

# Baseline assessment of current information provision to people with dementia and their carers

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Published May 2009

## **Acknowledgements**

Thank you to the Advisory Group for providing valuable comment on the project at every stage; to the survey participants; to those who agreed to be interviewed; to Dr Gillian McColgan who conducted the interviews; to Paul Lambert for assistance with quantitative data management and analysis and to NHS Quality Improvement Scotland for funding the project.

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First published May 2009

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## **Baseline assessment of current information provision to people with dementia and their carers**

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**Project reference number:** HRSE/2007/001

**Date of submission:** January 2009

**Funded by:** NHS Quality Improvement Scotland in conjunction with Alzheimer Scotland. Project work commissioned by staff at the Stirling Dementia Services Development Centre.

## **Executive summary**

### **Aims**

The aim of the project was to identify the current patterns and practices of information provision to people with dementia and their carers across Scotland:

- producing a national picture of current dementia information provision by a wide range of professionals in health and social care, working with people with dementia and their unpaid carers
- identifying barriers and enablers in relation to effective information provision for people with dementia and their carers at diagnosis and during the course of the illness and
- establishing a baseline for evaluation of NHS Quality Improvement Scotland (NHS QIS) support to NHS health boards to meet the information provision standards in their integrated care pathways (ICPs) for mental health.

### **Methods**

- Four focus groups with people with dementia and carers to help identify key survey questions
- a survey of 596 professionals in health and social care in six NHS board areas to identify current practice and views about information provision and
- Thirty-five follow-up interviews with a range of professionals to explore barriers and facilitators in depth.

### **Key findings**

#### *Giving information*

- Oral information giving predominates (98%) with leaflets and books also widely used (87%). As dementia progresses, there is more engagement with carers and less with people with dementia themselves.
- The most widely used publications are those published by the NHS and the Alzheimer Scotland helpline card.
- Twenty percent of respondents had used information in minority languages and 25% had used formats for people with disabilities.
- Professionals believe that people with dementia and their carers get their information both from professionals and from family and friends. Eighty percent consider that people should seek out information for themselves.
- Professionals, especially psychiatrists, community psychiatric nurses and community mental health nurses, were seen as the most usual and the best information sources.
- Fewer than half respondents felt they had sufficient published information available to give out. Problems that occurred 'sometimes' or 'often' for more than half the respondents included:
  - lack of suitable materials
  - Lack of knowledge of materials available and insufficient time to identify them

- too little time to address all the issues
  - people with dementia and carers are not always receptive to information
  - too many professionals are involved and
  - too little support for people with dementia and their carers to understand the information.
- Only half of the respondents were aware of the ICP for dementia, which had been published 7 months prior to the survey.

#### *Facilitators to good information giving*

- Interviewees emphasised their commitment to the individual and the need to tailor information appropriately.
- The need to understand what and how much information people need at different times.
- Information giving which is embedded in a good professional-client relationship.
- Attention given to communication issues, such as sensory impairment.

#### *Barriers to good information giving*

- As people with dementia and their carers experience referral to successive professionals and care settings, insufficient clarity regarding professional roles in information giving.
- Shortage of up-to-date materials and patchy knowledge of some professionals less expert in dementia
- Stigma attached to a diagnosis of dementia can inhibit information seeking and make people less receptive to information
- Lack of, or late diagnosis results in lack of support for people with dementia and their carers.

#### *Possible solutions*

- Better training for a wider range of staff.
- Improved public knowledge about dementia, the importance of diagnosis and the availability of support.
- Up-to-date, good quality information available in a range of formats.
- Improved coordination among staff.
- Dedicated staff, such as dementia nurses, to promote continuity of care.

#### **Recommendations**

- The patchiness of information giving and the problems highlighted by the project suggest a need for improvement and the collection of evidence about whether this occurs
- There is a need to understand the views and experiences of the recipients of information to ascertain the effectiveness of professional information giving strategies
- Information and understanding about dementia needs to be available to a wider public to promote improved diagnosis.

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## 1.0 Background

There is evidence that people with dementia and their carers do not receive sufficient, clear information about the condition, services available, what to expect as time goes on and where to get help. This has been highlighted repeatedly, eg Alzheimer Scotland Action on Dementia<sup>1</sup> (2007:24) report that 'only half' of 334 carers of people with dementia surveyed had received information and much of this was inadequate. The SIGN guideline<sup>2</sup> (SIGN 2006:21) review of research indicated little agreement on information needs or provision for people with dementia and their carers. There is, however, every indication that better information at the right times can sustain care partnerships and enhance quality of life for both people with dementia and their carers.

Alzheimer Scotland Action on Dementia has produced new guidelines on the content and delivery of information. These guidelines aim to ensure maximum benefit for mental health and well being and will, in conjunction with the findings from this report, contribute towards the development of an on-line toolkit produced by NHS QIS. Ultimately, the toolkit will support boards with the implementation of the Standards for Integrated Care Pathways for Mental Health<sup>3</sup>.

The advice of the National Research Ethics Service was that this project was defined as an audit, and NHS ethical approval was not required. The project sought and gained ethical approval from the University of Stirling. It was conducted according to the British Sociological Association's Statement of Ethical Practice. Participants gave informed consent to participate, and their confidentiality was assured. Approval for the work was also obtained from the Association of Directors of Social Work.

This project has been funded by NHS QIS as a baseline assessment of current information provision. The findings will contribute towards the implementation of the standards for integrated care pathways (ICPs) in mental health (2007) and the development of Alzheimer Scotland guidelines.

## **2.0 Aim and objectives**

### **2.1 Aim**

The central aim of the project was to identify the current patterns and practices of information provision to people with dementia and their carers across Scotland. The project focused on the views of service providers. Those of service users informed the content of the survey.

### **2.2 Objectives**

- To produce a national picture of current dementia information provision specialist clinics involving people with dementia and their carers (especially those involving old age psychiatrists).
- To produce a national picture of dementia information provision by GPs, social workers who work with people with dementia and their carers and community psychiatric nurses (CPNs) working with people with dementia.
- To identify barriers and enablers in relation to effective information provision for people with dementia and their carers at diagnosis and during the course of the illness.
- To establish a baseline for evaluation of NHS QIS' support for NHS health boards to meet the information provision standards in their ICP for dementia.

## **3.0 Methodology**

Three stages of work were conducted:

### **3.1 Focus group work with people with dementia and their carers to inform the questionnaire design**

Four focus groups were held, involving a total of 13 carers and 6 people with dementia. In addition, one person with dementia was consulted individually and one community group professional was consulted individually about issues for Polish people. Two focus groups involved, respectively, Chinese and Punjabi participants. The focus group discussions explored what information people had received; where they got it before, at and after diagnosis; how useful the information was and what suggestions they had for improving information provision. The comments were used to inform the questionnaire design. The focus group schedule is in [Appendix 1](#). The principal topic raised in the focus groups that was incorporated in the survey was that of support for people with dementia and carers to understand information.

### **3.2 Sample survey of relevant professionals who work with people with dementia and their carers**

A survey was conducted covering six NHS boards and their associated local authorities. The boards were selected to include major cities, smaller towns and rural and island areas. The survey was distributed by local gatekeepers to staff working with people with dementia including psychiatrists, geriatricians, GPs, community nurses working with people with dementia, social workers (including Mental Health Officers) and other care managers (including care home managers and occupational therapists (OTs)). Table 1 gives the breakdown of respondents.

