care professionals, the level of involvement they want (Waterworth & Luker 1990). With the care of their loved ones at stake, relatives may well find it difficult either to refuse to help or to complain that they had been asked in the first place. They may have concerns that their questions or worries may make no difference to the quality of care that is given, or worse still, may have detrimental consequences for the care their relative receives (Hertzberg & Ekman 2000).

Perhaps then, carers may need to learn how to be involved in formal care processes. How can they become empowered, and how can this learning process be facilitated by health care professionals, most appropriately perhaps, by nursing staff? One way may be for staff to actively encourage relatives to come forward with questions and suggestions. Sheard (1998) and Hertzberg and Ekman (2000) advocate the use of a ‘contact person’ for carers:

*It must be an advantage to assign one or two staff members as contact persons for the resident and relative. Another likely effect of having contact persons is the staff’s willingness not only to recognize the value of the relatives knowledge about the patient but also to accept their involvement in the care* (Hertzberg & Ekman p. 620)
(The notion of a ‘contact person’ was core for carers in Walker et al.’s (1999) research and receives further attention in Chapter 4 of this project).

Hansebo et al. (1998) suggest that relatives could be an active part of the assessment process and so be involved in care in a natural way, as relationships tend to be more equal and relaxed when relatives and nursing staff do things together.

Finding ways to involve users of the health service in decisions about care planning are endorsed through professional guidelines (e.g. UKCC 1997, 1998). Where carers provide home based care (as in the case of dementia) their involvement in decision-making and their access to information about their relative’s care is essential to ensure that their caring role is supported by professional care rather than undermined by it.

2.3. The reality of involvement for carers

According to Hertzberg and Ekman (2000), the contributions a patient's family makes to care processes are not formally recognised or recorded, hence there is a dearth of information pertinent to the roles and responsibilities family members have in the care of their relative. However, the literary evidence that does exist suggests that the needs of carers are,
on the whole, neglected by both community and hospital based services (Hertzberg & Ekman 2000; Walker et al. 1999; Warner & Wexler 1998).

Warner and Wexler (1998) in their survey of 1,346 carers concluded:

[carers] are seldom consulted – even on such basic issues as the hospital discharge of the person they care for. Training is not automatically available as it would be for a paid social or health care worker undertaking similar tasks. Frequently, nobody stops to ask them if they can cope. The report reveals that carers are taken for granted and left to get on with it. (p3)

Carers’ organisations stress the consequences of this neglect of voluntary carers for the future of the NHS and Community Care (Carers National Association 1998). The unpaid work of approximately six million carers in the UK saves the Government an estimated £34 billion a year (Warner & Wexler 1998). Should the capacity to provide quality community care depend on the continued goodwill and good health of these people?

Walker et al.’s study (1999) identified factors that inhibit carer involvement in care planning. These factors include lack of communication, lack of agreed agendas and lack of recognition of carers' expertise. Although carers in this study were involved in decisions relating to care planning in hospital, the level and nature of such involvement tends to depend on the practice of individual members of nursing staff. As no agreed set of principles and procedures for involving carers exist, opportunities for involvement depended on the assertiveness and pro-action of carers rather than on the initiative of nursing staff. Opportunities for involvement then are
only open to those who can clearly communicate their wish to be involved in decisions about care.

This observation supports findings from other studies which identify that it is the relatives who have to take the initiative and responsibility for establishing contact: (Collier & Schirm 1992, Duncan & Morgan 1994). Despite the fact that it ought to be the responsibility of the staff to provide information, relatives must be active in seeking this out for themselves. Hertzberg and Ekman (2000) qualitatively describe eighteen interactions between the relatives (of older people with dementia) and nursing home staff. Although both relatives and staff are of the opinion that information is forthcoming, it is only done so if nursing staff perceive this to be ‘essential’.

You have to find out every little thing for yourself. I thought they would attend to things like that but you have to find out everything by yourself. It is so annoying. (p. 619)

Relative’s comment

Rather than having an appointed time to talk to staff when they visited or having staff approach them for an informal chat (something that happened infrequently) relatives felt:

the nurses are always in such a hurry. They never speak personally with you. (p. 619)

This lack of communication between carers and health professionals was identified by Walker et al. (1999) as being a key impediment to carer involvement. More specifically there was no opportunity for carers to
discuss explicitly with nursing staff (or other health professionals) what potential there was for involvement and what level of involvement they wanted.

However, a perception that ‘involvement’ in care equates with ‘information giving’ is evidence of a paternalistic profession. Being the recipient of information, selectively given, denotes a lack of involvement and so disempowerment, as carers’ passivity indicates they are seen as no more than a ‘backcloth’ to nursing processes (Robinson 1994). Their expertise is not acknowledged or valued, and consequently, what they have to say is not given serious attention.

An additional problem for carers (as highlighted by Walker et al. 1999) is that the term, service user, tends to be levied at patients, and so it is the patient who is seen as the focus for involvement, not the carer of that patient. Consequently, carers are not really ‘seen’ by professionals as legitimate experts who have something tangible to contribute to care planning. This has implications for the building up of trust between relatives and staff – an essential factor for the promotion of carers’ well being and, according to Pask (1995), central to all interpersonal relationships.
The conclusion which researchers draw repeatedly when investigating this area is that carers’ needs and expertise are neither sufficiently acknowledged by health care professionals, nor adequately addressed.

2.4. Carers as experts

Personal accounts of what it is like to have dementia or to care for a relative with dementia help raise public awareness of this condition (for example Bayley 1998, Davis 1989, Grant 1998). Dementia presents a unique challenge to those who care for the person with dementia (Martin & Post 1992). Physical changes to the brain cause behavioural and personality changes which can be rapid but can also be interspersed with periods of lucidity. Consequently, a sense of having lost one’s self can be fundamental to the experience of dementia. In particular, the individual begins to lose their cognitive and rational capability and, with that, their ability to be autonomous (Post 1995). For this reason:

> care for the demented individual is not just sustenance of the individual’s body, but protection of the person. The values, choices, and dignity of the demented are also vulnerable to harm or neglect (Martin & Post 1992, p. 59).

Dementia care needs to respect and endorse the personhood of the individual (Kitwood 1997, Kitwood & Benson 1995) and ensure that the decisions made in relation to their care are morally defensible (Dresser 1992).
These studies demonstrate the vital importance of incorporating the carer’s knowledge of the individual with dementia into processes of planning care. The knowledge family carers possess can never be known by professionals. Intimate knowledge of the individual with dementia reveals critical signals to the carer that other professionals may neither see nor acknowledge. If professionals were willing to learn from carers the significance of these ‘critical concerns’ (Hertzberg & Ekman 2000), the all too familiar crisis situations that influence the quality of life for the person with dementia, and their carer, could be averted.

2.5. Barriers to carer involvement

As far as the involvement of carers in decision-making is concerned, the literature highlights two significant factors, within the current hospital environment, which can be obstructive:

(i). The attitude of professionals.

Willis 1989 and Friedson 1984 (cited in Gair & Hartery 2001) identify medical dominance as a structural feature of health care systems in western society. Displays of dominance include professional autonomy of doctors, control over patients and subjugation of professional status of other
health care workers - notably nursing staff (Bucknall & Thomas 1997).

Dissatisfaction with inter-professional inequality is demonstrated in professionals' lack of acknowledgement of patients' and families' expertise. Or, if expert knowledge is exhibited by those carers who are proactive, then often professionals feel threatened (Keady & Nolan 1994, Olsen et al. 1997). This lack of acknowledgement is perpetuated by a deeply rooted and socially constructed belief regarding the acquisition of expertise.

Although carers themselves may recognise they are experts, this expertise is acquired informally, through day to day experiences and taken-for-granted knowledge. Whereas professionals, because of their access to specialist formal education and training, are legitimately labeled by society as having expert knowledge. These traditional perceptions of professional and lay carers' roles exacerbate carers' hesitation in asserting their expertise, especially as health professionals have been exposed in harbouring prejudices about older people and their capacity to be consulted as experts (McGowan & Braithwaite 1992).

This socially constructed division in perceived expertise between professionals and lay carers legitimates decision-making power and consequently the autonomy professional bodies continually display. Continuation of such unquestioned power has consequences for delivering effective patient-centred care for the individual with dementia. ‘Personhood’
can never be understood by professionals without including the expertise of carers.

(ii).  *The imbalance of power.*

Terms like ‘participation’, ‘partnership’ and ‘involvement’ imply that patients, relatives and health care professionals have equal power (Ashworth *et al.* 1992). Yet as already demonstrated, assumptions which underpin traditional relationships between professionals/lay carers perpetuate power imbalances. Furthermore, involvement depends on carers having full access to relevant information and, for this, they are reliant on health care professionals (Myers & MacDonald 1996). Moreover, carers and patients may not know what role to adopt or where they may fit in when faced with unfamiliar caring environments, such as hospitals day centres or nursing homes, which aggravates power imbalances further (Laitinen 1992).

Despite political rhetoric, barriers to promoting genuine involvement of carers in decision making emphasise the problems that are manifest in the existing culture of our health care system. These include:

- difficulties in establishing a common understanding and working definition of what ‘involvement’ means with
resulting consequences for active implementation by healthcare professionals.

- power imbalances within current professional / carer relationships;
- limited acknowledgement of the nature of the carers' expertise and its vital contribution in endorsing the personhood of the individual with dementia.

Involvement in decision making is a complex process. Walker et al.'s study (1999) unravelled some of these complexities in hospital settings and produced a set of guidelines to enhance lay carer involvement. These guidelines are validated in this project.
CHAPTER 3

DESCRIPTION OF METHODS

3.1. Introduction

Following an overall summary of the methods and approaches used in the project, this chapter will outline what was accomplished with regard to:-

1. finding the carers and making initial contact;
2. outlining who they were as carers and the demands they faced in that role;
3. the four ways in which carers were involved in the project and how we kept them fully informed;
4. organising and managing focus groups;
5. ensuring data was reflexively analysed (an explanation of this process is given in the text);
6. the methods used in dissemination processes;
7. what happened during the dissemination meetings.

Finally an evaluation of how successful the dissemination meetings were in terms of achieving their purpose will be given. Appendix 2 outlines the overview of activities associated with the timing and organisation of the project.

3.2. Summary of approaches and methods

The project team has, part-time over a period of 12 months, been validating the accuracy, relevance and feasibility of ‘carer guidelines’ (Appendix 1) for carers caring for family members with dementia; and subsequently,
disseminating these guidelines to a variety of health / social work professionals and voluntary organisations. These processes of validation and dissemination have been established through collaborative approaches to inquiry with a group of lay carers. The focus of the guidelines is to increase the involvement and support of lay carers in the processes of care planning and delivery.

Fifteen carers shared their experiences with project workers in two separate workshops. These workshops were held at venues in different locations that were comfortable and accessible. Sitter services and transport were offered to facilitate attendance. The discussion and debate engendered by four concurrent focus groups in these two workshops enabled appropriate amendments to be made to the guidelines by the project team. Carers subsequently checked these alterations and agreed their validity for various care settings in the home, community and hospital.

Two dissemination meetings, facilitated by a small number of carers and the project team, enabled various professionals to agree the importance of these guidelines particularly in relation to the following:

- carers' expertise is valued and they should be more involved in decisions made about their relatives' care;
- the unique and constantly changing needs of an individual with dementia and their carer are met by an integrated, accessible and streamlined service;

Further work, subsequent to this project, will address ways in which these guidelines can effectively be implemented into various care settings.
3.3. **Ethical issues**

The local research committee granted permission verbally for the project to be undertaken. This project was seen by them to be an extension of the previous study (Walker *et al.* 1999) that had already gained approval.

Ethical concerns in this project relate to carer's time commitments as their expected level of involvement might impact on their caring responsibilities. The project team was sensitive to the unpredictable and ongoing demands of the carers, and opportunity was available to withdraw at any phase of the project should their commitments prove to great. Process consent was sought at all stages. Information relating to the project was provided, as well as the opportunity to speak to the project team verbally. Close liaison with the carers’ other support networks and the project team ensured appropriate supportive intervention when required.

3.4. **Finding a population of carers**

Various day centres, carer support groups and individual health professionals who had direct contact with carers in the community were approached. A range of professional agencies were targeted (Table 3.1) as their professional role enabled contact to be made with carers in the community.
TABLE 1: **Type and number of contacts made**

<table>
<thead>
<tr>
<th>CONTACT</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care centre</td>
<td>23</td>
</tr>
<tr>
<td>Carer support groups</td>
<td>10</td>
</tr>
<tr>
<td>Individual support workers: (HV’s, DN’s, CPN’s, Carer support workers, carer’s group co-ordinators, dementia care co-ordinators, members of Alzheimer Scotland)</td>
<td>14</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>47</strong></td>
</tr>
</tbody>
</table>

Mode of contact was at the discretion of professionals in each situation. This decision depended upon the individual’s professional knowledge of carers’ situations and so potential availability. For example, in some instances, professionals acted as ‘gate keepers’ for carers, and therefore contacted them on the team’s behalf. Where this occurred, letters devised by the team were sent outlining the purpose of the project and what the carer’s role would be as a full participating ‘expert’ (Appendix 3). However, in the majority of cases, names and addresses were forwarded directly to the project team to make contact themselves. Carers indicated their willingness to participate in the project by return of an ‘acknowledgement’ slip, attached to the letter.

