

Dementia Project News

Findings Summary 1

August 2011

Caring for People with Dementia Questionnaire Findings Summary

This project explores carers' views about, and experiences of, accessing health and social care services for people with dementia (PWD).

The aims of this study are:

- 1) to explore carers of people with dementia's everyday experiences of the regulation of care services;
- 2) to gain a greater understanding of the effectiveness of legal

frameworks surrounding dementia care; and



Caring for people with dementia

- 3) to identify key issues and concerns that carers of people with dementia have in relation to accessing health and social care support services.

185 carers of people with dementia responded to the questionnaire. Most (154) of these filled in the online version and 31 completed a paper version, over a 4 month period between February and May 2011.

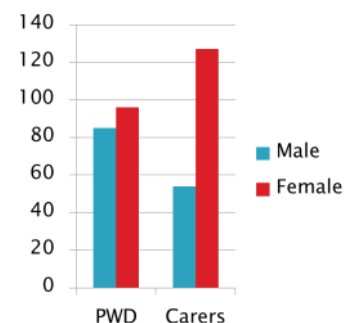
This Findings Summary sets out some of the key findings from the questionnaire responses.

Who Completed the Survey?

Full details of the demographic information provided by respondents to the questionnaire can be found on pages 2 and 3.

More women (70%, n=128) than men 30%

(n=56) were carers of people with dementia. The people that they cared for had an almost equal gender balance, with 87 men and 97 women.



Gender

Demographic Information

Gender	Carers: 30% (56) men, 70% (128) women. Person with Dementia: 47% (87) men, 53% (97) women
Age	Carers average age 62 yrs (range 26-87). Person with Dementia's average age 77 yrs (range 44-97)
Race/Ethnicity	Carers: 98% White, 1 Mixed White & Asian, 1 Black African, 1 Asian Other. Person with Dementia: 98% White, 2 Mixed White & Asian, 1 Mixed White & Maori
Country	82% (151) respondents live in England, 5.5% (10) Scotland, 6% (11) Wales, 5% (9) USA, 2 Australia.

The majority of questionnaire respondents were White, non-disabled, heterosexual, identified as Christian, and lived in England.

Equality Characteristics

Disability:

Twenty-three per cent (n=42) Carers who completed the questionnaire identified themselves as having a disability. These included: arthritis, cancer, diabetes and mobility impairment.

Respondents described 78.5% (140) of the people they cared for as disabled. Most people with

dementia who were described as disabled listed dementia as their disability, though a number of other health problems in addition to dementia were reported, including arthritis, deafness, diabetes and chronic obstructive pulmonary disease (COPD).

Sexual Orientation:

Carers: 98% (180) hetero-

sexual, 2 bisexual, 1 other. Person with Dementia: 99% (180) heterosexual.

Religion/Belief:

Carers: 75% (140) Christian, 21% (39) no religion, 2 Buddhist, 2 Jewish, 2 Muslim, 3 Other. Person with Dementia: 81% (149) Christian, 17% (30) no religion, 3 Muslim, 1 Spiritualist.

Who Cares for Whom?

The majority of respondents were carer for their spouse/partner (61%, 116) or a parent (33%, 62), 3 cared for a grandparent and 2 a sibling. Most provided day-to-day care (68%, 141) and over a third of respondents provided all of the day-to-

day care (38%, 71). Over half of respondents (62%, 110) lived with the person they care for in their own home (69%, 122). Nearly a quarter of those being cared for (22%, 39) were residing in a nursing or residential care home.

The majority (57%, 101) of people with dementia had been diagnosed within the last 5 years.

Dementia Diagnoses

The main dementia diagnoses reported were: Alzheimer’s disease (34%, 64), Vascular dementia (20%, 37) and Fronto-temporal dementia (20%, 37). The majority reported that gaining a diagnosis was ‘difficult’ or ‘very difficult’ (67%, 121), and the severity of the persons dementia was rated predominantly as ‘moderate’ (49%, 88) and ‘severe’ (46%, 82).

Anti-dementia medication:

In terms of the prescription of anti-dementia drugs, about half (56%, 103) reported that the person that they care for had been given them, with Aricept (donepezil hydrochloride) being the most commonly prescribed to people with dementia (78.5%, 81).

Antipsychotic medication:

Unfortunately, over a quarter of respondents (28%, 52) reported that the person that they care for had been prescribed antipsychotic drugs, the most common of which were Seroquel (quetiapine, 55%, 29), Risperdal (risperidone, 28%, 15) and Haldol (haloperidol, 23%, 12).

