

## **Home Care and Personal Assistance Services – Briefing Document and Position Paper**

### **Introduction**

As MS is a progressive condition, some people with MS may eventually require support and assistance with tasks of daily living such as washing, dressing, eating, carrying out domestic tasks and continuing to participate fully in their community of choice.

The Government provides various public health services to people who need care and assistance to live in the community, including Home Helps, Personal Assistants, Public Health Nurses, physiotherapy, occupational therapy, chiropody, day care and respite care.

The focus of this paper is on services that provide personal care and supports with independent living to people with MS or all ages, specifically the Home Help scheme, Home Care Packages and Personal Assistants. Therapeutic supports such as physiotherapy and occupational therapy and respite and day care services are outside the scope of this paper.

### **Background**

#### **Home care services**

The Health Service Executive (HSE) provides home care services through two different funding streams – the Home Help scheme and the Home Care Package scheme.

- **The Home Help scheme** – The Home Help service supports the assessed needs of vulnerable people in the community who through illness or disability are in need of help with day to day tasks. Home Help services are provided in order to assist people to remain in their own home and to avoid going in to long-term care. In practice, the HSE either provides the Home Help service directly or makes arrangements with voluntary organisations to provide them. The service is generally free to Medical Card holders. Other people may be asked to make a contribution to the cost of the service. In some cases, even Medical Card holders may be expected to make a contribution.

The Home Help is expected to provide a set number of hours' assistance each day or each week. The precise arrangements can usually be agreed between the person receiving the help and the HSE. The focus of the Home Help service is on 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). Home Helps are not expected to provide nursing or medical care.

The particular supports provided to each person will depend on the needs that are identified during the assessment which is undertaken by an HSE health professional, generally a Public

Health Nurse. The level of service provided to each person will also depend on available resources. With the exception of people with Hepatitis C, there is no statutory right to receive a Home Help service<sup>1</sup>.

- **Home Care Packages** - The Home Care Package (HCP) scheme is an administrative scheme, operated by the HSE. It includes extra services and supports that are over and above the normal public health services that the HSE provides directly or through an HSE funded service. It aims to help people who need medium to high caring support to continue to live at home independently. The scheme is not means tested, and there is no charge or contribution to be paid for the services provided. The Home Care Package scheme is not established in law; as it is an administrative scheme, there is no automatic right to the scheme, or to avail of services under the scheme. Home Care Packages are tailored to individual needs and may include the services of Home Helps as well as nursing care and various therapies including physiotherapy and occupational therapy<sup>2</sup>.

The main priority of the HCP scheme is older people (aged 65+) living in the community or who are in-patients in acute hospitals and at risk of admission to long-term care. Current guidance on the HCP scheme states that “if a younger person’s assessed needs can be best met by services designed for older people then occasionally such an application may be considered”<sup>3</sup>.

The HSE has advised that their total allocation for home care services in 2016 is €324 million<sup>4</sup>.

The Home Help service and Home Care Packages can be applied for via Local Health Offices. Assessments of need are carried out to determine what services will be provided and in the case of the Home Help scheme, what contribution, if any, the person would need to make to the cost.

Some people with disabilities are now also able to access home care services via a Direct Payment system. A Direct Payment is a cash payment made directly to an eligible person to enable them to purchase and manage their own care and support services<sup>5</sup>. The AT Network is an organisation founded by people with disabilities which provides support with accessing and managing a Direct Payment. Further information is available on their website [www.theatnetwork.com](http://www.theatnetwork.com)

## Personal Assistants

A Personal Assistant is an individual contracted by a disabled person to provide them with support in different aspects of daily life – this may include personal care and household tasks, but unlike Home Care Packages and Home Helps, the scope is much broader than this. Personal Assistants may also

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<sup>1</sup> [www.citizensinformation.ie/en/health/health\\_services/care\\_in\\_your\\_community/home\\_helps.html](http://www.citizensinformation.ie/en/health/health_services/care_in_your_community/home_helps.html)