The project team envisaged that this mode of contact would provide up to thirty carers, representing a cross section of various caring situations and locations throughout Edinburgh and the Midlothian region. A wider area was not targeted as this would have been difficult to resource in terms of access.
to venues for workshops and covering travelling expenses for carers or the project team.

3.5. Profile of carers

Chapter 4 describes the problems the project team faced in securing a population of carers, and addresses the potential issue of ‘transferability’ as the small select group of carers involved in this project can not represent the total needs of a wider group of carers.

In total thirty-four carers were contacted, with some carers needing reminder letters to assess their continued level of interest. These were sent to some carers as a time delay of two months between establishing contact and making arrangements for the workshops may have resulted in a lack of continuing interest.

Twenty-five carers acknowledged an interest in participating fully (Table 3.2), but six of these twenty-five subsequently decided that attendance at the workshops could not be managed as their situation had changed. The rapidity with which the demands on the carer fluctuates will be addressed in detail in Chapter 5, as this common and unsettling aspect of the carers' experience is an important issue that is addressed in the rationale underpinning guidelines (Chapter 5).

The six carers who were not able to attend the workshops were able, however, to independently scrutinize the guidelines, and their comments have been incorporated into guideline refinements. A further six carers could not participate in any aspect of the study, and three did not respond.
TABLE 3.2: Profile of responses

<table>
<thead>
<tr>
<th>TYPE OF RESPONSE</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total willing to participate</td>
<td>25</td>
</tr>
<tr>
<td>Total number available for workshops *</td>
<td>19</td>
</tr>
<tr>
<td>Not able to participate</td>
<td>6</td>
</tr>
<tr>
<td>Non responses</td>
<td>3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>34</strong></td>
</tr>
</tbody>
</table>

*Only 15 of the 19 who said they were available managed to attend the workshop.

Given the demands inherent in the carers role and the speed with which these demands can change, the final number of positive responses was high. The profiles of the carers who attended the workshops (Tables 3.3 and 3.4) indicate differences and similarities in caring contexts which indicates the extent to which the guidelines can be applied to a variety of situations.
TABLE 3.3: Profile of caring contexts

<table>
<thead>
<tr>
<th>Carers</th>
<th>Relationship of carer and person with dementia</th>
<th>Length of time as a carer in years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mother (in law)</td>
<td>Father</td>
</tr>
<tr>
<td>Age</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td>4*</td>
<td>3</td>
</tr>
<tr>
<td>55-64</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>65-74</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>&gt;74</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

* Number in this age bracket is 4 – but one carer looked after 2 relatives

TABLE 3.4: Profile of care being given

<table>
<thead>
<tr>
<th>Carers</th>
<th>Level of assistance</th>
<th>Services used (d = no. of days)</th>
<th>Improved by specific involvement of professional</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>24hr full</td>
<td>Daily help</td>
<td>Help some days</td>
</tr>
<tr>
<td>Age</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td>4*</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>55-64</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>65-74</td>
<td>5</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>&gt;74</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

* Number of carers in this age category is 4 but one carer looked after 2 relatives
3.6. First stage of carer involvement; consideration of original guidelines

To enable clarity of explanation of the approach please refer to diagrammatic representation – Chapter 1, Figure 1.

Twenty-five carers indicated their availability to attend the workshops. The first stage of involvement for these carers was to consider the original guidelines and the questions arising from them. These original ten questions and guidelines were devised to help carers take full advantage of meetings with health professionals in order to optimise collaborative processes in care planning. This information was sent to the carers for consideration, prior to attending the workshops. Prior to the workshops, carers were sent a copy of the guidelines and ten questions (Appendix 4) to consider in preparation for discussion. They were re-written in language more suitable for carers rather than academics and fellow professionals.

Rewriting the guidelines was aided by a representative for an advocacy organisation for carers and who was therefore skilled in constructing accessible documentation for carers who do not have a professional background. Validity of the reworded guidelines was further enhanced by two of the project team members, who were directly involved in the original research study, cross checking guidelines to ensure consistency of meaning.
3.7. Assessing carers understanding of involvement.

Once the guidelines were sent out, with accompanying letters indicating dates, times, and location of venues for the workshops, carers were telephoned to confirm availability and arrangements for transport or sitter services. Directly contacting carers at this stage was beneficial for two reasons.

Firstly, carers needed clarification as to what exactly the workshops were about, what their role would be, and the benefits (if any) in attending. This gave the project team an opportunity to address queries carers may have had at this stage, and also establish the level of understanding carers had regarding their involvement. Establishing flexible channels of open communication between the team and the carers, enabled consent to be continually checked out. The team were aware that the changing situation (and so fluctuating level of demand) upon carers could affect their ability to continue with the project. Carers were able to opt out at any stage of the project. Process consent occurred every time carers were contacted directly by the project team.

Retraction of involvement occurred in only two cases. These retractions demonstrate the level at which carers were informed about their role in the project and also their ability (and degree of comfort) in asserting their own
needs with the project team. Retractions were directly attributable to the rapidly changing contexts of caring for an elderly relative with dementia. The carers were, on the whole, elderly themselves with health needs of their own. This, combined with the sheer demands of caring, made it difficult for the carers to commit their time and attention to the needs of the project. Empathetic to their demands, the project team was expecting a greater number of retractions as they were developing a growing awareness of the chaotic and trying world of caring for someone with dementia. Those carers who did decide to leave the project at this stage knew that the team were wholly supportive of their decision.

Secondly, carers themselves appeared to welcome the personal contact with the project team, as this gave the project a ‘face’. They were enthusiastic about the opportunity this project afforded them for meeting other carers in similar situations.

3.8. Second stage of carer involvement: participating in focus group discussions

Two workshops were held, each facilitated by members of the project team. Eight carers attended the first workshop, seven attended the second. The workshops lasted for approximately three hours which enabled project team
members to facilitate one general discussion group followed by two smaller focus groups.

The general discussion group gave carers the opportunity to meet each other informally and 'offload' by sharing personal and intimate experiences. This discussion facilitated the exploration into individuals’ situations, and so engendered a feeling of trust that enabled information to be shared among the whole group. Sharing ideas and experiences gave carers an opportunity to obtain information they could use for their own situation; for example, addresses of day care organisations or the existence of carers' organisations, such as Alzheimer Scotland, and their role in supporting carers and individuals with dementia.

The smaller focus groups encouraged detailed personal narratives to inform debate on the relevance of each guideline and the ability they may provide in improving the service in terms of support, accessibility and understanding. Focus group discussion was tape recorded at the second workshop to allow project team members to fully participate and observe the group.

The overall positive ambience generated by supportive and enthusiastic project participants encouraged open, honest and frank debate and detailed discussion.
All carers were in full agreement that the guidelines were highly relevant and thus vital, but changes did need to be made to enhance clarification of their meaning and purpose. This would directly affect the level of transferability to a variety of settings, such as respite and day care services, home and hospital.

3.9. Description of analysis of focus group discussion – ‘reflexivity’

(i) Type of data collected

The focus groups were the main medium for collecting data. Carers were open and willing to share their own stories with the team and the other carers who attended the workshops. At the end of each focus group discussion, the team had collected a plethora of narratives that captured each carer’s perspective of their complex social situation. In short, the team had come away with in-depth ‘truths’ – mini autobiographies of the each of the carers lives. This rich data, although subjective and partial, was an authentic representation of the carer's situation and was triggered by discussions around each guideline.

Oakley (1993) and Richardson (1998) advocate the telling of stories to find out the truth about someone’s life. The strength of the autobiographical narrative depends on the ability of the story teller to discern objective and
collective truths embedded in each story. As each of the carers was experienced (Table 3.3), articulate, and shared a common role (although unique situational context of care), the depth of perspective and the degree to which comparisons could be obtained speaks for itself.

Although the team did not deliberately set out to use autobiographies as a means of data collection, they intuitively allowed the stories, which emerged around each guideline, to evolve. This facet of trusting qualitative processes, which were embedded in each of the focus group discussions, is discussed in more detail in Chapter 4.

(ii) Reflexive analysis

Reflexive analysis, a process used in reflection, describes a systematic method of testing personal theories and assumptions embedded in individual experiences. Subsequent to thinking reflectively, emergent theories, pertinent to previous experiences are deliberately applied to different situations. These theories are then either accepted or rejected depending on their usefulness in enabling appropriate actions to be taken.

The following depicts the use of ‘reflexive analysis’ to capture authentic issues in the carers’ narratives, which in turn enabled a reconstruction of each guideline.
Each focus group comprised four to five carers and two project workers. Dual facilitation by the project team enabled concurrent hand and audio recording of focus group discussion with process notes. These recordings were then further reflected upon by the project team members. Reflective frameworks were not used to critically analyse the carers stories (as advocated by Oakley: 1993 and Richardson: 1998), but the in-depth discussions that followed each focus group enabled the team to share these narratives and thematise emerging issues. This was achieved by analysing how individual process notes compared with all four project workers' perceptions and recordings. Emerging issues (the team’s personal theories) were then deliberately included in the second workshop. This validated the team’s assumptions about what they had heard and allowed for other tentative theories to emerge. Saturation of data was finally achieved by triangulating all of the above process notes with analysis of the audio taped recordings from the second workshop.

These personal perspectives were then captured in a rationale surrounding each newly constructed guideline, and subsequently checked out by all carers individually. The collective agreement between all carers authenticates the theoretical perspective which emerged from both workshops, and endorses validity and relevance of the guidelines and their supporting rationale.
This reflexive process has enabled rich evidence to emerge which not only validates the content and philosophical perspective of the guidelines, but reveals important issues embedded deep within the carers’ stories. These issues include, for example, the perceptions carers have of themselves and the contribution they could make to an over stretched and under funded service; and the perceptions they have of their role compared to the professional carer role. The fact that these issues were highlighted in the reviewed literature (Chapter 2) adds weight to the theoretical interpretation of the focus group data. Other issues pertinent to fostering collaborative ventures specific to the project also emerged through the data. These process issues that reflect the experiences of all co-participants are discussed in detail in Chapter 4.

3.10. Third stage of involvement for carers – analysing the data

Authentication of these guidelines was achieved through further analysis by the carers. All carers who attended the workshops were sent the five newly constructed guidelines and analogous questions, together with corresponding rationale and recommendations to each guideline (see Chapter 5).
All carers were telephoned by project workers one week later to assess their level of satisfaction, and to ensure that their voice was clearly evident and authenticated through the new guidelines. It was at this time that the project team identified that the carers had themselves held meetings with other carers informally, and had presented the guidelines to them for ratification before feedback to the team. This net gain in validating and disseminating guidelines reflects a broader context of care in which guidelines can be applied, especially as minimal modifications needed to be made. Follow up calls confirmed that all carers involved in the workshops supported the changes and believed their personal perspectives had been incorporated into this new data.

3.11. Disseminating the Guidelines

Dissemination processes are still ongoing (Chapter 6). This section will indicate what has been achieved to date.

The purpose of dissemination is to:

- Evaluate feasibility of guidelines for implementation in a variety of practice areas
- Discover areas of best practice which already exist to facilitate carer involvement in care planning processes for people with dementia
• Seek out assistance in disseminating and implementing guidelines in practice areas

• Raise the carers' profile further by offering an opportunity to make their voices heard in professional forums.

(i) Dissemination methods.

One hundred and fifty health and social work professionals were invited to attend one of two dissemination meetings (Table 3.5).

**TABLE 3.5 : Type and number of professionals invited to dissemination meetings**

<table>
<thead>
<tr>
<th>Type of Professional</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP practices</td>
<td>102</td>
</tr>
<tr>
<td>Day centres, respite care, nursing homes, hospital wards, carer support groups</td>
<td>30</td>
</tr>
<tr>
<td>Specialist professionals: <em>e.g. CPNs</em>, HVs, Dementia care co-ordinators, Carer support workers, carer’s group co-ordinators, DNs, occupational therapists*.</td>
<td>15</td>
</tr>
<tr>
<td>Social workers*</td>
<td>1</td>
</tr>
<tr>
<td>Others*: carer organisations</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>150</td>
</tr>
</tbody>
</table>

* = third party dissemination

A large cross section of professionals were targeted by writing to managers and area co-ordinators to disseminate invitations on behalf of the team (indicated by an asterisk). It is impossible to assess the effectiveness of this strategy, as the descriptive data does not reflect a true picture of who actually received what, when, and by whom.
For example, specialist social workers, dealing with older people in the central and outlying districts of Edinburgh, were contacted using a third party. At the time this seemed the most efficient method of obtaining contacts, as project workers did not have individual knowledge of specialists in this professional area. The project team therefore approached an area coordinator, who had responsibility for appropriate social workers throughout the main areas in central Edinburgh. However, the lack of response by social workers indicates that although this method of third party contact is efficient in terms of use of resources, in this instance, it was wholly ineffective.