**Table 1: Questionnaire respondents, areas and professions**

Profession	NHS Board Areas													
	Dumfries and Galloway		Fife		Grampian		Greater Glasgow and Clyde		Lothian		Orkney		Total*	
	No	%	No	%	No	%	No	%	No	%	No	%	No	%
Psychiatrist	1	0.2	4	0.8	4	0.8	11	2.1	6	1.2	0	0.0	26	5.0
Geriatrician	1	0.2	4	0.8	0	0.0	7	1.3	7	1.3	0	0.0	19	3.7
GP	0	0.0	8	1.5	1	0.2	0	0.0	40	7.7	3	0.6	52	10.0
CPN/Community Mental Health Nurse and other Nurses	0	0.0	10	1.9	30	5.8	28	5.4	40	7.7	8	1.5	116	22.3
Social Worker/Mental Health Officer	8	1.5	5	1.0	33	6.3	80	15.4	37	7.1	1	0.2	164	31.5
Other Social Workers		0.6	0	0.0	1	0.2	31	6.0	5	1.0	0	0.0	40	7.7
Occupational Therapist	0	0.0	0	0.0	9	1.7	21	4.0	10	1.9	0	0.0	40	7.7
Service Manager**	0	0.0	0	0.0	1	0.2	14	2.7	2	0.4	0	0.0	17	3.3
Care/Carer/Support Worker	0	0.0	0	0.0	0	0.0	21	4.0	2	0.4	0	0.0	23	4.4
Other***	0	0.0	4	0.8	0	0.0	14	2.7	5	1.0	0	0.0	23	4.4
<b>Total</b>	<b>13</b>	<b>2.5</b>	<b>35</b>	<b>6.8</b>	<b>79</b>	<b>15.2</b>	<b>227</b>	<b>43.6</b>	<b>154</b>	<b>29.7</b>	<b>12</b>	<b>2.3</b>	<b>520</b>	<b>100.0</b>

\* Totals are not exact due to rounding

\*\* 'Service manager' includes managers of care homes, day centres, carer centres

\*\*\* 'Other' includes other AHPs, welfare rights officers, commissioning officers and unspecified professions

The survey data were statistically analysed using a Statistical Package for the Social Sciences (SPSS) 16. Analysis included extensive cross tabulation and tests of significance. The cross tabulations showed almost no statistically significant results. In particular, we explored differences between areas and health or social care working. These proved not to be significant<sup>i</sup>.

Within the survey, reference is made to stages of dementia. These terms were employed as commonly understood by participants and none expressed any difficulties with them. Alzheimer Scotland defines stages of dementia as follows:

- 'In mild dementia, a person might have difficulty making decisions, coping with complexities in their work or hobbies, and may have problems remembering to pay bills or attend appointments.
- At a moderate stage, the person with dementia may have increasing difficulty recognising family, friends or familiar places, may need more help with everyday activities such as reading or dressing, and their behaviour may change.

<sup>i</sup> Our convention was that significant findings required a value of  $p < 0.05$ . Cross tabulations are available on request.

- In the later stages of dementia, the disease affects more functions of the brain, and problems of memory and everyday activity become more severe. Communication can become very challenging, and the illness is likely to increasingly affect the person's physical abilities'.  
(Source: <http://www.alzscot.org/pages/info/dementiafacts.htm>)

### 3.3 Follow-up interviews with a sample of professionals

A sample of 35 professionals, volunteers from among the survey respondents, was interviewed to explore issues in more depth, particularly barriers and enablers to effective information provision. A copy of the interview topic guide can be found in [Appendix 2](#). Table 2 gives the breakdown of interviewees.

**Table 2: Interviewees and their professions**

<b>Profession</b>	<b>Number of interviewees</b>
CPN and other nurses	9
GP and other doctor	3
Occupational therapist	3
Psychiatrist	3
Social workers (care managers and MHOs)	17
<b>Total</b>	<b>35</b>

The interviews were analysed thematically using NVivo8, a qualitative analysis toolkit. Themes included an exploration of current practice in information giving; perceptions of factors facilitating good information giving; barriers to good information giving; possible improvements; and ways to overcome difficulties. In addition, themes raised by the interviewees emerged through a process of open coding of the transcribed interviews.

## **4.0 Results**

This section gives the results of the questionnaire survey and highlights key findings from the analysis of the interviews.

### **4.1 Questionnaire survey**

596 people commenced the questionnaire, 47 per cent from health and 53 per cent from social care. They did not all complete every question, and we indicate for each table the number of respondents to the question concerned.

#### **4.1.1 Ways of giving information**

The most usual means of giving information were verbally (98 per cent) or using leaflets and booklets (87 per cent). A minority of respondents mentioned other means such as audio (5 per cent), DVDs or videos (7 per cent).

We explored how information was given at different stages of dementia and to whom. The methods of giving information were consistent with the general responses (above) with verbal information predominating throughout. At the mild cognitive impairment stage, information was given verbally to both patients and carers, with less frequent use of written information. In the early stages of dementia, engagement with patients started to decrease, and there was more communication with carers. At later stage dementia, the engagement with carers had again increased.

#### **4.1.2 Publications used**

We asked whether each of a list of publications were being used for people with dementia and carers at different stages of the condition. As Tables 3 and 4 show, the most widely used publications were the Alzheimer Scotland helpline card and the NHS publications. Other publications were reported to be little used. The survey did not seek reasons for the use or non-use of particular publications.

**Table 3: Publications and information sources about dementia and dementia care distributed to people with dementia<sup>ii</sup>**

This is a list of publications and information sources about dementia and dementia care. If you use them, please indicate which of these you give out to PEOPLE WITH DEMENTIA and at what stages of dementia.					
	At Mild Cognitive Impairment stage	Early dementia	Late dementia	Not used	Response Count
Facing Dementia (NHS Health Scotland)	22.9% (53)	34.2% (79)	9.1% (21)	63.2% (146)	231
Milk's in the Oven (Mental Health Foundation)	2.4% (5)	5.3% (11)	0.5% (1)	94.3% (197)	209
Helpline card (Alzheimer Scotland)	38.2% (97)	52.4% (133)	28.3% (72)	40.6% (103)	254
Websites e.g. www.alzscot.org	36.9% (83)	43.6% (98)	22.2% (50)	48.9% (110)	225
Understanding Dementia - a Handbook for Carers (NHS Health Scotland)	38.9% (100)	53.3% (137)	30.7% (79)	39.7% (102)	257
Safety in the Home (Health Scotland)	22.7% (50)	25.9% (57)	13.2% (29)	69.5% (153)	220
Getting Help from your Doctor (Alzheimer Scotland)	19.8% (41)	19.3% (40)	5.8% (12)	76.8% (159)	207
Worried about Your Memory? (Health Scotland)	26.5% (56)	20.9% (44)	5.7% (12)	71.6% (151)	211
Dementia, Money and Legal Matters (Alzheimer Scotland)	29.4% (69)	37.0% (87)	17.4% (41)	57.0% (134)	235
National Care Standards (Care Commission)	29.2% (62)	27.4% (58)	18.9% (40)	66.0% (140)	212
Other	32.4% (22)	26.5% (18)	19.1% (13)	64.7% (44)	68

Note: respondents could indicate that a publication was used at more than one stage

<sup>ii</sup> The survey did not define the stages for respondents. The broad stages mentioned were considered to be sufficiently common currency to produce reliable results. At the piloting stage, no professionals expressed difficulty with using the terms in the survey.

