

Home Care Consultation Questions

Your Opinion Matters

This public consultation is being carried out to help the Department of Health to develop plans for a new statutory scheme for home care services. We would like to find out what people think about current home care services – what is working well and what needs to be improved. We would also like to hear the public's views on what the future scheme should look like.

A report of the findings of this consultation process will be published. These findings will help the Department to develop the new home care scheme. This stage of the consultation is particularly aimed at people who use home care services, their families and the general public. However, everyone with an interest, including: health and social care providers; health and social care workers; advocacy groups; those providing complementary services (such as meals-on-wheels and social activities); and representative organisations is welcome to participate.

It is important to say that this consultation paper is just the start of a broader consultation process on home care. The Department also intends to consult by:

- Meeting with individuals and groups so they can tell us directly what they think;
- Meeting with home care service provider organisations and other organisations that represent people that use home care services so they have the opportunity to put forward their views; and
- Asking everyone with an interest in home care services to tell us what they think of our plans when they are developed.

Given that the Department will be consulting again throughout the process of developing the new home care scheme, this consultation does not attempt to address every issue related to home care.

Tell Us What You Think

In your opinion, what are the good things about home care services in Ireland?

When giving your answer to this question, you may wish to think about the following:

- **How you apply for home care**
- **How your need for home care services is assessed**
- **Who can access services**
- **What home care services are provided**
- **How home care services are provided**
- **How home care services are monitored**
- **How you can appeal a decision about your home care**

People with dementia have specific needs in relation to home care that differ to other cohorts, and it is important that this is highlighted at the outset of this Submission. The types of challenges associated with dementia create a need for personal care, social support and domestic assistance that take into account the changing needs of the person at various stages of dementia, mild, moderate and late. The HSE (2015) defines home care as essential personal care, such as washing, taking a shower, assistance with changing position, oral hygiene, or help at mealtime, and on essential domestic duties (like lighting a fire or bringing in fuel if there is no alternative heating source, or basic essential cleaning of the person's personal space). Dominic Trepel's 2014 report, 'An Economic Analysis of Home-Care Services for People with Dementia' acknowledges that these national definitions of home care services importantly set the context for the duty of care in dementia. However, dementia-specific home care, instead of being purely task driven, should also include social stimulation, offering company for the person with dementia or simply checking in to ensure the person is comfortable and not experiencing isolation and loneliness. Such supports are important because they enable the person with dementia to remain at home in the community for as long as possible without having to move to residential care.

Dementia-specific home care consists of person-centred, consistent and continuous care, provided by dementia trained staff and in partnership with the person with dementia and their carer, while promoting independence and inclusion.

ASI's consultation highlights the following positive aspects about home care services for people with dementia:

- There are isolated pockets of effective and integrated inter-disciplinary practices involving Primary Care Teams, Occupational Therapists and Public Health Nurses. Such timely and coordinated responses result in good outcomes for people with dementia, enabling them to remain at home in the community. Coordinated inter-disciplinary practices for people with dementia need to be further developed.
- Carers are increasingly better trained and educated in relation to dementia care, and as part of this Submission several carers offered examples of the beneficial impact of dementia-trained carers in alleviating stress and supporting their parent with dementia, thereby improving quality of life for the whole family. Nonetheless, dementia-specific training needs to be further developed and implemented, as stated in the National Dementia Strategy (NDS).
- Instances of carer continuity whereby the same formal carer visits the client can lead to rapport, trust and a good client-carer relationship, as indicated in ASI's consultation. Good carer-client understanding and communication can avert potential challenges and crises for people with dementia. One carer described how such a relationship meant the professional carer was able to recognise early symptoms of delirium in her mother, and alleviate potentially challenging health risks. Indeed, promoting continuity in care is highlighted in the NDS.
- Home care can have good outcomes even when it is available even for relatively limited time. For example, half an hour of home care might help a person with dementia prepare to attend a day care centre. However, as will be discussed, availability of home care should be led by demand and specific needs of the person with dementia rather than by availability of resources.

The next three questions ask whether the different services that are needed to help people stay at home work well together. This information will help to inform how services can work better together in the future.

Do you think that home care services work well alongside primary care and other community services to meet the needs of people who receive home care?

Note: Primary and community services include GP services, public health nursing, physiotherapy, speech and language therapy, occupational therapy, and respite care.

- Yes
- No
- Don't know

Do you think that home care services work well alongside hospitals to meet the needs of people who receive home care?

- Yes
- No
- Don't know

Do you think that home care services work well alongside informal carers to meet the needs of people who receive home care?

Note: informal carers are family and friends that provide care and support

- Yes
- No
- Don't know

If you have any comments in relation to how well home care services work with other providers of care, please include them below:

Good dementia care requires a multi-disciplinary approach, involving designated personnel at different levels in the health and social care system and effective inter-agency and interdisciplinary communication. Collaborative care monitors and co-ordinates the range of care providers involved in dementia care, including home care services, family carers, public, private and voluntary care providers.