<sup>2</sup> [www.citizensinformation.ie/en/health/health\\_services/health\\_services\\_for\\_older\\_people/home\\_care\\_packages\\_for\\_carers.html](http://www.citizensinformation.ie/en/health/health_services/health_services_for_older_people/home_care_packages_for_carers.html)

<sup>3</sup> [www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/HCPinfobooklet.pdf](http://www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/HCPinfobooklet.pdf)

<sup>4</sup> Care Alliance Ireland, 2016, p. 1

<sup>5</sup> [www.theatnetwork.com/wp-content/uploads/2014/05/Government-and-HSE-Policy-Update-for-Website.pdf](http://www.theatnetwork.com/wp-content/uploads/2014/05/Government-and-HSE-Policy-Update-for-Website.pdf)

provide assistance at school, university or the workplace, support with transport, interpretation and so on. These tasks are customised to the individual needs of the disabled person<sup>6</sup>.

There are three options open to someone who wishes to have a Personal Assistant:

1. Personal Assistants can be applied for via Local Health Offices. This service is funded by the HSE and may be provided by a voluntary sector organisation such as the Irish Wheelchair Association or it may be provided by some other organisation that the HSE chooses.

The application process for a Personal Assistant is different in each area and also depends on who will ultimately fund the service.

2. Prospective students planning to attend college or university can apply for a Personal Assistant who will assist them to access and participate in their chosen course. This service is funded by the Department of Education and applications should be made to the Disability Access Officer in the College or University that the course is to be delivered in.
3. Personal Assistant services can be purchased privately from voluntary sector organisations such as the Irish Wheelchair Association or from private companies<sup>7</sup>. Significant tax relief is available for those who purchase PA services privately. This can be applied for by sending an HK1 form to your local Tax Office<sup>8</sup>.

Research by the Disability Federation of Ireland suggests that funding for Personal Assistance services has become more limited in scope in recent years, with the emphasis shifting to providing for basic personal care needs, such as dressing and toileting, with less attention to supports for independent living<sup>9</sup>.

### **Nursing Home Support Scheme (Fair Deal)**

Under the Nursing Home Support Scheme (Fair Deal), the HSE provides financial support to people who need long-term nursing home care. The Fair Deal scheme affords a statutory right to residential care, unlike Home Care services which are not guaranteed by a statutory right<sup>10</sup>.

In 2015, the Government allocated nearly €900 million to the Fair Deal scheme, compared to the combined Home Care budget of €325 million<sup>11</sup>.

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<sup>6</sup> [www.enil.eu/wp-content/uploads/2014/05/FAQ\\_Personal\\_Assistance.pdf](http://www.enil.eu/wp-content/uploads/2014/05/FAQ_Personal_Assistance.pdf)

<sup>7</sup> [www.iwa.ie/component/zoo/item/how-do-i-get-a-personal-assistant](http://www.iwa.ie/component/zoo/item/how-do-i-get-a-personal-assistant)

<sup>8</sup>

[http://www.citizensinformation.ie/en/money\\_and\\_tax/tax/tax\\_credits\\_and\\_reliefs\\_for\\_people\\_with\\_disabilities/tax\\_relief\\_for\\_employing\\_a\\_home\\_carer.html](http://www.citizensinformation.ie/en/money_and_tax/tax/tax_credits_and_reliefs_for_people_with_disabilities/tax_relief_for_employing_a_home_carer.html)

<sup>9</sup> [www.disability-federation.ie/index.php?uniqueID=10810](http://www.disability-federation.ie/index.php?uniqueID=10810)

<sup>10</sup> [www.carealliance.ie/userfiles/file/Care%20Alliance%20Ireland%20Pre-Budget%20Statement%20-%20Budget%202017.pdf](http://www.carealliance.ie/userfiles/file/Care%20Alliance%20Ireland%20Pre-Budget%20Statement%20-%20Budget%202017.pdf)

<sup>11</sup> [www.hcci.ie/2015-05.html](http://www.hcci.ie/2015-05.html)

## **MS Ireland's position on Home Care and Personal Assistance services**

MS Ireland has a vision of Irish society where all people affected by MS live positive and active lives in their community of choice. Currently, many people with MS are denied this as they cannot access the supports they need to remain living in their own homes and to continue to actively participate in and enjoy community life.