**Table 4: Publications and information sources about dementia and dementia care distributed to carers**

This is a list of publications and information sources about dementia and dementia care. If you use these, please indicate which of them you give out to CARERS and at what stages of dementia.

	At Mild Cognitive Impairment stage	Early dementia	Late dementia	Not used	Response Count
Facing Dementia (NHS Health Scotland)	26.9% (60)	34.1% (76)	20.6% (46)	61.4% (137)	223
Milk's in the Oven (Mental Health Foundation)	4.6% (9)	6.2% (12)	3.6% (7)	93.3% (181)	194
Helpline card (Alzheimer Scotland)	41.8% (102)	50.0% (122)	41.4% (101)	40.6% (99)	244
Websites e.g. www.alzscot.org	38.1% (88)	49.8% (115)	39.0% (90)	44.6% (103)	231
Understanding Dementia - a Handbook for Carers (NHS Health Scotland)	43.0% (113)	58.9% (155)	44.9% (118)	35.0% (92)	263
Safety in the Home (Health Scotland)	24.0% (50)	24.5% (51)	19.7% (41)	70.2% (146)	208
Getting Help from your Doctor (Alzheimer Scotland)	19.5% (40)	21.0% (43)	15.6% (32)	74.6% (153)	205
Worried about Your Memory? (Health Scotland)	25.0% (50)	19.5% (39)	9.5% (19)	73.0% (146)	200
Dementia, Money and Legal Matters (Alzheimer Scotland)	27.2% (62)	36.8% (84)	31.6% (72)	56.1% (128)	228
National Care Standards (Care Commission)	23.0% (47)	24.5% (50)	26.5% (54)	66.2% (135)	204
Other	24.3% (18)	21.6% (16)	21.6% (16)	73.0% (54)	74

Note: respondents could indicate that a publication was used at more than one stage

#### 4.1.3 Alternative formats

Twenty percent of respondents had used information in languages other than English, though none had done so often. Of those who had done so, 33 per

cent had used information in Urdu, and 36 per cent in Chinese. Punjabi (26 per cent) and Polish (26 per cent) were also mentioned, but other languages only by one or two people each. We also asked about formats for people with disabilities, and 25 per cent had used these. The most frequently mentioned was large print, with British Sign Language, audio and video formats also being mentioned. Clearly, alternative formats are used in response to particular needs.

#### 4.1.4 Getting information

Eighty per cent of respondents felt that people should actively seek out information for themselves to help them understand dementia. This has to be seen in the context of the information that professionals were providing and does not necessarily imply that professionals felt that people should be left to find information for themselves. We asked what sources of information professionals felt people were currently using. While these are of course the opinions of professional and not the accounts of people with dementia and their carers, professionals indicated that people obtain information from a variety of sources. They were most likely to feel that information came from the following sources at the time of diagnosis, and later on in the dementia journey.

**Table 5: Where do you think people get information from during their dementia journeys?**

Information source	Used by some or most people			
	Around the time of diagnosis		At later stage dementia	
	per cent	number	per cent	number
GP surgeries or Health Centres	97.3	293	72.3	211
Hospital	93.7	267	75.3	220
Social Work Office	82.7	229	68.2	199
Alzheimer Scotland Dementia Helpline	90.8	266	74.3	217
Carers Centre	85.8	235	67.5	197
Dementia voluntary group/charity	81.6	212	64.4	188
Day Care Centre	78.3	202	55.8	163
Community Centre	52.4	122	10.3	30
Community Pharmacy/Local Chemist	52.4	122	10.3	30
Friends and family	91.3	242	45.9	134
Internet websites	86.5	231	44.9	131
Public Library	72.3	175	20.5	60
Housing Staff	33.6	75	4.5	13
Occupational Health Departments (at carer's place of work)	59.3	137	15.4	45
Scottish Helpline for Older People (SHOP)	51.9	119	13.4	39
Other	42.6	23	6.5	19

This table suggests that at later stages of dementia, people are less likely to get information from all sources. Professional sources of information are seen as particularly significant, as are family and friends, though these become markedly less important at later stages of dementia, along with help lines and carers' workplaces.

Respondents' views were sought on who was most likely to give information at different stages; the best ways to give information at different stages; and on the best sources of support to understand the information. The results are given in Tables 6, 7 and 8.

**Table 6: Who usually gives information to people with dementia and their carers?**

	Around the time of diagnosis		In the later stages	
	per cent	number	per cent	number
Psychiatrist	80.5	256	76.8	222
Geriatrician	45.6	145	47.8	138
GP	59.1	188	58.1	168
Community Psychiatric Nurse/Community Mental Health Nurse	65.7	209	79.2%	229
Social Worker/Mental Health Officer	24.2	77	47.8	138
Social worker/Care manager	29.9	95	51.6	149
Other Social Worker	7.2	23	10.0	29
Voluntary Organisation support worker on a 1:1 basis	12.6	40	28.4	82
Person at Helpline	6.3	20	9.0	26
Other	6.9	22	4.5	13

**Table 7: What are the best ways to give information to people with dementia and their carers?**

	Around the time of diagnosis		In the later stages	
	per cent	number	per cent	number
Orally by professional	97.2	304	89.1	253
Written material	95.4	285	72.5	206
DVD/video	79.7	153	23.9	68
Audio tapes	58.8	97	10.9	31
Other	71.3	10	6.0	17

Note: This table merges data from questions 20 and 25. For Q25, it includes answers 'excellent', 'very good' and 'good'.

**Table 8: Who are the best groups to support people with dementia and their carers in understanding information?**

	At early stage dementia		In the later stages	
	per cent	number	per cent	number
Psychiatrist	93.3	237	91.1	224
Geriatrician	86.8	184	86.7	175
GP	91.8	239	92.5	210
Community Psychiatric Nurse/Community Mental Health Nurse	99.4	299	99.6	273
Social Worker/Mental Health Officer	92.8	221	96.5	218
Social worker/Care manager	90.7	236	94.1	221
Other Social Worker	71.3	119	77.1	108
Voluntary Organisation support worker	92	217	92.5	184
Helpline	88.6	179	82.8	126
Advocate	78.5	160	78.9	127
Carer/Family	91.5	224	91.1	175
Other	100	15	94.5	17

These tables indicate that the ways in which individuals are believed to seek out information do not necessarily match professionals' views about the best sources of such information.

#### **4.1.5 Recording information**

Eighty per cent of professionals reported that they recorded in case notes the information that had been provided to individuals.

#### **4.1.6 Issues for professionals in providing information**

Fewer than half of the respondents felt that they had sufficient information available to give out either to people with dementia or to their carers. Health and social care professionals held similar views. They identified a number of specific gaps in the information available locally, including information on specific local services available, 'one-stop' information that could indicate routes to support for the many issues faced by people with dementia and easier access to more published information. There was significant comment on the lack of resources available locally, reflecting the limited use of the publications highlighted in the survey.

