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## Background

Providing the right type and quality of home-and community-based dementia care services may allow people with dementia to remain living well at home for longer<sup>1</sup>. However, access to formal dementia care services varies widely within and across EU countries<sup>2-3</sup>, and research has shown that people with dementia and their informal caregivers experience many difficulties accessing services. Furthermore, some available services have been found to be under-used and informal caregivers often wait a considerable time before seeking help<sup>4</sup>. The uptake and utilisation of services is a complex process. While psychosocial and cultural factors are widely thought to influence service use decisions, service-related factors are also thought to play an important role<sup>5</sup>.

The Actifcare project ([www.actifcare.eu](http://www.actifcare.eu)) is being conducted in 8 countries (DE, IE, IT, NL, NO, PT, SE, UK). It will analyse the pathways to care for people with dementia and their families in an attempt to better understand the reasons for inequalities in access to dementia care services.

This first Actifcare study explores the personal experiences, and perceived barriers and/or facilitators to accessing dementia care from the perspectives of family caregivers. The results of the Irish group are presented here.

## Method

An exploratory qualitative design with purposive sampling was used. Three focus groups were conducted with informal caregivers already using, or having previously tried to access, formal care. Two groups took place with the help of the Carers Association of Ireland; the first in a rural county town (n=4; mean age = 65; female = 4) and the second in a Country Dublin suburb (n=4; mean age = 66.7; female = 4). The third group comprised of relatives of people with dementia attending a dementia-specific day care centre in a central Dublin neighbourhood (n=8, mean age = 59.5; female = 4). In total nine spouses and seven children participated in the groups. Discussions followed an agreed structure, were tape-recorded, transcribed, and analysed using inductive content analysis.

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## Results

Six common themes the emerged across the two focus groups:

### 1. Accessing Services

The main barriers to accessing services which emerged were:

- Delays resulting from carers' own hesitance in seeking support and GPs' failure to listen to carers' concerns
- The person with dementia refusing or disengaging with services
- Inequity in service access and the need to fight for services.

Triggers for accessing services were crises for the person with dementia or for the carer and recommendations from people external to the family.

*“But I feel if I hadn't kind of sat up in [Elderly Care Clinic] that day and said, “Listen here, I want something done here and now, I'm not prepared to go on dithery-dothery for another year, I feel that I might still be attending there on a three-monthly basis getting his blood pressure checked.”*

### 2. Service Acceptability & Availability

Lack of appropriate services, limited resources, and restrictions in the timing of available care, emerged as the main barriers to service use and carers described how often this resulted in their relative's needs being unmet. Once actively using dementia services, the overwhelming concern for carers was that they would be reduced or removed in the future.

*“They said to me that... I, kind of, said, ‘Will there ever be a chance of a second day here?’ and I think it was [day care manager], I've never met her but on the phone she said, ‘No, because [husband's] wants only fit in on a Thursday.’ They could only cope with him on a Thursday. She said, ‘You won't get another day here.’”*

### 3. Education & Awareness

Lack of knowledge emerged as a major sub-theme related to education and awareness. Carers described how they themselves did not know what to expect from dementia, how to manage the condition or what services were available. They felt that GPs also lacked knowledge relating to dementia diagnosis and support. A lack of accurate dementia knowledge in the public domain and the stigma associated with the condition was also highlighted by carers.

*“The way it happens, that somebody tells you. You never knew that there was anything out there. Well, I never knew there was a district nurse. I never knew anything about it. And somebody came along and said, ‘You should get help.’”*

### 4. The Impact of Caring

The challenge and complexity of the carers' role was evident from their stories as they described the physical and emotional toll it took on them, and the disruption it caused to family and day to day life. Carers felt ignored and abandoned by the healthcare system.

*“Because you've kind of – to use these modern expressions – you kind of park your family and your husband and you take over. It just causes its own problems too, that your whole time is given over to your parent”*

### 5. Caring for the Carer

Carers felt that they were at risk due to the overwhelming nature of dementia care and that they needed support. Carers expressed that it is difficult for them to know exactly what support they would need while they are in the middle of the caring role. They did, however, expect that they would receive at least some tangible support. Carers' clearly expressed the view that with just a little more help, they would be better able to care for the person with dementia for longer.

*“If you know you have that for two days ... you can cope with three or four or five days full on because you know you are going to do... there is a gap coming, there is a break. It is not that it is every day for ever more.”*

### 6. Capacity & Rights

Carers highlighted the difficulties which arise when the person with dementia refuses support or services. In some carers' past experience this had meant that their own needs were subsequently not met, other carers worried about this situation arising in the future. Some carers felt that the decision to accept or decline services should be their own as they best knew what was right for their relative. Others were less strident in their view and acknowledged that the person with dementia has the right not to want to do something but all could relate to the difficulty of this situation.

*“I've accepted it, but I'm very, very worried because I don't think [husband] will accept it. I haven't told him yet. But I've accepted it because I was advised left, right, and centre not to refuse it and I was told to try it”*

### 7. Best Practice

Carers outlined what they would expect from good formal dementia care. Carers felt that the needs of the person with dementia and their own needs should be reassessed over time and good care should be appropriate and timely. They expressed a wish for knowledgeable healthcare professionals and a key person who keeps in touch with them. Being provided with information about the different stages of dementia was hugely important to all carers. Finally, all carers agreed that it was important that they had relief from their caring role for short periods of time on a regular basis.

## Conclusions

The findings from the three focus groups support an increasing body of evidence that highlights the very clear gaps that exist between the formal home- and community-based services and supports that are available in Ireland. The recent Irish National Dementia Strategy<sup>6</sup> has selected better awareness and understanding, timely diagnosis and intervention, integrated services, supports and care for people with dementia and their carers, training and education, and leadership as priority action areas. The challenge will be implementing this strategy alongside other current and significant health and social care policies, but it presents an opportunity to identify appropriate home- and community- based care that will truly benefit people with dementia and family carers.