In total, only eight health care professionals attended the dissemination workshops together with two carers. For a profile of attendees, see Table 3.6.

Other professionals who did attend meetings either received the invitations directly, found out about the meetings accidentally, or were approached directly by their manager as the perception of their role/interests would, according to the manager, seem to coincide with the nature of the project.
### TABLE 3.6: Profile of professionals who attended

<table>
<thead>
<tr>
<th></th>
<th>MEETING 1</th>
<th>MEETING 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>CARER</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>STAFF NURSE*</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>GP</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>N/HOME MANAGER</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>CARER ORGANISATION</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Alzheimer Scot')</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>4</strong></td>
<td><strong>5</strong></td>
</tr>
</tbody>
</table>

* = community nurses, rehabilitation nurses

Problems inherent in the process of dissemination would have been eased, had comprehensive databases been readily accessible. Apart from information pertaining to GP services, no other databases for allied health professionals seem to exist. Had there been such a facility, individual professionals and support workers could have been identified and sent personal invitations. This may have resulted in a larger attendance at the workshops, but the resulting quality of debate among different professionals who did attend offset the problems associated with low numbers in this instance.
(ii) Attendance at the dissemination meetings: (and fourth stage of carer involvement)

A detailed account of both the discussion at the meetings and potential solutions to implementing the guidelines are addressed in detail in Chapter 4. This section offers a brief synopsis.

The new guidelines, rationale, recommendations and analogous questions that were issued to cares for authentication, were edited so they could be used at the meetings to promote general debate. This information package was issued to professional workers at the start of each meeting. As participants in the project, carers were telephoned to invite them to attend whichever dissemination meeting they could manage. Their expertise would be valuable in emphasising the importance of the guidelines, and also give them an opportunity to identify what they see to be the obstacles within the service that need immediate attention. Two health care professionals who could not attend the meetings, but expressed an interest in the project were sent the information package and encouraged to give feedback to the project team.
(iii) Subsequent developments in dissemination

All people who did attend the workshops were there because they believed in the importance of carer involvement, and so it could be argued dissemination was targeted at a skewed population who had a vested interest in this area.

This argument, however, contradicts the purpose of the meetings, and so is counter-productive to debates regarding rigour of process or transferability of data, especially as ways of increasing news of the guidelines has snowballed as a direct result of these meetings. For example, one community nurse has taken the guidelines to her own health centre to generate further discussion as to how they can be used to develop effective practice among a variety of health care professionals in her area of work. Also, the project team had subsequently been invited to present the guidelines to a core group of GPs in a ‘care for the elderly’ course.

This is extremely encouraging and a reminder to other project workers and researchers that quantity in numbers is no indicator of an effective and quality driven process.
CHAPTER 4

COLLABORATING WITH CARERS: CHALLENGES AND ACHIEVEMENTS IN THE PROCESS

4.1. Introduction

Accessing a group of carers and articulating the challenges and achievements inherent in the project has been a test in itself. The team has reflected on the positive aspects of this process and the lessons we have learned.

This chapter will begin by exploring the difficulties in accessing and securing a group of carers, the background and experience of our group of carers, and the implications for transferability of findings.

A brief description of the carers and the issues they brought to the project is also presented, in order to understand how their context of caring shaped the key emerging issues in this project, which include collaboration, getting the true picture, and the expectations of the carers of this project.

Fostering good relationships throughout the project has been positive, but nevertheless has subsequently evoked a moral obligation of meeting
carers’ high expectations of the team and the consequences of this work. This issue is discussed in the context of bringing about change in the health care system.

Getting the ‘true’ picture from carers through hearing their stories has not been straightforward, as this demanded that the team wholly trusted qualitative processes, which at times proved to be messy and convoluted. A frank and honest discussion of how these issues were addressed has provided the team with an opportunity to demonstrate what the project has achieved, as well as emphasising the carers’ level of collective expertise.

4.2. Problems in finding carers.

Securing a group of carers for this project was not a straightforward process. Difficulties arose in relation to the following aspects:

- indirect approaches via gatekeepers
- timing of sampling process
- difficulty in commitment due to constantly changing circumstances
- possibility of coercion with more direct sampling approaches
- tight time limits which reduces flexibility in sampling.

Indirect approaches via gatekeepers, for example, managers of day centres, nursing homes and respite care, or leaders of carer support groups
(see Chapter 3 for sampling approach) were not productive. The team’s rationale for using indirect approaches to sampling reflected our concern for a vulnerable group of people who could well be elderly, not in the best of health, and feeling overloaded with the burden of caring. They may not have welcomed letters requesting their help in a project when they had so much else to attend to. Deliberately using managers as gatekeepers may have been theoretically defensible, but on balance, impractical. However laudable our intentions, using this indirect process enlisted only ten carers into the project at this stage.

Attempting to contact relevant managers during the summer months meant that letters lay unopened in mail trays for days on end over holiday periods. A second round of phone calls and letters, to all but three of the original forty-seven contacts, confirmed this to be true. This exacerbated a further time delay to the project as the team waited for promised responses that, in the main, never materialised.

The most fruitful method of securing a group of willing carers came about by using face-to-face contact. This opportunity was made possible through using the professional role of one member of the steering group who had direct contact with carers in the community setting, and was able to invite them to participate in the project. This directly helped the team move the project forward and saved an inordinate amount of time. It did mean,
however, that the largest group of carers involved in the project were already receiving excellent specialist support. This could have an implication for the representativeness of the group.

Using a direct method of contact was more productive, but there could have been a danger of carers feeling coerced. In an attempt to minimise this, our follow up calls allowed carers to opt out; indeed some did due to their changing situation. This option for withdrawal also acknowledged the rapid change in contexts of caring both for the carer and the person being cared for. For example, ill health on the carer’s part, or difficulties in managing a whole afternoon away from their caring situation.

Casting our net wider in order to secure a group that reflected a wide range of experiences and backgrounds could have been achieved if the project team had had more time. This familiar aim for project workers is invariably challenged by time and resources, but lessons have been learned regarding the importance of over estimating numbers for a population group whose lifestyle is dictated by rapidly changing circumstances.

4.3. Representation of carers – challenges for transferability of guidelines

The team acknowledges that the final group of carers in this project is not necessarily representative of all carers of people with dementia. For
example, where were the younger carers or the carers looking after younger sufferers with dementia? Where were the carers who may be de-skilled interpersonally or disabled physically or mentally? Where were the many carers who live in Edinburgh who come from different ethnic backgrounds? Why could we only access carers who all had, at least at one time, access to formal support in the community? There may be plenty who choose to 'go it alone' rather than accessing social workers, CPNs, respite services or day care.

It is important therefore, to acknowledge carers who were not participants in the project and to question why it was not possible to find them through our sampling methods. Our difficulty in accessing as diverse a sample of carers as possible reflects the fact that carers themselves are associated with a variety of health, social, and voluntary agencies. With no central record of carers and the fact that professionals often work independently, accessing a wide range of carers is difficult.

The fifteen carers who managed to attend the workshops and the six others who sent written comments, were fairly homogenous in terms of their caring situations (Tables 3.2 and 3.3), making it possible for the team to confidently translate suitability of the guidelines to other carers in similar caring situations. On the other hand, differences in carers with respect to their educational/professional backgrounds, time served, relationships with
individuals needing care, levels of caring responsibility and contexts of care giving allowed for a wide range of perspectives and opinions to inform the content of the guidelines. This legitimises the extent to which the guidelines are relevant for carers at different stages of the caring continuum, whether the care be at home in the community or in hospital.

This broad context of care to which guidelines can be applied is further enhanced by the ‘hidden’ sample group who inadvertently took part in the latter stages of the project. This group, comprising friends and acquaintances of the carers, met independently of the project team to discuss the newly constructed guidelines to assess their worth as applied to their own situations. Although empirical data about this invisible group is not to hand, this certain net gain affords increasing confidence in how transferable guidelines are to a variety of situations.

4.4. Carers’ backgrounds and caring experience

The carers who participated in the study were experienced, articulate and assertive in their role. The following quote illustrates the how one carer expressed this assertiveness:

‘if a door is slammed in our face – we will probably keep on hammering – many others would give up after the first slamming’
Some were retired health professionals, some were still working in the health care field. This is important to emphasise, as irrespective of their professional background or their perception of themselves as capable carers, they often felt the power or locus of control for caring still lay with others rather than themselves. They believed therefore, in the philosophy of the guidelines, as they emphasised the importance of the carer in care planning processes. For the carers, recognition of the knowledge they had about the individual they were caring for was fundamental for person-centred care planning. Really knowing the person they were caring for, better than anyone else, meant their ability to detect subtle changes in mental, personal and physical well being of their loved one outstripped any professional assessment, unless the professional possessed the same degree of ‘knowing’ that the carer did.

People with dementia, (and their carers), generally reflect a population which is elderly and often has multiple health problems. Our group was no exception to this. Carers indicated that often, the consequent multiple health needs of the person with dementia affected the total experience of caring for them. Therefore, they were holistic carers who understood what made the person they were caring for happy or unhappy. They could interpret the meaning of the person’s perceived environment and so manage this accordingly. They could identify what could make a difference to the individual’s day and what quality time meant to that person. The
people these carers were attending to were loved, and as such they would ideally like health professionals to respect this level of 'loved' attention, and, when possible, reflect this same attention in their own professional care giving.

However, the carers were realistic in their perceptions of what could be achieved from a service that was understaffed and had limited resources. For example, when this service met their immediate needs, they felt grateful rather than angry:

‘it is difficult for them……a health visitor has responsibility for us and for the under 5’s….this is huge, something has to go’

They were frustrated by bureaucracy rather than any professional individual whom they recognised were doing the best they could in difficult circumstances. Despite the fact that they had financially shored up this system of health and social care support all their working lives, they were thankful for anything they perceived as ‘free at the point of delivery’.

However, this façade of gratitude could also be seen to mask the carers’ aim to maintain a lower status and lack of autonomy relative to the professional role. It was important to them that they were seen to be doing a good job in the professional’s eyes, and therefore seen as ‘copers’ rather than ‘complainers’. This feeling that to criticise would make them appear ungrateful, and therefore make them reluctant to complain, is
echoed in other work (Walker et al. 1999: Hertzber & Ekman 2000). Also, complaining too much could have consequences for subsequent services they might need and could affect the quality of care given to their relative,

‘I am always frightened that if I go against them then my wife will suffer’

‘I feel it (complaining) is just shooting yourself in the foot’

They accepted therefore, that the major burden of caring had to be shouldered by themselves, seeing anything that can be taken from the service as a bonus, not a political right as a tax paying citizen. This could reflect one of two things; an older group of altruistic and stoic carers who are typical of a generation that is strongly independent and believes in ‘looking after one’s own’ (see Barder et al. 1994 and Waterman & Luker 1990). Making demands on a beleaguered health service or fighting for one’s own political ‘rights’ and personal needs is not, after all, characteristic of an elderly carer who has chosen, willingly or not, to care for their family member. It could also be indicative of the medical dominance which influences the structural features of a health care system that perpetuates silence and so ‘good behaviour’ in careworn users of an equally careworn service (Davies et al. 1997).

Counter arguments regarding passivity and lack of assertion of service users, implicitly blame the carer for the ineffective service they receive. By
placing the onus on the carer to raise their voice loud enough to be heard, the professional effectively abdicates all responsibility for directly challenging prevailing attitudes that are blind to the faults in the system.

Each and every one of the carers the team worked with were not aware of how they could make their demands heard. Despite some having quite extensive knowledge of how health care systems operated (some carers being ex-nurses and managers of day centres), they knew of no mechanisms or formal procedures that welcomed, listened to or acted upon any complaints they may have had about the system.

