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Suzanne M. Cahill, Matthew Gibb, Irene Bruce, Mary Headon and Mary Drury
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'I was worried coming in because I don't really know why it was arranged'

The subjective experience of new patients and their primary caregivers attending a memory clinic

SUZANNE M. CAHILL *Dementia Services Information and Development Centre, Dublin, Ireland, and Trinity College Dublin, Ireland*

MATTHEW GIBB *St James's Hospital, Dublin, Ireland*

IRENE BRUCE *St James's Hospital, Dublin, Ireland*

MARY HEADON *Dementia Services Information and Development Centre, Dublin, Ireland*

MARY DRURY *Dementia Services Information and Development Centre, Dublin, Ireland*

Abstract Whilst in the Western world, memory clinics are fast becoming an evolving feature of the Geriatric Service landscape, little is known from a user's perspective about the expectations and experiences of people with memory problems referred to a memory clinic for the first time and about the attitudes and concerns of their family caregivers. This article reports quantitative and qualitative data emerging from a study of 28 patients with dementia and their family caregivers who attended a first appointment at a National Memory Clinic in Ireland. Data show that despite initially feeling unnerved by the clinic appointment, immediately afterwards the majority of patients felt content with the assessment process, were satisfied with the explanations and information received, felt the appointment had benefited them and by the end of the visit felt more positive than negative about their experience. A large number of patients who responded to a question about feedback, requested that this information be given to them in writing as well as orally. Some recommendations are made about small procedural changes which can be made to help to demystify the memory clinic experience.

Keywords assessment; family caregiver; memory problems; person with dementia; service

Introduction

The National Memory Clinic at St James's Hospital, which has been in existence for some 13 years, offers a countrywide diagnostic, treatment and advice service for people experiencing memory or cognitive problems. The waiting time for clinic appointments is approximately three months and patients are referred to the clinic by a general practitioner, a geriatrician or old age psychiatrist. Neuropsychological testing normally takes up to two and a half hours during which time patients are seen by a research nurse, a neuropsychologist and a medical doctor. A medical social worker is also available for consultation. Preliminary feedback is generally given to patients and their family caregivers prior to their leaving the Memory Clinic and written feedback is sent to referring doctors subsequently. To date no attempt has been made to evaluate patients' satisfaction with the Memory Clinic service and their attitudes to, and expectations about, attending the Clinic, undergoing memory and cognitive testing and their attitudes to the information and feedback they receive. In an attempt to improve our service this research set out to explore eight key questions, namely:

- What are the subjective experiences of patients immediately prior to and after assessment at a memory clinic?
- What are primary caregiver's attitudes to and experiences of attending a memory clinic?
- Why do patients believe they are attending a memory clinic appointment?
- Do patients and their primary caregivers perceive they have a memory problem?
- Do patients and primary caregivers anticipate any benefit will be derived from attending a memory clinic?
- How do patients and their primary caregivers feel before and after they attend for appointments?
- How do patients rate their own performance on the tests conducted?
- Do patients believe feedback about the assessment is well communicated?

Literature review

There has been limited research undertaken into people's experiences of being assessed for memory or cognitive problems and their opinions about memory clinic attendance. Indeed asking people with dementia about their experiences and involving them in service planning has not, until relatively recently, been actively pursued, despite the fact that calls for work which seeks the perspective of the person with dementia have been made for some time (Cotrell & Schulz, 1993). Some authors have described how the individual is 'often relegated to the status of object rather than a legitimate

contributor'. Cheston and Bender have suggested that the social context of memory assessment needs to be a critical component of the assessment process since without its integration into routine practice, neuropsychological testing can produce 'a sense of anxiety and threat' (Cheston & Bender, 1999, Cheston, Bender, & Byatt, 2000). Wilkinson (2002), an advocate for including people with dementia in service planning and research, argues that there is a need 'to shift the power inequalities inherent in some research' and that an understanding of the experiences of dementia cannot be gained from second-hand reports. She further suggests that to combat this power inequality it is necessary to remove the stigma surrounding dementia and to do this the 'diseased brain' medical view of dementia must be challenged.

