

The Home Care Coalition: Experiences from the Grassroots

22 CHARITIES, NOT-FOR-PROFIT ORGANISATIONS AND
CAMPAIGNERS WORKING TOWARDS HOME CARE 2021

Age Action

Age and
Opportunity

ALONE

Acquired Brain
Injury Ireland

Care Alliance Ireland

Cheshire Ireland

Disability Federation
of Ireland

Family Carers Ireland

Irish Association of
Social Workers

Irish Heart
Foundation

Irish Hospice
Foundation

Irish Motor Neuron
Disease Association

Irish Wheelchair
Association

Migrants Rights
Centre Ireland

MS Ireland

National Women's
Council of Ireland

Neurological Alliance
of Ireland

Northside Home Care
Services

SAGE Advocacy

The Alzheimer Society
of Ireland

Third Age Ireland

The Home Care Coalition: experiences from the grassroots

The Home Care Coalition is a group of 22 charities, not-for-profit organisations and campaigners, established with the aim of ensuring the implementation of an adequately resourced, person-centred statutory home care scheme with equality of access and availability across the country.

From our work on the ground, the Coalition sees the monumental challenges being faced by older people and people with disabilities in accessing the essential home care they require, as well as the difficulties being faced by those employed as home care workers and unpaid family carers. Although it has been reiterated on multiple occasions that there has been no 'freeze' of home care in any area, this has not been our experience, nor is it what we have been hearing from our client bases. At best, home care services are being maintained at the previous year's level, and at worst they are being frozen to the extent that those assessed as needing home support cannot access help. We know that widely, those assessed as needing home care are being placed on waiting lists, without knowing when to expect a service.

Recent media reports have confirmed what we have seen through our work that access to home care packages is limited, that waiting lists and times are continuing to lengthen, and that discharge from hospital is the primary means of access to home care, to the detriment of those living at home. Other issues with the current home care system include, but are not limited to, the under-resourcing of home care workers, insufficient standards and quality systems, insufficient training for staff, an exclusively task-centred approach to home care, inadequate safeguarding and monitoring, and inconsistencies across CHO areas in terms of prioritisation, access and assessment processes, reporting, and waiting list management.

The Home Care Coalition also note that the shortfall in home care provision is resulting in delayed discharges from hospital settings and are impacting on waiting times in Accident and Emergency departments, despite priority being given to applications from acute hospitals to facilitate discharges. In one large urban hospital, 14 patients who no longer require acute hospital care continue to await funding for packages to support their discharge home. The same hospital continues to experience long delays in their Emergency Department due to lack of available beds onwards. This pattern is replicated nationally. Acute hospital requirements are growing (see Appendix 1) and this is resulting in both an increase in wait times for community applications and delays in discharge for patients no longer requiring acute hospital care.

The Coalition believes that the current situation is unacceptable and unsustainable for the thousands of people being affected by these issues. While the Coalition is aware of and is working to support the Department of Health in the development of a statutory scheme to be introduced in 2021, people cannot wait until 2021 to receive the care they need. The Coalition aims to raise awareness and to drive sustained public discourse in order to compel policy makers to ensure that increased home care provision is delivered to keep pace with increased demographic pressures and to ensure that everyone can receive the high-quality care they need.

It is vital that funding for home care packages is made available in the community and to support discharge and enablement services. **An investment of €110 million is required in Budget 2020 to meet demand for home care.** With this document we hope to amplify the voices of those people whose lives are currently being affected by the scheme and to urge that action is taken.