The carers that we worked with in this project, therefore, were a small special group of individuals who were able and willing to attend and participate. We acknowledge that what they brought to the groups may be different from other carers. It is important to note, however, that the overriding concerns of the importance of knowing the person with dementia, their expertise in caring going unrecognised, their difficulty in having a voice in the health and social care arena are common concerns of carers that are echoed in other literature, specifically Almberg et al. (1997), Jansson et al. (1998), Jones and Mieson (1992), Keady (1996), McCarty (1996), Motenko (1989), Walker et al. (1999).
4.5. **Carers' expectations of the project**

Carers' hopes for the project were (and still are) high in that they firmly believe the outcomes of this study will immediately impact on the service they are currently trying to access. We know that some of the carers who attended the workshops were frustrated and at the end of their tether with a system they felt was failing them and that they felt powerless to affect. We know that some needed advice, and all needed encouragement and support. We also know that some carers had come to the workshops with problems and wanted solutions. Some of the carers disclosed to us that they were suffering from physical ailments themselves, and so were worried for their own health and the consequences of this for the person they were caring for. Another carer shared feelings of vulnerability, by telling us that dementia ran simultaneously with old age in the family, and so understandably wanted to see immediate improvements in the system.

It was important to us that carers felt safe to ventilate these concerns, and equally, it was important that we could be supportive to them as exemplified by our professional role.

Some of the carers were motivated to initiate their own dissemination groups outside the workshops, which, we concluded, was indicative of their enthusiasm for the project. Their enthusiasm was understandable and wholly appropriate given that they felt this was an opportunity to
demonstrate to others the nature of their caring role and the responsibilities that went along with it.

All carers involved in the project had a vested interest in that they believed that this project was tangible evidence that something could be done for carers. Even though the team knows this expectation to be unrealistic (a justifiable criticism levelled at small projects), we nevertheless felt obliged to deliver change and improvement. This moral obligation may be because the team knows the carers and their situations fairly well - a by-product of the successful ways in which collaborative ways of working have been achieved. Feeling morally obliged to effect a positive change in their circumstances is therefore not surprising, but the team also recognises the importance of enabling this through a process of carer empowerment. If the project were to make the carers' role more visible by shaping guidelines that challenge attitudes and faults in the system, then it is hoped that carers themselves will have the power to intervene directly.

This moral obligation is a continuing dilemma, but in many ways a typical feature of how collaborative methods of inquiry never knowingly end. Ordinarily, co-inquirers have a collective responsibility to implement and monitor change, but for reasons pertinent to our population of carers, (such as their limited autonomy, demonstrated through minimal status and power relative to professional workers) this is not possible with this short-
Validation of these guidelines is very much a part of a future staged process of work that entails wider dissemination, implementation and evaluation.

Carers' belief in the project is welcoming and emphasises the importance of seeking funding to enable further development of this work. What carers may not understand is the length of time associated with such ventures and the difficulty small projects such as this have in impacting on a multidisciplinary system which is fragmented in terms of communication, ideology and purpose.

4.6 The challenge of maintaining collaborative relationships

The team were acutely aware from their collective extensive experiences in professional and academic fields, that consumers of care, especially the elderly, are dominated by prevailing patriarchal attitudes within health care organisations (Gair & Hartery 2001). The team wanted to ensure that the processes used to involve carers in this project should reflect inclusion and empowerment (consistent with collaborative inquiry).

Opportunity to collect data and share experiences with carers would be provided by the focus group method used in the workshops. However, previous experiences some members of the team had had with this
method (Runciman et al. 1998) have alerted us to problems with having a ‘one off’ focus group, as was planned for in the overall structure of this project. This missile method of inquiry, that emulates traditional hit and run approaches to data collection, does not encourage open or trusting relationships between researchers and participants, or in this instance, the project team and expert carers. The time the carers were giving to this project was precious as they had so little of it. The team was concerned therefore that carers should perceive their involvement in a positive light, as this experience would give them a real opportunity to become involved in processes which could effect necessary improvements. Not having time or opportunity to arrange more follow up focus groups with carers could have made them feel just the opposite - a means to an end.

This was countered by facilitating opportunities for carers to become involved throughout all stages of the project (see Chapter 3 for stages of involvement), and not just within the workshops. This demanded effective communication between the project team and the carers in order to establish relationships that were open and comfortable.

The degree to which relationships were perceived as mutually beneficial can be evidenced by the various occasions on which carers and project team members spoke about issues which may or may not have had a bearing on the project. For example, on one occasion, a carer phoned to
seek advice regarding benefit applications. On another occasion, a carer sought the team's assistance in finding an exercise trainer for frail and elderly people. Another carer was contacted to speak about availability of respite services and other carers have since offered their time for any subsequent work that may involve the role of carers. One carer has since been in contact with a member of the project team indicating a willingness to help with other departmental work that involves older people. All these positive indicators demonstrate that carers have found their involvement in the project worthwhile.

This wholly befits any collaborative project, especially one that acknowledges collective expertise in a particular area – in this instance, caring for older people with dementia. However, at times, the trust carers’ had in the team’s level of expertise fed into their expectations as to what this small project could achieve. Carers’ belief in the team’s professional role and influence over changing the organisational and professional culture at times transcended the boundaries of reality!

Fostering co-ownership of the project through collaborative processes was further enhanced by:

- our collective beliefs regarding nursing/collaborative processes;
- the fact that we were seen as nurses rather than researchers;
- our educational skills as facilitators.
Each of these issues will be addressed sequentially. The issue pertinent to facilitative skills demands more than a cursory analysis and so will be addressed under a specific heading.

Firstly, the project team members, who are all nurses, shared a philosophical outlook on professional practice which valued person-centred approaches to care delivery through the enlightenment and enablement of others. Adopting an approach to inquiry that reflected this philosophical viewpoint, through collaboration and empowerment, was therefore a natural choice for the team.

Secondly, the team was conscious of how professional titles and roles could impose hierarchical divisions. From the outset, it was fundamental to establish non-hierarchical relationships in order to put carers at ease with their role as co-inquirers. This could be achieved if they knew the team could be empathetic and sensitive to their concerns. For this reason, introductions with carers emphasised the nursing rather than academic roles, and the team were subsequently perceived as such by the carers throughout the duration of the project. This degree of empathy and sensitivity was genuine, as the project team were either specialists in the same area as the carers, or at least familiar with their plight, having encountered other carers caring for people with dementia in previous research projects (Walker et al. 1999, Walker & Dewar 2001 – in press).
Despite the team’s professional level of expertise, a genuine connection with the carers’ situation could never be realised, as caring for or having responsibility for someone with dementia twenty-four hours a day is outside any professional’s remit of practice. The carers involved in this project were experts in their own right, which was apparent from the start. The team wholly respected this level of knowledge and was touched by their courage, tenacity and positive perspectives on life that was demonstrated in their sense of humour and the warmth with which they told their stories.

Thirdly, the team’s academic background in education and research has provided a level of experience in facilitating group processes to enable carers to co-own the emergent data. How facilitation of these processes was accomplished is a vital component of this project’s development.

4.7 Facilitating focus group discussion.

Effective collaborative inquiry is dependent upon establishing a partnership between all parties. No one member is more important than anyone else; all members in the collaborative venture have a role to play and value themselves and each other for this role as they know how each contributes to the collective task (Henneman et al. 1995).
However, knowledge of this was difficult to realise practically when the team and carers first met at the workshops. The level of expertise exhibited by the carers, at times, overshadowed the role of the project team as facilitators of each focus group. Because of the carers uniformity in expertise, conceptual understanding was shared rapidly between the carers. This had the effect of potentially excluding team members from group discussions, as the speed at which specifics of one personal situation were recognised by another resulted in the need for individual team members to either pitch in or catch up!

Although this had implications for facilitation of group discussion, it did demonstrate that information was easily shared between carers and that the facilitation style primarily re focused debate. The team needed to recognise this role early on in the proceedings so that the full flow of frank and unhindered discussion between carers could continue with the minimum of interruptions. Letting go was difficult as the tight time frame prohibited a totally unstructured discussion. At times, the team sensed tensions in various groups as the propensity to ventilate, rather than validate experiences, shortened attention spans of carers which resulted in two or even three discussions occurring simultaneously. Having two project team members to facilitate each group was therefore extremely valuable as this enabled an inter-change of roles where one took process notes of the interactions, while the other helped the group to refocus!
Intuitively interchanging roles made allowances for facilitator fatigue. Two facilitators also enabled subsequent data analysis to be contextually rich as well as personally enlightening! (see Chapter 3 for details of reflexive analysis).

Previous experiences of using focus groups in educational, clinical and research settings, have alerted members of the project team to the problems of dominant voices. Leading voices tend to either silence or influence others which negates the purpose of a focus group discussion, namely, to facilitate the emergence of a group perspective (Reed & Roskell Payton1997). The carers at each workshop were a cross section of people who demonstrated a variety of characteristics fairly typical of groups and their respective dynamics. With some active encouragement by group members, the quieter members found their voice, which occasionally opened up competition as carers vied for ‘ventilating’ space.

The fact that carers were able to talk freely with the team present was a positive sign that they did not feel threatened by professional roles. This could have been for reasons relating to the team’s unfamiliarity with the practical realities of a carer’s own world of caring, our role as empathetic professional carers or the fact that the venues for the workshops helped to create a safe space. With regard to this latter point, we were careful to
ensure that the venues were in the vicinity of the carers’ own communities but had no association with any formal caring environment.

This experience of using focus groups as a method of data collection has continued to increase our awareness as to how complex this approach is. Previous experiences of focus groups have been with qualified nurses of varying professional backgrounds and skill mix (Runciman et al. 1998). This project, using a mixed grouping of people in terms of age, educational and professional background has nevertheless indicated markers of success to using this method. We believe that group homogeneity in terms of collective level of expertise, and a deep regard for the focus of the discussion (and each other) must be combined with skilled facilitation. These markers, identified in this project, have allowed the open and honest discussion between participants, to reveal valid information.

4.8. Getting the true picture

One interesting observation on how the team facilitated the groups was that carers were not asked directly about what they thought of the service they received. Instead the team encouraged carers to describe their experiences. This less threatening and indirect approach to questioning enabled carers’ responses to be spontaneous and so authentic. This
approach to obtaining valid data about peoples’ evaluative comments is supported by Staniszewska and Ahmed (1999)

Another observation relates to the way in which competing agendas emerged at the workshops. The team’s agenda was to ascertain relevance and feasibility of the guidelines through the carers’ expert perspectives – this was the team’s perception of ‘good’ data. The carers’ agenda reflected this in part, but mainly they saw the workshops as an opportunity to voice their experiences by telling their own individual stories. For the carers, this agenda was not just important, but fundamental, as it was perhaps their raison d’être for attending. At the time we felt this to be yielding secondary data, rather than seeing these competing agendas as a vital component of qualitative processes, which authenticate carers’ perspectives.

Carers’ experiences, while similar in theory, were all very different in practice. Unraveling the complex issues inherent to each person’s situation was an important aspect of the workshops, as indirectly this would inform the guidelines. However, the time needed to address these personally complex issues in each of the workshops was far greater than the team envisaged. Facilitators often found that they had to exercise their judgement in deciding when to interject and when to let things go. Maintaining the team’s agenda for each workshop – the collection of data which fulfilled the aims of the project and funding body’s requirements –
within a negotiated time frame, became a real issue for the team in the following way. If the carers’ agenda fully dictated processes of the workshops, there would be limited opportunity to validate guidelines. On the other hand, controlling the carers’ agenda would have been insensitive, and with hindsight, would have had consequences for co-owning qualitative processes of inquiry which made real the carers’ experiences, and so authenticity of the guidelines.

Processing experiences from the workshop around these issues raised questions for the project team such as: –

➢ When embarking on collaborative ventures, who should ‘lead’ the process and whose agenda should be followed?
➢ What does ‘partnership’ mean in terms of the project’s research focus?
➢ How does this concept of ‘partnership’ influence:
  • relationships?
  • retrieval of ‘good’ data?

Had it been possible, the team believed that follow up focus groups may have been necessary to acquire ‘good’ data. However, this concern preceded reflexive analysis that revealed that these anxieties were not warranted. Not only did reflexive analysis of the data reassure the team that flexibility in facilitation of focus group discussion was effective in
gleaning informative data, but (more importantly) the subsequent re-
construction of the guidelines was led by the carers' own emergent personal
perspectives.

There is a great deal of rhetoric regarding the value of qualitative data
because it represents the 'other's perspective'. While this is so, it can only
be thus if the researcher believes in qualitative processes, where the
researcher abdicates control.

Allowing the process to take control in the workshops was a disconcerting
journey for the project team. However, knowledge about ourselves as
qualitative inquirers has increased, and this method has demonstrated how
fitting narratives/autobiographies are for future studies, especially those that
involve older people.

4.9 Challenges and achievements in dissemination processes.

The opportunity to disseminate the guidelines was welcomed by all who
participated as it brought the project to life, realising that the guidelines are
practical and feasible and with further work could have a huge impact on
enabling inclusive health care practices.
Originally the team intended holding three meetings with health and social care professionals to disseminate the guidelines and assess their feasibility for immediate implementation into various practice areas. A very poor response (Table 3.6) relative to the number of invitations issued, resulted in only two meetings being needed rather than three. A detailed account of the problems we encountered is given in Chapter 3.