Views such as these have led researchers to look at different ways of involving people with dementia in research and service development (Keady & Gilliard, 2002). There is a realization that there is a difference between the 'cognitive' and the 'feeling' self (Frogatt, 1988) which enables the subjective experience of people with dementia to be valued in its own right. This more inclusive approach can yield a better understanding of the experiences of those living with dementia. This study set out to adopt such an inclusive approach by interviewing a small sample of patients attending a first appointment at a memory clinic.

Three main literature searches were undertaken using Ovid, PubMed and Gerontology Journals. An additional search of the *Journal of Dementia Care* was also done. The literature search yielded only four articles directly relevant to this work. The first was a small-scale, UK-based pilot study in which the researchers investigated users' views of a day hospital and other community care services received (Sperlinger & McAuslane, 1994). Although somewhat dated now, what was unique about this study was that the views of persons with dementia were sought out. Findings showed that all but one of the clients interviewed ($n = 6$) could competently tell their story and had definite opinions about the services they received. Interestingly, whilst it was believed that the physical aspects of the day hospital these clients attended would be of interest to them, findings showed that the service users were more anxious to talk about interpersonal relationships. The authors concluded that in attempting to undertake service evaluation research with persons with dementia, service users should be interviewed more than once and both quantitative and qualitative methodologies should be used.

Following this pioneering study, a number of other researchers began to include the experiences and expectations of people with dementia in service assessments. (Hill, O'Brien, Morant, & Levy, 1995; Van Hout, Vernooij-Dassen, Hoefnagels, & Grol, 2001). The work of Hill and her

colleagues is particularly relevant to this article since data was collected from both family caregivers and patients attending a memory clinic before and after the assessment. Hill et al.'s findings were equivocal; whilst fewer than half the sample believed events had been well explained and only a small number of those who expected drug treatment and advice on managing memory problems thought their expectations were well met, nonetheless the vast majority (79%) reported they had been given 'sufficient time with doctors to talk over their problems' and 50 percent of patients left the clinic feeling positive (Hill et al., 1995). The authors concluded that the information component of their service was not being satisfactorily met and that efforts to improve the service were required.

Van Hout and his colleagues' Dutch work, reported some years later, was different from Hill et al.'s in that patient and family caregiver interviews were conducted separately thereby enabling the individual with dementia to speak out privately (Van Hout et al., 2001). Findings showed that both patients and caregivers were satisfied that memory clinic results were appropriately communicated to them. Both groups were less convinced about the appropriateness of the diagnostic information provided with as many as 40 percent of carers believing this information was vague. The authors concluded that future quality improvement should focus on the clarity of the diagnostic information for patients and on better advice for relatives.

In another UK study reported in the same year, (Keady & Gilliard, 2002) the researchers, who used grounded theory to construct the meaning of assessment for the individual, interviewed a sample of 15 patients and their family caregivers recently diagnosed with an Alzheimer's type disease. Findings showed how the delay between referral and memory clinic attendance caused much anxiety for those referred. For many patients neuropsychological testing was considered a stressful experience and several patients felt 'trapped' or 'caught out' by the process. Whilst it was suggested that the assessment process was often beneficial for caregivers, for the patient it may have reinforced concerns about the seriousness of their problems. The authors concluded that a model of assessment whereby patients were treated as partners and wherein they had more control over the process was desirable.

In summary, the literature reviewed for this article shows how there is a gap in published research on the topic of patients'/caregivers' experiences of memory clinic cognitive assessment. There is a need to explore ways by which the views and aspirations of people with dementia can be better reflected in service outcomes with recognition of the tensions between how services are conceptualized and designed and how they are received and experienced. There is a need to hear the voice of people with dementia and gain a better understanding of the dilemmas and difficulties

they are experiencing at this critical phase in the process of the disease. A review of the literature suggests that combining quantitative and qualitative methodologies may be the preferred methodological approach towards conducting this type of research.

