



Submission to the Competition and Consumer
Protection Commission on the contracts of care in long-term
residential care services for older people

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1. Introduction

Age Action is the leading advocacy organisation on ageing and older people in Ireland. Our mission is to achieve fundamental change in the lives of all older people by eliminating age discrimination, promoting positive ageing and securing their right to comprehensive and high-quality services.

A core component of our work is raising awareness about the lived experience of growing old in Ireland. Our organisation ensures that the authentic voice of older people is carried into relevant policy and lobbying spaces.

2. Age Action's position on nursing home contracts

Age Action is concerned at the unclear position of many nursing home residents and their relatives, who find themselves unsure what services, fees, costs and charges they are contracted to pay nursing homes. These fees are in addition to the amount which the nursing home receives for their care under the Nursing Home Support Scheme (NHSS).

Age Action does not believe that it is acceptable that there are many older people, who having contributed their work and caring commitments throughout their lives, now find themselves:

- Paying above the agreed fee for their care for services and activities which they are not able to access due to their frailty and level of dependency., thus reducing, or obliterating, their remaining disposable income;
- Paying for services which they may be entitled to under the General Medical Card Scheme;
- Paying for services which to many would appear to be unjustified i.e. attendance at mass.¹

These additional unforeseen, and at times non-itemised, charges are pushing the costs of nursing home care beyond the reach of many older people and causing serious financial stress to their families.

¹ <https://www.irishtimes.com/news/ireland/irish-news/higa-aware-nursing-home-residents-charged-for-religious-services-1.3196305>

The impact of these additional charges goes against the core principle of the scheme on its introduction that an individual's choice of a nursing home under the scheme would not be restricted by their income or wealth.

This submission sets out our recommendations for strict guidelines for nursing homes. The recommendations reflect the lived experience of those actively involved in caring for their loved ones living in a residential setting.

3. Policy context

Age Action welcomes this call for public submissions by the Competition and Consumer Protection Commission (CCPC) to review the contracts of care in long-term residential care services for older people.

This issue has been a concern for Age Action for some time and is a regular topic in calls and emails to our information service from older people, their relatives and families.

In June 2017 we published a briefing paper on *Regulating Nursing Home Charges*² exposing the scale and nature of the additional fees imposed on nursing home residents who are participating in the Nursing Home Support Scheme (NHSS).

This briefing paper described the type of problems encountered by relatives and friends of older people during the process of transitioning a loved one into a residential setting.

On foot of this briefing paper we have been working with the relevant political, policy and sectoral leads to achieve more transparency, equity and affordability within the NHSS. Recent advocacy activity includes:

1. We met with the Minister for Mental Health and Older People in late 2017. We remain in correspondence regarding the ongoing problems facing relatives of people transitioning into nursing home settings, particularly in relation to progress being monitored by the Nursing Home Support Scheme Inter Departmental Review Group.

² https://www.ageaction.ie/sites/default/files/attachments/briefing_paper_4_-regulating_nursing_home_charges.pdf

2. We met with the CCPC in December and have actively promoted the call for submission to our members, older people and their families in general. Age Action advocacy groups around the country have also been briefed on the consultation and encouraged to inform their friends and neighbours. We have also extracted relevant material from our information line's database.
3. We have also highlighted the issue in national and regional broadcast and print media.

4. Demographics of ageing

Evidence based policy makes for the best use of available and projected resources. We know that it is critical that adequate heed is taken of future demographics to plan appropriately for emerging need.

The recent ESRI report *Projections of Demand for Healthcare in Ireland 2015-2030*³ forecasts that one in six people will be aged over 65 years by 2030. The number of people aged over 80 will increase by between 89 per cent (128,000) and 94 per cent (135,000) in the period in question. It also predicts an increase in nursing home residents of between 40 and 54 per cent (by an extra 15,600).

Regional projections for 2016-2031 show the number of older persons (over 65) will almost double in every region over this time period.⁴

5. Sustainable funding model needed for the NHSS

Approximately 4 per cent of the older population in Ireland (over 65 years) are currently nursing home residents under the scheme. The number of residents who will be supported in the NHSS is projected to be 23,040 in 2018.⁵ This number will continue to rise, in line with the increase in the population cohort in question. Ensuring that the scheme is configured and appropriately funded to provide quality care in an equitable and transparent way is critical to its fitness for purpose for future users.