The two identified venues for dissemination were either hospital based or located within the city centre. To further facilitate attendance for professional workers, evening meetings were arranged and hospitality provided.

Even though numbers at the meetings were small, the various backgrounds of the professionals enabled a wealth of ideas and observations around the guidelines to surface. The project team was able to trigger debate, having different clinical backgrounds and experiences relative but complementary to the professional groupings present.

It became apparent that fruitful and open discussion was directly attributable to the fact that the two groups were small and multi-professional. A larger group comprising people with different or similar backgrounds may not have engendered the profusion of ideas as our smaller groups could. We can be certain that everyone had the opportunity
to participate, and did so, which is certainly not a feature of larger groups. Carers also had space and opportunity to contribute their own opinions, beliefs and values about the quality of services received, which were receptively heard by the health professionals present.

Professionals who attended were interested in dementia care and were aware of the carers’ identified problems. They were sympathetic to what the guidelines were attempting to achieve, were wholly supportive of them but realistic about the difficulties of implementation. It could be argued that those present were already professionally motivated toward this area of health care and therefore would have biased opinions about the importance and value of the guidelines. It was interesting to note that there were no representatives from social services. However, as experts in this area, they could readily assess how worthy each of the guidelines was by reflecting on how they could help to improve the quality of practice in their own area. Indeed, this was the main focus of the discussion at each meeting. As experts, they also have the professional influence to further legitimise the guidelines’ credibility and so worth for practice, and have the authority to implement them in their area of work. In fact, it was the team’s impression that, following the second meeting, guidelines were to be discussed at a multi-disciplinary group meeting at one Health Centre.
The problems of implementing guidelines which professionals raised in the meetings, were endemic to a fragmented health care system which lacked common vision and so integration of professional services - as indicated by the carers’ own experiences – details of which are discussed in Chapter 5.

The future impact of the guidelines for the carers will need systematic evaluation, but the fact that their philosophical underpinning was so readily accepted by health professionals is an excellent indicator of success. The subsequent work in dissemination and implementation does seem daunting but this may be because long lasting, bottom-up approaches to initiating innovative change always do. The team identifies from their experience that there is a need for comprehensive databases, readily accessible by professional and non-professional people alike, to use to develop and subsequently increase potential networking for a variety of purposes. For example, nurse researchers would find an accessible network to help them rapidly secure appropriate sample groups or target relevant professionals for dissemination purposes. If carers could access these databases, they could assess what services were available to support them with immediate and long-term needs.

Complementing our dissemination strategy with top down approaches still need to be addressed (see Chapter 6), as hopefully the influence in policy will make the task of implementation more manageable. Eventually,
integrating the guidelines into educational programmes, by inviting carers onto the teaching team will complete the circle in this wholly worthwhile collaborative process.
CHAPTER 5

THE GUIDELINES AND ACCOMPANYING RATIONALE

5.1. Beliefs and values underpinning the guidelines

The following guidelines reflect a process of negotiated care (Walker et al. 1999) which emphasises that:

- carers are experts in their own field of caring;
- relationships between carers and professionals should embrace inclusion, negotiation, openness and honesty irrespective of care context;
- The goal of care planning is to achieve person centred care that addresses the biopsychosocial needs of the carer as well as the person with dementia.

This process of negotiated care needs to be central to interactions between carer and health/social care professionals, irrespective of care context. In order to reach a situation of negotiated care, carers and professionals may need help in finding ways to work together.

The carers identified factors that would promote more integrated and consistent ways of working with a health service which valued the
contribution they could make towards the well-being of the person with dementia:

- open communication between different professionals and carers;
- knowing who is available to contact at certain times;
- easy access to and awareness of resources available;
- acknowledgement for the work they do, the knowledge they possess and the expertise they demonstrate.

For the carers, the guidelines offered potential ways of working with professionals that fostered non-hierarchical relationships, characterised by honesty and openness. Fostering such relationships would enable carers to:

1. feel comfortable and able to assert their needs;
2. communicate these needs to professionals;
3. participate in decisions as desired, knowing that their expertise and knowledge was valued by health care professionals.

As one carer stated:

“You should be able to talk to your key worker once you have formed a relationship. You must be honest and let them know when there is help needed, before you become exhausted. If you don’t care for yourself, you can’t care for anyone. They need to know you are able to cope’.

(Carer – workshop 1).
CARER GUIDELINES

Background discussion supplementing each guideline will facilitate a more comprehensive understanding of how the carers' perspectives inform each guideline. This discussion will be presented as a 'rationale' for each guideline. The team recommends, therefore, that each guideline is read in conjunction with the corresponding rationale. Recommendations for implementing each guideline to reflect good practice are presented in Chapter 6.

Each guideline marks a stage in the carers journey from initially 'making contact' (G.L. 1) to 'making sure it's all working' (G.L. 5). The stages in this process are thematesised accordingly.

5.2. THEME 1 - MAKING CONTACT:

5.2 (i) GUIDELINE 1

You can expect your GP or other health/social care professional you are seeing for the first time about the condition of your relative to:

- understand the physical, social and practical problems you are facing as a carer and the impact this is having on your life;
• help you to identify a person who can act as a key person who can co-ordinate, inform, listen, involve and support you with your immediate but also long term needs and decisions.

5.2(ii) RATIONALE FOR GUIDELINE 1

(a) Initiating contact - The importance of the GP’s role

The notion of a key person that carers could negotiate care with arose out of previous work (Walker et al. 1999; Sheard 1998). Although carers may need several ‘key people’ to assist with the multitude of needs associated with caring for someone with dementia, initiating contact with key professionals is normally effected through the GP. The importance of the GP and the primacy of their role in facilitating stability for the carers or averting a crisis in their lives cannot be overestimated.

The GP was often the carers’ first port of call and they were seen as a vital link in either making appropriate connections with other key workers or maintaining continuity of service for the carer. The GP’s role was therefore seen as essential in establishing both long and short term support for the carer and the person needing care.
(b) Multi-faceted nature of carers problems

Reasons for carers attending GP surgeries at this stage of their caring journey, were usually on behalf of the person with dementia rather than themselves. The main reasons which prompted them to seek an appointment was a ‘crisis’ - defined as a physical / mental deterioration in the person with dementia, which in turn had a severe impact on the carers' ability to manage the home situation. Carers faced a multitude of problems, some of which were medical (for the attention of the GP), but many reflected everyday social and practical problems that impacted on the carers' ability to cope. For instance, if carers needed to attend an appointment for their own health or social needs, but were worried about leaving their relative alone, who could they contact to request help and support? They certainly would not directly contact their GP, as this does not require medical expertise. Nevertheless, this significant social problem for the carer needed direct supportive intervention, which if not addressed, could precipitate a crisis.

Carers would not think to emphasise their own health needs when attending the GP surgery, despite the social and psychological burden they carried. They found it difficult to express their own feelings to professionals in order to reveal the emotional labour associated with their role. Carers were reluctant to keep contacting (especially) their GP or other professional
workers in case they were perceived as a nuisance. Reasons for legitimately ‘bothering’ the GP could be justified if the problems were physically orientated rather than social, yet they relied on the GP’s insight to perceive the multi-faceted issues associated with their context of caring, and not just deal with the predisposing physical problem.

Obtaining a medical label of ‘dementia’ early on in the diagnostic stages was often the carers’ prime motivation in attending GP surgeries, as this label legitimised access to a number of support services. Indeed, some carers felt they could not access systems of support without such a diagnosis. However, GPs do not always give a diagnosis in these early stages. This was frustrating for the carers:

‘it took ages to get a diagnosis’

‘I pushed and pushed for 4 or 5 months until finally they gave him a scan’

‘it is so difficult to get people to realise my mother had dementia and that she just wasn’t getting old and forgetful – I stressed for months about this before something was done’

Receiving appropriate support should not depend on a provisional medical diagnosis, but on a service which readily perceives how a crisis or physical deterioration impacts on the carer’s own life. Carers felt that the over-riding medical model of care, which classifies individuals according to pathology, can limit the access carers have to professional care. As medical conditions
are more easily treated, carers inferred that the medical pathology was prioritised by health professionals, and seen as separate to, rather than integrated with, the overall picture of dementia. This had implications for what the carers felt the nature of caring was, their role in this, and what they saw as important for the key contact person to be doing.

Caring for someone was more than attending to medical or physical needs. It reflected really knowing the individual, and identifying subtle changes in mental and personal well being. Carers indicated that often, these presenting multiple needs dictated the need for a variety of health professionals to be involved in the individual’s care, so requiring a number of key contacts to be available, rather than just one individual. Many of the carers felt the first contact was their GP, but this individual would not necessarily act as a key person. The nature of the multiple health needs determined what is needed from the ‘key person’.

(c) The concept of the ‘key person’

An important issue that arose from discussions with carers was the nature of the support the carers required, irrespective of the setting in which care was given or how the ‘key person’ could be interpreted practically. Carers perceived best support as someone (or some people) who could anticipate and meet long and short term caring needs for the carer and their
dependent. Support then was seen as being involved with the whole picture of care giving and not just a ‘quick fix’ to a physical health related problem. The importance of knowing the person was stressed

‘they need to meet them (the person with dementia) early on in the process so that they can meet the ‘real’ person’

The people these carers were attending to were in many cases their own loved ones, and as such they would ideally like health professionals to respect this level of ‘loved’ attention and, when possible, reflect this care in their own professional care giving. For example, understanding what makes an individual happy or unhappy, what makes a difference to the person’s day and what quality time means to an individual. Understanding the type of relationship that the carer has with the person with dementia was also seen as crucial to the type of involvement that they might want. We had an example of a son finding it very difficult to help his mother to have a bath, yet on assessment it was difficult for him to get help for this as it did not warrant intervention from a district nursing service.

(d) Different models of working with key people

Differences in accessing the key person depend on individual situations and what makes them change. Discussion regarding the benefits of having access to a dementia care specialist as ‘key person’ was proposed. Where this role was evident, carers found the support they received and the
degree to which they were included in care planning decisions was excellent. Other carers who had not had this experience saw the benefit of having a team of professionals acting as 'key people' – for example key people would include health visitors, social workers, community psychiatric nurses, GPs, day care support services. However, carers reiterated the point that if the carer does not know who these people are, what they do and how they can help, carers can not know who should act as their ‘key person’ for all occasions.

The idea of a key person could be one individual professional (social worker, community nurse, carer support coordinator etc.) who is supporting the carer throughout all stages of care, irrespective of care context. Alternatively, the ‘key person’ could be one of a number of key people the carer will come into contact with, for example, from day centres, respite services or institutional settings. This person would act as the carer’s main support and contact at a given point in time, as the support the carer requires is determined by the context in which care is needed. The interpretation as to how a ‘key person’ could be implemented in practice could therefore be:

1. several professionals acting as key people for the carer at any one point in time;
2. one individual professional supporting the carer at a specific point in time;
3. one key person who supports the carer throughout the whole experience of caring, irrespective of care settings.

Whether one individual or a team of people, the key person would act as the carer’s main support. This concept of a key person was welcomed by all carers.

A stepwise approach to contacting key people could be initiated through the GP, to probably a community based professional, such as district nurse or CPN. depending on what the health need is at this first stage. This professional will probably act as the carer’s first key person. After a period of time, this key person may change. Change might be determined by the deterioration of the individual’s mental or physical health that directly impacts on level of care required. The key person could progress then from community nurse/social worker: nursing home/day centre manager: hospital nurse(s): occupational therapists working in day care centres, respite services or institutional care settings.

Quality of communication with the ‘key person’ is vital, and this guideline address ways of ensuring professional assistance is accessed, especially when changes in an individual’s condition precipitate a crisis in care giving. Often crises occur out of conventional working hours, and so contacting
appropriate help to support the carer through these times is vital. This aspect of the guideline is further developed in guideline two.

(e) The carers’ perceptions of themselves as carers

One final aspect which emerged from the general discussion regarding this guideline was how the label of ‘carer’ was engendered. Often, thinking of themselves as carers did not occur until a situation – usually prompted by a crisis – initiated a GP visit. At the first stage of contacting professional help, the label of carer is imposed on an individual. Up until this time, a duty to care had stemmed from the type of relationship the carer has with the individual (wife, husband, son daughter etc) rather than any socially ascribed label.

The label of carer is conferred with no negotiation of what that role means to the carer or should entail practically. Carers just don’t know enough about the health care system at this first stage to know what to expect from this role or what others are expecting of them. The lack of clarity about their role prompted questions from the carers about what their role entailed and how this role could be supported by a service which comprises a multitude of specialist professionals whose roles are not always clear in relation to carers.
Carers identified that they needed help to appropriately use the health and social care system at the start of their 'journey'.

