

Advocacy Matters:

Advocating for People Living in Nursing
Homes During the Covid-19 Pandemic



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About this Report

This report has been developed by the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service.

It is the last of four reports which outline the observations and experiences of our Advocates when providing independent advocacy to people living in nursing homes during the Covid-19 pandemic in Ireland, particularly during the period from March 2020 - March 2021.

This report, theme four, explains the issues people faced in relation to the restrictions in nursing homes during this traumatic period. It focuses on our work, outlining the support we provided and the positive outcomes this advocacy helped to achieve. It shows the key role that advocacy services play in supporting people who may be vulnerable in Irish society, particularly during periods of crisis.

Established in 2011, the National Advocacy Service for People with Disabilities (NAS) is an independent, free and confidential service, funded and supported by the Citizens Information Board. NAS provides representative advocacy to people with disabilities across Ireland, to ensure that their will and preferences are sought and heard in decisions that affect their lives.

NAS also hosts the Patient Advocacy Service, established in October 2019, which is commissioned and funded by the Department of Health. This free, independent and confidential service provides information and empowerment advocacy to people who want to make a formal complaint through the HSE 'Your Service, Your Say' complaints policy in relation to their care in a public acute hospital and in the aftermath of a patient safety incident.

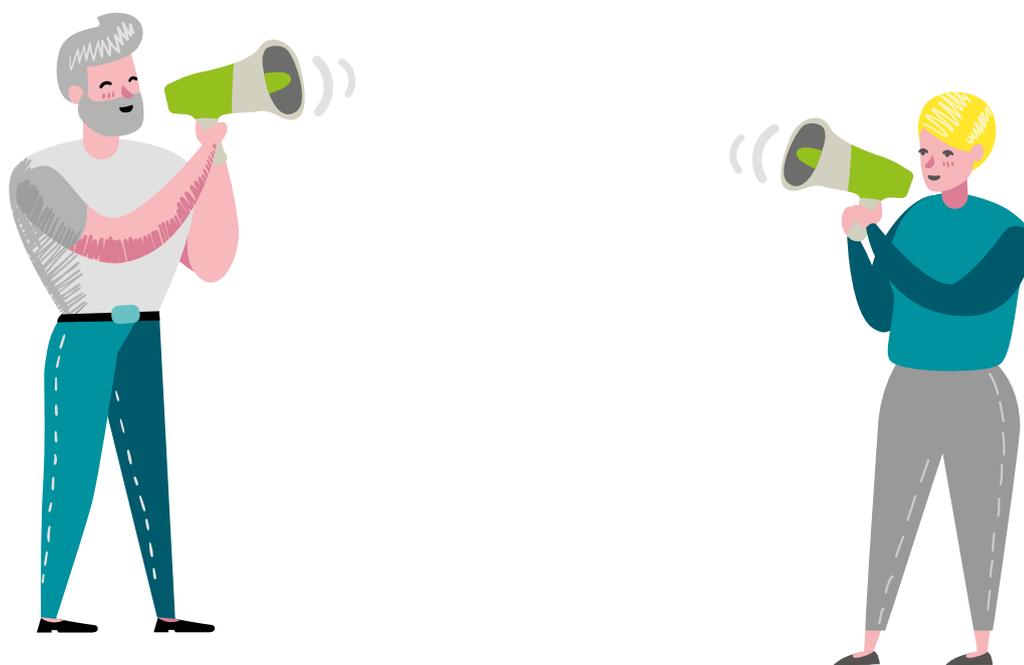
The Covid-19 Nursing Homes Expert Panel¹ report highlighted the need for nursing home providers to promote, facilitate and engage meaningfully with independent advocacy services. Following consultation with the Department of Health (DoH) and in response to the findings of its Expert Panel Report, the Patient Advocacy Service expanded its remit from 14th May 2021, to provide advocacy services to users of HSE Funded nursing homes, and users of nursing homes operated under arrangement pursuant to S.38 of the Health Act 2004. The Service will empower those who wish to make a formal complaint through the HSE 'Your Service, Your Say' complaints process about the care they have received in their nursing home.