Research methods

In-depth interviews using fixed choice and open-ended questions were used to collect data from both patients and their primary caregivers' about their experiences of memory clinic attendance. Two short in-depth interviews were conducted with the patient before and after memory clinic assessment and one in-depth interview was conducted with the primary caregiver immediately prior to their relative's assessment.

Data collection instrument

A semi-structured questionnaire was designed to collect quantitative and qualitative data about events leading up to the appointment: about patients' and caregivers' expectations of the service and about the assessment procedure itself. Patients' own assessment of their performance and their overall satisfaction with the service received was investigated.

Data analysis

Quantitative analysis was undertaken using SPSS for Windows, version 11. Frequency distributions and measures of central tendency were undertaken. Qualitative data emerging from the open-ended questions was transcribed verbatim and later coded thematically. The two researchers who undertook data collection developed agreed codes, categories and themes. This assisted in the appropriate openness and utility of the coding developed, producing a systematic and rigorous method of analysing and storing data. Where differences of opinion in coding data emerged, transcripts were cross-checked to ensure inter-rater reliability.

Sample

The non-random sample ($n = 28$) was purposively drawn. All new patients over a five-month period who were accompanied by a primary caregiver and who having been advised about the study, agreed to participate, were included.

Research approach

On the day of memory clinic attendance and prior to contact with the neuropsychologist and doctor, the research nurse approached the patient's

family caregiver and, having explained the rationale behind the study, invited study participation. After consent was granted, both patients and caregivers were interviewed separately by the researcher who was either a social worker or research nurse. Interviews took no longer than 15 minutes. Some hours later and following their memory and cognitive assessment the patient was re-interviewed by the social worker or research nurse. The second interview took approximately 10 minutes. All of the families approached (n = 28) agreed to participate in the research.

Results

Table 1 reports the gender, age distribution, diagnosis and MMSE scores of the 28 patients at the time of assessment.

Table 1 shows how the sample was predominantly female with a mean age of 73 (range = 55 to 89). At the time of assessment, approximately one quarter (n = 8) were diagnosed with Alzheimer’s disease and fewer (n = 3) had vascular cognitive impairment (VCI), mild cognitive impairment (n = 3) and depression/anxiety (n = 3). Their mean MMSE score was 24 (range = 17 to 29) reflecting the fact that most had a mild dementia. Data analysis also revealed (not shown) that most primary caregivers were either spouses (six husbands and five wives) or adult children (nine daughters and three sons). Two people shared the primary caregiver role with another first-degree relative.

Table 1 **The profile of new patients attending a memory clinic appointment (n = 28)**

Patient	Numbers	Percentage
Female	18	64%
Male	10	36%
Range	55–89	
Mean Age	73	
Diagnosis after clinical work-up		
AD	8	28.5%
Mixed dementia	5	18%
VCI	3	10.5%
MCI	3	10.5%
VD	1	4%
Depression/Anxiety	3	10.5%
Unsure	5	18%
MMSE		
Range	17–29	
Mean	24	

Attitudes to having a memory problem and attending a memory clinic

A series of questions was asked of patients and primary caregivers about their attitudes to and expectations of memory clinic attendance. Table 2 reports these results.

The table shows that over one-third of patients, compared with almost two-thirds of their carers, reported they were asked to attend the memory clinic by either a GP, hospital doctor or a neurologist. Analysis of qualitative data (not shown) revealed that the lead-up time to memory clinic attendance was often distressing for patients and family members. Some patients saw several different doctors, including specialists, before their appointment. In one case there was much family disharmony over the appointment with a daughter arguing the appointment would benefit her father, whilst her brother feeling very strongly that this would be harmful and should be cancelled. Another man openly admitted he was so frightened of clinic attendance he had tried to cancel the appointment. Apart from the actual lead-up time, data analysis revealed how almost half of the patients (46%) arrived at their appointment feeling quite negative. Several patients talked about their anxieties and were uncertain about what would happen:

Coming in I was wondering what the hell are they going to do with me, putting all sorts of things on my head. (Male patient, aged 82, mixed dementia)

One woman worried the appointment might mean a hospital admission: another was frightened of being left alone and was concerned about the physical examinations:

I dread the blood tests. (Female patient, aged 75, mild cognitive impairment)

Table 2 **Patients and caregivers attitudes and expectations of a memory clinic service in percentages (n = 28)**

Reasons for memory clinic attendance	Patients	Caregivers
Advised by GP or consultant or hospital doctor	36%	60%
Told had memory problem	22%	11%
Advised by family members	16%	18%
Other	18%	11%
Don't know	10%	
Feelings on the day prior to attendance		
Positive	50%	57%
Negative	46%	39%
Neither positive or negative	4%	4%
Awareness of memory problem	54%	68%
Worried about a memory problem	50%	71%

One man whose friend with dementia was blind assumed that if diagnosed he would automatically lose his sight – something he feared more than the actual dementia:

I thought with Alzheimer's disease I'd go blind but he [the psychologist] explained that there are different kinds of AD . . . that I wouldn't die from it. (Male patient, aged 55, Alzheimer's disease)

Others it seems had forgotten the reason behind the assessment or were not told:

I was worried coming in because I don't really know why it was arranged. I've been wondering if they thought I couldn't take it in and that's why they didn't explain it. (Female patient, aged 78, vascular cognitive impairment)

In response to another question asked, 'do you think you have a memory problem?', a little over half of the new patients ($n = 15$) compared with two-thirds of their carers ($n = 19$) believed they had a memory problem and half of the patients ($n = 14$) compared with almost three-quarters of the carers ($n = 20$) reported they were worried about the memory problem in advance of the appointment. In fact some patients provided detailed accounts of how they themselves noticed their memory gradually deteriorate:

I used to have a pretty sharp memory but now I've lost a lot. (Male patient, aged 68, Alzheimer's disease)

I've noticed myself making mistakes with words and spelling things incorrectly – something I would never have done, in fact I always prided myself in that area. (Male patient, aged 63, Alzheimer's disease)

I'm not as good as before. Sometimes I put things in the wrong place like put something in the fridge and then couldn't find it and it shouldn't be in the fridge. (Female patient, aged 70, vascular cognitive impairment)

Reasons behind memory problems

A question was asked of both patients and caregivers regarding what in their view was causing the memory problem. Figure 1 reports these results.

It shows that patients were likely to attribute their memory problems to stress or depression or to deny they had a memory problem:

If upset I just close down and don't remember things. (Female patient, aged 65, depression)

No I wouldn't say so [don't have a memory problem], not when I eventually remember things, it's just it's slow. (Female patient, aged 76, mixed dementia)

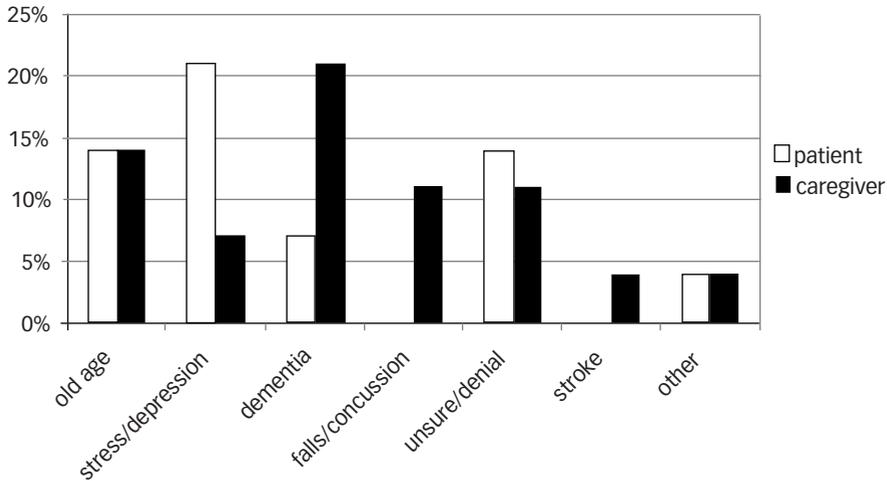


Figure 1 **Patients and family caregivers' perceptions of causes of memory problem (n = 28)**