‘invariably what happens is you’re left to your own devices and it is assumed everything is okay- you don’t know what is available’

‘there are services available but people don’t know about them’

The key people carers may need to contact at any one time indicates a stepwise process of caring for someone with dementia. The steps involved in caring at the early stages may well be unknown to the carer, and so they need assistance in identifying what their immediate and long-term needs are and who could help them address these needs. This important observation has implications for the timing of care provided, the priority of need arising, and the most appropriate individual to help address this need. Contextual issues and individual perspectives would decide whether or not this initial contact is seen as the ‘key person’.

5.3. THEME 2 - MAINTAINING CONTACT:

5.3(i) GUIDELINE 2

The key person will be:

Accessible:
the carer will be able to contact the key person at mutually agreed times;

**Committed:**
to maintaining ongoing contact. Agreement as to the flexibility of this contact will be mutually agreed.

**Available:**
alternative arrangements will be identified and put in place if the key contact person is not around;

5.3(ii) RATIONALE FOR GUIDELINE 2

(a) **Role clarification of key person**

The role of key person is more than a co-ordinator of services for the carer.

One carer stressed the need for co-ordination in the following statement:

‘you often find that all the people you contact say I’ve got my job, he’s got his job, but nobody knows what each other’s jobs are – there needs to be a coordinator’

The role should help establish a relationship with the carer that reflects continued commitment to them over a period of time, while the carer is the primary carer. The relationship between the carer and key contact therefore should reflect detailed understanding and knowledge of the carers' situation and the person they are caring for. This implies contact with this key professional should be continuous, accessible and sustainable.
This will enable assessment to be regular, individualised and holistic. As short and long term needs are dictated by the progression of the dementia, continuity of assessment is vital. Holistic assessment includes an assessment of carers' health needs, as the physical and mental deterioration associated with dementia affects the emotional and physical well being of the carer. How regularly carers negotiate assessment with key people will be an individual decision, as will the type of support offered as a result of the assessment, for example 'time out, or time off' to allow space for the carer.

(b) Continuity of regular assessment and support

As mentioned in the rationale for guideline one, quality of communication with key people is fundamental if professional workers are to understand the carers' situation and be on hand when carers need assistance - especially when changes in an individual's condition precipitate a crisis in care giving. Crises usually occur out of office hours, so contacting people who are appropriate to help in these situations is problematic – further exacerbating levels of anxiety and frustration born from a feeling of isolation. Maintaining contact and communication to support the carer through times when resources are reduced to emergency cover is vital, and not necessarily idealistic.
Alternative contacts could be available during out of hours situations or when the key person is not accessible, for instance, periods of absence through sickness or holidays. To facilitate this, an out of hours surgery number or crisis number should be given to carers, as should other named people who could step in for the key person on a temporary basis. Alternative contacts who had no knowledge of the situation was however seen as problematic,

‘do they know the case, do I have to start from scratch – in this set up both sides get fraught’

Continuity in carer support could be assisted by a carer's diary, which, if it captured the salient problems specific to the individual with dementia, could facilitate better understanding for other workers unfamiliar with the carer's situation and the person they are caring for.

5.4. THEME 3 - INVOLVEMENT IN CARE:

5.4(i) GUIDELINE 3

As a carer, you may work with several groups of professionals who may be involved with planning care (not just the key person). Your knowledge and expertise about the individual needing care will be valued by these different groups of health/social care professionals,
as this knowledge will ensure your relative remains central to any decisions made about their care. This will ensure that care given to your relative, irrespective of care setting, is appropriate, manageable and supported. You can therefore expect health/social care professionals:

- to ask you how you would like to be involved in decisions made about your relatives care;
- to involve you in any decisions made about the care of your relative;
- to understand if you want someone to support you in this process e.g. your key contact person, a family member, someone from your carer support group, or a member from an advocacy organisation.

5.4(ii) GUIDELINE 4

When you are involved in decisions made about care in more formal settings, such as family meetings, case conferences and review meetings, you can expect:

- to be told what is going to be discussed at the meetings;
- your own issues about your relatives care / personal support to be included on the agenda for these meetings;
• a health/social care professional to support you during the meeting, by ensuring your issues are fully discussed; after the meeting, by checking out with you that you are satisfied with the overall process of the meeting and how decisions were made.

5.4(iii). RATIONALE FOR GUIDELINE 3 & 4

(a) Supporting carers’ choice to participate in decision making

The involvement carers have with different workers at different times will change according to care demands and priorities, dictated by the progression of dementia. The degree to which carers choose to participate in decision making processes about the planned care of their relative may change according to their level of physical and emotional energy. The carer’s key people, or professional contacts should therefore respect the carer’s autonomy by supporting their choice to either become involved or continue to be involved in care planning processes. In exercising choice, carers should not be made to feel their continuing level of involvement is suddenly not required, or that their knowledge about the individual needing care is now not valued. Rather, alternative ways of maintaining involvement
need to be considered which do not compromise the carer’s physical and mental health at various times.

Supporting the carer’s choice to be involved may be especially important when formal meetings occur, such as family meetings, case conferences, or reviews. Involvement includes negotiating with carers the time and place of meetings, but more importantly, finding the appropriate means whereby the carer's concerns are addressed. Carers find it difficult sometimes to do this in the health care arena,

‘often I want to put things forward but I forget’

‘It would be good to meet after a meeting to say here are the things I want to say but I could not say’

Putting forward carer issues may involve carers directly, or it may include involvement of others who can adequately represent the carer, and act as an advocate. This advocate could be, for example, a health care professional, a member of advocacy agencies, or a friend. The key person's role is to facilitate this advocacy if required. This means that carers and health/social work professionals should meet beforehand to prepare the agenda for the meeting together, and decide on how to represent the carer’s concerns. The advocate is able to express what carers sometimes find difficult, their level of emotional stress,

‘it's difficult, you need somebody on your side who understands your problems’
They will have insight into the situation from the carers’ perspective and be able to articulate knowledge of this situation by identifying and clarifying current problems.

The carer may want to forward their own itemised agenda, drawn from their own notes or diaries, to ensure that the crux of a problem is effectively presented at the meeting. Following the meeting, carers should be given an opportunity to discuss with their professional representatives, how they felt about the meeting, how they felt outcomes were achieved, and whether they felt their concerns were adequately addressed. The carers should expect this information to be acted upon by health/social work professionals and ensure appropriate changes are made when necessary. This feedback is vital for the carers so that they understand the rationale for certain decisions by understanding of the process. In this way, carers can appreciate reasons for decisions made, which is especially important when outcomes do not meet carers’ expectations.

(b) *Issues which hinder carer involvement*

Unfortunately, the level of carer involvement in decision making processes proposed above is not typical currently. Several factors could explain this, including time, lack of knowledge and the inequity in power between professional and lay groups to make decisions, based on perceived
expertise (see Chapter 2). The authority the professional has over the carer when making decisions about care has major consequences for encouraging open and honest relationships that empower carers. Although carers themselves may recognise their contribution, traditional roles hamper them in asserting this. The assumptions underpinning traditional professional/carer relationships may perpetuate the role of the carer as being a passive recipient of care who does not challenge, question or make demands on an already overstretched service, as this may be perceived as being ungrateful or complaining. These deep-rooted beliefs which carers and health professionals hold, need to be acknowledged and addressed in order to challenge the professional ownership of power and authority to make decisions about care.

(c) Coaching carers and professionals in exchanging expertise

Professionals may need ‘coaching’ in how to involve and value carers. For example, obtaining information from carers will help professionals understand the person they care for, who the person is behind the diagnosis of dementia, and how this disease affects this essence of personhood. Likewise, carers need coaching in how to articulate this vital knowledge so that professionals are enabled to initiate processes of care which are individually orientated.
One way of achieving this coaching could be for professional workers to encourage carers to share the knowledge they have of the person they care for. Carers, for example, could be encouraged to talk openly about the sort of things they think are important for professionals to know about their relative, who they are, what they like, their history, their preferences, their politics, their influences, what makes them happy or what makes them sad. One carer, for example, emphasised the importance of telling health care professionals about:

‘the number of different ways to entice them (the person with dementia) to do something’

They may need help in thinking about different ways of presenting this information to various professionals at different times. For example, recording these things in a diary or a note book or writing their histories, may help professionals understand the little things about the individual which make such a difference to the ways in which care is planned for, organised and delivered.

Questions (Figure 2) were derived from the initial research study (Walker et al. 1999) that may help the carer articulate the kind of information that might be useful to share. These questions were modified by the carers in this project. The questions could be used by carers before, for example, a meeting with their GP, social worker or CPN to help them marshal their
thoughts so they could identify what their problems were and how their short term needs may have changed.

FIGURE 2: ‘Enabling questions’ for carers

1. **What concerns do you have about the care planned for the person you care for?**

2. **What is most important to you about that person’s care – that they are happy, loved, receive good physical care from other health professionals?**

3. **What sort of help, if any, do you have from others such as home help, sitter services?**

4. **Would you like to be involved in the decisions made about your relatives care?** Remember, this is your choice entirely and so its completely OK if you choose not to be involved. You can renegotiate this at any time with your key contact or health, social care worker if you change your mind.

5. **If you could be involved in care planning, in what ways would you like to be involved?**
6. **What do you think other professional workers need to know in order to provide the best possible care for the person you care for** – for example: physical abilities, their different mood swings, things they like, a history of their life the important people in their life?

7. **What do you need to know from other professional workers (who are involved in the care of your relative) that may be of help to yourself?** For example, when they go on holiday; any changes in practice at the day centre; what your relative achieved today or what they particularly enjoyed. These things may affect you and the person you care for.

8. **As a carer what support do you need?** As well as the physical or social things, think about the support you need with coping with the same routine, needing to let off steam, talking to others, knowing who is there in a crisis.

9. **Is there any information you need at the moment?**

10. **What might get in the way of you getting in touch with your key worker or stop you being involved in discussing the care of the**
person you care for? For example, time, transport, family commitments, worry about talking to professionals.

11. How will you let professionals know you are satisfied with the service you are receiving with regard to, for example, involvement in decisions, the relationship you have with key professionals, overall support?

Discussing the merits of these questions with carers revealed a variety of situations where carers felt they needed support and highlighted the ways in which this support should be given. For example:

- in helping carers to broach sensitive issues surrounding an individual’s personal needs - for example sexuality;
- being given ‘time out’ to think about any proposed decisions that may affect the care and support given to carers and their relatives. Carers felt they were often pushed into decisions if there was no thinking time;
- being given practical support; such as arranging a sitter to come regularly so that carers can get on with things, or help them with filling out grant application forms;
- being given psychological support; such as having a ready and sympathetic ear following traumatic incidents while helping the carer maintain a sense of perspective through humour;
being given educational support; such as teaching and instructing carers on the use of lifting aids, or managing increasingly difficult situations that are precipitated through for example, sleeplessness or increased restlessness.

Equally important are the things carers need to know from the different professionals who have a contribution to make to their relative's care. Professionals also need coaching in thinking about things carers may like professionals to inform them about. They could organise regular meetings with carers, and encourage them to write things down in a diary or a note book or construct a list of questions which could act as an aide-memoire. Perhaps sharing a diary or a note book with carers which capture the little things that happened when their relatives are in day care or respite care could encourage continuity of communication and prompt the professional workers into openly sharing with carers major events of the day.

Carers may like to be more involved in the experience of their relatives/friend's day when away from home. Sharing information or, if required, getting more actively involved in care away from the home environment could facilitate continuity in the execution of care between care in the home and other carer settings which would promote holistic practices. Mood swings or restlessness often exhibited in the individual with dementia following transitional care could be accounted for. Carers could meet
someone regularly in care centres to assess what is occurring, or share in particular aspects of care delivery. If professionals and carers were mutually receptive and open to what each has to offer the other, tacit expertise will be revealed which will enhance effectiveness of care delivery, not to mention mutually beneficial relationships between carers and professionals.

5.5. THEME 4 - MAKING SURE ITS ALL WORKING:

5.5(i) GUIDELINE 5

As part of the process of being involved in reviewing care issues and decisions, you can expect:

- health/social care professionals to listen to how you feel about the care being given;
- support for yourself and the person you care for;
- to negotiate the best methods to feedback information (ideally at the outset) e.g. keeping a diary or planning regular times for face-to-face / telephone meetings with care professionals;
- health/social care professionals to offer you the opportunity to look at any plans of care so you can consider their continued relevance
RATIONAL FOR GUIDELINE 5

(a) **A model of evaluation of carer involvement**

This guideline will give carers an opportunity to review how progress of care and the level to which they are involved contributes to the quality of care the person receives. The guideline emphasises that a *spiral* model of evaluation, (whereby feedback of involvement leads to action which is further evaluated and subsequently acted upon and evaluated), enables review processes to be continuous and dynamic.

Two-way processes of pro-active feedback means that carers and health/social work professionals can make immediate amendments to processes of involvement and outcomes of care by sharing experiences and thinking about new ways ahead.