The focus groups and the background information identified a number of possible problems with information provision. Survey respondents were asked about these in turn, and the results are shown in Table 9.

**Table 9: What are the common problems with information provision?**

How common do you think these problems with information provision are for people with dementia and their carers?						
	not a problem at all	sometimes a problem	often a problem	always a problem	Rating Average	Response Count
Lack of suitable materials	10.6% (26)	49.2% (121)	33.3% (82)	6.9% (17)	2.37	246
I can't obtain suitable materials	13.2% (30)	50.2% (114)	27.8% (63)	8.8% (20)	2.32	227
I don't always know what's available	8.4% (21)	37.2% (93)	37.6% (94)	16.8% (42)	2.63	250
I don't have enough time to address all the issues that might be relevant	9.4% (23)	40.4% (99)	31.8% (78)	18.4% (45)	2.59	245
I don't have enough time to identify appropriate material	11.1% (27)	36.2% (88)	34.2% (83)	18.5% (45)	2.60	243
I find that people with dementia and their carers are unreceptive to written information	39.5% (92)	45.9% (107)	12.9% (30)	1.7% (4)	1.77	233
I find that too many professionals are involved to keep track of what information has already been given	24.6% (58)	51.3% (121)	20.8% (49)	3.4% (8)	2.03	236
A lack of one-to-one support to help people to understand the information	13.0% (31)	40.2% (96)	37.2% (89)	9.6% (23)	2.44	239
Other	25.0% (2)	37.5% (3)	12.5% (1)	25.0% (2)	2.38	8

#### 4.1.7 Awareness of ICP standards for dementia

Finally, we asked respondents whether they were aware of these standards, which had been published in December 2007. Fifty two per cent were aware and 48 per cent were not. There were no area differences and no differences across care sectors (health and social care) in the levels of awareness.

## **4.2 Interviews**

The purpose of the interviews was to explore barriers and facilitators to effective information provision. All those who took part were volunteers, clearly interested in the issue, and all commented at some length on the issues we raised. The following section provides a summary of the main results following detailed analysis of the interview data, concentrating on widely held views.

### **4.2.1 Current practice**

This committed group of people clearly felt that giving good information to people was important. They explained that oral information predominated in their current practice, and that written information was given as backup or for later reference. It was clear that an individual was likely to be spoken to by a range of professionals, all giving information as people came to them for specialist support. Thus, a psychiatrist would give a diagnosis, and a patient would then be referred to a CPN or a social worker for a care needs assessment, or to an OT for other support. Professionals spoke emphatically of the need for information to be tailored to the person and to the stage of their dementia. Their focus was generally on the person with dementia, and they explained that family care givers would often be involved in consultations, but that this was negotiated according to individual cases. Referral emerged as a strong theme in the interviews, with almost everyone speaking about either receiving or making referrals. There was a strong impression given of the person with dementia moving from one consultation to another, receiving information along the way. Alongside that possibly negative experience, however, should be set the commitment to the individual highlighted above and some instances described where the person with dementia would find a professional who stayed with them throughout.

### **4.2.2 Facilitators for good information giving**

Tailoring the information to individual needs was seen by these professionals as one very important way in which information-giving could be more effective and appropriate. They emphasised how professional skills could facilitate this – perhaps reflecting some of the scepticism apparently shown in the survey about alternative sources of information. Tailoring information for individuals was described as involving an understanding of how much knowledge people already had; consideration of the quantity of information being given; understanding that small amounts of information given at a time might be more appropriate than a deluge – one respondent spoke about a ‘dripping tap’ of information, that is, a gradual process of giving information; paying attention to the timing of information, recognising for example that some people could be ‘freaked out’, as one interviewee put it, by too much too soon and presenting information as part of a sound professional-client relationship. Interviewees also spoke about the requirement to pay attention to people’s particular needs, such as support to hear and/or see the information, or to have it presented in appropriate language and/or media. Braille, internet and audio-visual materials were all mentioned as being more appropriate for some people. One respondent highlighted the specific communication needs of people with learning disabilities who develop dementia, emphasising the

overall perspective on the importance of meeting individual needs. No-one spoke about ethnic diversity in the interviews, although this had come up in the survey as a recognised issue.

#### **4.2.3 Barriers to and difficulties in good information-giving**

Reflecting the impression of people with dementia moving from one professional to another, our interviewees identified insufficient clarity in individuals' responsibilities for information giving among the team of professionals. Whilst it was clear that psychiatrists provided diagnoses, once a diagnosis is given it seems that a range of people may be involved in giving further information concerning topics such as progression, care available and how to access it, benefits, carer support, bereavement and many other issues. Since it is not clear who gives what, there is potential for people to be left without the information they need. One voluntary group co-ordinator noted that people referred for support would often say 'no-one told us that before'. However, in the light of the other finding concerning the importance of information being given at appropriate times, the difficulty of judging this for the individual must be noted – people may feel they have not received information because they were not receptive to it when it was given or it was inappropriate to provide it at that time.

Some interviewees referred to the quality of information available. They noted that some printed materials were out of date, incomplete or inaccurate. Also, they noted that while some professionals in the field were highly knowledgeable and expert and could give good information, other professionals lacked accurate up-to-date knowledge and were, therefore, unable to advise people properly or to refer them to expert sources of support.

The stigma attached to a dementia diagnosis was seen as a barrier to information-giving and receiving. Patients and their carers were reported to be 'in denial' about the diagnosis, at least partly because they believed little could be done. One result of this was lack of diagnosis or late diagnosis, resulting in lack of support for people with dementia and their family care givers.

#### **4.2.4 Possible solutions**

In accordance with the identification of barriers, interviewees recommended that training and improved knowledge could help with information-giving. They referred to a need for better training for staff, emphasising that those who were not dementia specialists needed to have better knowledge about the condition and where to refer people for support. Also, they suggested that wider public knowledge about dementia, the importance of diagnosis; and the support that could be given would make a difference. Other improvements seen as having the potential to improve matters significantly included better attention to the formats of information; more sensitive working by professionals; dedicated dementia nurses (or other lead professionals) who could stay with a person throughout; better attention to sensory impairment when giving information; and routine support for carers. These improvements emphasised the twin themes of attention to the person and co-ordination between professionals.

## 5.0 Key findings

- Information provision for people with dementia and their carers appears, from the points of view of professionals to be somewhat patchy
- Nevertheless, professionals see the provision of information as central to their own roles, and feel they have the necessary expertise above other possible sources
- Three central factors emerged as having the potential to improve information provision. These are:
  - improved education for a wider group of health and social care staff in relation to the condition of dementia and how people with dementia and their carers can be supported
  - improved public education about dementia to reduce stigma, encourage early diagnosis and make people more receptive to information about the condition and the support available and
  - improved co-ordination between professionals who work with people with dementia and their carers, so that information is provided consistently and appropriately, according to individual needs.