Others were quick to attribute their memory problem to the ageing process:

Old age accounts for it – I think that it's well known that as you age your faculties fail. It's like everything that's in your brain is grooved and you have to get like a needle into the groove and it gets harder as you get older. (Male patient, aged 75, Alzheimer's disease)

Carers on the other hand were more likely to be already considering dementia. Analysis revealed that about one-fifth of family caregivers (n = 6) referred specifically to dementia or Alzheimer's disease, questioning this as being the root cause of the memory problem:

I would like to know whether or not it is Alzheimer's disease . . . (Spouse caregiver)

Don't know whether he's beginning to suffer [from] Alzheimer's disease. (Daughter caregiver)

Caregivers' and patients' expectations about the service

Prior to assessment, both patients and caregivers were asked how might the appointment might benefit them. Data analysis revealed how caregivers tended to be very clear in their expectations of service outcomes with approximately one-third (n = 9) responding that they hoped they would find out more about the cause of the memory loss problem. Another one-third expected that treatment would be offered to their relative and others (n = 4) hoped for reassurance and practical advice (n = 2). In contrast, new

patients were more vague in their expectations with about one-third ($n = 10$) reporting that they came to get some 'help':

Might get something to slow down the process. (Female patient, aged 65, depression)

(I) just prayed to Jesus everything would be okay and I'd get cured. (Female patient, female, aged 75, mild cognitive impairment)

Hoping they'll tell me there's nothing wrong. (Female patient, aged 65, depression)

. . . give hope that I will return to normal. (Female patient, aged 78, Alzheimer's disease)

Patients' attitudes to cognitive assessment and feedback

Table 3 reports data on patients' attitudes to being cognitively assessed and to the feedback received on the day of the appointment.

Data show how, by and large, patients reported more positive ($n = 11$) than negative feelings ($n = 8$) about the overall experience of undergoing memory and cognitive assessment. A total of 13 out of 26 (50%) reported they performed well at assessment. Despite these findings, qualitative data revealed that the assessment process was probing, demoralizing and frightening for several patients:

A bit frightening . . . more intense than I was expecting . . . knew I wouldn't be able to answer some of them. I get defensive when someone starts asking me questions. (Male patient, aged 63, of uncertain diagnosis)

(I) felt really stupid when I couldn't do some of them. I couldn't remember what he would ask me . . . (Female patient, aged 58, Alzheimer's disease)

It was embarrassing . . . I couldn't even draw the house . . . even a child could do that . . . it is embarrassing. Maybe I would have done better at home . . . if I wasn't so nervous. (Male patient, aged 55, Alzheimer's disease)

Nonetheless in terms of service evaluation, more than two-thirds of these new patients ($n = 20$) claimed that there were no issues concerning the assessment left unclear to them and that explanations provided were very satisfactory ($n = 21$). Nine out of the 14 (64%) who responded to the question about feedback would also have liked written feedback. More than two-thirds ($n = 21$) found the appointment beneficial and 19 out of the 24 who answered the question (79%), felt positive as they were leaving the clinic:

It is good there is this kind of place you can come to and get things off your chest, you know if you're worried. Everyone was very nice. (Female patient, aged 85, Alzheimer's disease)

Table 3 **Patients' perceptions of cognitive assessment and their attitudes to feedback and information received**