The scheme is providing – and will continue to provide – a critical service for a very vulnerable cohort of our population. Robust governance is needed to guarantee its

³ <https://www.esri.ie/pubs/RS67.pdf>

⁴ <http://www.cso.ie/en/releasesandpublications/er/rpp/regionalpopulationprojections2016-2031>

⁵ <http://www.budget.gov.ie/Budgets/2018/Documents/7.Nursing%20Homes%20Support%20Scheme%20E2%80%93%20Trends%20and%20Figures.pdf>

current and future implementation, and funding. The spend for 2018 is €961.7 million,⁶ up from €940 million in 2017, with nursing home residents contributing €68.2 million from their own resources. While the funding of the NHSS has remained relatively stable in recent years, future sustainability of funding is not without risk given demographic trends and the rising cost of providing nursing home care.

Age Action notes that there will be a review this year of the price of care in private nursing homes which the National Treatment Purchase Fund has negotiated with providers.

Alongside this pending review, the fact that the CCPC has undertaken this public consultation on contracts in nursing homes shows the growing public dissatisfaction at the additional charges being levied on residents of private and voluntary nursing homes.

6. Issues regarding contracts in nursing homes

The feedback to Age Action on the issue of nursing home contracts clearly shows a wide variance in the clarity of explanation provided at individual nursing home level regarding what services are included in the fee structure.

There is a high level of variation in how these costs are negotiated and the depth of detail in which they are discussed prior to the contract between resident and nursing home being signed.

We are aware that the details of the additional charges are not always offered at point of inquiry and often not itemised clearly enough in the contract. It is obvious that many people find it difficult to determine and understand what items are charged for separately on a pay-as-you-go usage system (e.g. hairdressing, chiropody) and what services are included in an ‘additional charges’ monthly fee which often bundles together a variety of activities and services.

Below is a summary of the issues surrounding nursing home contracts which have been shared with us face-to-face, or via phone calls, emails or letters. Clear themes are evident.

⁶ <https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2018.pdf>

Residents not availing of services

We were contacted by an Age Action member to share her experience of negotiating extra charges for her bed ridden mother who “could sometimes make it to a chair beside her bed on a good day”.

She shared a copy of the document which lists the activities she was being forced to pay for:

The Proprietor and the Resident agree that the Proprietor will provide the following Nursing Home Services to the Resident for the further additional remuneration as the Nursing Home Service Charge specified in Part 2 of Schedule 2:

(a) Social programmes, including Arts and Crafts, Games such as Bingo/Name that Tune etc., Board Games, Book Club, Bowling, Card Games, Cookery, Daily Exercise Classes, Daily Prayer Group, Extend Class, Film Nights, Garden Parties, Nail filing and painting, Massage Therapy, Pet Therapy, Occasional Lectures, Sonas, Special Occasions Celebrations, Visiting Musicians, Visiting Theatre Groups, Visiting Library, Art Therapy Classes, Summer barbeques and garden parties. Evening social events such as for example, Fish and Chip Supper night. Occasional trips and outings, for example to...and evening trips to the local pub, visits to local theatres, shops and our annual summer outing to Dublin Zoo.

In this case the member negotiated the weekly fee for activities from €70 to €50 but was adamant that her mother, who was rarely able to leave her bed, never participated in any of the activities during her time in this setting.

“My mother is being charged for activities that she cannot take part in...one expects a bill in relation to prescription fees, hairdressing, chiropody etc but not for activities she cannot take part in”

Maureen⁷

Similar experiences were reported by other members:

“It seems outrageous that the nursing homes are taking these extra fees from people who cannot

⁷ Throughout this document the names of individuals who contacted Age Action have been changed to protect their identities.

avail of them. Essentially every penny of her pension was going to them and if she didn't have a family to ensure what extra she needed was taken care of then how would she have managed?"