The variety of potential providers contributing to dementia care, compounded by continuously changing demands and variations in competencies of carers increases the likelihood of inefficient arrangements of care. Currently, there is a pressing need to address and improve integration of health care professionals including providers of home care services. The delivery of care for people with dementia needs to be coordinated, involving a close working relationship with HSE structures, working collaboratively with services for older persons, diagnostic services, PHNs and home care services.

Indeed the 2017 Slaintecare Report acknowledges that “The experience from other countries has shown that integrated care is more efficient, reduces cost, enhances the quality of care and improves overall health and wellbeing of the community”. ASI’s 2018 Pre-Budget Submission (PBS) calls for investment in Dementia Care Coordinators to play a key role in coordinating the care of each person with dementia and promoting continuity of care, which is a stated key priority in the NDS.

Crucially, a recent mapping exercise of dementia-specific services prepared by ASI and the HSE clearly indicates that there are extraordinary differences in terms of service provision across counties, ranging from 23 dementia-specific services (CHO 9, Dublin North, Dublin North Central and Dublin North West) to 44 such services (CHO 1, Donegal, Sligo, Leitrim, Cavan and Monaghan), including social clubs, Alzheimer cafes, carer support groups and dementia day care. There are also significant variations in the types of services provided in various counties, e.g., three counties, Wexford, Laois and Leitrim have no reported dementia-specific day centre. Inequity in relation to availability of dementia-specific service provision needs to be addressed.

The next two questions ask for your views in relation to choice of home care services and providers.

Do you think that people who receive home care should have more of a say in the range of services that are provided to them?

- Yes
- No
- Don't know

Do you think that people who receive home care should have a choice in who provides their care?

Note: Home care can be provided by the HSE, not-for-profit providers and private providers.

- Yes
- No
- Don't know

If you have any comments in relation to choice of home care services and providers, please include them below:

The All-Party Oireachtas Group on Dementia, involving Ms Mary Butler, TD, and Senator Collette Kelleher, has set out a vision for home care that highlights a clear need for a scheme that meets the preferences of people to remain at home and the need to move from an ad hoc, piecemeal approach to home care (this report is attached to this Submission). In the work of the All-Party Group, it is identified that choice should be a key principle of home care. Indeed, ASI recognises that there needs to be a move towards personalised client-centred care. There should be a response to individual need through a richer menu of interventions and supports. Choice should be central to dementia-care including choice in relation to home care services and providers of such services, and people with dementia should have a say in relation to the types of home care services they receive to meet their specific needs.

People with dementia all have varying needs ranging from minimum to high levels of support need. Some cannot get out of bed and dress themselves and require blocks of care, while others may simply need someone to briefly check on them. However, often this is not acknowledged and there is no time allocated for such non-medical needs. Home care tends to be task oriented, such as providing assistance with showering. Task-oriented home care is not always conducive to dementia care, and this type of approach does not adequately meet need and indeed may be frightening for a person with dementia. People with dementia would benefit from social stimulation whereby instead of coming to provide task-based care, the carer comes to engage socially with the person with dementia, and this would help with cognitive function and indeed with mood and mental health.

Care should be customised and related to individual need and requirements of the person with dementia. Carers and family members should also be involved in determining and designing homecare packages. This requires a menu of choice and increased dialogue with people with dementia and their carers to ascertain their views and needs. Home care packages should be led by demand and based on specific need rather than being fixed according to resources available. Specific individualised packages of formalised support mechanisms need to be available for people who are highly dependent in the community. Intensive Home Care Packages have been delivered to 217 people with dementia to the end of April 2017. An ongoing review by the National Dementia Office indicates the complexity of need and that these packages of care are immensely beneficial in meeting the complex and specific needs of people with dementia.

In your opinion, how could home care services in Ireland be improved?

Note: When giving your answer to this question, you may wish to think about the following:

- **How you apply for home care**
- **How your need for home care services is assessed**
- **Who can access services**
- **What home care services are provided**

- **How home care services are provided**
- **How home care services are monitored**
- **How you can appeal a decision about your home care**

- **Improved Home Care Resources**

ASI's consultation for this Submission indicate there is significant unmet need regarding levels of home care and respite, as also outlined in its 2018 PBS. In 2016 there were over 800 people nationally recorded with ASI alone awaiting dementia specific home care. Home care supports are under-resourced and are not available when people need them. Home care is not currently needs-based and instead tends to be resource-fixed. Availability is ad-hoc, fragmented and inconsistent, and there is a shortage of time for packages and visits. While it is acknowledged that people can manage with limited home care support, many people do not even have such limited supports.

Under-resourcing of home care has implications for carers of people with dementia, as highlighted in the 2017 De-Stress study of carer well-being undertaken by the ASI, Trinity College and the HRB. This study indicates that 40% of carers experienced mild to moderate burden or perceived stress due to the caring role, while 36% experienced moderate to severe levels of burden. Such care burden can impact negatively on carers' health putting the carer at risk of burn-out and person with dementia at risk of neglect.