## 6.0 Recommendations

- Data collection for this baseline study preceded implementation of the information guidelines produced by the Alzheimer Scotland Information Working Group. It highlights a number of issues which the guidelines may serve to address. We would recommend a re-survey after an appropriate period which seeks to examine developments in information provision, bearing in mind that these may also be influenced by increased policy priority for dementia and increased resources for dementia services, including training over the relevant period.
- The study has focused only on professionals and their views about how information should be given. As we noted, they see the role of the professional as particularly important and consider their focus on individual needs as the most appropriate. We would recommend that people with dementia and their carers' views about the information they receive are also sought, as this will provide important lessons concerning the effectiveness of professional strategies.
- Whilst information provision for people with dementia and their carers is crucially important, there is also a need to consider wider information provision about the condition. This may facilitate people with dementia obtaining a diagnosis earlier on and getting the support they need.

## **7.0 Dissemination**

This report is published by NHS QIS.

A summary of the findings will be presented at the Alzheimer Europe Conference in Brussels, May 2009.

## 8.0 References

- 1 Alzheimer Scotland Action on Dementia (2007) *The Dementia Epidemic – Where Scotland is Now and the Challenge Ahead* Edinburgh: Alzheimer Scotland.
- 2 Scottish Intercollegiate Guidelines Network (SIGN) (2006) *Management of Patients with Dementia: a National Clinical Guideline* Edinburgh: SIGN.
- 3 NHS Quality Improvement Scotland (2007) *Standards for Integrated Care Pathways for Mental Health* Edinburgh: NHS QIS.

## 9.0 Appendices

### 9.1 Appendix 1 Focus group schedule

What information have you received?

- Written leaflets/booklets? Aural tapes? Audio-visual DVDs of condition or dramas about the condition?
- Are these in alternative formats? Which ones?
- Discuss content of information? – about dementia? About other relevant issues? Directed at person with dementia? Directed at carer?

Where did you get information from early on? Who gave it to you?

- GP surgeries/health centres? Hospital? Voluntary sector? Social worker/care manager?
- Other? E.g. internet, friends, family?
- Check timing – anything before diagnosis?
- Discuss content of information
- Discuss how information was given/acquired (including e.g. professionals talking through it; leaflets being picked up; active seeking information)

Did you get more information later on?

- What did you get?
- Where did you get it from?
- Discuss content of information?
- Discuss how information was given/acquired (including e.g. professionals talking through it; leaflets being picked up; active seeking information)

How useful did you find the information you received?

- What was most useful and informative?
- What was least useful?
- Comments on information delivery

Was the information you received enough to help get the services and support you needed? If not, what else would help?

## 9.2 Appendix 2 Interview topic guide

Thank you very much for agreeing to be interviewed. The interview will follow up some of the issues raised in the questionnaire and focus on barriers and facilitators to giving information to people with dementia and their carers.

Could I just check some details before we start?

- The Local authority/NHS Board area you work in?
- Your profession?

Could you tell me about your current practice in terms of giving information to people with dementia and their carers?

PROBES:

How information is given, who gives it, what form it takes  
Whether practice differs according to stages of dementia

What factors would you say facilitate information giving?

PROBES:

e.g. availability of written information, time available, receptiveness of patients and carers, clear roles for different professionals

What are the main difficulties you perceive in giving information?

PROBES:

e.g. patients and carers have different needs/wants, too much information, lack of time, too many professionals involved

How do you think information giving could be improved for people with dementia and their carers?

How do you think the particular difficulties you have identified could be overcome?

Is there anything else you would like to say about giving information to people with dementia and their carers?

### 9.3 Appendix 3 Survey with results

<b>Assessment of current information provision to people with Dementia</b>		
<b>1. In which area do you work?</b>		
<b>1. I work in</b>		
	Response Percent	Response Count
Health	46.8%	279
Social Care	<b>53.2%</b>	317
<b>2. Which Board area do you work in?</b>		
<b>1. I work in</b>		
	Response Percent	Response Count
Dumfries and Galloway	2.2%	6
Fife	13.5%	37
Grampian	17.5%	48
Greater Glasgow and Clyde	26.5%	73
Lothian	<b>36.4%</b>	100
Orkney	4.0%	11
<b>3. Which Local Authority area do you work in?</b>		
<b>1. I work in</b>		
	Response Percent	Response Count
Aberdeen City	8.6%	24
Aberdeenshire	2.5%	7
Argyll and Bute	1.4%	4
City of Edinburgh	8.6%	24
Dumfries and Galloway	4.3%	12
East Dunbartonshire	12.5%	35
East Lothian	1.4%	4
East Renfrewshire	3.6%	10
Fife	2.5%	7
Glasgow City	<b>35.5%</b>	99
Inverclyde	2.5%	7
Midlothian	9.0%	25
Moray	1.8%	5
Orkney	0.4%	1
Renfrewshire	2.9%	8
West Lothian	2.9%	8

4. Your profession							
1. What is your profession?							
	Response Percent		Response Count				
Psychiatrist	5.1%		25				
Geriatrician	3.8%		19				
General Practitioner	10.5%		52				
Community Mental Health Nurse/Community Psychiatric Nurse	10.9%		54				
Social Worker/Mental Health Officer	6.5%		32				
Social Worker/Care Manager	25.3%		125				
Other Social Worker	7.1%		35				
Other	30.8%		152				
5. Information currently given							
1. Please indicate how you (or your team) give information to people with dementia and carers. (Tick all that apply)							
	Response Percent		Response Count				
Verbally	98.1%		466				
By written leaflets/booklets	87.4%		415				
By audio tapes/CDs	4.8%		23				
By audio-visual DVDs/videos of condition	7.4%		35				
Other	11.4%		54				
2. How frequently are these types used to inform people with dementia and carers?							
	Always used	Often used	Sometimes used	Seldom used	Not used at all	Rating Average	Response Count
Orally	87.1% 412	10.8% 51	1.5% 7	0.4% 2	0.2% 1	1.16	473
By written leaflets/booklets	24.6% 113	46.5% 214	21.5% 99	5.4% 25	2.0% 9	2.14	460
By audio tapes	0.0% 0	3.0% 7	9.4% 22	13.7% 32	73.8% 172	4.58	233
By audio-visual DVDs/Videos of condition	0.4% 1	2.9% 7	12.9% 31	14.6% 35	69.2% 166	4.49	240
Other	12.5% 17	18.4% 25	14.0% 19	6.6% 9	48.5% 66	3.60	136
6. Information you may be giving out							
1. Please indicate how you or your team give information about the following topics to people with MILD COGNITIVE IMPAIRMENT and their carers. (Tick all that apply)							
	Verbally to the patient	Written to the patient	Verbally to the carer	Written to the carer	Other	Response Count	
Understanding mild cognitive impairment and its progression	94.5% 312	39.1% 129	88.5% 292	44.5% 147	4.2% 14	330	
Other	58.3% 14	4.2% 1	70.8% 17	16.7% 4	33.3% 8	24	

**2. Please indicate how you or your team give information about the following topics to people with EARLY STAGE dementia and carers (Tick all that apply)**

	Verbally to the patient	Written to the patient	Verbally to the carer	Written to the carer	Other	Response Count
Explaining the diagnosis and progression of the condition	84.7% 254	33.0% 99	<b>85.7%</b> <b>257</b>	41.7% 125	10.0% 30	300
Informing family and others of the diagnosis	66.5% 159	23.8% 57	<b>77.8%</b> <b>186</b>	33.9% 81	12.6% 30	239
Information about services	81.2% 246	44.9% 136	<b>83.5%</b> <b>253</b>	53.8% 163	9.2% 28	303

