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Support & Advocacy Service

# The Nursing Home Support Scheme: Charges and Related Issues

**A Discussion Paper**

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# The Nursing Home Support Scheme: Charges and Related Issues A Sage Discussion Paper

## Nursing Home Charges: Main Issues Identified

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- Nursing home residents regularly incur additional charges not covered by the fees agreed between the nursing home and the NTPF, e.g., social programmes. This practice gives rise to the following concerns:
  - People have to pay these additional charges out of their own (sometimes very meagre) resources;
  - There is a lack of clarity among residents and their families as to what the additional charges cover;
  - There is little or no independent monitoring of how additional charges are applied;
  - Residents may be charged for services/activities whether or not they want or use them
  - There is little or no accessible information for individuals and families on, for example, their right to appeal or how to reduce a charge
- The 'one-size fits all' approach to pricing and charging, inadequate access to therapies, supports and mobility equipment and the difficulty low-income families have in meeting the additional costs associated with nursing home care out of their own resources raises major public interest questions.
- The fact that the care package provided for in the NTPF negotiated fee is frequently not adequate to meet the actual care needs of individuals is a matter of grave concern.
- The current charging system is not a 'Fair Deal' for those on low incomes, especially those who have only an Old Age Pension as income. How can people in this situation be reasonably expected to pay additional charges, pay the costs of therapies and cover the costs of, for example, a specialised chair?
- The exclusion from the NHSS package (as negotiated and agreed with nursing homes by the NTPF) of therapies, specialised seating, aids and equipment impacts in a significant way on many nursing home residents both in terms of their care and the impact on their finances.
- While there is provision for a multi-disciplinary approach to needs assessment for nursing home residents, this does not translate into the contracts for care or the related pricing structure. This must be regarded as a major deficit of the current system in that it effectively undermines the person-centred approach.

- The system of pricing operated by the NTPF does not fit well with an individually-tailored model of care -- the NTPF model thus also runs contrary to the 'money follows the person' principle frequently articulated in policy documents.<sup>1</sup>
- Once a person is in a private nursing home, there is little or no access to primary care professionals, including physiotherapy, occupational therapy, social work and essential equipment. This is contrary to national policy which promotes equal access to primary care services regardless of place of residence and falls far short of the level of care generally aspired to by society.
- The pricing system makes no provision for basic personal care needs such as incontinence wear – it is reasonable to suggest that this would be universally acknowledged as a fundamental denial of human dignity.
- Even without any additional costs, a person in receipt of financial support under the NHSS whose only income is the State Non-contributory Pension retains about €44.40 per week for people under 80 and €46.40 for those aged over 80. When additional charges, which nursing homes are allowed to levy on residents, are factored in, this leaves people with a very low figure to cover clothing, personal care items, books, newspapers, hairdressing, family gifts, etc. Lack of disposable income greatly curtails participation in social life and leads to the all too familiar scenarios of institutionalisation, dependency and isolation.
- There is a need for further analysis and debate around the fact that public nursing homes are much more expensive in comparison to the private sector – this is critical in the context of ensuring both value for money and high quality care.
- A core question that must be addressed urgently is how to achieve a better fit between (a) the quality of care to be delivered as stipulated by HIQA and as required by best practice standards; (b) the physical infrastructure of nursing homes and the staff skill sets required in order to deliver that quality of care; and (c) the current NTPF funding model, both in terms of the level of fees negotiated and the care to be provided.
- Since pricing contracts are entirely a matter for agreement between the NTPF and the nursing home in question and neither the Department of Health nor the HSE can influence the process, a crucial question arises as to who is responsible for monitoring the link between nursing home charges and the quality of life of residents and the role of additional charges/'top-up' fees levied.
- Given the number and type of issues outlined in this Discussion Paper relating to the role of the NTPF, and given its unique role and status, there is a strong prima facie case for the NTPF to appear before the Oireachtas Public Accounts Committee.

## Introduction

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There is an urgent need for more debate around nursing home fees and charges as these apply to people who avail of the Nursing Home Support Scheme (NHSS), the so called 'Fair Deal'. This issue needs to be looked at afresh in the context of both current provisions for long-term care and support generally and the way the NHSS charging system operates. It should be noted at the outset that the voice of users and potential users of the NHSS has to date been largely unheard and policy and related funding structures are planned without any input from users.

## Context

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As is widely acknowledged, current law and government policy clearly favour care in nursing homes over care provided in people's own homes. There is a clear legal entitlement to nursing home care under the NHSS whereby the cost is co-funded by the State and the individual. However, there is no such provision for people (the majority) who wish to be cared for in their own homes or in another community-based setting. It is reasonable, based on research and anecdotal evidence, to form the view that many dependent older people who are 'put into' long-term nursing home care do not wish it and have not given their full consent.<sup>2</sup> The reality of the nursing home option is that, in many instances, it is the only response available currently in the absence of community and home based care and support commensurate with dealing with chronic age-related disease and disability – dementia, Parkinson's, loss of function as a result of stroke or chronic arthritis. It is also the case that the care and support needs of people who have to go into nursing homes are frequently complex.<sup>1</sup>

Nursing home care in Ireland is provided through a mix of public, voluntary and private provision. There is an estimated 29,600 residential care beds operational in Ireland at present. The breakdown is private (76%) and public (24%). These beds are a mix of long stay and short stay beds. Some 1,866 out of 7,180 public beds (26%) are short-stay, while the number of short stay beds in the private sector is approximately 1,800. The net budget for long-term residential care in 2016 is €40m and the Nursing Home Support Scheme (NHSS) will support 23,450 people (on average per week) - an increase of 649 per week on 2015 numbers. With regard to private facilities, it was announced in Budget 2016 that nursing home expansion works would henceforth be included in the Employment and Investment Incentive Scheme.

