

# Supporting people with dementia to die at home in Ireland.

## IHF Brief Report 2016

We estimate that:



### INTRODUCTION

With the publication of the National Dementia Strategy, there is a welcome emphasis on early diagnosis and establishing a dementia friendly Ireland to enable people with dementia to live well in their local communities (1). However, the needs of people with advanced dementia are not often discussed and little is known about what supports people with dementia need to enable them to live well and die well in their own homes. In response to a gap in knowledge in this area and an increase in dementia referrals to the Nurses for Night Care service<sup>2</sup> (NNC), the Irish Hospice Foundation (IHF) carried out an audit on referrals of people with dementia to the NNC service in 2015.

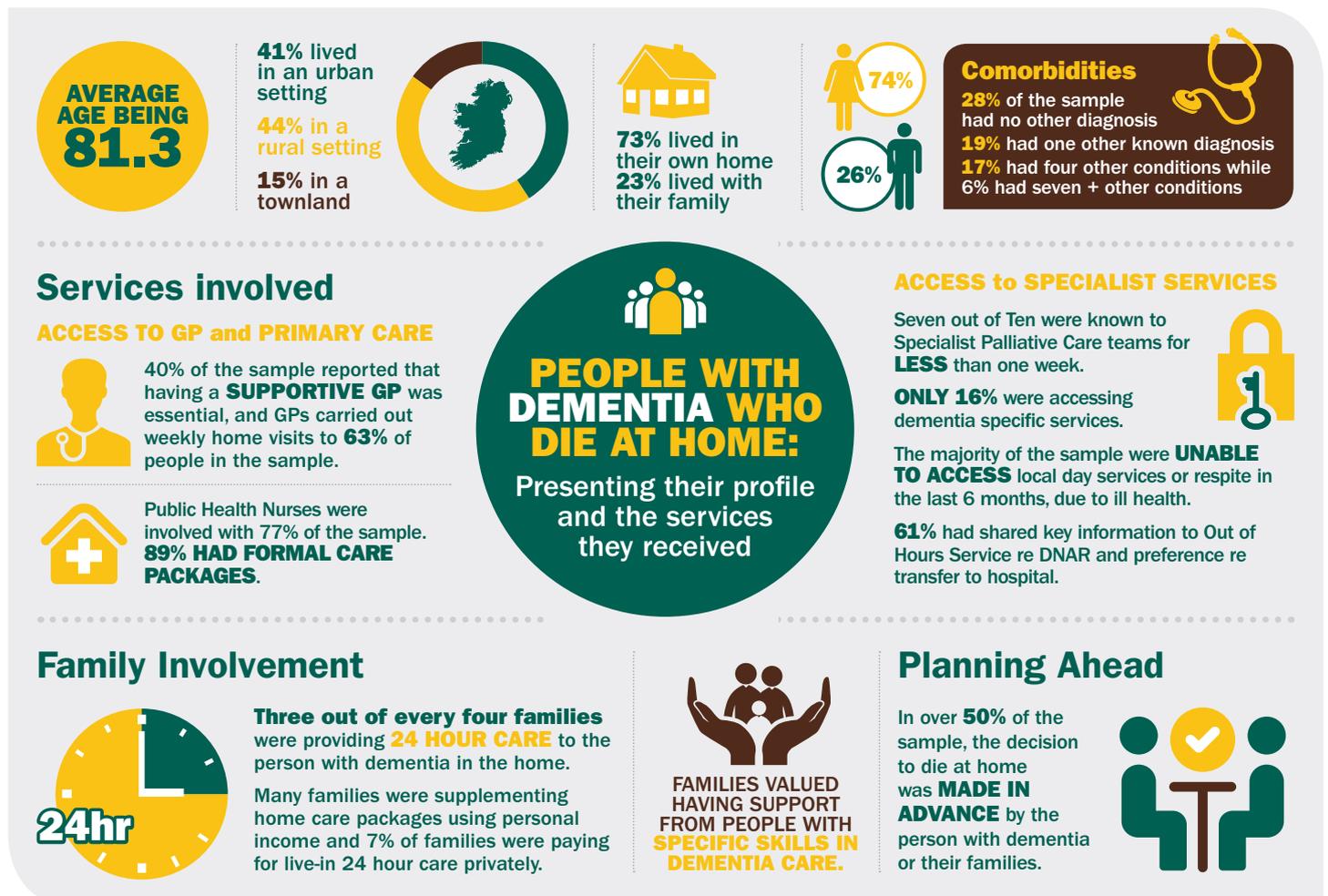
### METHODOLOGY

Following a review of the literature, an audit tool was developed to gather supplementary information on people with dementia referred to the NNC service. Information was obtained by phone from the referring Specialist Palliative Care teams on receipt of each referral. 56 people with dementia were referred to the NNC service between June and December 2015. Supplementary information was gathered on 52 people.

### REPORT OUTLINE

This report will:

- Describe the profile and components of care received by 52 people with dementia referred to the NNC service (see infographic below)
- Compare our findings with the literature available on dying at home (page 2)
- Outline the IHF's recommendations to healthcare staff and service planners on supporting people with dementia to die at home (page 3).



<sup>1</sup> Figures extrapolated from UK figures (3)

<sup>2</sup> The IHF has funded the **Nurses for Night Care service** for people with conditions other than cancer since 2006. The service enables people to receive expert care, support and reassurance at night time in their own homes during their final days. The number of people with dementia referred to the service has increased by approximately 30% every year and 118 referrals were received in 2015. More information on this service is available on page 4.

# COMPARING OUR FINDINGS WITH THE LITERATURE

Below is a synopsis of the findings of a literature review on the factors that increase the likelihood of a person with dementia being supported to die at home, followed by a brief commentary comparing these findings against the IHF audit. This section is divided into personal factors and practical supports, services and resources.

## PERSONAL FACTORS

- The availability of family/friends to provide care to the person with dementia in their home is one of the most significant factors in achieving a home death (4–7).
- The availability of additional income to supplement formal care may increase the likelihood of a person remaining at home (4).
- Having one or no other co-morbidities increases the likelihood of a person dying at home (8,9).