Eileen

"My relative is not high dependency and is paying an extra €195 per month for activities she doesn't take part in"

Vincent

"My mother is in X house nursing home and is immobile she is being presented with a contract with group therapies costing €70 which are non-negotiable"

Kevin

Margaret's uncle, aged 87, has bladder cancer and is on a waiting list for the NHSS. The nursing home that is being considered is levying an additional charge which his relatives are unhappy with as he is bed-ridden and will not be taking part in any activities.

Veronica's father received his invoice from the nursing home and questioned the included weekly social charge of €30. They asked which programmes were being offered but received no reply to their request. Veronica's father has dementia and has not engaged in any activity for quite some time.

Another invoice arrived with an accompanying letter noting that the nursing home management had discussed the issue of the social charge at their weekly meeting and stated that 'they cannot forgo this charge as it is paid by all residents'.

Anne told us that she pays for the extra charges (such as hairdressing and chiropody) for her mother who is a NHSS resident in a nursing home. She is angry at the fact that she has received a non-itemised bill for an extra €30 per week for activities that her mother does not always take part in. She says her mother cannot afford this and she is not going to pay it. She has tried to have a conversation with the nursing home Manager on this but feels she is been ignored.

Lack of clarity around additional charges

Michael shared the below example of a contract of care which, while it clearly shows that an additional monthly charge is levied for 'diversional, reminiscence and other therapies' for residents in receipt of the NHSS, does not list what these therapies are and if they are optional.

This contract also contains a list of services and appliance (such as incontinence pads, chiropody for those without a medical card) which are charged for separately, on top of the additional monthly charge.

The standard weekly charge ...
in the standard weekly charge ...
Bed and Board
Nursing Care as assessed by nursing staff and as appropriate for each person
Basic aids and appliances necessary for daily living
Laundry and domestic services
The standard charge for Residents not in receipt of Fair Deal or other support will be billed monthly.
From 1 July 2017 €5,500 per month
For those in receipt of Fair Deal, in addition to the rate agree with the HSE an additional charge will be made for diversional, reminiscence and other therapies relevant for ongoing care.
From 1 July 2017 €210 per month
Additional services will be provided at cost, in line with the indicative figures given below. This list is not exhaustive.
Incontinence wear Where the Resident does not qualify for a Medical Card a typical weekly cost would be €25-€30
Transport (including staff costs) A typical trip to St Vincent's Outpatients Department (staff and taxi) would cost €50-€70
Hairdressing and other similar services Standard fee for hairdressing in-house is €10
Chiropody €60 per in-house treatment
Dry cleaning Charged at cost
Ophthalmic and Dental Services Not provided in-house. Private visits facilitated.

It is worth noting that an individual in a nursing home under the NHSS whose sole income is the full contributory State Pension is left with a weekly income of €47.66.

The additional charges rate of €210 per month in this specific nursing home, which is not at the most expensive end of prices quoted to Age Action, is just over 90 per cent of that person's income.

In the overwhelming majority of cases individuals cannot pay their own fees. Where they have no family to support them or their family member lack funds, this reduces their ability to go into the nursing home of their choice. Where their family is able to support them, the cost of nursing home care is, in effect, being partially outsourced to the resident's family.

"In the initial contract there is a note stating that there would be charges for hairdresser, newspapers, hospital visits and also social activities the latter of which we were verbally led to believe were for outings outside the nursing home but no details of charges for these services was offered"

David

Unaffordable additional charges

Age Action regularly receives calls from relatives of nursing home residents who are in financial hardship because of these additional fees and are worried about how they will afford the additional costs. The range of additional charges is wide and often families are simply unable to cope with this additional cost.

Many callers to Age Action's information line simply want to express their concern and worry regarding how they will meet these additional costs.

Below are some examples of the types of calls we receive from worried relatives:

Therese is worried that as the Care Representative for her relative, she would be personally liable for the extra service charges imposed by the nursing homes.

Similar quotes regarding the lack of clarity on additional charges and a lack of itemised details include the following:

"The service charges are very high at approximately €50 for an out of hours GP call even though she has a medical card"

Susan

"Our concern is that we cannot see justification of a 200 per cent increase in social activities charges, no invoice was ever provided for these services"

Amanda

"My brother in law is being charged a fee of €12,000 for special bandages he has needed since 2016. We were never informed of these charges, he has a medical card "

Sandra

Patricia told us about her mother's nursing home which demanded an additional payment of €2,173 after 30 months even though her mother had not been participating in the activities for which she was being charged due to her age and frailty.