A marked shift has occurred in recent years towards the private sector, and to a much lesser extent the voluntary sector, in the provision of nursing home care, with a correspondingly smaller proportion in public (state provided) nursing homes. For example, in 2008, public provision accounted for 29% of long-stay beds while in 2013, 66.8% of all beds were provided by the private sector, 10% by the voluntary sector, and only 23.1% by the public sector. Most places are majority-funded by the state, regardless of the sector.

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1 Submission to the Forum on Long-term Care from the Policy Group on Ageing of the Royal College of Physicians of Ireland (RCPI), <https://www.rcpi.ie/wp-content/uploads/2016/05/Sage-Long-Term-Care-final-Format.pdf>

A DKM report for the Department of Health published in 2015<sup>2</sup> found that the lack of reference to efficient cost levels and return on efficient capital in the Fair Deal negotiations represents a disconnect from the reality that the State expects the private sector to potentially provide 80% of nursing home capacity going forward. The report concluded that this was unsustainable in terms both of rational market operation and enabling new investment in areas of the country where payment rates are lower.

The growing number of older people likely to require long-term care, while still a minority (5%) of the older population, highlights the need to ensure that the current nursing home charging system as it applies to NHSS recipients is transparent and inclusive of all people's care and support needs. Obviously, nursing home charges are but one aspect of long-term care and the broader issues relating to long-term care have been set out in a recently published Sage Report on the Forum on Long-term Care of Older People.<sup>3</sup> Such issues include, in particular, choice, equality of access to care in the community and to nursing home care and, most importantly, matters relating to quality of life and well-being and best medical and nursing care practice.

## Nursing Home Support Scheme: Main Provisions

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At present, long-term residential care is financed via a combination of direct State support and a contribution from residents based on their means – the average contribution for nursing home residents is approximately 25% of the cost of care. Under the NHSS, a person makes a contribution towards the cost of his/her care in the nursing home (the level of which is determined in accordance with means-test criteria laid down in legislation) and the State pays the balance of the cost.<sup>4</sup>

The Nursing Home Support Scheme (NHSS) was established under the Nursing Homes Support Scheme Act 2009 to provide equitable access to nursing homes for older people of all financial means. Under the legislation, all entrants into long term residential care, both public and private/voluntary, are dealt with in a similar fashion in respect of their care needs and means assessment. The State provides financial support towards the cost of the standard components of nursing home care:

- Nursing and personal care appropriate to the level of care needs of the person
- Bed and board
- Basic aids and appliances necessary to assist the person with the activities of daily living, and
- Laundry service

Crucially, the fee negotiation process with nursing homes in respect of the NHSS makes no provision for some core aspects of care and support (see below).

<sup>2</sup> Potential Measures to Encourage Provision of Nursing Home & Community Nursing Unit Facilities, <http://health.gov.ie/blog/publications/potential-measures-to-encourage-provision-of-nursing-home-community-nursing-unit-facilities/>

<sup>3</sup> Responding to the Support and Care Needs of our Older Population: Shaping an Agenda for Future Action, [http://www.thirdageireland.ie/assets/site/files/pr/Report\\_of\\_Forum\\_on\\_Long-Term\\_Care\\_for\\_Older\\_People\\_FINAL.pdf](http://www.thirdageireland.ie/assets/site/files/pr/Report_of_Forum_on_Long-Term_Care_for_Older_People_FINAL.pdf)

<sup>4</sup> See [http://www.citizensinformation.ie/en/health/health\\_services\\_for\\_older\\_people/nursing\\_homes\\_support\\_scheme\\_1.html](http://www.citizensinformation.ie/en/health/health_services_for_older_people/nursing_homes_support_scheme_1.html)

The NHSS makes available 2 types of financial support to people who are assessed as needing nursing home care:

1. State Support
2. A Nursing Home Loan (referred to as Ancillary State Support)

People are assessed financially on the basis of both income and assets<sup>5</sup> and their personal contribution to their nursing home care is comprised of 80% of their assessable income and 7.5% of the value of their assets per annum.<sup>6</sup> A person's principal residence is only considered as part of their assets for the first 3 years.

Where an individual's assets include land and property in the State, the contribution based on these assets may be deferred and collected from their estate after their death. This is the optional nursing home loan element of the scheme, legally referred to as Ancillary State Support.

A person's eligibility for other schemes such as a Medical Card, GP Visit Card or the Drugs Repayment Scheme is unaffected by participation in the NHSS or by residence in a nursing home.

There are a number of safeguards built into the NHSS to protect both the person entering long-term nursing home care and his/her spouse/partner. These include:

- Nobody paying more than the actual cost of care
- The first €36,000 for a person's assets (€72,000 for a couple) not taken into account during the financial assessment
- The principal residence (and farms/businesses in certain circumstances) only included in the financial assessment for the first three years of a person's time in a nursing home
- Individuals retaining a personal allowance of 20% of their income, or 20% of the maximum rate of the State Pension (Non-Contributory), whichever is the greater
- A spouse/partner remaining at home retaining 50% of the couple's income, or the maximum rate of the State Pension (Non-Contributory), whichever is the greater
- Certain items of expenditure, (allowable deductions), taken into account during the financial assessment – health expenses, levies required by law (e.g., Local Property Tax), rent payments and borrowings in respect of a person's principal residence.