This can lead to greater risk of neglect among vulnerable adults with dementia. One carer explained she was strongly advised from asking HSE for a review of her elderly mother's care needs as it was perceived that a review may lead to a service cut. Many carers feel that the current practice is towards cutting home care services at every opportunity.

The majority of people with dementia live in the community, over 63%, and want to live at home in a familiar environment, receiving care when it is needed in this setting. Home care supports need to be expanded and developed. Adequate investment, as set out in ASI's 2018 Pre-Budget Submission, would provide home care supports for those in the early to mid-stages of dementia and enhanced packages for those with more complex care needs.

- **Client-Centred**

Importantly, ASI's Charter of Rights for people with dementia incorporates a PANEL approach emphasising principles of participation, accountability, non-discrimination, empowerment, and legality. It emphasises that people with dementia should have the right to full participation in deciding and arranging their care, support and treatment, and should be enabled through accessible information and supports, to exercise their right to participate in decisions and policies which affect them. ASI recognises that a one-size-fits-all approach to home care does not work for people with dementia. There is a need for a suite of services to respond to differing and changing needs in line with the trajectory of dementia, as also identified in the above All-Party Oireachtas report on dementia. Even when one can access limited home care, it often does not adequately respond to the specific needs of people with dementia and their carers. The list of tasks included on the package can include cleaning, feeding, but the needs of people with dementia can differ. Packages involving 'box-ticking' merely serve to address tasks and not the need of the person with dementia.

- **Flexibility**

There is no flexibility in home care supports and no increase in home care availability, if the person with dementia experiences increased challenges. This can result in the person with dementia being sent to hospital, an unnecessary step which could be avoided. While increasing funding invested in home care is pressing, increasing flexibility and responsiveness is crucial.

- **Early Onset Dementia**

Home care services should include and meet the needs of people with dementia who are under the age of 65. In Ireland 4000 people have early onset dementia, and there are a dearth of home care supports to assist this cohort who often has no choice but to avail of inappropriate generic services and nursing homes. People with early onset dementia need dedicated home care services to meet their complex needs.

- **Complex Need**

People with dementia can experience complex medical needs. An increasing ageing population means that people with dementia are presenting with an additional illness or condition. Co-morbidity needs to be given due consideration in relation to home care for people with dementia. Dual diagnosis means there can be changes in the person's care needs and care may need to be altered appropriately.

- **Accessing and Assessing Home Care**

There is a lack of clear information about how to access home care and family carers can be uncertain about where to find the necessary information. Carers are uncertain about what defines home care and what it entails, and this lack of transparency needs to be addressed.

While it is stated at the outset of this document that home care is not means tested, several carers who took part in this consultation insisted that they have been refused access to home care because they do not have a medical card or are deemed too 'well-off' to receive a home care package. This concern has been highlighted by callers to ASI's Helpline.

There is concern that the Single Assessment Tool (SAT), currently being piloted to assess home care needs, does not apply to people with dementia under the age of 65. Nor does it refer specifically to dementia but instead alludes to general cognitive impairment. Furthermore, SAT does not seem to give due consideration to the person's own wishes, instead focusing on specific scores indicating if the person is more suitable for home care or residential care. SAT must take into account the needs and wishes of the person.

As well as taking into account the needs of the person with dementia, SAT and home care assessments should also consider the needs of the carer. In this consultation, carers were emphatic that an individualised care plan must also focus on the carer to ensure he/she is supported and facilitated. This will improve quality of life for the person with dementia and the carer and alleviate social isolation often experienced by both the family carer and person with dementia.

- **Communication and Carer Services**

There is a need for a better system of communication between home care service providers and recipients of care and their carers. There can be a lack of consistency in the delivery of home care

and frequent changes in professional carers can prove very challenging for people with dementia and their carers. This lack of continuity can be unexpected and the informal carer is often not informed in advance. This can lead to stress and confusion for the person with dementia who needs consistency. It takes time for the carer to understand the need of the person with dementia, their background and personality, and changing carers can be immensely frustrating for the person with dementia and their family.

In addition, carers may be put at risk by being asked to provide short blocks of care for 15/30 minutes, for a person with dementia, who may exhibit aggressive behaviour because they are being rushed and therefore feel stressed and frustrated. Developing rapport and a good carer-client relationship is crucial to person-centred care, and this requires time and continuity.

- **Training and Monitoring of Home Care**

Standardisation should be implemented in relation to the delivery of home care by professional carers, and formal home care should be monitored and regulated by HIQA, as discussed further below. Different approaches to home care issues among companies can lead to challenges in relation to dementia care. There is also a need for dementia-specific training among formal carers to adequately address specific needs.

Questions on Information on Home Care Service

This section asks who you would contact if you needed information on home care services. It also asks whether you are aware of the tax relief that is available for privately purchased home care.

If you, a relative or friend needed home care services, who would you ask for information first?

If you have any comments on this issue, please include them below:

Carers report being uncertain about where to seek information about home care services, and describe getting varying pieces of information from different sources, which can lead to confusion and stress. There is a lack of clear and transparent advice on home care information. This is an additional stress in addition to caring for the person with dementia.

Are you aware that tax relief is available to people that pay for home care services?