(b) **When to evaluate**

Methods of establishing evaluation processes should be negotiated at an early stage and framed around questions such as:

- how frequently should carers and professionals agree to meet to review processes of care and involvement?
- who should be included in this review process?
what is the best method to feedback immediate and long term concerns?

Feedback and input into care is vital. Awareness of issues and developments in care could be improved through increasingly effective communication processes. Methods of reviewing carer involvement may differ according to the variety of situations carers have been involved in. For example, the pre-planned formal meetings may require a different method of evaluation from the more informal day to day situations. It may be useful therefore to consider these two types of situations for evaluation separately. During formal meetings, carers' views, opinions, and beliefs about their relatives care will influence what decisions need to be made about care, how these are made, and when action points will be achieved. Multi-professional seminars or workshops could be organised and used to supplement these formal evaluation processes to further share information and swap ideas with carers.

Finding ways to feedback on issues pertinent to formal settings, will differ from the more informal situations which deal with day-to-day concerns. Evaluation for these scenarios may address situations where carers may like to know about what happens to the person they care for while they are in day care / respite / hospital with respect to what is working well and what is not.
they tell me if he was sleepy or tired, whether he ate his meal or not……..we write it all in a book, I’m really very lucky’

Alternatively, carers and professionals may need to find out how newly acquired knowledge regarding different approaches to care delivery, perhaps learned from each other, have worked out in the home or institutional setting.

Ongoing review of care, between carers and professionals, informs new ways of working and is crucial to ensuring the best possible care for the individual with dementia is achieved.
CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1. CONCLUSIONS

This project set out to validate a set of guidelines (Walker et al. 1999) devised to facilitate the involvement of carers in care planning for people with dementia in hospital and community settings.

The move towards involving carers in care planning reflects Government initiatives which seeks to involve users both in policy development and in decisions relating to their own care. Evidence suggests, however, that involvement depends on either the assertiveness of the carer or individual initiatives and good practices of professionals. There is also a lack of clarity about what involvement means in practice.

Caring for someone with dementia is physically and mentally exhausting and can be socially isolating. The experience of the carers in this project indicated that the health service is not responsive to their needs and often takes for granted or ignores the work that carers do. The original guidelines were developed in response to this current situation. The guidelines were
However developed in a hospital setting with a small number of carers (n=20) and needed to be validated further.

Therefore the specific objectives of this project were:

- To evaluate the relevance of the guidelines for carers of people with dementia.
- To differentiate between the degrees of relevance of guidelines for carers at different stages of the caring continuum.
- To explore the guidelines fitness for purpose in various community and hospital settings
- To disseminate with core groups of carers revised guidelines to carer organisations, local education institutions and local Trusts

6.1.1 To evaluate the relevance of the guidelines for carers of people with dementia.

Involvement in care planning person centred care for the person with dementia is not formally recognised or acknowledged by professionals. Indeed traditional attitudes persist regarding locus of expertise and expert knowledge and so powers of decision making remain with professionals rather than carers. Carers’ expertise (and so involvement in care planning processes) is often undermined rather than supported by professionals.
The group of carers in this project (n=19) found the guidelines relevant to their situation. In particular, they valued the emphasis the guidelines placed on the knowledge they had of the person with dementia they cared for, the open communication between different professionals and carers, the availability of contact, and awareness and accessibility of resources. The guidelines offered potential ways of working with professionals that fostered an equality of relationship. This would allow them to feel comfortable, and better able to assert their needs with the consequence of enhanced participation in decision making in partnership with health professionals. Carers in this project believed that involving them in decision making would benefit both them and the person they cared for by ensuring services are responsive to everyone’s needs.

6.1.2 To differentiate between the degrees of relevance of guidelines for carers at different stages of the caring continuum

Carers of people with dementia in this project had experience of a wide variety of care settings including, day centres, respite care, hospital and community care. Some carers were relatively new to this role, whilst others had been caring for many years. Overall, the guidelines were relevant to carers' individual situations. However, the guidelines propose a key person to act as both a co-ordinator of services and someone who knows the person with dementia well, and the carer. Carers welcomed the notion of a
key person to support their emotional and resource needs. It was acknowledged that in the community setting, carers may need several key people to assist with the multitude of needs associated with caring with someone with dementia. It was clear that the GP had a prime role in initiating and facilitating stability for carers.

6.1.3 To explore the guidelines' fitness for purpose in various community and hospital settings

From the carers' point of view, the guidelines met their needs. However, the carers were realistic about the practical difficulties in implementing these guidelines. These included attitudes and accessibility of professionals, lack of co-ordination between services, and lack of specialist knowledge of both caring and dementia. The professionals that attended dissemination workshops echoed these concerns. Our recommendations attempt to address some of the potential barriers to putting the guidelines in place.

6.1.4 To disseminate with core groups of carers revised guidelines to carer organisations, local education institutions and local Trusts

Dissemination of this work to date has been minimal. Despite targeting a wide professional audience, the number of attenders at workshops was low. Further dissemination is required, together with additional research (see
recommendations), in order to assess feasibility of the guidelines from a professional viewpoint. The professionals who were able to comment on the guidelines were generally positive, but also noted similar practical difficulties in implementation as the carers.

This project involved close collaboration with carers. The experience of involving them fully as participants in the project has presented a number of challenges common to collaborative ventures. These include; delineation of roles, differing agendas, and practical issues, such as the time required to foster good relationships. Working through these challenges enabled us to develop strong relationships with the carers, which in turn yielded rich meaningful data.

6.2. RECOMMENDATIONS

6.3. RECOMMENDATIONS FOR GUIDELINES:

(i) Guideline 1: Initiating Contact:

This guideline addressed the importance of professionals making an insightful assessment of the carers situation when they first make contact in order to receive help and support with the care of their
relative. This professional is usually the GP and their role as gatekeeper to other services accessing key people was endorsed by carers.

1. Raise awareness in professionals and carers of the importance of establishing a key person for the carer early on in the caring experience.

2. Inform carers as to how a ‘key person’ could support them. This could prompt discussion, so that carers could identify appropriate contacts relevant to their immediate and long term needs. It could also help them identify what services are available (e.g. financial), as often carers do not know what to ask about or what they are entitled to.

3. Formalise this referral process by establishing internal mechanisms of contact (GP will refer, key person will then contact carer).

4. Establish a ‘key person’ register to be available in GP surgeries, and accessible to carers through formalised processes of referral. The register could include a list of potential key contacts, for example who the name of the social worker attached to the GP practice, what they offer in the way of support, and how to access them. This register could then act as an ongoing resource for both carers and health professionals. Other professionals who could be included in the register – district nurses, community psychiatric nurses, day centres, occupational therapists, sitter services, advocacy agencies, a range of voluntary agencies and Alzheimer Scotland.
5. Information, generally available for carers in health centres and surgeries outlining this ‘key person’ resource. This would enable carers caring for relatives with dementia to inquire about this service during their GP consultation.

6. Develop evidence to support the appointment of dementia care specialists across all community health care settings to take on the role of key person

(ii) Guideline 2: Maintaining Contact

This guideline addresses the importance of maintaining flexible, open and negotiated approaches to ensure contact with the key person is effective. Notably, carers felt the contact with the key person should be accessible, committed and available.

- The processes involved in establishing a relationship with a key person should be negotiated mutually and checked out regularly to make sure they are working. (For example, what to do if a problem suddenly arises, how to feedback information to the key person regarding changes in care, experiences in respite, needing advice on matters, when is the best time to meet, and maintain regular contact).
• Ongoing holistic assessment of both the person with dementia and the carer should be undertaken. This should include identification of any training needs of the carers (for instance, moving and handling, helping the carer to re-establish their relationship with the person with dementia (Walker et al. 2001 – in press)

• Documentation needs to be developed to assist with these processes (for example an initial negotiated contract, a diary to record feedback)

(iii) Guidelines 3 & 4: Involvement In Care

**Guideline 3** reflects the ways in which the carers’ expertise about the person needing care will be valued by different professionals carers encounter. Carers will know their expertise is valued because their involvement in care planning activities will be sought by professionals in different ways, depending on the care setting. How carers are involved, and the level to which they want to be involved, will be decided by the carers themselves, as this too may be dependent upon the care setting or degree of need exhibited by their relative.

**Guideline 4** addresses what involvement entails for carers in more formal settings (such as case conferences or family meetings) and the support and communication strategies carers require depending on their level of involvement at that specific time.
1. Health or social work professionals should actively encourage and empower carers to participate fully in all processes in which decisions are made about the care of their relative.

2. All carers should have access to advocacy services. Given the tenacity of deep rooted beliefs about professional expertise, carers may identify the need for an advocate to support them in their interactions with professionals, especially at significant points on the care continuum - such as admission to and discharge from hospital or respite, or when carers participate in more formal meetings.

3. Professionals need to be sensitive to the ways in which carers would like to be involved in decisions made about care, and the extent they wish to be involved.

4. Information needs to be shared between professionals and carers, and processes for sharing should facilitate open and honest dialogue. This will help professionals really begin to ‘know’ the person needing care, and the little things that make a difference to their relative's day, for example, what makes them angry, sad, calm, excitable, withdrawn or participative.

5. Professionals should also consider the quality of information they share with carers, as this will reflect ways in which carers choose to be involved in decisions about care.
(iv) Guideline 5: Making Sure It’s Working

This guideline will give carers an opportunity to review how progress of care and the level to which they are involved contributes to the quality of care the person is receiving. Ongoing review of care between carers and professionals informs new ways of working, and is crucial to ensuring the best possible care for the individual with dementia is given.

• Evaluation of carer involvement must be seen as an integral part of the process. As the carer encounters many different situations in which care needs should be reviewed, each setting should be regarded carefully to clearly identify:
  • what the issues are that need to be reviewed – for example, the care itself and the success of the involvement
  • the best method of reviewing these elements.

6.4. RECOMMENDATIONS FOR POLICY MAKERS

• Standards are developed from these guidelines that relate specifically to this process of lay carer involvement. This will allow auditing and further development. Current standards documents generally refer to
involvement as a philosophy underpinning good practice but do not specifically unpick the complexities of the process of involvement.

- Develop a comprehensive database of carers and professionals involved in dementia care, at local and national level, that is readily accessible by professional and non-professional people alike to use to develop and subsequently increase potential networking. For example, nurse researchers would find an accessible network to help them rapidly secure appropriate sample groups or target relevant professionals for dissemination purposes.

- Develop a database of professionals and non-professionals interested in information and networking in relation to dementia care. Work in establishing such databases is crucial and demands urgent attention, especially when the ethos of health care purports to value systems such as ‘integrated’ or ‘critical care pathways’ supported by multidisciplinary teams. Service users' demands for developing efficient and effective strategies for integrating an accessible and streamlined service is evidenced by the carers in this project. Establishing such databases is one way in which integration could be improved.

- Develop a dissemination strategy for project findings. This should include a wide range of organisations e.g. Consumer Councils, Better Government for Older people, Older People Projects, Health Advisory Services, Health Education Boards, NHS Direct and NHS24 and appropriate websites.
6.5. RECOMMENDATIONS FOR PROFESSIONALS

- Enabling the professional to engage in successful involvement with lay carers through professional coaching. For example by:
  - developing ways in which they can help carers to broach sensitive issues surrounding an individual’s personal needs
  - developing communication skills that reflects an equality in the relationship with the carer
  - developing skills in self evaluation
- Recognising opportunities for carer coaching. For example, coaching that enables carers to be more assertive in their relationships with professionals.
- Work in close partnership with, for example voluntary organisations who have some personal contact with carers.

6.6. RECOMMENDATIONS FOR MANAGERS

- Contribute to, resource and be supportive of carer involvement

6.7. RECOMMENDATIONS FOR EDUCATIONALISTS

- The concept of carer involvement needs to be more explicit in nursing education curricula
• Involvement of users in both the planning and delivery of educational programmes will ensure their perspectives are represented and a culture of partnership is engendered.

• Educational methods should be employed to facilitate and accredit professional workers in order to promote, implement and evaluate clinically effective working practices through initiatives such as Work Based Learning.

RECOMMENDATIONS FOR FUTURE RESEARCH AND DEVELOPMENT

WORK

• Extend this work to validate the guidelines with other client groups e.g. stroke, palliative care.

• Extend this work to validate the guidelines with other health care professionals e.g. occupational therapists, social workers.

• Evaluation of the implementation of the guidelines in practice.
References


Duncan MT & Morgan DL (1994) Sharing the caring: family caregivers' views of their relationships with nursing home staff *Gerontologist* 34(2), 235-244.


Hertzberg A & Ekman S (2000) 'We, not them and us?' Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes *Journal of Advanced Nursing* 31(3), 614-622.