“Over a quarter of respondents reported that the person they care for had been prescribed anti-psychotic drugs”

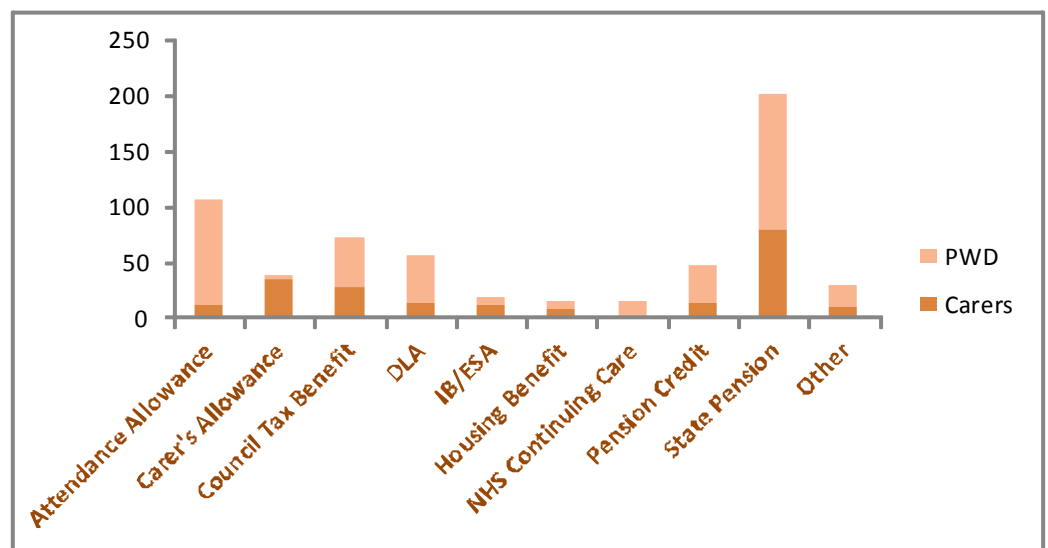
Education, Work and Social Class

Class	Carers: 60% (109) self-identified as middle class, 40% (73) as working class. Person with Dementia: 54% (100) middle class, 42% (77) working class, 7 Other.
Occupational Status	45% (91) respondents retired, 24% (49) full-time carers, 11% (23) working full-time, 14% (28) working part-time, 2.5% (5) unemployed/long term sick, 1 student, 3% (7) Other, including part-time carer.
Educational Attainment	Carer: 17% (28) Postgraduate level, 43% (72) University/College/Professional qualification (e.g., nursing or teaching), 12% (20) A Level, 20% (33) GCSE or equivalent, 3% (5) School certificate, 9% (15) None. Person with Dementia: 10% (14) Postgraduate level, 23% (33) University/College/Professional qualification, 6% (9) A Level, 16% (22) GCSE or equivalent, 9% (13) School certificate, 35% (49) None.

Benefits and Financial Support

Respondents received a range of state benefits. Most common benefits carers received: 42% (78) State pension; 18% (34) Carer’s Allowance; 15% (27) Council Tax benefit and 7% (12) Disability Living Allowance.

Most common benefits people with dementia received: 67% (124) State pension; 52% (95) Attendance Allowance; 25% (45) Council Tax benefit; 24% (43) Disability Living Allowance and 8% (14) NHS Continuing Care.



Views about Service Provision

As shown in the graph of professional support below, while the majority of respondents had a General Practitioner involved with the person they care for, only half (49%, 89) were having input from a psychiatrist and only a quarter (24%, 43) a neurologist.

About half of respondents (54%, 96) agreed that 'overall, the standard of care the person I care for receives from profes-

sionals is excellent'.

The majority agreed (59%, 103) that 'professionals involved with the person I care for are knowledgeable about dementia'. However, about a third of respondents (32%, 58) agreed that professionals 'are not sensitive to my needs'.

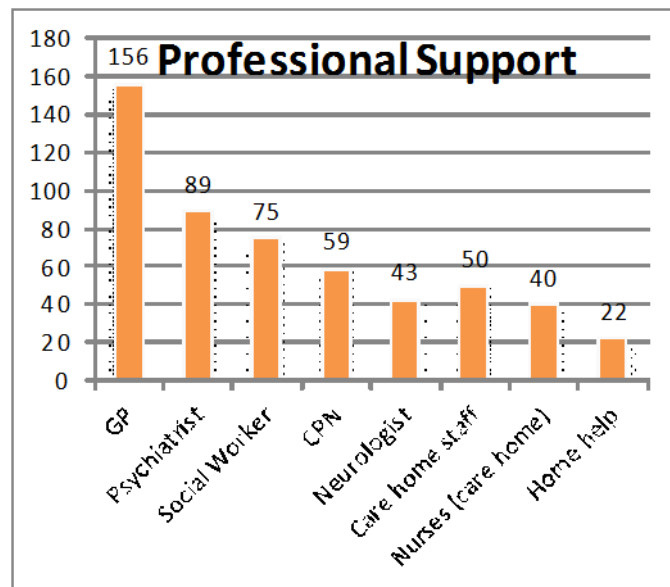
Less than a quarter of respondents agreed that care staff in a residential (24%, 32) or community setting (23%, 31) are 'trained

to an appropriate level'. Furthermore, about a third (34%, 45) disagreed that 'care homes are appropriately regulated'.

A minority (40%, 65) agreed that they 'never have cause to complain about the quality of care provided by professionals'.

However, over half (57%, 96) agreed 'I am confident that the person I care for is always treated with dignity by professionals'.

"Less than a quarter of respondents agreed that care staff in a residential or community setting are 'trained to an appropriate level'."