MS Ireland is aware from people affected by MS who contact our Regional Community Workers and Information Line that many people have to wait considerable lengths of time to access Home Helps, Home Care Packages and Personal Assistants. In some cases, this may result in someone remaining in an acute hospital setting for many months because they cannot access the supports they need to return home. MS Ireland is also aware of many people with MS under the age of 65 who are availing of long-term nursing home care because the supports they need to continue living in their own homes are not available or are inadequately resourced.

MS Ireland also observes that currently home care services are costed and resourced primarily with older people over the age of 65 in mind. As noted above, the Home Care Package scheme is only intended to be used for younger people "occasionally". There are also huge regional variations in how home care services and Personal Assistants services are assessed and accessed<sup>12</sup>.

Whilst the Fair Deal scheme is undoubtedly a valuable initiative, MS Ireland also notes the considerable weighting of funding in favour of nursing home care and the fact that this scheme establishes a statutory right, unlike home care and community supports which are not guaranteed in law. This means that people may be forced into accepting long-term residential care because this is where the resources are targeted.

MS Ireland calls on the Government to do the following:

- Increase spending on Home Care Packages, Home Helps and Personal Assistance services.
- Establish access to supports with care and independent living as a statutory right.
- Properly assess, map and cost the support needs of younger people under the age of 65 who are living with a long term illness or disability, so that a robust plan for resourcing these services into the future can be developed.
- Develop a standardized assessment tool for accessing home care and Personal Assistant services and a protocol for prioritization of resources so as to address the regional discrepancies that currently exist.
- Establish an equivalent to the Fair Deal scheme with ring-fenced funding which guarantees access to age and need appropriate community-based care, and publish a plan with timescales for this. Funding for this scheme could be managed in a similar way to Fair Deal, i.e. by drawing upon assets that the individual has access to including property<sup>13</sup>. As well as

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<sup>12</sup> Donnelly et al, 2016, p. 11

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[http://www.citizensinformation.ie/en/health/health\\_services/health\\_services\\_for\\_older\\_people/nursing\\_homes\\_support\\_scheme\\_1.htm](http://www.citizensinformation.ie/en/health/health_services/health_services_for_older_people/nursing_homes_support_scheme_1.htm)

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home care and Personal Assistants, examples of supports that people with MS might access through such a scheme include aids and appliances (including telecare and telehealth, environmental controls and mobile communication), home adaptations, respite care, and therapeutic supports such as physiotherapy and occupational therapy.

## **References**

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Donnelly, S., O'Brien, M., Begley, E. and Brennan, J. 2016. *Meeting older people's preference for care: policy but what about practice*. Dublin: Age Action, Alzheimer's Society of Ireland, Irish Association of Social Workers & UCD.

Information for this paper has been taken from the following websites:

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[www.citizensinformation.ie/en/health/health\\_services/health\\_services\\_for\\_older\\_people/home\\_care\\_packages\\_for\\_carers.html](http://www.citizensinformation.ie/en/health/health_services/health_services_for_older_people/home_care_packages_for_carers.html)

[www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/HCPinfobooklet.pdf](http://www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/HCPinfobooklet.pdf)

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[www.hcci.ie/2015-05.html](http://www.hcci.ie/2015-05.html)

[www.enil.eu/wp-content/uploads/2014/05/FAQ\\_Personal\\_Assistance.pdf](http://www.enil.eu/wp-content/uploads/2014/05/FAQ_Personal_Assistance.pdf)

[www.iwa.ie/component/zoo/item/how-do-i-get-a-personal-assistant](http://www.iwa.ie/component/zoo/item/how-do-i-get-a-personal-assistant)

[www.carealliance.ie/userfiles/file/Care%20Alliance%20Ireland%20Pre-Budget%20Statement%20-%20Budget%202017.pdf](http://www.carealliance.ie/userfiles/file/Care%20Alliance%20Ireland%20Pre-Budget%20Statement%20-%20Budget%202017.pdf)

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