**3. Please indicate how you or your team give information about the following topics to people with LATER STAGE dementia and carers (Tick all that apply)**

	Verbally to the patient	Written to the patient	Verbally to the carer	Written to the carer	Other	Response Count
End of life issues	50.6% 134	9.8% 26	<b>90.9%</b> <b>241</b>	27.2% 72	7.9% 21	265
Respite	77.5% 251	19.1% 62	<b>93.8%</b> <b>304</b>	36.7% 119	5.6% 18	324
Falls prevention	69.8% 196	23.5% 66	<b>86.5%</b> <b>243</b>	38.8% 109	8.2% 23	281
Care homes	75.6% 236	31.4% 98	<b>90.4%</b> <b>282</b>	53.2% 166	9.3% 29	312
Financing long term care	55.0% 142	26.4% 68	<b>85.7%</b> <b>221</b>	54.7% 141	10.9% 28	258
Communication and dementia	60.4% 168	18.3% 51	<b>90.3%</b> <b>251</b>	41.4% 115	8.3% 23	278
Bereavement support	39.2% 98	14.8% 37	<b>83.2%</b> <b>208</b>	38.8% 97	12.4% 31	250
Practical care information e.g. pain identification, help with swallowing difficulties	57.2% 143	15.6% 39	<b>84.4%</b> <b>211</b>	34.8% 87	14.0% 35	250
Other	44.4% 16	11.1% 4	<b>66.7%</b> <b>24</b>	30.6% 11	27.8% 10	36

**4. This is a list of publications and information sources about dementia and dementia care. If you use them, please indicate which of these you give out to PEOPLE WITH DEMENTIA and at what stages of dementia (Tick all that apply)**

	At Mild Cognitive Impairment stage	Early dementia	Late dementia	Not used	Response Count
Facing Dementia (NHS Health Scotland)	22.9% 53	34.2% 79	9.1% 21	63.2% 146	231
Milk's in the Oven (Mental Health Foundation)	2.4% 5	5.3% 11	0.5% 1	94.3% 197	209
Helpline card (Alzheimer Scotland)	38.2% 97	52.4% 133	28.3% 72	40.6% 103	254
Websites e.g. <a href="http://www.alzscot.org">www.alzscot.org</a>	36.9% 83	43.6% 98	22.2% 50	48.9% 110	225

Baseline assessment of current information provision to people with dementia and their carers,  
AM Bowes, May 2009

Understanding Dementia – a handbook for Carers (NHS Health Scotland)	38.9% 100	53.3% 137	30.7% 79	39.7% 102	257
Safety in the Home (Health Scotland)	22.7% 50	25.9% 57	13.2% 29	69.5% 153	220
Getting Help from your Doctor (Alzheimer Scotland)	19.8% 41	19.3% 40	5.8% 12	76.8% 159	207
Worried about your Memory? (Health Scotland)	26.5% 56	20.9% 44	5.7% 12	71.6% 151	211
Dementia, Money and Legal Matters (Alzheimer Scotland)	29.4% 69	37.0% 87	17.4% 41	57.0% 134	235
National Care Standards (Care Commission)	29.2% 62	27.4% 58	18.9% 40	66.0% 140	212
Other	32.4% 22	26.5% 18	19.1% 13	64.7% 44	68

**5. This is a list of publications and information sources about dementia and dementia care. If you use them, please indicate which of these you give out to CARERS and at what stages of dementia (Tick all that apply)**

	At Mild Cognitive Impairment stage	Early dementia	Late dementia	Not used	Response Count
Facing Dementia (NHS Health Scotland)	26.9% 60	34.1% 76	20.6% 46	61.4% 137	223
Milk's in the Oven (Mental Health Foundation)	4.6% 9	6.2% 12	3.6% 7	93.3% 181	194
Helpline card (Alzheimer Scotland)	41.8% 102	50.0% 122	41.4% 101	40.6% 99	244
Websites e.g. <a href="http://www.alzscot.org">www.alzscot.org</a>	38.1% 88	49.8% 115	39.0% 90	44.6% 103	231
Understanding Dementia – a handbook for Carers (NHS Health Scotland)	43.0% 113	58.9% 155	44.9% 118	35.0% 92	263
Safety in the Home (Health Scotland)	24.0% 50	24.5% 51	19.7% 41	70.2% 146	208
Getting Help from your Doctor (Alzheimer Scotland)	19.5% 40	21.0% 43	15.6% 32	74.6% 153	205
Worried about your Memory? (Health Scotland)	25.0% 50	19.5% 39	9.5% 19	73.0% 146	200
Dementia, Money and Legal Matters (Alzheimer Scotland)	27.2% 62	36.8% 84	31.6% 72	56.1% 128	228
National Care Standards (Care Commission)	23.0% 47	24.5% 50	26.5% 54	66.2% 135	204
Other	24.3% 18	21.6% 16	21.6% 16	73.0% 54	74

## 7. Accessibility

**1. Have you ever needed to access information in a language other than English for a person with dementia and / or his or her carer?**

	Response Percent	Response Count
Yes	20%	68
No, never	80%	272

<b>2. If YES, in which language(s) and how often? (If NO, go to the next question)</b>						
	Often	Sometimes	Seldom	Never	Rating Average	Response Count
Urdu	6.1% 3	30.6% 15	<b>32.7%</b> <b>16</b>	30.6% 15	2.88	49
Punjabi	7.0% 3	30.2% 13	25.6% 11	<b>37.2%</b> <b>16</b>	2.93	43
Hindi	0.0% 0	26.7% 8	13.3% 4	<b>60.0%</b> <b>18</b>	3.33	30
Tamil	0.0% 0	0.0% 0	9.1% 2	<b>90.9%</b> <b>20</b>	3.91	22
Bengali	0.0% 0	15.4% 4	23.1% 6	<b>61.5%</b> <b>16</b>	3.46	26
Chinese (traditional /simplified)	2.2% 1	26.7% 12	<b>35.6%</b> <b>16</b>	<b>35.6%</b> <b>16</b>	3.04	45
Polish	2.6% 1	23.7% 9	26.3% 10	<b>47.4%</b> <b>18</b>	3.18	38
Russian	0.0% 0	0.0% 0	4.5% 1	<b>95.5%</b> <b>21</b>	3.95	22
Gaelic	0.0% 0	8.7% 2	4.3% 1	<b>87.0%</b> <b>20</b>	3.78	23
Other	5.0% 1	10.0% 2	40.0% 8	<b>45.0%</b> <b>9</b>	3.25	20
<b>3. Have you ever needed to access information in any alternative formats for a person with dementia and/or his or her carer?</b>						
				Response Percent		Response Count
Yes				24.8%		81
No, never				<b>75.2%</b>		246
<b>4. If YES, how often? (If NO, go to the next question)</b>						
	Often	Sometimes	Seldom	Never	Rating Average	Response Count
Large print	8.1% 6	<b>59.5%</b> <b>44</b>	21.6% 16	10.8% 8	2.35	74
Braille	0.0% 0	6.1% 2	33.3% 11	<b>60.6%</b> <b>20</b>	3.55	33
Signed BSL	2.7% 1	24.3% 9	21.6% 8	<b>51.4%</b> <b>19</b>	3.22	37
Audio tape/CD	0.0% 0	32.6% 14	20.9% 9	<b>46.5%</b> <b>20</b>	3.14	43
DVD	0.0% 0	20.0% 6	20.0% 6	<b>60.0%</b> <b>18</b>	3.40	30
Other	16.7% 2	16.7% 2	25.0% 3	<b>41.7%</b> <b>5</b>	2.92	12

<b>5. Do you think people themselves should actively look for information to understand the condition?</b>		
	Response Percent	Response Count
Yes	<b>80.3%</b>	257
No	9.1%	29
Don't know	12.2%	39

## 8. Information availability around the time of and after diagnosis

### 1. Do you have any published information to give to people PRIOR TO CLINICAL DIAGNOSIS?

	Response Percent	Response Count
Yes	29.2%	88
No	<b>71.1%</b>	214

### 2. From which place(s) do you think people with dementia and their carers get their information AROUND THE TIME OF DIAGNOSIS?