The Home Care Coalition's experiences of the Home Support Service

Members of the Home Care Coalition range from NGOs working with older people and people with disabilities and long-term illnesses, to organisations working directly with carers, to groups working in the primary care sector. As a result, we have an insight of how the current situation with home care is impacting on recipients of Home Support services, their families, home care workers and on a broader level, the primary healthcare system. Due to budget restraints, the Home Care Coalition understand that restrictions have been implemented on the Home Support Service across CHO areas, including:

- CHO 4 has been told there is no funding for new packages until the end of November. Difficulties accessing home care packages were not evident in this CHO area until recently.
- CHO 1 are not allowed to recycle packages.
- CHO 9 is under pressure with only very urgent cases being allocated home care.
- CHO 8 are not taking on new clients, only palliative care and people with paraplegia. In CHO 8 it is also noted that the home support service is not covering annual leave of home support workers which it had previously done, resulting in short notice period to the client and requirement for client to pay privately for care to cover annual leave.

Older people and people with disabilities are experiencing extreme difficulties in accessing home care, and where packages are provided, often do not receive consistent, high-quality care of the nature they require. Our experiences show:

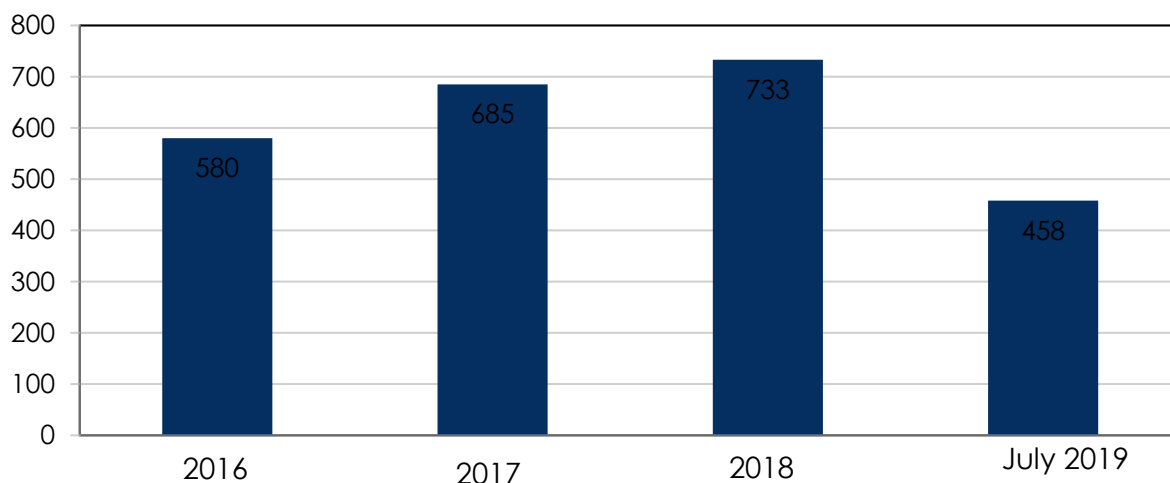
- There is inequality and inconsistency of provision and availability of home care packages across geographical areas. Funding difficulties in some areas have resulted in home care becoming more of a 'postcode lottery' than ever before. This is supported by the recent ESRI report that points to geographical imbalances in the provision of primary health and social services. It is now almost impossible in many areas to be granted a home care package unless the person is being discharged from hospital, and even then there are often significant delays. There is a lack of transparency and consistency regarding assessment of a person's needs and eligibility for home support across CHO areas.
- The lack of legal clarity regarding the State's obligation to provide care to our older and disabled population mean that families are increasingly filling the deficits in care provision. Ireland's 375,000 family carers are the largest providers of care, with 80 percent of care required by older people and those with care needs provided by family members.
- The lack of qualified home care workers is impacting on the provision of home support services, and despite the reported lack of workers for the sector there is no indication of a plan to increase the workforce. In spite of this shortage, a recent review by the Department of Business, Enterprise, and Innovation has not recommended the changing of VISA requirements for non-EU applicants, despite receiving evidenced recommendations from members of this Coalition in 2018. Availability of care workers is particularly insufficient in remote areas, due to many agencies not being funded to pay mileage. The current system for funding Home Care Packages in Ireland disadvantages care workers employed by non-HSE agencies many of whom continue to work off If-and-When contracts, work unsociable hours and are not reimbursed for all travel costs as the HSE do not afford these payments to non-HSE workers.