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5 Where a person is deemed to lack decision-making capacity, s/he is appointed a Care Representative by the Circuit Court.

6 The inclusion of a provision in Budget 2017 for a different method of assessing assets will be centrally relevant to farm assets.

## Care Needs Assessment

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A person's eligibility for the NHSS is based on an assessment of his/her care needs carried out by a HSE multidisciplinary team which focuses on abilities to carry out activities of daily living, including:

- Cognitive ability
- Extent of orientation
- Degree of mobility
- Ability to dress unaided
- Ability to feed unaided
- Ability to communicate
- Ability to bathe unaided
- Degree of continence

A standardised Common Summary Assessment Record (CSAR) is used to carry out the assessment.<sup>7</sup> It should be noted that a Single Assessment Tool (SAT) to uniformly assess dependency levels is being introduced.<sup>8</sup> The HSE's National Service Plan 2016<sup>9</sup> refers to a phased implementation of SAT being planned with an initial focus on access to long-term care, resulting in a minimum of 50% of NHSS applications assessed using SAT by the end of 2016.

## Selection of Nursing Home

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The applicant (or his/her family) selects the nursing home (either public or private). The selected nursing home must have availability and confirm they can meet the applicant's care needs. If the preferred nursing home is not available, an alternative must be identified and chosen by the individual or his/her family.

## Contracts between residents and nursing homes

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Under legislation, registered nursing home providers must agree a contract with each resident within one month of their admission. This contract must include details of the services to be provided to that resident and the fees to be charged. Critically, however, the HSE is not party to such contracts which are conducted between each resident and the nursing home and the fee to be charged has already been negotiated and agreed between the National Treatment Purchase Fund (NTPF) and the nursing home (see below). Since the NTPF is currently under the operational governance of the HSE, there may be an issue in relation to compliance with EU competition law which needs to be addressed.

7 <https://www.hse.ie/eng/services/list/4/olderpeople/nhss/CSARGuidanceDocument.pdf>  
 8 <https://www.iasw.ie/attachments/1d2210cd-89c2-4b62-b95d-1ac3392234e8.PDF>  
 9 HSE National Service Plan 2016 [www.hse.ie](http://www.hse.ie)

# Nursing Home Charges: The Role of the National Treatment Purchase Fund

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The National Treatment Purchase Fund (NTPF) has been designated by the Minister for Health pursuant to Section 40 of the Nursing Homes Support Scheme Act 2009 as a body authorised to negotiate with proprietors of registered nursing homes to reach agreement in relation to the maximum price(s) that will be charged for the provision of long-term residential care services to NHSS residents. The NTPF has statutory independence in the performance of its function. Its role within the NHSS is to negotiate and agree prices with private and voluntary nursing home owners on behalf of the State. A weekly price for the cost of care in public nursing homes is also provided. These agreed charges are the basis for the financial support payable by the HSE under the NHSS.

The Guidelines for Negotiating Prices<sup>10</sup> include the following:

- Costs reasonably and prudently incurred by the nursing home and evidence of value for money
- Price(s) previously charged
- Local market price

Budgetary constraints and the obligation of the State to use available resources in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public;

The existence of a specialist unit may be included as part of the discussions at the time of the price negotiations.

There is also provision for examination of records and accounts of participating nursing homes.

It is noted that Nursing Homes Ireland, the representative body for private nursing homes, takes the view that the current NTPF funding model fails to recognise the reality of the costs incurred in providing nursing home care.

The negotiations by the NTPF are with each nursing home (as opposed to collective negotiations with a representative body). This typically involves a series of contacts and face-to-face meetings with each proprietor.<sup>11</sup>As part of this function, the NTPF<sup>12</sup> enters into “Approved Nursing Home Agreements” with registered private and voluntary nursing homes to record the maximum price(s) that have been negotiated. The NTPF provides the HSE with the details of all Approved Nursing Home Agreements.

## Deed of Agreement

The Deed of Agreement is the contract between the nursing home and NTPF specifying the maximum price that the nursing home can charge NHSS residents for long-term residential care as defined in the deed. These prices are fixed for the term of the deed. The Deed of Agreement specifies the commencement date and the expiry date of each deed. Prices agreed are fixed for the term of the Deed of Agreement. At the end of the agreement term a new process of negotiation on pricing is entered into with the nursing home and all issues, including price, are again open for discussion and agreement.

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10 <http://www.ntpf.ie/home/nhss.htm>

11 This is likely to be hugely resource intensive as there are some 580 ‘designated centres’ currently listed by HIQA.

12 <http://www.ntpf.ie/home/nhss.htm>

Across the 440 plus nursing homes, the duration of the Deed of Agreement with NTPF varies. In 2010 NTPF offered 1, 3 and 5 year deeds with the average being less than 3 years at that time. There are indications that this average has reduced to less than 2 years. Some of this may be due to uncertainty for nursing homes arising from changing cost pressures and increased dependency levels of residents.

