

# **“I know what it is but how bad does it get?” Insight into the Lived Experience and Service Needs of People with Early-Stage Dementia**

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**Abstract:** This paper provides insights into formal service utilisation of people living with early-stage dementia. It links the ‘personal’ to the ‘political’ by placing their experiences within a framework of the Irish health and social care system.

Taking a person-centred and Interpretive Phenomenological Analytical approach, in-depth interviews were carried out with 17 people living with dementia. In 13 cases, care-partners were also interviewed. The third data source comprised of interviews with six policy experts; highlighting current policy priorities within dementia care.

Findings show that there are few formal services for people living with dementia. Where services were available, respondents were low service users. Reasons for this were that participants (i) did not perceive their situation as critical enough, (ii) they never used social services before, (iii) they did not know their entitlements and (iv) felt a stigma in using social services.

Findings provide valuable data on the lack of a relationship respondents had with the broader health and social care system. The basis of this relationship can be broken down into: (i) the type of model that exists in Ireland (predominantly a medical model); (ii) incentives and currency needed to engage with services (physical ill-health); (iii) diagnosis (or lack thereof) and (iii) relationship with service providers, which was often *ad hoc* due to a lack of guidelines on best practice in relation to dementia diagnosis and referral.

Findings offer rich evidence of the issues people living with dementia confront in a system which provides inadequate and often inappropriate supports. Findings emphasise the need for formal services where the focus is on disability, rehabilitation and the promotion of the rights of people living with dementia as citizens.