How did you find the experience of doing the tests? (<i>n</i> = 25)	Number of Patients
Positive	11
Negative	8
Unsure	6
Did you perform well at assessment? (<i>n</i> = 26)	
Yes	13
No	7
Don't know	6
Were there issues about the assessment unclear? (<i>n</i> = 24)	
Yes	4
No	20
Were the explanations given to you satisfactory? (<i>n</i> = 21)	
Yes	21
No	0
Did you receive feedback? (<i>n</i> = 26)	
Yes	15
No	10
Don't know	1
Would you like feedback in writing? (<i>n</i> = 14)	
Yes	9
No	2
Don't know	3
Has appointment been of benefit to you? (<i>n</i> = 25)	
Yes	21
No	0
Don't know	4
How were you feeling leaving the clinic? (<i>n</i> = 24)	
Positive	19
Negative	3
Ambivalent	2

The whole experience was good, when you go to your own doctor, the man has 50 or 60 people. Here it's one to one. (Male patient, aged 68, diagnosis uncertain)

Staff are great. It's free and a very good service. It's relaxed here. I had visions of people dashing in and out. (Female patient, aged 67, depression)

I think it's a very professional series of meetings I underwent even if it's unpleasant and slightly nerve racking. (Male patient, aged 67, vascular dementia)

Discussion and conclusions

This study is a first attempt to gain a 'snapshot' picture of patients' and their family caregivers' expectations and experiences of attending a first appointment at a National Memory Clinic in Ireland. Its findings have yielded a wealth of insight into the experiences that families have leading up to a first memory clinic appointment, their own explanations behind the emergence of memory problems, their expectations of the benefits of cognitive and memory assessment, patients' attitudes to undergoing assessment, and their reactions to the way in which information and feedback is communicated to them.

Overall we have learned that for approximately half the patients, the prevailing feelings on the day of assessment and on arrival at the clinic were unease, nervousness and apprehension, but that by the end of the visit, over two-thirds felt very positive about their experience. Both patients and caregivers wanted predominantly the same thing from the assessment – knowledge or information, help of some sort, a cure or treatment. Family caregivers were better able to articulate their desires and perhaps were more realistic about expected outcomes of clinic attendance compared with their relatives. The data show that most patients were reasonably happy with the assessment process: they felt more positive than negative about the actual experience; they reported that explanations given to them were satisfactory; and overall they considered that the appointment had benefited them. A small minority found the process long and tiring. A few were somewhat uncomfortable or embarrassed about the way the assessment exposed their memory deficits.

These findings support and build on an already small but valuable body of literature. For example Keady and Gilliard in their earlier research, noted that feelings of insecurity and uncertainty around neuropsychological assessment were not uncommon (Keady & Gilliard, 2002) and that the assessment process needed to give those subjected to it more control. These authors also highlighted the fact that the lead-up time to assessment was often stressful for families and for patients. Hill and her colleagues also reported that patients found memory and cognitive assessment stressful (Hill et al., 1995). Both these authors have suggested that the provision of more detailed information about neuropsychological assessment might be very useful.

As a direct result of our findings, the Memory Clinic Information Booklet at St James Hospital has been significantly revised to provide more detailed information about what patients and family caregivers can expect on the day of assessment. Unnecessary information that might overload patients has been removed, and new information about coping strategies and potential

treatments has been inserted. A map of the hospital premises indicating where the Memory Clinic is located has been provided and a detailed account is given of the actual process of assessment including the timeframe that should be allowed. It is hoped that the new booklet will help reduce some of the fears and anxieties associated with Memory Clinic attendance.

Whilst neuropsychological testing is designed to be probing and difficult, the qualitative data emerging from this research provided new evidence of the benefits derived from assessment for the individual, particularly as a result of more in-depth interactions with professional staff including neuropsychologists, medical doctors and clinical nurses. Clearly many of those attending the Clinic were worried and, as the research revealed, several were aware of their memory problems. They needed more time than the average GP can devote. They tended to appreciate the longer interactions and the listening skills and sensitivity of expert Memory Clinic staff with years of experience in this area. They may have benefited even further from these interactions and performed better in the neuropsychological testing had the assessment taken place at home and outside of a clinical setting.