- Extensive waiting lists result in the length of time from applying for a homecare package to the carer actually started being too long, particularly where a person is in urgent need. Where packages are approved and put in place, inadequate hours are being provided, particularly for people with complex needs and progressing diseases. This often results in the need for families to provide additional care or for the person to fund additional care themselves, at their own expense.
- The availability of a family carer is unfairly taken into account when allocating home care hours. 'Rationing' of home care hours often takes place in these cases; the question of whether someone in the family receives Carer's Allowance is prominent on most home care assessment forms and PHNs admit that the presence of a family carer is a significant factor in deciding whether someone is considered a priority for home care or how many hours they should be allocated. However, their presence should only be taken into account if and when the carers own support needs have also been assessed through a Care Needs Assessment. Many carers regard services as inadequate to meet their needs.
- Limited supports available within the Home Support Service, and limitations to provision of personal care, prevent a person who has minimal or moderate needs to remain at home. Support with medication management/prompting, food preparation and some supervision if provided would enable people with minimal or moderate needs to remain living in their own homes. A lack of supported housing options for older people results in people having to move to nursing homes despite the fact that their needs could be met at home if appropriate supports were in place.
- Home care staff may not always be adequately trained or qualified, particularly in relation to dementia care. The quality of the service provided varies hugely. Care workers are under time pressure to perform the list of tasks required and move on to their next client, rather than responding directly to the person's needs on that day. The task-led approach to home care not only means that there is a risk of issues falling through the cracks and not being addressed, but it can also be inappropriate for those living with dementia.
- Informal and family carers are concerned that if they raise questions about the quality of care or complain about concerns such as inadequate hygiene, the level of care provided to their family member may be reduced. Different approaches to home care between companies can lead to challenges in relation to dementia care.
- Family carers and people with dementia who are reliant on a medical card expressed concern about the financial implication of home care. Some have reported not being able to receive home care because they do not hold a medical card.
- There is insufficient funding for respite care, including Nurses for Night care which enables people to die at home and provides family carers/friends with respite when providing end of life care to a loved one at home. The Palliative Care Three Year Development Framework committed to funding 50% of the service by the end of this year and so far, they have only provided 8% funding.
- It is noted that women undertake the majority of unpaid care work and women depend on social infrastructure and public services to support their disproportionate care responsibilities. In Ireland, women and their families are increasingly reliant on private homecare services as they seek to balance caring and work. Lack of investment in public

services and infrastructure will inevitably keep, or transfer back, care needs to the unpaid, undervalued and often invisible labour of women.

Appendix: 1

HCP Applications from 1 Large Urban Hospital, July 2019.



Appendix: 2

Experiences of people using Home Support Services

Irish Motor Neuron Disease Association

- We have a lady registered the IMNDA who has been in University College Hospital Galway (UCHG) for 16 weeks, although she has been deemed medically fit for discharge, because her multidisciplinary team have determined that clinically she should not go home until there is an adequate home care package in place that reflects the decline in her condition. The lady has a life-limiting, progressive illness.

She is in receipt of a 10-hour package but her team feel she requires 4 more hours and will not discharge her until these hours are put in place. Her assessment indicated she was no longer deemed a “fall hazard” because she is now wheelchair bound and thus requires fewer hours of care. While it was agreed that her package would not be reduced, this is not sufficient to allow this lady to be able to safely return home and so she remains in limbo in the hospital.

Not only is this unnecessary prolonged stay in the hospital extremely stressful and upsetting for the lady in question and her family as she has an extremely life-limiting illness, but it is also a huge waste of taxpayers’ money as the cost of keeping this lady in hospital far exceeds the cost of the requested four additional hours per week it would take to allow her to return to her home.