The NTPF price agreement covers the provision of long-term residential care services as defined in the deed. Changes in operating conditions as a result of new regulations or standards form part of the discussions at the time of the price negotiations. However, once agreed prices will be fixed for the term of the agreement. The NTPF only deals with nursing home owners and managers for the purpose of agreeing a maximum NHSS price and does not deal directly with residents or families whose link with the NHSS is through the HSE.

The function of the NTPF in respect of the NHSS is solely to negotiate prices with private and voluntary nursing homes. Neither the Department of Health nor the HSE has any role in such individual negotiations. The NTPF does not have any role in looking at standards of care in the nursing homes with which they negotiate prices. This is the responsibility of HIQA which sets nursing home standards and inspects facilities to ensure that these standards are being met.

## Role of HSE

The role of the HSE is to liaise with NHSS applicants, assess their eligibility for the scheme (their care needs), determine financial co-payment arrangements between nursing homes and individual residents and disburse State payments to private and voluntary nursing homes.

## Issues relating to charges under the NHSS

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While it is generally acknowledged that the NHSS has been successful in providing access to nursing homes for older people of all financial means, a number of important issues relating to the operation of the scheme have emerged<sup>13</sup>.

### The role and operation of the NTPF in respect of the NHSS

A 'one-size fits all' approach'

Inadequate provision for residents' well-being and quality of life domains

Additional charges in nursing homes not provided for in the NTPF negotiated price

Inadequate provision for access to therapies, equipment and aids required by individuals

Negative and unfair impact of reduced personal and family income

<sup>13</sup> Some of these were identified in which are documented in the 2015 Review of the Nursing Homes Support Scheme <http://health.gov.ie/wp-content/uploads/2015/07/Review-of-Nursing-Homes-Support-Scheme.pdf>

Nursing homes charging model different to that for other health and social care services

### **The role and operation of the NTPF in respect of the NHSS**

A number of criticisms have been made of the NTPF role in the NHSS. The main one refers to the fact that the NTPF is an agency of State under the HSE which ‘negotiates’ prices with the non-statutory sector based on an approach which does not really take account of the complexity and challenging nature of the care required by people with complex care and support needs, particularly people with dementia. This is the case despite the fact that a large majority of nursing home residents suffer from cognitive decline and dementia. Another issue identified is that the HSE’s own providers do not seem to be subject to ‘negotiation’ and are only prohibited from charging more than the actual cost of the care.

The 2015 NHSS Review recommended that the National Treatment Purchase Fund (NTPF) review the present pricing arrangements with a view to:

Ensuring value for money with the lowest possible administrative cost and burden for clients, the State and providers

Increasing the transparency of the pricing mechanism so that existing and potential investors can make as informed decisions as possible; and

Ensuring that there is adequate residential capacity for those residents with more complex needs.

### **A ‘one-size fits all’ approach’**

There are major difficulties around the way nursing home charges are negotiated and operate. Fees are agreed by the National Treatment Purchase Fund (NTPF) on behalf of the State with each individual nursing home. These fees provide only for ‘bed and board’ and basic nursing and personal care. There is no provision for individual support needs, e.g., therapies, specialised wheelchairs, incontinence wear, chiropody, transport, social programmes. Indeed, it is the case that incontinence wear is effectively excluded from the pricing process given that it is explicitly stated by the Department of Health that, under the ‘Fair Deal’ scheme, “existing arrangements with regard to the provision of incontinence wear to residents in public and private nursing homes will remain in place”.<sup>14</sup>

While HIQA has regularly called for improved person-centred care in nursing homes, better protection of people’s rights and dignity, there is no reference to these matters in the way fees are negotiated. Neither is there any focus on quality of life or on providing services in accordance with the will and preferences of people. A ‘blanket’ approach is adopted and the voice of potential residents and their families is effectively ignored in the fee negotiation process.

The DKM 2015 report, referred to above, noted that that the lack of reference to the level of dependency of residents discourages the development of more specialised facilities (for dementia, etc.) where more expensive care is required, and creates an incentive to actively discourage acceptance of high-dependency residents by nursing homes.

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14 <http://health.gov.ie/wp-content/uploads/2014/04/Information-Sheet-on-Payment-of-Fees.pdf>

## Inadequate provision for residents' well-being and quality of life domains

The question of costs and charges in nursing homes cannot be dealt with in isolation and nursing home charges need to be looked at within the broader framework of quality of life domains which include physical health, psychological and emotional well-being, level of independence, social relationships and relationship to the environment in which people live. It is essential that any discussion of funding mechanisms for nursing homes and related charges is intrinsically linked with basic quality of life components. These have been identified as follows with reference to people with dementia:

Competent cognitive functioning

The ability to perform activities of daily living (ADL)

The ability to engage in meaningful use of time

Social behaviour; and

Achieving a favourable balance between positive emotion and the absence of negative emotion.<sup>15</sup>

Current regulations for constructing nursing homes do not specifically incorporate modern concepts in nursing home care, such as the Green House or Eden Alternative.<sup>16</sup> Neither is it clear to what extent enforcement is carried out of design elements such as those contained in Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013 (e.g., Regulation 17 relating to communal space for residents suitable for social, cultural and religious activities appropriate to the circumstances of residents). For example, HIQA's 2014 Overview Report on Regulation of Designated Centres for Older People<sup>17</sup> found that only 29% of inspections showed compliance with Outcome 12 'Safe and Suitable Premises'. It is also the case that much of the recent growth in the private nursing home sector has been in the form of relatively large units at the periphery of urban areas, distant from the localities where residents formerly lived.