Note: tax relief reduces the amount of tax that an individual has to pay

Yes

No

If you have any comments on this issue, please include them below:

While one can claim tax relief on the cost of employing a carer, stakeholders involved in this Submission expressed frustration that such information is not transparent and it can be difficult to access this information. Further, carers experience the rules governing tax relief as restrictive, specifically that the individual must be totally incapacitated for the complete tax year (January to December) in which one is claiming the tax relief.

Questions on Standardisation

At the moment, home care services operate in different ways across the country. This means that the amount and type of home care available can vary depending on where you live or the time of the year. Many other countries have home care systems that make sure that home care is provided in the same way across the country.

Do you think that the same approaches should apply across the country in relation to the following?

- **Do you think that the same approaches should apply across the country in relation to the following?**
- **How you apply for services** Yes ___ No ___ Don't know ___
- **How your need for services is assessed** Yes ___ No ___ Don't know ___
- **Who can access services** Yes ___ No ___ Don't know ___
- **What home care services are provided** Yes ___ No ___ Don't know ___
- **How home care services are provided** Yes ___ No ___ Don't know ___
- **How home care services are monitored** Yes ___ No ___ Don't know ___
- **How you can appeal a decision about your home care** Yes ___ No ___ Don't know ___

ASI will reply 'yes' to all of the above

If you have any comments on this issue, please include them below:

Currently, there are significant geographical variations in access to home care support and respite for people with dementia. The mapping exercise, as mentioned above, clearly highlights geographical inequity and points to a significant gap in service provision in rural areas, e.g., CHO2, comprising Galway, Roscommon and Mayo, has no social clubs. Providing rural home care can pose unique challenges, and people in rural areas often need blocks of care, which is currently lacking. Geographical inequity can be a source of immense frustration for carers, and such inconsistencies need to be addressed so that the home care system operates with equity and the same home care approach is applied across the country in relation to assessment of need, and how and what home care services are provided and monitored.

The Health Reform Alliance, of which ASI was a founding member, outlines core principles guiding a health and social care system. One such principle recognises that access to social care including home care packages is subject to budget caps in local areas, meaning that access is dictated by geography rather than equity. The Health Reform Alliance calls for a health and social care system which treats everybody equally.

Questions on Quality Standards

At the moment, there are no national standards for home care. This means that the quality of home care can differ among home care providers. Other countries have introduced national standards. We would like to know your views on whether or not you think national quality standards should apply in the future to home care providers in Ireland.

Note: National standards would mean that every home care provider would have to meet a minimum standard of quality in order to continue providing home care services.

Do you think that the same national quality standards should apply to all (public, private and not-for-profit voluntary) providers of home care?

- Yes**
- No**
- Don't know**

If you have any comments on this issue, please include them below:

The delivery of home care by public, private and non-for-profit providers needs to be adequately monitored, standardised and regulated. Various providers have different approaches to care, and this variation can lead to challenges in relation to dementia care. Informal carers of people with dementia are concerned that if they raise questions about quality of care or complain about concerns such as inadequate hygiene, their level of care may be reduced. There is a need to implement a minimum standard of quality and national regulations in relation to home care. HIQA could develop national standards to improve quality and safety, and also be responsible for regulation of all providers of home care. Importantly, standardisation, monitoring and regulation of home care should take place in the context of holistic care and support provision, including medical, social and task oriented supports.

Questions on Training for Care Workers

Currently, there is no minimum level of training required in order to be a home care worker in Ireland, though many have completed relevant training. Other countries have introduced minimum training levels in order to help ensure a better quality of service. We would like to know whether or not you think this would be a good idea for Ireland.

Do you think that formal home care workers should have to complete a minimum level of training that would be set by the Government?

Note: formal home care workers are people who are either self-employed or work for a home care service provider organisation

- Yes
- No
- Don't know

If you have any comments on this issue, please include them below:

Care staff may not always be adequately trained or qualified in relation to dementia care, and many family members and informal carers of people with dementia are concerned about the quality of care being received. Generally, there is a critical lack of training and development for carers in various agencies relating to dementia and managing dementia-related behaviours. Dementia-specific training need to be rolled out to meet the specific needs of people with dementia and their carers. While there is a bank of carers who have dementia-specific training, their time needs to be protected so they can respond directly to people with dementia. Consideration needs to be given to ensure their dementia-specific skills are reviewed and assessed annually.

Questions on Funding

In Ireland, there is no means test for home care services that are funded by the HSE. People who receive these services do not have to pay for them. This is different to many other countries which have some form of charging or means test.

Taking account of limited State resources, do you think that people who receive home care services should make a financial contribution to the cost, based on their ability to pay?

- Yes
- No
- Don't Know

If you have any comments on this issue, please include them below:

The total baseline annual cost of dementia in Ireland has been estimated at approximately €1.69 billion (see attached infographic and reference). This figure offers insight into the economic cost borne by carers, as almost half of the above cost, 48%, is attributable to informal care provided by friends and family of people with dementia, also noted in the attached All-Party Oireachtas Report. A further 43% is accounted by residential long-term care. Thus, the economic burden of dementia is largely carried by informal carers.