Rights and Responsibilities

In terms of respondents views about rights and responsibilities, the majority (92%, 167) agreed that 'it is my responsibility to make sure that the person I care for gets the health care they need'. Around half (49%, 85) agreed that 'health care professionals take my needs into account when considering what is in the best interests of the

person I care for', but the majority (73%, 128) agreed that 'I am always consulted about significant medical decisions regarding the person I care for'.

Most (82%, 145) agreed that 'when a decision is made on behalf of the person I care for, it is always after their best

interests have been considered' and that they were 'confident that the person I care for always has their rights respected' (70%, 124). However, only a quarter (26%, 45) agreed that 'care professionals are well trained about the rights of people with dementia'.

Power of Attorney

	Yes	No	Don't Know
POA over financial affairs	65% (118)	34% (63)	1% (2)
POA over health & welfare	34% (60)	56% (100)	10% (18)
Court of Protection 'Deputy'	10% (18)	66% (122)	14% (26)

As the table above shows, most (65%, 118) reported having POA over the financial affairs of the person they care for, but the more

recent welfare POA was less common and there was more uncertainty about this legal framework (10%, 18) and that of the

court of protection deputy (15%, 25).

“A large minority have had cause to complain about the way the person they care for had been treated by another person or service.”

Cause to Complain

A large minority (45%, 83) had experienced cause to complain about the way their relative had been treated by another person or service. The complaints fell into three main categories: inappropriate treatment in hospital, incidents of abuse or inadequate care, and lack of communication. One respondent offered the view that: 'you quickly learn to be careful when raising concerns as there is a likelihood that your relative may suffer', and many respondents had not formally complained about problems they had encountered.

Inappropriate treatment in hospital was a common focus of complaints, predominantly because 'some hospital staff have no idea how to treat patients with dementia'. Respondents referred to 'deplorable treatment' and hospital stays being 'the most traumatic experience ever'.

Incidents of abuse or inadequate care were described as occurring in various settings including nursing care - 'my mother being physically and sexually assaulted by staff at

nursing home'; and respite care - coming out of respite care 'with lots of bruises'.

Lack of communication between informal and paid carers was also an issue, for example: 'mum had fallen while carer was there. Her face was black and blue the next day and the carer hadn't even let us know'; 'care staff...did not always make the calls they were supposed to...I relied on them making the calls for peace of mind that my mother was ok'.

Sources of Support

The most common forms of help with aspects of caring were: Alzheimer's Society (68%, 123), Solicitor (49%, 89), Carers UK (32%, 58) and Age UK (25%, 46).

Only half of respondents (51%, 92) had been offered a carers assessment of their own needs. In contrast, the majority of respondents (78.5%, 142) were 'under strain' as indicated by their responses to the Caregiver Strain Index.

There was a high level of support/information seeking from these respondents. Most had accessed websites (84%, 152), joined a membership organisation (e.g., Alzheimer's Society) (71%, 128), read books (69%, 125), accessed health professionals (62%, 112), or a support group (56%, 102). A large minority (41%, 74) had accessed an online support group and only 3% (5) had not accessed any sources of support/information. The Alzhei-

mer's Society (including their website, factsheets and local branches) featured prominently in response to the question 'Which sources of support/information have you found most helpful?'. Three books were mentioned by name: *Contented Dementia* (by Oliver James), *The Selfish Pig's Guide to Caring* (by Hugh Marriott) and *What if it's Not Alzheimer's?* (edited by Lisa Radin & Gary Radin).



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The 'Duties to care' project is interested in the experiences of carers of people with dementia. Dementia is an umbrella term which describes a range of degenerative brain diseases that have common symptoms. These symptoms include memory loss, decreased reasoning and communication skills, and a reduction in the skills needed to carry out activities of daily living. In particular the project focuses on carers' experiences of accessing health and social care services.

This project is funded by a British Academy small grant, and is a collaboration between Dr Rosie Harding (Keele University) and Dr Elizabeth Peel (Aston University).

If you wish to cite this findings summary please do so as follows: Peel, E. & Harding, R. (2011) *Duties to Care Project: Caring for people with dementia questionnaire - Summary of findings*. Aston University, UK: Unpublished document.

Dementia Project News...

Dementia Talking: Care, conversation and communication

Dr Elizabeth Peel has been awarded a Fellowship grant by the British Academy to carry out a follow on project focusing on communication with people with dementia.

The 'Dementia Talking' project focuses on communication as this aspect of dementia care is a significant problem for people with dementia and their carers. The aim is to understand how talk about, and to, people with dementia is constructed, with the goal of improving

communication with people with dementia.

More information about this exciting new phase to the dementia project will be available soon, but if you are interested in this research and would like to know more, do please get in touch with her at:

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Phase 2: Focus Groups with Carers

The second phase of the Duties to Care project involves a series of focus groups, taking place in Autumn 2011. We plan to hold focus groups in Birmingham, Brighton, London and Oxford.

As we understand the difficulties that carers can experience in finding the time to participate in research, we also hope to hold one or more online focus groups. If you would like more information or would like to participate in a focus group, please do get in touch.