Given the importance of social connectedness for people's health and well-being,<sup>18</sup> there is a need to focus more on maximising individual capacity to engage as well as on developing more inclusive linkages with the broader community and valued social connections. This is all the more important because many people in nursing homes do not want to be there. The growing number of nursing home residents with dementia and related high levels of support needs presents a major challenge for enhancing social connectedness. This challenge is made more difficult by the fact that not all nursing homes have adequate appropriately trained and skilled staff to work with these residents.

## Additional charges in nursing homes not provided for in the NTPF negotiated price

Nursing homes can levy charges on residents which are additional to what is covered by the NTPF-negotiated fee. As the NTPF contract with nursing homes provides for just bed and board in nursing

15 Suzanne Cahill and Ana Diaz (2010), Living in a Nursing Home, Quality of Life: The Priorities of Older People with a Cognitive Impairment, in association with Dementia Services Information and Development Centre, [http://www.nhi.ie/zuploads/page\\_docs/living%20in%20a%20nursing%20home%20quality%20of%20life%20dr%20suzanne%20cahill.pdf](http://www.nhi.ie/zuploads/page_docs/living%20in%20a%20nursing%20home%20quality%20of%20life%20dr%20suzanne%20cahill.pdf)

16 See, for example, <http://www.edenalt.org/>

17 <https://www.hiqa.ie/publications/annual-overview-report-regulation-designated-centres-older-people-%E2%80%93-2014>

18 McKeown K., Pratschke, J. and Haase, T. (2014), Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People: Assessment of National Business Case, Dublin: Fourth Age Trust.

homes, there are extra mandatory charges in most private nursing homes for activities and other items. These are reported as being as high as €100 a week in some instances. This results in not only a significant additional drain on people's resources but also in some instances of people having to pay for activities in which they do not wish or are unable to participate. Frequently, it is unclear what these additional charges cover.

One instance reported by a Sage advocate referred to a charge of €70 a week being levied on residents which was regarded as excessive, particularly because it was unclear what activities were covered and what the actual level of activities input was. Two residents in another nursing home complained of an increase of €5 a week in charges introduced earlier this year. Another instance reported referred to a person being asked to pay €80 a week charges out of what is left of his social welfare payment after his contribution to the fees is deducted. These issues are illustrated starkly in the case examples which follow:

#### Impact of additional charges: Illustrative case examples

A 61-year old man who has epilepsy has been placed in a nursing home following a period in hospital. His only income is the Disability Allowance. Prior to coming to the nursing home, he used to walk to the village each day to buy the newspaper and cigarettes. His contribution to the nursing home charge is €43.30/week and he is also asked to pay a €80 weekly charge for 'social services charge' He has no money left for cigarettes or newspapers. Medication fees and transport charges are not included in his weekly contribution. There is no place near the nursing home where he could walk to buy anything and the Nursing Home will not allow him to leave the nursing home unaccompanied – this means that every time he wants to go out socially, he has to pay for a taxi and companion which he clearly cannot afford. He gets extremely frustrated that he has to live so far away from his familiar place, and has difficulty (understandable) in accepting that almost his entire income is taken for fees and charges.

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A nursing home resident in has an income of €22/week, pays fees of €20.60 daily and additional charges of € per day (since 2012 he never attended any activities), along with medication fees of €5 per month. He was recently charged €9 for a taxi trip to a dental appointment (this used to be €6.30) He has to pay € for a haircut.

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A nursing home resident, who shares a room with two other residents, pays weekly fees of €88.87, additional social therapy charges of €5.50 a day, a toiletries charge every 3 months and was charged €100 recently for clothing tags.

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A resident with only one income source (a DSP payment of €70 weekly) has to pay €43.60 weekly in basic fees. Transport to hospital appointments, transport to the local Social Welfare office, fees for applying for a birth certificate, medication fees are all additional expenses incurred recently which he cannot afford, so his arrears are building up.

The following case example illustrates the significant lack of fit between mandatory additional charges and individual need where individually-tailored activities are not provided, as may typically be the case.

#### Lack of appropriate 'activities' relating to additional charges

This woman has been in a nursing home since 2005. While the family would have wished to continue to provide care and support for her at home, the absence of any home care package made this impossible

--she has dementia and very limited mobility or physical functioning capacity. She is being charged €20 per month for 'activities' but the activities provided do not in any way meet her needs. The activities seem to consist of facilitated dance and movement (organised weekly) which, in the view of a relative, appeared to have little or no resonance with many the nursing home residents (all of whom had mid to late stage dementia) and was not in any way tailored to their individual needs. This woman's family would have had an expectation (not unreasonable) that the 'activities' would have involved some individually-tailored physiotherapy. Despite being unhappy with the 'activities' charge and, indeed, a lack of clear information about what the charge actually covered, they were reluctant to question it because of a fear on the part of this woman's husband that she would be asked to leave the nursing home and, therefore, they have continued to pay the charge.

In effect, this woman has been charged €20 per month over a period of more than 10 years (totalling €2,460 to date) for, as one relative put it, activities that she could not possibly participate in because of her significantly reduced mobility and advanced stage dementia.

The application of additional charges is a crucially important issue because it is very likely that some activities do not involve a cost to the nursing home, e.g., singing, playing cards or games. A key question is how much added value is actually being provided for this additional charge which can generate significant additional income annually for nursing homes, depending on the number of residents, (e.g., €20 x 52 weeks= €1,040 x number of residents). While nursing homes can be under financial pressures to generate increased revenue, this should be a matter between Nursing Homes and the NTPF (and ultimately Government). It should not result in additional costs to residents.