This family was shocked as they had always paid for the extra charges for hospital visits, chiropodist etc. plus a small charge of €10 per week for social activities introduced by the nursing home in 2011.

When they queried the charge, they were told that it was for 'social activities' and that they had been advised of the increase back in 2013 by email. They asked for proof of the email and for details of what the social activities were but have not had a response.

Martin told us about his father who has a medical card and is in a nursing home under the NHSS. He broke his hip in a fall in the home and is being treated in hospital. He is now ready for discharge and needs picot leg dressings three times a week which are not covered under the General Medical Card Scheme.

The nursing home charges €200 per leg dressing which the family cannot afford. Our helpline staff suggested a meeting with the Clinical Nurse Manager in the hospital ward, nursing home management and the family to negotiate a longer stay in hospital.

Tom's father had been in his nursing home for just four weeks and was billed an extra €200 for a bed alarm (which is already integrated into furniture in the room according to Tom) and €500 per month for oxygen he does not need. When this was questioned he was told that he might need it in the future.

The payment for oxygen in this case highlights an ongoing issue whereby residents of public nursing homes do not pay for oxygen while those in private and voluntary settings do.

Age Action understands that this issue is part of an ongoing discussion between Nursing Homes Ireland and the Department of Health in relation to the issue of excluded items from the NHSS.

Sourcing a nursing home under time pressure

Often the move to a nursing home happens within a tight timeframe – at times accompanied with additional pressure, perhaps to vacate a bed in an acute setting. This is an emotionally charged and stressful time when the older person's health has deteriorated, and they are considered no longer capable of independent living.

This situation can often evoke a sense of loss for that individual and their relatives, which does not always lend itself to people being in the right frame of mind to analyse complex legal documents when looking at nursing homes and their fee structures.

Consequently, the important and far reaching financial decision around moving to a nursing home is often made at a time of stress and sadness. Availability and location of a nursing home are usually primary drivers in the search, rather than the small print in a contract of care, often written in an inaccessible legal format without sufficient clarity regarding what actual services and activities are being charged for.

“The hospital was putting us under pressure to accept the first available home in order to free up a hospital bed.... we were looking at several homes under time pressure”

Peter

7. Recommendations

The existence of the additional charges levied by nursing homes for a range of services (e.g. therapies, social activities, specialised equipment and appliances and transport) which are not covered for residents under the NHSS continues to cause conflict and stress.

This is an equity issue which must be addressed at Ministerial level to ensure more fairness in the system.

Age Action is aware that Nursing Homes Ireland, the representative body for private residential care setting providers, has communicated with its members on the need for openness and transparency in nursing home contracts.

We have been informed that the organisation has disseminated its template contract of care and relevant information booklets to its membership to enable these nursing

homes to offer as much clarity as possible to prospective residents and their families. Age Action welcomes this initiative.

However, not all private and voluntary nursing homes are members of Nursing Homes Ireland. There is also no obligation on individual members of Nursing Homes Ireland to follow or heed the advice provided by their representative body.

There is no guarantee that prospective residents' needs for information and clarity on costs are being currently being met.

Indeed, it is clear from the experiences of callers to Age Action that the quality and accuracy of critical information around these charges, as well as its accessibility, is completely inadequate. Clear information around additional charges (and other aspects of the contract) is not always provided nor made accessible (e.g. on their website) at this important stage of the transaction/negotiation period.

We await with interest the outcome of the work being undertaken by a Department of Health/HSE Group established to look at the issue of additional charges levied on residents who cannot participate because of their level of dependency.

We are also mindful that a Value for Money Policy Review which will examine HSE public long-term residential care facilities is expected to report in 2018 which will look at differences in the comparative cost of public and private long-term residential care.

We believe that more clarity is needed to ensure that the rights of older people entering nursing homes are upheld and that best practice is apparent in all aspects of the process of selecting a nursing home and entering into a contract of care.

We note the recommendation in the 2015 *Review of the Nursing Homes Support Scheme* which proposed that all nursing homes should provide an accessible fee schedule showing all costs for residents.