- Having a longer term functional disability with a gradual decline can increase the likelihood of a home death due to giving the person and their family time to plan ahead; (5, 12, 16).
- The person with dementia making the decision to die at home in advance and communicating this with their family increases the likelihood of them being able to die at home (5,10,11).
- A person is more likely to die at home if they:
  - Are married or living with another person (4).
  - Have a higher level of education (6,8).
  - Are male (9,12).
  - Live in a rural area (22).

## PRACTICAL SUPPORTS, SERVICES AND RESOURCES

- Having access and early referral to Specialist Palliative Care services in the community almost doubles the likelihood of a person remaining at home and achieving a home death (5,7,9,12–17).
- Having access to home care packages and local services to support the person with dementia and their family carers (5,8,18).
- Having a supportive GP who discusses preferences with people about their future and end-of-life care, shares this information and is flexible in relation to providing home visits/ telephone support to the family (11,19,20).
- Having access to specialised equipment required to care for a person at the end of their life (e.g. hoists, wheelchairs, oxygen, profiling beds etc.) (5,21).
- Living in an area with a high ratio of care home bed availability may increase the likelihood of a person dying in a care home (22).

## COMMENTARY

Findings from the audit were broadly in keeping with these findings, with the exception of two factors: gender (there was a high number of females (74%) who were supported to die at home by the NNC service) and where a person lives (the IHF sample showed a roughly even split between urban and rural locations).

The IHF audit did not explore marital status, education levels, ratio of care home availability or socioeconomic status, but these would be important factors to explore in future research. What was not evident in the literature or the IHF audit was the availability of specialist dementia services to support care in the home at end of life and the extent of carer specific support available both during their time as carer and after the person with dementia's death. Recommendations to progress these findings are detailed on page 3.



# RECOMMENDATIONS

While we recognise that dying at home may not be feasible or desirable for everyone, a recent IHF perspectives paper highlighted that more can be done to facilitate people at end of life to be cared for and die in their home if that is their wish (23). The biggest enabler to address improvements in this area will be the commitments from service planners to provide the resources and policy to support more people to die at home. Based on the findings of this audit the IHF has prepared a number of recommendations for healthcare staff and service planners that could support more people with dementia to die well at home.