ASI supports the Health Reform Alliance's core principle of universal healthcare through a universal, publically funded system. This would be the most effective and financially sustainable way to provide universal access to health and social care, including dementia-related care. Such a funding system should be based on need and not on ability to pay. Funding for health and social care should also be based on taxation or social insurance. Citizens who can afford to pay more support those on low incomes. The funding and resourcing supporting such a system must be secure, realistic and sustainable, even in times of economic hardship, properly managed to ensure seamless integration between health and social care services. Importantly, there must be incentives for people to choose home care over residential care, otherwise people may veer toward residential care.

If the State could only provide a certain amount of home care services based on health need, would you be prepared to purchase additional hours with your own money, if you needed them?

Yes No Don't know

If you have any comments on this issue, please include them below:

It is pertinent that the home care support system is based on principles that value all citizens equally, and as outlined above, should be funded through a universal, publically funded health and social care system. At present, there are major health inequities and people with chronic conditions including dementia need access to care, both health and social care. However, access to social care tends to be treated very differently to access to healthcare. While society accepts collective responsibility to meet the health needs of citizens, social care is primarily viewed as an individual responsibility subject to complex criteria and means-testing.

Carers and people with dementia who took part in this Consultation and who are reliant on a medical card expressed concern about the financial implication in the above question. Emphasis should be shifted from financial and technical arguments and instead placed on the larger question of how we can provide universal care for all citizens, a system that should incorporate the following principles:

1. The health and social care system treats everyone equally.
2. The health and social care system is focused on the needs of all social groups in society.
3. People have an entitlement to health and social care, free at the point of access.
4. Different elements of the health and social care system work together and are connected.
5. The health and social care system is a universal, publically funded system.

Other Issues:

If there are any other comments that you would like to make, please include them below.

Many stakeholders are concerned that this survey and opportunity to partake in this Consultation are not reaching an adequate number of relevant people affected by the issue of home care. Also, the shorter version of the survey is aimed at people who have already experienced home care and several questions relate directly to the individual's experiences of home care. These survey questions are not designed for people who have symptoms of dementia but are not at the stage

where they require home care services. Nonetheless the issue of home care is pertinent to these individuals, and in such instances the respondent has to hypothesise about how and what home care should be delivered.

Regarding the phrasing of the survey, the closed-ended questions are very limited and, the options 'Yes', 'No', 'Don't know' do not allow for a middle-ground response. For example, it would be better if the question, 'Do you think that home care services work well alongside hospitals to meet the needs of people who receive home care?' included choice in the response options- 'Yes', 'No', 'Sometimes', 'Don't know' instead of 'Yes', 'No', 'Don't know'.

Carers also pointed out that some questions appear to be leading questions. For example, under the question on funding:

In Ireland, there is no means test for home care services that are funded by the HSE. People who receive these services do not have to pay for them. This is different to many other countries which have some form of charging or means test.

Taking account of limited State resources, do you think that people who receive home care services should make a financial contribution to the cost, based on their ability to pay?

Yes No Don't know

Some carers feel this question is selective, partial and biased, clearly desiring a 'yes' response. While the question acknowledges that in other countries home care services entail charging or means testing, the question does not acknowledge that family carers are sometimes financially disadvantaged because of the carer burden.

THIS SUBMISSION ALLOWS THE RESPONDENT TO ATTACH FURTHER NOTES:

Additional Notes

In developing this comprehensive Submission, ASI consulted a broad range of stakeholders, including,

- Irish Dementia Working Group (IDWG)
- Dementia Carers Campaign Network (DCCN)
- Informal carers external to DCCN
- Professional carers
- ASI Dementia Advisers
- ASI Operations Managers
- ASI Helpline Staff
- ASI Quality, Safety & Practice Development Team
- Prof Eamon O'Shea
- Dr Tony Foley
- Prof Brian Lawlor
- Members of the Neurological Association of Ireland

Consultations with the above stakeholders highlighted key concerns regarding home care, described by one stakeholder in economic terms as a “wicked problem”, that is challenging to solve because of incomplete, contradictory, and changing requirements. Many carers live with anxiety and fear that their home care will be reduced and perceive they have to constantly “battle” to maintain even paltry home care supports. Currently there is significant unmet need in the community regarding home care supports, which are often not available when people need them, and when available can be characterised as limited, inadequate and inflexible.

Home care supports require further investment and should be needs-assessed, customised, comprising a menu of care choices, as set out in the report from the All-Party Oireachtas Group on Dementia (see attached). Further, it should be supportive of the specific needs of people with dementia instead of consisting of generic packages. Home care assessments should be transparent and delivery of home care should be equitable, irrespective of where people with dementia live.

Home care service providers should offer consistent care to people with dementia. This means there should be minimum change in professional carer and in cases where this happens, it should be discussed with the family carer. Dementia-specific training should be more widely available and undertaken by carers. The delivery of care should be standardised by implementing a minimum standard of quality and national regulations in relation to home care.