Age Action, like other stakeholder organisations such as SAGE, also wants to see the insertion of an opt out clause into the National Treatment Purchase Fund contract which can be used when a resident does not partake of certain activities. This is currently being examined by a Working Group within the Department of Health.

Recommendations

- 1. Age Action wants nursing home contracts to clearly specify which services residents are paying for in addition to the NHSS fee in an itemised manner and in accessible language.**
- 2. Age Actions wants the contracts of care to contain an opt in or out clause which clearly refers to the individual's capacity to participate in certain activities.**
- 3. Require all nursing homes participating in Fair Deal to submit their fee schedule to the NTPF for publication online.**
- 4. All nursing home contracts and handbooks must be written in plain English (with the assistance of the National Adult Literacy Agency (NALA) if needed) and must be obliged to provide in a prominent position information on how to make a complaint to the Office of the Ombudsman.**
- 5. Failure to comply with these recommendations, and other recommendations as put forward by the CCPC, should be punishable by fines.**

We also fully endorse the following SAGE⁸ recommendations on the issue of contracts of care.

The following practices should stop immediately:

- ✓ Increases in charges without any communication with the resident;
- ✓ Residents paying for services they are unable to avail of;
- ✓ Inclusion in the contract of charges for non-essential items which are voluntary and not compulsory.

Contracts of care should contain the following:

1. Full details of the services to be provided as a part of the "basic bed and board charge";
2. Full details of whether or not the services are being provided under the Nursing Homes Support Scheme or any other health entitlement;

⁸ <http://sageadvocacy.ie/wp-content/uploads/2017/10/Sage-Nursing-Home-Contracts-Discussion-Document-Sept-2017.pdf>

3. Inclusion in the contract of a specific list of services which are covered in the additional charges;
4. Details of any additional services/amenities being provided which are not covered under the Nursing Homes Support Scheme or any other health entitlement;
5. Differentiate between which of those additional services/amenities are regarded as essential (and therefore payment for them is compulsory) and which are regarded as non-essential (where payment is voluntary);
6. List the fees, if any, to be charged for each such additional service/amenity both essential and non-essential;
7. Provide a statement that non-essential services/amenities are voluntary and detail how the resident may opt out of them;
8. Clearly state the arrangements for the receipt of financial support under the Nursing Homes Support Scheme.

Nursing home contracts should not contain following terms:

Termination

The right of the Proprietor to terminate the contract without good and reasonable stated reason due to circumstances which are not within the control of the resident, or without consultation with the resident.

Alter Terms

The right of the Proprietor to alter the terms of the contract or charges without consultation with the resident and their relatives.

Vary Terms

The right of the Proprietor to vary the terms of the contract or charges without consultation with the resident.

Waiver or Presumption of Legal Advice

Any statement that the resident shall be assumed to have obtained independent legal advice on the contract or has waived their right to do so.

Restriction on Visitors

The right of the Proprietor to restrict visitors, except in exceptional circumstances e.g. where there is a risk of infection and where the restriction is also being applied to other residents.

Moving a Resident

The right to move a resident from their allocated room or another nursing home or hospital without their specific consent.

Changes to Fees or Charges or Services

The right to the nursing home to review fees and or services save in accordance with a set procedure which is clearly set out in the contract.

“Best Endeavours”

That the Proprietor shall use their “best endeavours” to comply with all Regulations and legislative provisions governing the provision of long term residential care to residents. This is not sufficient (see above under heading “Duties of Proprietor”).

8. Conclusion

To conclude, Age Action urges that the CCPC creates guidelines that incorporate the recommendations above in the interests of fairer, more transparent and equitable services for our most vulnerable citizens.

We note and endorse the speech made by Ombudsman Peter Tyndall at the launch of the Sage discussion document in October 2017 in which he said:

“What anyone would want for themselves or for their relative, as a resident of a nursing home, is that their loved one is cherished, in a place that makes them feel at home, comfortable and protected but all the while honouring their civil rights and freedoms. One of the first steps in this process when entering a nursing home, be it a public or private setting, is to ensure that the contract of care, which is agreed between the resident and the provider, is amenable to achieving this aim”

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