Our findings in terms of service evaluation compare well with those reported elsewhere. For example, an earlier Dutch study found that over one-third of caregivers considered the information provided at a memory clinic vague (Van Hout et al., 2001) and a British study reported some 10 years back, concluded that more information and better feedback needed to be delivered at memory clinics (Hill et al., 1995). Despite the positive feedback received, we cannot be complacent. Rather we need to be constantly striving to improve the structure and delivery of the service, bearing in mind the vulnerability of this group of people often waiting several months for an appointment and worried both about their memory deterioration and undergoing assessment.

Finally, the issue of whether or not a diagnosis should be disclosed to a patient or family caregiver following memory clinic assessment was not investigated in this study. The policy adopted at our National Memory Clinic is one whereby if the diagnosis is known and if the patient specifically asks the question 'Have I dementia?' or 'Have I Alzheimer's Disease?' then he or she is told.¹ This may be different from approaches adopted at other memory clinics around the world, where it may be common practice to disclose a diagnosis if known, irrespective of whether or not a patient asks the question. The fact that many of our patients specifically requested information about their diagnosis to be sent to them in writing may well reflect a desire on their part to be more included in the diagnostic process. Future research now needs to be done investigating approaches to sharing information about a diagnosis of dementia at memory clinics.

This work has enabled us to hear the voice of people presenting to a memory clinic with a memory problem, listen to their views about the service being offered and identify areas where our practice can be changed in relatively simple ways that may enhance their experience of the service.

Note

1. Since the time of writing this paper, the disclosure policy at the Memory Clinic has changed significantly and is now guided by the patient. On first meeting, patients' preferences are explored by the interviewing doctor and staff ask patients explicitly do they wish to know their diagnosis. It is explained to any accompanying relatives that where a patient wishes to know their diagnosis this will not be withheld from them. Upon returning for feedback, patients are given the opportunity to receive their diagnosis on their own or with family, according to their preference.

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Biographical notes

SUZANNE CAHILL is the Director of the Dementia Services Information and Development Centre in Ireland, Associate Professor of Social Work and Social Policy (Adjunct) at the University of Queensland, Australia, and Lecturer in Social Policy and Ageing at Trinity College Dublin. She has a background in Social Work practice, teaching and research and wrote her PhD on Social Policy, Dementia and Family Caregiving.

IRENE BRUCE qualified in Dublin as a Registered General Nurse in 1982. Following midwifery training in Scotland she worked as a midwife in both London and Dublin. She worked as a research nurse in phase one clinical drug trials for several years. She moved to work in care of the elderly in 1989 working in both extended care and rehabilitation. In 1991 she commenced work in the first Memory Clinic in Ireland as a research nurse. She now works as clinical nurse manager in a memory clinic and is undertaking a Masters degree in dementia studies.

MARY HEADON qualified in Dublin as a Registered General Nurse in 1982. She worked in the USA for three years in this capacity before returning to Ireland to Trinity College to undertake a Bachelor of Social Studies degree and at the same time completed the professional qualification for social work practice in 1990. She spent 15 years in social work practice in Ireland and the UK with most of that in hospital-based posts specializing in work with older people. This was followed by short period in a combined post in a memory clinic providing social work input and research assistance in a dementia information and development centre. Mary has recently moved to a primary care nursing setting and spent two years as a practice nurse in general practice and more recently as a research nurse in the general practice/academic department of a university in Ireland.

MATTHEW GIBB has a professional background in social work practice and has a Masters degree in Social Policy and Social Work Studies from the London School of Economics. He worked in Edinburgh and London for 16 years and has particular experience working with older people, carers and people with sensory and physical disabilities. Matthew moved to Dublin to take up the position of Senior Social Worker at St James's Hospital in 2003. His role is divided between conducting research for the Dementia Services and Information Development Centre and providing social work support for the Mercer's Institute for Research on Ageing.

MARY DRURY has a professional background in social work and has a Masters degree in Social Science from University College Dublin. She has many years experience as a Medical Social Worker, Educator and as an advocate lobbying for the rights of older people and for people with dementia.