Person-centred care that also gives consideration to the needs of the carer is crucial, as acknowledged by one carer:

“We need to make sure the proper supports are there and that they’re person-centred. As a carer your back is against the wall and you have no choice. You try to get the best support you can with your begging bowl. You can push for so long but you run out of energy and you run out of steam”.

Personalised home care can have good outcomes for people with dementia. Initial findings from the delivery of Intensive Home Care Packages under the NDS, indicate they provide a high level of support to people with dementia with complex needs through a personalised and flexible approach that allows them to remain living at home. It also found that they are effective in supporting people with advanced dementia living at home.

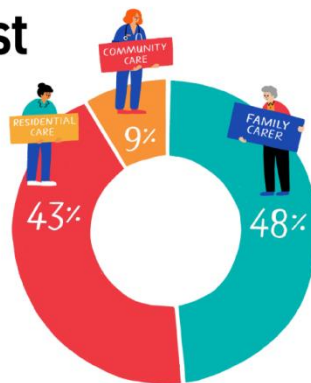
However, the 2017 Slaintecare Report acknowledges that “Under the current health and social care system, people with dementia and their carers face serious barriers in equity of access and outcomes from the point of diagnosis to end of life”. Addressing the above home care concerns and developing an equitable and effective statutory home care scheme can achieve the following:

- Meet the demand for home care, allowing for greater flexibility to appropriately meet need and reverse cuts to home care services;
- Reduce unnecessary hospital admissions and shorten length of hospital stay for people with dementia;
- Avoid unnecessary, inappropriate or premature admission in for long-term residential care;
- Reduce carer stress and support family carers, as carer burn-out is the main reason for entry into long-term care.

During the consultation, former carer Ann Twomey, explained the importance of dementia care at home, *“What we must remember is the terrifying prospect it must be for a person to receive a diagnosis of dementia, to know that one day they may no longer be in charge of their own autonomy. The catastrophic nature of the condition itself is why we, as a community, must support them, their primary carer and family to live with and live well with dementia as they begin or continue their journey.”*

The annual cost of dementia is €1.69 billion

Ref: Cahill, S. O'Shea, E. and Pierce, M. (2012) Creating Excellence in Dementia Care report. Trinity College Dublin/ NUI Galway





All-Party **Oireachtas Group**
on **Dementia**

Report Two

A Statutory Scheme for Home Care

Round Table Event

23rd March 2017

Deputy Mary Butler & Senator Colette Kelleher



Houses of the
Oireachtas
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Background

The All-Party Oireachtas Group on Dementia was formed in 2016 to enhance cross party collaboration on dementia issues, to act as a forum for learning and knowledge sharing and ultimately to help improve the lives of people with dementia through better policies and practices. The group is run in partnership with The Alzheimer Society of Ireland, which acts as secretariat for the group.

There is a wide-spread recognition of the need for a fair and equitable network of home care across Ireland. The All-Party Group therefore welcomed the announcement in January 2017 that Minister of State for Mental Health and Older People, Helen McEntee TD, will be launching a consultation process with a view to establishing a new statutory home care scheme.

The group hosted a round table event on 23rd March 2017 to advance the discussion on how we can develop a scheme for home care that is equitable, well-resourced and well-regulated.

This report sets out the key stakeholders involved in this round table discussion and their vision for home care in Ireland.



Key Points:

- The meeting highlighted the clear need for a scheme that meets the preferences of people to remain at home and the need to move from an ad hoc, piecemeal approach to home care;
- The proposed statutory scheme for home care will be essential in meeting the needs of those who require support to remain living at home. We must take brave steps in designing this scheme, using the lessons learned from the past and other jurisdictions;
- Home care must be adequately regulated with appropriate licensing and standards;
- In relation to potential funding models for home care, options include private insurance, general taxation and social insurance, which has a number of positive aspects such as visibility, reciprocity and clarity.

Speakers:

- Minister of State for Mental Health and Older People, Helen McEntee TD;
- Dr. Rachel A. Kiersey and Dr. Jean Long, Health Research Board (HRB);
- Senator Colm Burke;
- Professor Eamon O'Shea, Irish Centre for Social Gerontology, NUIG;
- Mr. Michael Fitzgerald, Head of Operations and Service Improvement Services for Older People, HSE;
- Mr. Ronan Smith, Irish Dementia Working Group;
- Mr. Pat McLoughlin, The Alzheimer Society of Ireland;
- Dr. Marita O'Brien, Age Action.

Other Contributors:

- Senator John Dolan;
- Deputy Anne Rabbitte;
- Senator Alice-Mary Higgins;
- Representative for Senator Lorraine Clifford-Lee.