## HEALTHCARE STAFF

### SUPPORTING A PERSON WITH DEMENTIA AND THEIR FAMILIES

1. Staff should create early and repeated opportunities for people with dementia to engage in discussions about their preferences relating to their future and end-of-life care.
2. Staff should provide information and support which is tailored to suit the needs of the person with dementia and their families at each point of contact with them to assist them anticipate future changes and plan ahead.
3. All staff have a responsibility to share information relating to a person with dementia's end-of-life care needs and preferences with one another in order to support and promote continuity of care for the person with dementia living at home.
4. GPs and Out-of-Hours Services are encouraged to continue to provide flexible home responses for people with dementia.
5. Staff should ensure timely referral and sharing of information with specialist services such as Specialist Palliative Care teams, Out of Hours Providers and Dementia Specialist Services<sup>3</sup>.

## SERVICE PLANNERS

### SERVICE RESPONSE

6. The HSE should continue to fund home care packages that respond to the needs of people with dementia and enable them to be cared for and die at home.
7. The IHF will advocate for incentives which would facilitate GPs to carry out home visits for people with advancing life-limiting illness, including those living with dementia, who wish to die at home.
8. Dementia specific services should be designed to reach people with advanced dementia living in the community and those nearing the end of their lives.

### PALLIATIVE CARE

9. Specialist Palliative Care services should promote and increase awareness of their important role with people with dementia in order to encourage earlier referrals to the service.
10. Education and Training for Primary Care teams should include information on the relevance of a palliative care approach for people with dementia.

### CARER'S NEEDS

11. Healthcare staff and services should strive to provide appropriate and timely supports to family carers to enable them to continue to provide care for their family member with dementia to enable them to live well and die well at home. Support for family carers should include the provision of follow-up bereavement care after the death of their family member with dementia.

### AWARENESS AND FURTHER RESEARCH

12. The IHF will disseminate the findings of this audit to the HSE and service providers in order to increase awareness of the components of care which enable people with dementia in Ireland to die at home and to promote further research in this area.

<sup>3</sup> The IHF have produced a GP Out-of-Hours Palliative Care Handover Form to support the transfer of information between GPs and OOH providers. See [www.hospicefoundation.ie](http://www.hospicefoundation.ie) for more details.

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## ABOUT THE NURSES FOR NIGHT CARE SERVICE:



The Irish Hospice Foundation strives for the best care at end of life for all. As part of our mission, we seek to give more people the option to be cared for in their final days and die at home. We work closely with the Irish Cancer Society to provide a Nurses for Nightcare service for people with illnesses other than cancer all over Ireland. This service is provided free of charge by the IHF and is funded solely through donations from the Irish public. This service has been funded by the Irish Hospice Foundation since 2006. Demand for the service grows by about 15% every year. In 2015, over 1700 nights of nursing care was delivered to over 500 people across Ireland at a cost of over €500,000.

**What the service offers:** This service enables those people who are living with dementia, motor neurone disease, advanced respiratory disease, heart failure and end stage kidney disease to receive expert care, support and reassurance at night time in their own homes.

**How the service works:** The nurses stay in the home throughout the night, providing nursing care, practical help and reassurance to both patient and family. The service can give a significant support to families at what can be a very difficult time.

**How to access the service:** The Specialist Palliative Care team make the referral to the Irish Hospice Foundation.

**Further information is available on our website:** [www.hospicefoundation.ie/healthcare-programmes/palliative-care/palliative-care-for-all/night-care/](http://www.hospicefoundation.ie/healthcare-programmes/palliative-care/palliative-care-for-all/night-care/)

## IHF DEMENTIA RELATED EDUCATION AND RESOURCES

### Resources for people with dementia and their families



see [www.thinkahead.ie](http://www.thinkahead.ie) for more details



### Resources for healthcare staff



The IHF have developed 7 guidance documents on specific aspects of dementia palliative care. These are suitable for those supporting people with dementia at home.

To access these resources and for more information see [www.hospicefoundation.ie](http://www.hospicefoundation.ie)



### Education and training

There are a number of training courses and workshops available for healthcare staff and family members. For more information visit the education pages on [www.hospicefoundation.ie](http://www.hospicefoundation.ie)

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Striving for the best care at end of life for all