	No-one	Some people	Most people	Don't know	Rating Average	Response Count
<b>GP surgeries/Health Centres</b>	1.0% 3	<b>5.05%</b> <b>152</b>	46.8% 141	1.7% 5	2.49	301
<b>Hospital</b>	1.4% 4	<b>50.2%</b> <b>143</b>	43.5% 124	4.9% 14	2.52	285
<b>Social Work Office</b>	6.5% 18	<b>65.0%</b> <b>180</b>	17.7% 49	10.8% 30	2.33	277
<b>Alzheimer Scotland Dementia Helpline</b>	1.7% 5	<b>65.5%</b> <b>192</b>	25.3% 74	7.5% 22	2.39	293
<b>Carers Centre</b>	2.9% 8	<b>69.7%</b> <b>191</b>	16.1% 44	11.3% 31	2.36	274
<b>Dementia voluntary group/charity</b>	3.8% 10	<b>68.1%</b> <b>177</b>	13.5% 35	14.6% 38	2.39	260
<b>Day Care Centre</b>	7.8% 20	<b>68.2%</b> <b>176</b>	10.1% 26	14.0% 36	2.30	258
<b>Community Centre</b>	15.5% 36	<b>49.4%</b> <b>115</b>	3.0% 7	32.2% 75	2.52	233
<b>Community Pharmacy/Local Chemist</b>	16.7% 39	<b>49.8%</b> <b>116</b>	2.6% 6	30.9% 72	2.48	233
<b>Friends and family</b>	1.5% 4	<b>75.8%</b> <b>201</b>	15.5% 41	7.2% 19	2.28	265
<b>Internet websites</b>	2.2% 6	<b>79.8%</b> <b>213</b>	6.7% 18	11.2% 30	2.27	267
<b>Public Library</b>	7.9% 19	<b>68.2%</b> <b>165</b>	4.1% 10	19.8% 48	2.36	242
<b>Housing Staff</b>	29.6% 66	32.7% 73	0.9% 2	<b>36.8%</b> <b>82</b>	2.45	223
<b>Occupational Health Departments (at carer's place of work)</b>	11.7% 27	<b>53.7%</b> <b>124</b>	5.6% 13	29.0% 67	2.52	231
<b>Scottish Helpline for Older People (SHOP)</b>	11.8% 27	<b>48.0%</b> <b>110</b>	3.9% 9	36.2% 83	2.65	229
<b>Other</b>	1.9% 1	29.6% 16	13.0% 7	<b>55.6%</b> <b>30</b>	3.22	54

### 3. In your experience, who usually gives the key information AROUND THE TIME OF DIAGNOSIS? (Tick all that apply)

	Response Percent	Response Count
Psychiatrist	<b>80.5%</b>	256
Geriatrician	45.6%	145
General Practitioner	59.1%	188
Community Psychiatric Nurse / Community Mental Health Nurse	65.7%	209
Social Worker/Mental Health Officer	24.2%	77
Social Worker/Care Manager	29.9%	95
Other Social Worker	7.2%	23
Voluntary Organisation support workers on a 1:1 basis	12.6%	40
Person at Helpline (Which Helpline?)	6.3%	20
Other	6.9%	22

### 4. In your experience what are the best ways to give information to people with EARLY STAGE DEMENTIA and their carers?

	Excellent	Very good	Good	Not so good	Not good at all	Rating Average	Response Count
Orally by professionally	<b>37.4%</b> 117	<b>37.4%</b> 117	22.4% 70	2.9% 9	0.0% 0	1.91	313
Written material	27.8% 83	<b>46.5%</b> 139	21.1% 63	4.0% 12	0.7% 2	2.03	299
DVD/Video	20.8% 40	27.1% 52	<b>31.8%</b> 61	14.6% 28	5.7% 11	2.57	192
Audio tapes	9.7% 16	17.6% 29	<b>31.5%</b> 52	30.9% 51	10.3% 17	3.15	165
Other	<b>57.1%</b> 8	7.1% 1	7.1% 1	14.3% 2	14.3% 2	2.21	14

### 5. Who can best support people with dementia and their carers at the EARLY STAGE of dementia to understand the information?

	Extremely effective	Very effective	Effective	Not so effective	Not effective at all	Rating Average	Response Count
Psychiatrist	26.4% 67	31.5% 80	<b>35.4%</b> 90	6.3% 16	0.4% 1	2.23	254
Geriatrician	19.8% 42	24.1% 51	<b>42.9%</b> 91	11.3% 24	1.9% 4	2.51	212
General Practitioner	23.8% 62	28.8% 75	<b>39.2%</b> 102	7.7% 20	0.4% 1	2.32	260
Community Psychiatric Nurse / Community Mental Health Nurse	<b>43.5%</b> 131	42.9% 129	13.0% 39	0.00% 0	0.7% 2	1.71	301
Social Worker/Mental Health Officer	21.8% 52	<b>39.9%</b> 95	31.1% 74	6.7% 16	0.4% 1	2.24	238
Social Worker/Care Manager	21.5% 56	31.5% 82	<b>37.7%</b> 98	8.5% 22	0.8% 2	2.35	260
Other Social Worker	12.0% 20	21.6% 36	<b>37.7%</b> 63	26.3% 44	2.4% 4	2.86	167
Voluntary Organisation support worker	21.6% 51	<b>36.9%</b> 87	33.5% 79	7.6% 18	0.4% 1	2.28	236

Helpline	15.3% 31	33.7% 68	<b>39.6%</b> <b>80</b>	10.4% 21	1.0% 2	2.48	202
Advocate	11.8% 24	25.5% 52	<b>41.2%</b> <b>84</b>	20.6% 42	1.0% 2	2.74	204
Carer/Family	24.1% 59	33.5% 82	<b>33.9%</b> <b>83</b>	8.2% 20	0.4% 1	2.27	245
Other	<b>60.0%</b> <b>9</b>	33.3% 5	6.7% 1	0.0% 0	0.0% 0	1.47	15

## 6. What information is it most important that people with dementia and their carers receive at EARLY stage?

	Response Count
Write in	235

## 9. Information for later stage dementia

### 1. Where do you think people with LATER STAGE DEMENTIA and their carers get their information from? (Tick all that apply)