Family Carers Ireland

- Family Carers Ireland has worked with a 94-year-old woman who lives alone in a rural area. She has applied for home care hours to help her get up in the morning and get to bed at night, but her family have been told that home care is currently frozen and there will be no new applications processed. The lady has fallen on a number of occasions and is now unable to be left alone. She refuses to leave her home or go into nursing home.
- We also worked with a 47-year-old man with MS. He currently receives 5 hours of home care each week, but his condition has deteriorated rapidly and he and his wife have been approved for an additional 10 hours per week. Despite being approved over a year ago, the family have yet to receive the additional 10 hours.

MS Ireland

- At MS Ireland we have worked with 45-year-old man with MS and diagnosis of cancer, for which treatment is failing. His wife is his primary carer and they have an adult daughter who is working in Dublin but travels home by train for weekends to spend time with the family, especially at this critical time. The family live approximately one hour from the train station. The husband has applied to the HSE for an extra two hours home care to facilitate this journey as his wife will have to be absent from the home for the two hours to collect their daughter, leaving him alone. His application has not been refused outright but has been delayed, and the information they are receiving is that it is a funding issue. The man is dependent on assistance for all activities of daily living, has continence issues and acute spasticity relating to his MS and is unable to mobilise even with assistance. Coupled with this are the side-effects of his cancer treatment and a prognosis which is uncertain, but not very optimistic. He has a small allocation of hours from the HSE through a local provider, but the additional hours are not forthcoming. This is causing great distress to the family given the uncertain cancer prognosis and the effects of living with MS and other co-morbidities. Their experience is that of a service that is the least person-centred service imaginable. They continue on a waiting list and are fraught with the constant battle when they need to focus on other aspects of living.

ALONE

- At ALONE we have worked with a man who spent six months between three hospitals following a bad fall he had in his home. He was ready to be discharged after four months, but due to delays in accessing home care he remained in hospital for two months longer than he needed to.
- We are working with a woman in her 80s who is a carer for her 60-year-old daughter, who has MS. The woman has had several strokes and had a home care package until she moved in to provide support to her daughter, whose condition has worsened in recent years. Now that she has undertaken a caring role and is in receipt of Carers Allowance, she cannot access home care herself.

- We are also working with a woman in her 70s who remained in hospital for months because she needed an additional half an hour of home care per day and could not be discharged without it. She describes her experience as being told she “had to wait in line and wait for her turn to come”.

**Details have been changed to protect anonymity*

Experiences of family carers and professional carers

Alzheimer’s Society of Ireland

- ASI are aware of numerous cases where persons with dementia cannot leave long-term care, and return home, as is their preferred choice, because they cannot secure home care support. This is a source of immense distress for people with dementia.
- Family carers report experiencing immense strain and burn-out. This can lead to greater risk of neglect among vulnerable adults with dementia. One carer explained she was reluctant to ask the HSE for a review of her elderly mother’s care needs as she feared 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, and there is no clear logic to allocating home care.
- Family carers express concern that short blocks of care for 15/30 minutes are inappropriate for a person with dementia, and lead to stress, confusion and frustration on the part of the person with dementia.

Family Carers Ireland

- We have worked with the family of an elderly lady who were advised not to bother applying for home care as they simply won’t get it due to the waiting list.
- Another case we have seen is that of a 66-year-old lady who cares for her husband. He has recently been admitted to hospital and is awaiting discharge. She has applied for a Home Care Package but was told that because she receives Carers Allowance, she will either have to give up the payment or forego the Home Care Package.

ALONE

- At ALONE we worked with a woman who experienced a long delay in discharge due to waiting for an increase in her home care package, which hasn’t come. They gave up on waiting for the additional package in hospital, and her son took her home. He has already had to reduce his hours of work to care for his mother and he is concerned about what will happen when he has to go back to work*.

**Details have been changed to protect anonymity*