In order to deal with the issue of additional charges, the 2015 Review of the NHSS recommended that nursing homes should have a published fee schedule showing all the costs associated with being a resident. It was suggested that consideration should be given to introducing a new provision under the scheme to prohibit the levying of additional charges for any service or facility from which residents cannot readily opt out without penalty while remaining as a resident of that facility, or in which they cannot participate because of the level of their dependency.

## **Inadequate provision for access to therapies, equipment and aids required by individuals**

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The lack of adequate access by nursing home residents to specific therapies, e.g., physiotherapy, occupational therapy, chiropody, which they need and may be eligible for under the public health service, is regularly highlighted by nursing home residents, their families and advocates. These therapies are not funded under the 'Fair Deal' and there appears to be a de-prioritisation of nursing home residents in terms of the HSE providing these services. This means that the only option is for people to pay for such therapies privately, which many cannot afford to do. The Ombudsman in a 2010 report<sup>19</sup> identified as

19 WHO CARES? An Investigation into the Right to Nursing Home Care in Ireland <https://www.who.cares.ie/>

an issue of concern the fact that in practice the range of services covered by the NHSS is quite narrow and excludes many elements which, on the face of it, are services which one would expect to be included as part of long-term nursing home care. The NTPF agreement with the nursing homes specifically excludes some fundamental care elements such as all therapies, chiropody and social programmes. The Ombudsman has reported receiving a number of complaints concerning these restrictions to the NHSS. The 2015 Review of the NHSS highlighted concerns about the lack of uniformity for nursing home residents when accessing certain services, and in particular therapies.

### **Availability of suitable seating and other aids/appliances in nursing homes**

Nursing homes have no obligation to provide specialized equipment under the 'Fair Deal'. A number of instances have been reported by Sage advocates where people do not have access to appropriate seating to meet their needs, e.g., wheelchairs. One case reported referred to a woman who needs a larger wheelchair due to her size/weight. She is currently on a HSE waiting list and informal feedback from the HSE is that only a limited budget is available for such purposes and that this tends run out relatively early in the year.

In theory, nursing home residents should have the same entitlement to assessment for and provision of equipment as people living at home, i.e., entitlements under the Medical Card scheme. A wide variation in practice is reported from area to area. The experience of Sage advocates suggests very different practices in different HSE catchment areas. In some areas, equipment needed and recommended by Occupational Therapists is extremely limited while in other areas Primary Care teams are reported as providing a comprehensive service to nursing homes and, indeed, providing access for nursing home residents to their clinic for specialised equipment.

A factor which impacts directly on equipment provision is a lack of agreement nationally as to where responsibility lies for the funding of equipment for nursing home residents. Nursing Homes Ireland argue that, since the NHSS funding package does not provide for the provision of anything other than basic equipment, nursing homes have no obligation to provide specialized equipment and that residents should access such equipment via HSE Primary Care Services. This debate is ongoing and unresolved, and in the meantime the arbitrary provision as outlined above is what is in place and vulnerable nursing home residents are forced to rely on their own resources, or on the goodwill of relatives, friends or charitable bodies.

## **Other Charges**

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### **Increase to Nursing Home Charges**

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[ombudsman.gov.ie/en/Publications/Investigation-Reports/HSE-Nursing-Homes/Who-Cares/Who-Cares.pdf](http://ombudsman.gov.ie/en/Publications/Investigation-Reports/HSE-Nursing-Homes/Who-Cares/Who-Cares.pdf)

**An issue that impacts significantly on low income families is where nursing homes unilaterally increase the weekly charge without approval from the NTPF or HSE. Evidence has been reported of at least one Nursing Home increasing its charges to residents without appropriate approval from the NTPF and this increase not being sanctioned by the HSE in respect of the amount the resident is liable for under the means assessment. The justification by the Nursing Home for increasing the fees was that the fee negotiated with the NTPF had not changed for 10 years and that the NTPF did not take into account the facilities, the level of care provided, the wide range of activities and events provided or increase in the National Minimum Wage. There is no legal basis whatsoever for passing on increased charges to residents and doing so is clearly in breach of the NTPF Agreement and, indeed, contracts with residents.**

### Charge for GP Service

An additional mandatory charge in one nursing home reported refers to a €5 per week charge for the 'nursing home doctor service'. The basis for this charge is somewhat spurious in that all people over 70 have free access to GP services and all would already have their own GP or could get one.

## Impact of reduction in family income

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Additional charges can be a particularly significant burden on the families of older people on low incomes. For example, those who are reliant on the State Pension as their only source of income have only a small amount of discretionary income left over after paying their contribution towards Nursing Home Support Scheme. The issue is very pertinent in some instances in the case of spouses who remain at home. A particular issue arises where the spouse of an NHSS recipient is a Qualified Adult in social welfare terms<sup>20</sup>. This spouse, still living at home, may end up with reduced income but having to incur increased costs in relation to, for example, visiting their spouse in the nursing home, paying the additional nursing home charges and buying aids and appliances.

### Additional charges and low income

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The matter of additional charges comes more sharply into focus when considered in the context of the relatively low income/assets of a significant section of 'Fair Deal' users.<sup>21</sup>

18% of scheme participants have no declared cash assets;

<sup>20</sup> Some people may no longer be able to get the Household Benefits package because they happen to be Qualified Adults on their spouse's social welfare pension.