*Mr. Pat McLoughlin, Professor Eamon O'Shea and
Mr. Michael Fitzgerald*



Minister Helen McEntee

Overview

- The Department of Health acknowledges that home care support can be a cost-effective alternative to long-term residential care for some older people. In particular, home care is a vital issue for the 55,000 people living with dementia in Ireland and their families.
- The 'Meeting Older People's Preferences for Care' report was launched in 2016 by The Alzheimer Society of Ireland, the Irish Association of Social Workers (IASW), Age Action and University College Dublin. This report found that the current system is focused on delayed discharge, there is a lack of information around services, and geography not need is determining access to care.
- It is stated Government policy to support people to live at home, but at present we are spending nearly four times more on residential care.
- In Ireland we are coming from a residential care model and it is difficult to move beyond that. If we want to increase home care we need to push resources towards community care.
- In relation to potential funding models, options include private insurance, general taxation and social insurance. Cost sharing is happening across all sections of care and if this is used it should be introduced in the context of collective responsibility.
- If we want to live at home successfully we need a menu of community based care to suit individual needs, which includes broader community based services, such as day care and respite care.

- There was political bravery around the introduction of the Fair Deal Scheme and we need to take brave steps to design a system for home care. If we don't act now, we could still be talking about this issue in ten years' time. We need to proceed, using the lessons learned from the past and other jurisdictions.
- The Health Research Board has identified six key principles of home care-standards, consultation, transparency, equity, choice and sustainability.



Senator Colette Kelleher



Senator Colm Burke and Deputy Mary Butler

Aim of Home Care Round Table

Ms. Mary Butler TD, Co-Chair of the All-Party Oireachtas Group on Dementia & Fianna Fáil Spokesperson on Older People

- There is wide-spread recognition of the need for a fair and equitable network of home care across Ireland and today's event is a unique opportunity to bring together key stakeholders to discuss where we are and where we need to go.
- The Department of Health acknowledges that home care support can be a cost-effective alternative to long-term residential care for some older people. In particular, home care is a vital issue for the 55,000 people living with dementia in Ireland and their families. The majority of people with dementia want to live at home and to do this they need access to flexible home care that meets individual needs.
- The aim of this event is to advance the discussion on how we can develop a scheme for home care that is equitable, well-resourced and well-regulated.

Home Care in Ireland - Challenges and Solutions: Learning from Other Places

Minister of State for Mental Health and Older People, Helen McEntee T.D.

- With an ageing population we need access to better data so that we can adequately assess the level of funding required for home care. We all agree that not enough money is being spent on home care at the moment. The current budget for older people is €765 million.
- The Department of Health asked the Health Research Board to examine the provision and regulation of home care in other jurisdictions and the report they have prepared will be very important in determining what a statutory scheme for home care could look like and how it could be regulated.
- The upcoming consultation process will provide an opportunity for everyone, including organisations working directly with older people and the All-Party Oireachtas Group on Dementia, to have their say and we will progress this process as soon as possible.

Dr. Jean Long and Dr. Rachel A. Kiersey, Health Research Board (HRB)

- The HRB examined the provision of home care in four jurisdictions- Germany, the Netherlands, Sweden and Scotland. All four jurisdictions have a governance framework, with a national overarching policy, legislation and regulation.
- Germany and the Netherlands have long established long-term care insurance schemes and there is an increasing reliance on co-payments (particularly in Germany) to fulfil all home care service needs. Scotland and Sweden have their own country-specific universal home care schemes, with an increasing reliance on co-payments (usually fixed or capped) to fulfil all home care service needs.
- All four jurisdictions have a defined needs assessment and include home help services in their basket of services. This research has identified six principles of home care- standards, consultation, transparency, equity, choice and sustainability.

Homecare Entitlement and Regulation

Senator Colm Burke

- The number of people retiring will increase dramatically in coming years and home care will become even more important so we need to deal with this issue

now. At present, there is nothing to prevent a person with a criminal record becoming a home care provider and Senator Burke brought forward a Bill in the Seanad to address current gaps in the regulation of home care.

- Another issue we need to address is the provision of home care in rural areas. In some areas there aren't enough home care workers to meet the level of need. It will not be possible for the State to meet all of the costs associated with home care and we need to work on educating the public on that.

Planning and Paying for Homecare

Professor Eamon O'Shea, NUIG

- As the number of older people in Ireland has increased, spending on this group per capita has decreased and we need to recover this spending. In 2009 it was €3,514 and by 2015 spending had reduced to €2,612 per capita.
- Although stated policy is a community support model for older people, we are coming from a residential care model and it is difficult to move beyond that. If we want to increase home care we need to push resources towards community care and support. People want certainty, if there is no statutory scheme for home care they will be drawn to the Fair Deal scheme.
- An important question to consider is what is a family's responsibility with regard to the care of an older loved one? What do we want and expect families to do? Older people often don't want as much as people think. They want good information, choice, individualisation of care and timely, integrated care.
- Care requirements should determine funding, not the other way around. We need to implement and accelerate the use of the Single Assessment Tool. Need should be seen as the determining factor for care, not geography or funding.
- In relation to potential funding models, options include private insurance, general taxation and social insurance, which has a number of positive aspects such as visibility, reciprocity and clarity. Cost sharing is happening across all sections of care and if this is used it should be introduced in the context of collective responsibility and framed as being about shared values.
- At present we are spending nearly four times more on residential care as community care and this will require additional funding. It is not possible to do what we need to do without more funding. The question is how we can get more funding into the system.