Walker E, Dewar B & Riddell H (1999) *Guidelines To Facilitate The Involvement Of Lay Carers In The Care Planning Of The Person With Dementia*. Queen Margaret University College: Edinburgh.


APPENDICES

APPENDIX 1
Guidelines to facilitate the involvement of lay carers in the planning of care for the person with dementia in hospital:
(Walker E, Dewar B & Riddell H (1999) : section 9-GUIDELINES

APPENDIX 2
Gannt Chart of Project

APPENDIX 3
Letter to day centre managers and enclosure-First contact letter to carers

APPENDIX 4
Guidelines presented at workshops for validation:
Appendix 1

GUIDELINES TO FACILITATE THE INVOLVEMENT OF LAY CARERS IN THE PLANNING OF CARE FOR THE PERSON WITH DEMENTIA IN HOSPITAL: (Walker, Dewar and Riddell 1999)

Section 9: Guidelines

9.1 Team Philosophy

The multidisciplinary team should develop a team philosophy which expresses a genuine commitment to involving carers in decision-making by identifying:

- How does the involvement of carers benefit patients, carers and health care professionals?
- What are the goals for involvement?
- How can these be achieved?

9.2 Key Contact

- Treat as a priority the provision of a key contact for carers (using the named nurse system if appropriate). Nominate a deputy (e.g. a care assistant) to act in the absence of the key contact. This arrangement would recognise the role that care assistants play, under supervision, in providing patient care.
- Support the availability of that key contact for admissions, meetings etc through the duty rota (where shift work is in operation)
- Designate time during the week for the key contact to have contact with the carers of his/her patients either through phone calls, domiciliary visits or by having an 'open surgery' once a week where carers can come and talk specifically about their relative. Once designated, this time needs to be given priority.
- Ensure that if there are any changes in personnel (e.g. the key contact retires or leaves) the carer is informed.
- Ensure that if a carer phones up to speak to the key contact and neither s/he nor the deputy are available, then they take the next available opportunity to contact the carer.
- Ensure that the key contact or deputy are proactive in contacting the carer to keep them informed about matters which have previously been agreed between them (e.g. of critical incidents, of changes in behaviour, of changes in medication).
- Ensure that the key contact or the deputy gets in touch with the carer before a family meeting to address any concerns, questions etc. they may have, and also afterwards to check whether the carer is satisfied with the outcome and, if they are not, to take appropriate action (e.g. arranging a phone call with consultant).
## Appendix 2

<table>
<thead>
<tr>
<th>Activity</th>
<th>2000</th>
<th>JUNE</th>
<th>JULY</th>
<th>AUGUST</th>
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<tr>
<td>SET UP PROJECT</td>
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<tr>
<td>Contact EVOC to get names / addresses of voluntary organisations</td>
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<td></td>
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<tr>
<td>Contact voluntary organisations</td>
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<tr>
<td>ACCESS SAMPLE</td>
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<tr>
<td>Target individual carers outside voluntary organisations</td>
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<tr>
<td>Letter contacting original sample group</td>
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<tr>
<td>Access sample group through voluntary organisations</td>
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<tr>
<td>ORGANISE WKSHOPS</td>
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</tr>
<tr>
<td>Look for appropriate venues</td>
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<tr>
<td>Book venues</td>
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<tr>
<td>Organise refreshments/cater</td>
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<tr>
<td>Develop paperwork/guidelines for carers</td>
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<tr>
<td>Write letters after workshops and send out</td>
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<tr>
<td>Set dates for workshop</td>
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<tr>
<td>Draw up frameworks for workshop/analysis</td>
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<td>Photocopy papers, for workshops</td>
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<tr>
<td>Prepare S.A.E’s</td>
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</tbody>
</table>
### INVITATIONS
- Discover Carer backgrounds, re. Experience and facilities accessed
- Confirmation letter and copies of guidelines/individual characteristics
- Book sitter services

**Gantt Chart; Validation of guidelines for lay carer involvement:**

<table>
<thead>
<tr>
<th>2000</th>
<th>SEPTEMBER</th>
<th>OCTOBER</th>
<th>NOVEMBER</th>
<th>DECEMBER</th>
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<td><strong>WORKSHOPS</strong></td>
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<td>Hold workshops(2)</td>
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<td>Finalise frameworks for workshop/analysis</td>
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<tr>
<td>Possible individual visits for evaluation of guidelines</td>
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</tbody>
</table>

**1ST ROUND FEEDBACK**
- Collate feedback from workshops
- Receive further comments back from carers via SAE’s
- Collate feedback, analyse via thematic clustering

**2ND ROUND FEEDBACK**
- Amend guidelines following workshops
Send out amended guidelines for final approval

Gannt Chart : Validation Of Guidelines For Lay Carer Involvement  

<table>
<thead>
<tr>
<th>2001</th>
<th>JANUARY</th>
<th>FEBRUARY</th>
<th>MARCH</th>
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<tr>
<td>DISSEMINATION</td>
<td>Contact Trusts, HEI’s to set up meetings</td>
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</tr>
<tr>
<td></td>
<td>Contact carers to locate key people for dissemination</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Hold dissemination meetings</td>
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<tr>
<td>Final Report</td>
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Gannt Chart : Validation Of Guidelines For Lay Carer Involvement;
20 June 2000

Dear Sir / Madam

We are a team of nurse lecturers in the Department of Health and Nursing at Queen Margaret University College currently engaged in a project that is designed to improve the quality of the contact between carers of people with dementia and health care professionals.

We are currently seeking carers who would be interested in being involved in this short - term project. We are looking for approximately five carers who are directly involved in caring for an individual with dementia. Length of time as a carer is not important to the project.

Enclosed is a copy of the letter that outlines what this involvement entails.

We would be very grateful if you would be prepared to supply us with names and addresses of carers using your service so that we may contact them directly. Alternatively, if you feel this is inappropriate we will supply you with the letters to issue to carers directly.

Enclosed is a stamped addressed envelope for your response.

We look forward to hearing from you in the near future.

Yours sincerely

Alison Goulbourne
Project leader.
Dear  

We are three nurse teachers based in the Department of Health and Nursing at Queen Margaret University College. We are contacting you because we would be very interested in finding ways to improve the quality of the contact carers like yourself have with health professionals. We believe this is important because improving contact means that carers can be more involved in deciding what happens when the person they care for needs professional help.

We are therefore asking whether you would be interested in taking part in a small project. This project is looking at previously developed guidelines with a view to making sure that they are suitable to meet your needs. Knowing your opinion of these guidelines is very important to us, as this will be helpful in ensuring that carers, like yourself, become more involved in the professional care given to your relative or friend.
If you would like to be involved, you will receive a copy of these guidelines in the post. A ‘comments’ sheet will be attached to these guidelines which we would like you to complete. You will then be invited to attend a meeting at a convenient location for yourself. We propose to hold this meeting in late September early October. At this meeting, there will be other carers and together we will discuss your views and concerns regarding these guidelines. It would be helpful, therefore, if you could bring your comment sheet with you.

The meeting will last approximately two hours. If necessary, we will arrange and / or pay for a sitter service and transport costs. Refreshments will be provided at the meeting.

If you would like to be involved, please return the slip in the stamped addressed envelope provided and post this back to us by Friday August 4th. We will then contact you again in due course.

Thank you for your interest.
Yours truly,
Alison Goulbourne,
Helen Riddell,
Lindesay Irvine (The project team)
Yes, I would like to be involved in your project.

SIGNED: _______________________________________

NAME: _____________________________________________________________________

ADDRESS: ___________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

TELEPHONE NUMBER: _______________________________________

Please return by August 4th to:
Alison Goulbourne,
Project Leader,
Department of Health and Nursing,
Queen Margaret University College,
Clerwood Terrace,
Edinburgh.
EH12 8TS.
Appendix 4

GUIDELINES PRESENTED AT WORKSHOPS FOR VALIDATION:

| EVALUATION OF GUIDELINES TO IMPROVE CARER INVOLVEMENT IN THE CARE OF A PERSON WITH DEMENTIA IN HOSPITAL. |

INFORMATION FOR CARERS

We are hoping to improve the quality of the contact which carers are likely to have with professionals in order to allow them to have more involvement in the decision making which goes on when a person with dementia requires professional help. We have developed the guidelines below from a series of discussions with carers and nurses. We would like to find out if they are relevant and useful to you as a carer. These guidelines are in their early stages. We would welcome your comments and if you would like to add anything or change anything please go ahead and do so.

We will be inviting you to a meeting with other carers to discuss these further. Please bring along the guideline sheet with your comments. Following the meeting we plan to take on board all suggestions and will send you out a final version. These guidelines are relevant to you as a carer when receiving either hospital or community support.
STEP ONE; MAKING CONTACT.

We propose that all carers have access to a specific person (called a ‘key contact’) who they can talk with on a regular basis about the care of the person with dementia. This ‘key contact’ might be a nurse (hospital) or other person who knows the individual and has up to date information about their condition and care. In the community it might be your community nurse, social worker or district nurse who is your main contact.

Guideline 1
Make sure you know who the person is who will act as your ‘key contact’ and how to contact them.

Guideline 2
Your key contact will contact you if you have not managed to speak to them when they first start providing care for the person you care for.

Guideline 3
You should agree with your key contact how they can get in touch with you and how often you would like them to contact you. For example, do you want them to phone, when is most convenient to you, would you prefer them to write to you etc.

Guideline 4
Whatever you decide, the key contact should make it a priority to contact you when you have asked them to contact you

Guideline 5
You and your key contact also need to agree on what you would like to be informed about concerning the person you care for. For example, do you want to know if there are any changes to the care they are being given, or if tests are being carried out etc.

Guideline 6
Your key contact should inform you if any family meetings are being arranged. These family meetings are usually between health professional, care staff, family members and any others involved in the care of the person. Your key contact should discuss with you any concerns or questions you have which you would like discussed at the meeting. Your key contact should ensure that these are added to the agenda for the meeting.
Guideline 7
Your key contact should arrange to meet with you after the meeting to discuss what has happened and to check that you have understood any decisions that have been made. It is important that you are happy with what has been discussed and agreed upon.

Guideline 8
Your key contact should tell you the name of the person you should contact if they are not available or are off duty.

STEP TWO: WORKING TOGETHER WITH YOUR KEY CONTACT

Whether the person you care for is in hospital or has care at home or a day centre, they will have a ‘Care Plan’. The care plan outlines what the person you care for needs. It is drawn up by those who care for the person. This might be a hospital nurse, community nurse or social worker. It is important that you know what is in the care plan so that you know what care is being provided. You can help in making sure that the care plan meets the needs of the person being cared for by:

Guideline 9
Working with the key contact to plan care for your relative. They will value your knowledge about the person being care for

Guideline 10
Going over the care plan to ensure that it meets the need of the person being cared for and that it is being carried out.

In what way can I be involved in care decisions with my key contact?

Some carers want to be involved in every decision regarding the person they care for, others are happy to leave it to the professionals. We are all different. Your key contact will discuss with you what sort of involvement you want and explain how you can be involved and informed. They will arrange to meet with you and go over the following questions. It may be helpful to think about them before that meeting.

As a carer, please think about these questions to see if they would help you plan the level of involvement you would like with your key contact.

Questions to ask to get the most out of your involvement with your key contact

• Do you have any concerns about the care planned for the person you care for?
• What is *most important to you*, about that person’s care?

• How involved in care are you when the person you care for is at home?

• How involved would you like to be?

• What do you feel nursing staff or other professionals need to know in order to provide the best possible care for the person you care for?

• What do you need to know from those providing the care about the things that may affect you or the person you care for. For example, hospital procedures, daily hospital routines, when is the best time to contact you key contact etc.

• As a carer, what support do you need?

• What information do you need?

• What might get in the way of you getting in touch with your key contact or stop you being involved in discussing the care of the person you care for. For example, time, transport, family commitments, worry about talking to professionals.

• How will you let professionals know whether you are satisfied with the arrangements you have made with your key contact?

**Would these questions better if they were made as guidelines for involvement rather than general questions?**

**Guidelines to get the most out of your involvement with your key contact**

• Indicate your concerns about the care planned for the person you care for

• Say what is *most important to you*, about that person’s care

• Tell your key contact how involved in care you are when the person you care for is at home

• Say how involved would you like to be

• Tell your key contact what you feel nursing staff or other professionals need to know in order to provide the best possible care for the person you care for

• Decide what you need to know from those providing the care about the things that may affect you or the person you care for. For example, hospital
procedures, daily hospital routines, when is the best time to contact you key contact etc.

- Think about what support and information you need as a carer. (You may wish to write this down before you meet with your key contact)

- Consider the things that might get in the way or which might stop you getting in touch with your key contact or being involved in discussing the care of the person you care for. For example, time, transport, family commitments, worry about talking to professionals.

- Decide how you will let professionals know whether you are satisfied with the arrangements you have made with your key contact.