<sup>21</sup> Review of the Nursing Homes Support Scheme, A Fair Deal p.19.

15% of participants have no declared cash or other relevant assets;

Just over 9% of applicants opt to defer the portion of their contribution that is based on other relevant assets, including property;

15% of applicants have no declared income other than the Non-Contributory Old Age Pension;

The average declared weekly income for applicants assessed on a single basis is €81 per week (€62 for people assessed jointly (as part of a couple)).

## Nursing Home Charges and the NHSS: Key Considerations

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There are a number of aspects of nursing home charges that need to be considered more fully and in a transparent manner.

### **Nursing homes charging model different to that for other health services**

Charges under the 'Fair Deal' scheme (20% of the value of a person's house, 80% of income and 7.5% per annum of assets) does not apply to other health services – this inequity is aggravated by the policy (largely unstated) of favouring private provision and, more recently, a focus on the fact that public nursing homes are much more expensive in comparison to the private sector. A related issue is the fact that the price agreed between the NTPF and each nursing home does not, as already stated, make any provision for access to equipment or personal care requirements (such as incontinence wear), transport for health needs, therapies or social work support, all of which, it can be reasonably argued, are essential requirements for care. This gap in care provision is exacerbated by the fact that many community HSE services do not provide a service to private nursing homes, for example, occupational therapy and dietetics, which disadvantages nursing home residents. Although HIQA regulations state that residents should be referred to care services, they do not specify how these should be provided. The Irish National Audit of Stroke Care<sup>22</sup> has indicated a low level of provision of such services to residents with stroke.

### **Distinguishing between the cost and quality of nursing home care**

There is a clear need to distinguish between 'cost of care' and 'quality of care' in nursing homes. The focus on the former results in an unbalanced discourse where the emphasis is on the cost to (and related

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<sup>22</sup> [http://www.stroke.ie/media/pub/strokereports/ihf\\_hse\\_national\\_stroke\\_audit\\_2015\\_\\_web\\_version.pdf](http://www.stroke.ie/media/pub/strokereports/ihf_hse_national_stroke_audit_2015__web_version.pdf)

burden on) the State – this has the effect of removing the focus off people who require long-term care and their needs.

The 2015 Review of the NHSS notes that although prices vary significantly between facilities, at individual facility level a single price is given for all residents regardless of the level of dependency and need for care. While Nursing Home operators have argued (understandably) that higher rates should be paid for residents with more complex needs, including those with dementia, the NTPF position is that existing prices are averaged to take account of the levels of dependency that currently prevail among nursing home residents who include a significant proportion of people with dementia.

Since pricing contracts are entirely a matter for agreement between the NTPF and the nursing home in question and neither the Department of Health nor the HSE can influence the process, a crucial question arises as to who is responsible for monitoring the link between nursing home charges and the quality of life residents. This is an issue which requires further attention, particularly, given the problematic nature of additional charges levied and the likelihood that these are being used to ‘top up’ fees. A crucially important related issue is the difficulty that people with very high dependency and complex care needs may have in finding accommodation appropriate to their needs, e.g., those with severe dementia coupled with a physical/sensory disability.<sup>23</sup>

### **Meeting people's individual care and support needs**

The question of charges for nursing home care and related issues needs to be addressed from the perspective of nursing home residents. The majority of older persons in nursing homes are vulnerable for reasons of dependency and reduced capacity to self-care and manage their own affairs. They may also be vulnerable because the system of residential care has historically tended to be based on a dependency model rather than on an approach that maximizes choice, supported decision-making and independence. This latter factor is likely to be more pertinent in the case of persons with dementia because of their frequently multi-faceted support needs. The Ombudsman has expressed concern that, in many individual cases, the NTPF agreed care packages were not adequate to meet the actual care needs of that individual and that, in this event, the agreements made by the NTPF may be falling short of the level of care generally aspired to.

It is reasonable to argue that the exclusion from the NHSS package (as negotiated and agreed with nursing homes by the NTPF) of therapies, specialised seating, aids and equipment impacts in a significant way on the people involved. While a person's eligibility for other schemes, such as the Medical Card Scheme or the Drugs Payment Scheme, is unaffected by the NHSS and, while, in theory, a nursing home resident can continue to receive supports and services in accordance with the terms of these other schemes, in practice, this is not the case in private nursing homes. People in public nursing homes are likely to have better access to services and supports. It appears to be the case that the HSE has only a limited capacity to provide services such as physiotherapy, occupational therapy and chiropody and it certainly appears that residents of private nursing homes (NHSS beneficiaries) are sometimes not provided with these services even though they are eligible for them and might well have benefitted had they continued to live in their own homes or gone to a public nursing home.

Indeed, the provision of therapies would be better dealt with comprehensively rather than in the context of the NHSS. This would be consistent with Government policy which acknowledges the preference of people to remain in their own homes and communities for as long as possible and which endeavours

<sup>23</sup> It is noted that the Minister for Health has asked NTPF to review pricing levels and to make proposals in relation to pricing to ensure that there is adequate provision for those needing more complex care.

to support them in achieving this through the provision of community-based long-term care services. This would have the added advantage of enhancing connectedness with the community which is a core quality of life domain for nursing home residents.