	Response Percent	Response Count
GP surgeries/Health Centres	72.3%	211
Hospital	<b>75.3%</b>	220
Social Work Office	68.2%	199
Alzheimer Scotland Dementia Helpline	74.3%	217
Carers Centre	67.5%	197
Dementia voluntary group/charity	64.4%	188
Day Care Centre	55.8%	163
Community Centre	10.3%	30
Community Pharmacy/Local Chemist	10.3%	30
Friends and family	45.9%	134
Internet websites	44.9%	131
Public Library	20.5%	60
Housing Staff	4.5%	13
Occupational Health Departments	15.4%	45
Scottish Helpline for Older People (SHOP)	13.4%	39
Other	6.5%	19

### 2. In your experience, who usually gives the key information in the LATER stages (Tick all that apply)

	Response Percent	Response Count
Psychiatrist	76.8%	222
Geriatrician	47.8%	138
General Practitioner	58.1%	168
Community Psychiatric Nurse / Community Mental Health Nurse	<b>79.2%</b>	229
Social Worker/Mental Health Officer	47.8%	138
Social Worker/Care Manager	51.6%	149
Other Social Worker	10.0%	29

Voluntary Organisation support worker	28.4%	82
Person at Helpline (which Helpline?)	9.0%	26
Other	4.5%	13

### 3. In your experience, what are the best ways to give information to the person with later stage dementia and their carer? (Tick all that apply)

	Response Percent	Response Count
Orally by professional	<b>89.1%</b>	253
Written material	72.5%	206
DVD/Video	23.9%	68
Audio tapes	10.9%	31
Other	6.0%	17

### 4. Who can best support people with dementia and their carers at the LATER STAGE of dementia to understand the information?

	Extremely effective	Very effective	Effective	Not so effective	Not effective at all	Rating Average	Response Count
Psychiatrist	30.1% 74	28.5% 70	<b>32.5%</b> <b>80</b>	8.9% 22	0.0% 0	2.20	246
Geriatrician	22.8% 46	31.2% 63	<b>32.7%</b> <b>66</b>	11.4% 23	2.0% 4	2.39	202
General Practitioner	22.0% 50	29.5% 67	<b>41.0%</b> <b>93</b>	7.5% 17	0.0% 0	2.34	227
Community Psychiatric Nurse / Community Mental Health Nurse	<b>48.5%</b> <b>133</b>	38.0% 104	13.1% 36	0.0% 0	0.4% 1	1.66	274
Social Worker/Mental Health Officer	28.8% 65	<b>42.9%</b> <b>97</b>	24.8% 56	3.1% 7	0.4% 1	2.04	226
Social Worker/Care Manager	29.4% 69	<b>37.0%</b> <b>87</b>	27.7% 65	5.5% 13	0.4% 1	2.11	235
Other Social Worker	16.4% 23	27.1% 38	<b>33.6%</b> <b>47</b>	19.3% 27	3.6% 5	2.66	140
Voluntary Organisation support worker	20.6% 41	<b>39.2%</b> <b>78</b>	32.7% 65	7.0% 14	0.5% 1	2.28	199
Helpline	13.8% 21	27.6% 42	<b>41.4%</b> <b>63</b>	14.5% 22	2.6% 4	2.64	152
Advocate	11.8% 19	31.1% 50	<b>36.0%</b> <b>58</b>	19.3% 31	1.9% 3	2.68	161
Carer/Family	25.5% 49	<b>35.4%</b> <b>68</b>	30.2% 58	8.3% 16	0.5% 1	2.23	192
Other	27.8% 5	<b>38.9%</b> <b>7</b>	27.8% 5	0.0% 0	5.6% 1	2.17	18

### 5. What information is it most important that people with dementia and their carers receive at the LATER stage?

	Response Count
Write in	200

## 10. Record of information provided

### 1. Do you keep a record in the individual's care notes details of any information (oral and printed) that you have provided?

	Response Percent	Response Count
Yes	79.9%	239
No	20.1%	60

## 11. Information gaps

### 1. Do you have access to sufficient information for PEOPLE with all stages of dementia in your area? (Tick one answer)

	Response Percent	Response Count
Yes	43.2%	126
No	43.5%	127
Don't know	13.4%	39

### 2. Do you have access to sufficient information for CARERS of people with all stages of dementia in your area? (Tick one answer)

	Response Percent	Response Count
Yes	45.4%	132
No	40.2%	117
Don't know	14.4%	42

### 3. What other information might be needed for people with dementia and their carers in your area? (Please write in box)

	Response Count
Write in	117

## 12. Problems with information provision in your area

### 1. How common do you think are these problems with information provision for people with dementia and their carers?

	Not a problem at all	Sometimes a problem	Often a problem	Always a problem	Rating Average	Response Count
Lack of suitable materials	10.6% 26	49.2% 121	33.3% 82	6.9% 17	2.37	246
I can't obtain suitable materials	13.2% 30	50.2% 114	27.8% 63	8.8% 20	2.32	227
I don't always know what's available	8.4% 21	37.2% 93	37.6% 94	16.8% 42	2.63	250
I don't have enough time to address all the issues that might be relevant	9.4% 23	40.4% 99	31.8% 78	18.4% 45	2.59	245
I don't have enough time to identify appropriate material	11.1% 27	36.2% 88	34.2% 83	18.5% 45	2.60	243
I find that people with dementia and their carers are unreceptive to written information	39.5% 92	45.9% 107	12.9% 30	1.7% 4	1.77	233
I find that too many professionals are involved to keep track of what information has already been given	24.6% 58	51.3% 121	20.8% 49	3.4% 8	2.03	236
A lack of one-to-one support to help people to understand the information	13.0% 31	40.2% 96	37.2% 89	9.6% 23	2.44	239
<b>Other</b>	25.0% 2	37.5% 3	12.5% 1	25.0% 2	2.38	8

### 13. Any other comments

**1. Please write here anything else you would like to say about information provision for people with dementia and their carers.**

	Response Count
Write in	85

### 14. Integrated Care Pathways for dementia

**1. Are you aware of the new NHS Quality Improvement Scotland standards for Integrated Care Pathways (ICPs) for Dementia which was published in December 2007? (Tick one answer)**

	Response Percent	Response Count
I am aware of the above	51.6%	133
I am not aware of the above	48.8%	125

### 15. Follow up interviews

**1. We will conduct a number of in-depth interviews with a range of professionals following this questionnaire, when we hope to discuss barriers and facilitators to effective information provision. A telephone or face-to-face interview would take about 30 minutes. Would you be willing to take part? (Tick one response)**

	Response Percent	Response Count
Yes	29.5%	75
No	70.5%	179

**2. If you agree to a follow up interview, please enter your contact details in the space provided below. We will be in touch.**

	Response Percent	Response Count
<b>Name</b>	100.0%	76
<b>Telephone Number</b>	93.4%	71
<b>e-mail address</b>	86.8%	66

**Thank you very much for taking the time to fill in this questionnaire. If you have agreed to participate in an in-depth interview, you will be contacted in the next few weeks using the details you provided.**

You can read and download this document from our website.  
We can also provide this information:

- by email
- in large print
- on audio tape or CD
- in Braille, and
- in community languages.

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