Home Care – Current Provision

Mr. Michael Fitzgerald, HSE

- A lot of money is invested in residential care services. The amount spent on the Fair Deal Scheme is approximately €1 billion and this benefits 23,000 people. In comparison, approximately €370 million is spent on home care, with 49,000 people receiving home help and 16,700 people receiving home care packages.
- Residential care has a huge value for people. The difficulty is that residential care is more visible so if you close a hospital or residential bed people may object, but if you lose 1,000 hours of home care from a budget people may not realise.
- If we want to live at home successfully we need a menu of community based care and support to suit individual needs, which includes broader community based services, such as day care and respite care.
- We must take this opportunity to address home care, using learning from the Fair Deal Scheme and dealing with issues around equity, choice and how people can contribute towards the cost of care. The issue of co-payment will be the most difficult political element and we don't want a scheme that requires the HSE to collect money directly from people.
- The assessment used for home care will be important and the Single Assessment Tool will highlight areas where we are not meeting peoples' needs.
- We need to be careful about how we approach regulation. We need licensing and standards, but we will lose services if we go too far with regulation. We also need to be careful about what we include and exclude in the scheme, for example the need to include services and supports for those under the age of 65.

Meeting Peoples Needs

Mr. Ronan Smith, Irish Dementia Working Group

- We must take as much action out of today's event as possible. There is a possibility that we could become paralysed by the scale of work to be done on home care. Action must be taken, even if it is experimental and involves risks.
- Carer burnout is crisis driven and home care packages can bring relief to carers and postpone the need for long-term care. What is needed is action, even if it

appears daunting. People with dementia and carers need politicians to be brave.

Mr. Pat McLoughlin, The Alzheimer Society of Ireland

- 48% of the costs associated with dementia are borne by family carers and research shows that carers' own cognitive ability can decline due to stress.
- The Single Assessment Tool needs to be flexible to meet the specific needs of people with dementia and the Understand Together campaign and HSE mapping project will result in more emerging needs.
- It is important not to overregulate this area and to ensure there is ring-fenced funding for home care.

Dr. Marita O'Brien, Age Action

- The 'Meeting Older People's Preferences for Care' report was launched in 2016 by The Alzheimer Society of Ireland, the Irish Association of Social Workers (IASW), Age Action and University College Dublin. This report found that the current system is focused on delayed discharge, there is a lack of information around services, and geography not need is determining access to care.
- The report recommends that ring-fenced budgets be introduced in each CHO area, that a fair and equitable way of administering care is introduced and that funds are matched to socio-demographic needs and health disparities.
- We need a new definition of home care, which currently focuses on personal care and takes a deficit approach, rather than a strengths-based approach which encourages independence.

Summary

Senator Colette Kelleher, Co-Chair of the All-Party Oireachtas Group on Dementia

- We need a system for home care which is rooted in legislation, is regulated and deals with the issues of financing, entitlement and reflects people's preferences. There was political bravery around the introduction of the Fair Deal Scheme and we now need to take brave steps to design a system for home care. If we don't act now, we could still be talking about this issue in ten years' time. We need to proceed, using the lessons learned from the past and other jurisdictions.

Final Comments

- *Pat McLoughlin*: links with the Irish Dementia Working Group and Dementia Carers Campaign Network can ensure the new scheme is grounded in the real needs of people with dementia and their families. Informal family care has been taken for granted, but this can't continue. There must be dedicated resources for home care.
- *Michael Fitzgerald*: the most immediate need is a commitment to increasing resources for home care year on year by €30 – €40 million.
- *Minister McEntee*: a key priority for this year is the need for additional funding for home care. The consultation process will take around eight weeks.
- *Senator Dolan*: when talking about home care, it is important to talk about choice, empowerment and autonomy.
- *Senator Burke*: we need to establish a proper structure for home care or there is a risk someone will seek to enforce their constitutional rights before the Courts.

Conclusion

A scheme for home care is required to meet the demands of a growing older population and the needs of people with dementia and other conditions, and to make good on Government policy to support people's preferences to remain living at home. We need a well-designed system that will allow us to move on from the current bias towards residential care as the only form of certainty and from the current ad hoc system of home care, which is subject to the vagaries of funding.

A consensus emerged at this round table event that we require an infrastructure for home care, similar to the jurisdictions cited in the Health Research Board report (Germany, the Netherlands, Sweden and Scotland). This system must involve putting home care on a legislative basis and statutory footing, including an entitlement to home care; regulation of home care to ensure quality standards and safety; and an agreement on funding which is likely to include co-payment from social insurance or other funding models.

Next Steps

- This report will be circulated and presented to the relevant Ministers and to all party leaders;

- The All-Party Oireachtas Group on Dementia will prepare a submission for the upcoming consultation process on a statutory scheme for home care, following consultation with The Alzheimer Society of Ireland and other civil society organisations;
- Members of the All-Party Oireachtas Group on Dementia will continue to highlight the importance of a statutory scheme for home care and to campaign for increased investment in home care.