### **Individually-tailored additional charges**

A centrally important question to be addressed is how can additional charges be effectively used to promote autonomy and enable residents to participate in valued aspects of life, for example, 24

Contact with family members

Intimacy and privacy

Relationships with significant others

Keeping active, feeling useful

Having meaningful activities

Religion, spirituality and prayer

Positive interactions with staff members

#### **Urgent Need for a Debate on Nursing Home Charges**

The question of charges for nursing home care and related issues needs to be addressed from the perspective of all nursing home residents. The majority of residents in nursing homes are vulnerable for reasons of dependency and reduced capacity to self-care and manage their own affairs. They may also be vulnerable because the system of residential care has historically tended to be based on a dependency model rather than on an approach that maximizes choice, supported decision-making and independence.

There is an urgent need for more debate around nursing home fees and charges. While nursing homes are under financial pressures to increase charges, this should be a matter between nursing Homes and the NTPF (and ultimately Government). It should not result in additional costs to residents. There is clearly a need for a robust debate around the interface between nursing home charges and quality of nursing home care. The fact that nursing home residents frequently have to surrender independence and choice relating to practical aspects of daily living is not conducive to well-being. The question of higher costs and fees in public nursing homes needs to be considered in this context.

#### **Implementing the Recommendations of the 2015 NHSS Review**

An Interdepartmental/Agency Working Group<sup>25</sup> has been established to progress the recommendations contained in the 2015 Nursing Homes Support Scheme Review. A crucial factor is that the Review Group

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24 Suzanne Cahill and Ana Diaz (2010), Living in a Nursing Home, Quality of Life: The Priorities of Older People with a Cognitive Impairment, in association with Dementia Services Information and Development Centre, [http://www.nhi.ie/zuploads/page\\_docs/living%20in%20a%20nursing%20home%20quality%20of%20life%20dr%20suzanne%20cahill.pdf](http://www.nhi.ie/zuploads/page_docs/living%20in%20a%20nursing%20home%20quality%20of%20life%20dr%20suzanne%20cahill.pdf)

25 This Group is chaired by the Department of Health and includes representatives from the Department of the Taoiseach, the Department of Public Expenditure and Reform, the HSE the Revenue Commissioners and, when required, the NTPF. The Working Group was due to report on its progress to the Cabinet Committee on Health in June 2016

does not appear to have any involvement from older persons' representative groups or from users and potential users of the scheme.

## Appendix

### Review of the Nursing Homes Support Scheme, A Fair Deal<sup>26</sup>

#### Recommendations on the Price of Long-Term Residential Care

Having examined the overall cost of long-term residential care in public and private nursing homes and the effectiveness of the current methods of negotiating and setting prices it is recommended that:

- 1) Nursing homes to consider offering access to a 'house' doctor in each facility.
- 2) A person in a long-term residential care setting should receive the same level of other health services as they would if they remained in their own home and it is important that this policy is implemented consistently by the relevant HSE personnel.
- 3) The existing system of agreeing prices facility by facility should continue for the immediate future.
- 4) Within 18 months, the NTPF should review the present system and submit future pricing proposals to the Minister for Health with a view to:-
  - i) Ensuring that there is adequate residential capacity for those residents who require higher level or more complex care;
  - ii) Ensuring value and economy, with the lowest possible administrative cost for the State and administrative burden for providers;
  - iii) Increasing the transparency of the pricing mechanism so that existing and potential investors can make as informed decisions as possible
- 5) The cost of public long-term residential care should be based on a pricing model that is objectively and consistently formulated, and which takes account of and accurately quantifies unavoidable price distortions.
- 6) It is important that the position of section 39 voluntary agencies be addressed. A clear plan must be developed by such facilities, supported by the HSE to agree their purpose and function and where necessary to get the cost structures into line within a reasonable and specified timeframe.
- 7) Nursing homes should have a published fee schedule showing all the costs associated with being a resident.
- 8) Consideration should be given to introducing a new provision under the scheme to prohibit the levying of additional charges for any service or facility from which residents can not readily opt out without penalty while remaining as residents of that facility, or in which they cannot participate because of the level of their dependency.
- 9) Consideration should be given to including in the price contracts with facilities, details of what additional charges are proposed, of the opt-out arrangements that exist for residents and confirmation that residents will not be charged for extra services that they cannot participate in because of their dependency or lack of capacity.
- 10) It may continue to be necessary for the HSE to make additional payments in circumstances where very specialist care is required. Engagement with acute, disability and other services is required to give a

<sup>26</sup> <http://health.gov.ie/wp-content/uploads/2015/07/Review-of-Nursing-Homes-Support-Scheme.pdf>

more comprehensive service for this co-hort.

11) The HSE should publish the cost of care on an annual basis.

12) The HSE should continue to review the costs in its facilities to examine if facilities can be made more cost efficient. The review should start with the most expensive nursing homes and then cascade down.

13) A value for money and policy review will be undertaken of HSE public long-term residential care facilities to examine the extent to which cost differentials with care in private facilities can be attributed to patient dependency characteristics or other objective factors for which a higher level of cost is justified.

(Footnotes)

- 1 [http://www.fedvol.ie/\\_fileupload/Next%20Steps/Time%20To%20Move%20On%20From%20Congregated%20Settings.pdf](http://www.fedvol.ie/_fileupload/Next%20Steps/Time%20To%20Move%20On%20From%20Congregated%20Settings.pdf)