¹ COVID-19 Nursing Homes Expert Panel (August 2020)
<https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>

The vision of NAS is one where people with disabilities can exercise their rights, with dignity, autonomy, equality and independence at the core. NAS recognises the capacity of people with disabilities to make their own decisions equally with others, in accordance with the United Nations Convention on the Rights of People with Disabilities² (UNCRPD). NAS works to advocate for the person's will and preference and to have their voice heard.

Both NAS and the Patient Advocacy Service recognise the rights of all people to support, guidance and information when issues arise in relation to their care and treatment which may lead to their wish to complain about their treatment or care or seek answers in the aftermath of a patient safety incident.

Please note, all statistics presented in this report are specifically looking at the period March 2020 – March 2021. They report on emerging and ongoing issues, resulting from the Covid-19 pandemic, which impacted on the lives of people supported by NAS and the Patient Advocacy Service.



² United Nations Convention on the Rights of People with Disabilities
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Key Recommendations in this Report

- ▶ It is crucial that nursing homes reflect on, review, and continue to improve their service delivery, adapting to the evolving situations arising from the ongoing pandemic. Nursing Homes should also consider the experiences of people supported by NAS and the Patient Advocacy Service, along with the learnings of our Advocates, to improve service delivery. It is imperative that people are supported to have their voice, will and preference heard and are included in decisions that impact on their lives.
- ▶ NAS should be adequately funded and resourced to ensure that it can continue to support people with disabilities to have their will and preference in decision making upheld.
- ▶ There is an over-reliance on the nursing home sector to provide care to a wide range of the population. The only statutory funding available to people is the Fair Deal Nursing Home support scheme. This limits the choice people have to access services.
- ▶ There should be increased funding for alternatives to nursing homes such as rehabilitation, supported accommodation and home care hours. Less emphasis should be placed on the Fair Deal Scheme, especially in cases following a stay in an acute setting.
- ▶ It is crucial that the Nursing Home Expert Panel (NHEP) Report³ recommendations are implemented regarding the integration of private nursing homes into the wider framework of public health and social care.
- ▶ In private nursing homes there is a need for a suitable structure and process for external oversight of individual care concerns arising in nursing homes, once internal processes have been exhausted without satisfaction as recommended by NHEP recommendation 15.3.
- ▶ Recommendation 13.1 of the NHEP report should be implemented which provided for support and communication for residents and their families to be a continuing priority.

³ Covid-19 Nursing Homes Expert Panel
<https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>

- ▶ Recommendation 15.4 of the NHEP report which provides that HIQA and each nursing home provider should continue to highlight and promote independent advocacy services available to residents should be implemented. However, there should be regulatory or statutory requirement for access to advocacy.
- ▶ A more robust standardised complaints policy, like the HSE's 'Your Service Your Say'⁴, should be put in place across all private nursing homes to ensure there is good governance over the complaints process. The recommendations from the NHEP report also highlight the need for better governance in private nursing homes and these recommendations should be implemented.
- ▶ There must be a standardised consultation, planning and handover process involved in the discharge and transfer of patients from acute hospitals to nursing homes. People need to have a choice about where they are moved to. For those people who are inappropriately placed in nursing homes, additional staff are required to provide one-to-one support for these people to engage in meaningful activities.
- ▶ The proposed HSE pilot project⁵ to support people under 65 living in nursing homes must be instigated and properly funded. Longer term, a cross departmental group that also includes people living in nursing homes and families, the nursing home sector, the HSE and other stakeholders should be established with the aim of moving all people under the age of 65 out of nursing homes into accommodation of their choice.
- ▶ There is a need to review the bedroom and communal space capacity of nursing homes. All people living in nursing homes should ideally have single rooms with ensuite bathroom facilities, smaller numbers in communal areas, and outdoor space for activity in isolation. This offers the ability to contain infection in one area should the need arise.



⁴ Your Service Your Say <https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/ysys2017.pdf>

⁵ <https://www.thejournal.ie/younger-people-in-nursing-homes-report-5428570-May2021/>

- ▶ Recommendations 13.3 and 13.4 of the NHEP report stress that nursing homes should develop plans to improve their communication with those living there and families by providing information in an accessible format and establishing IT infrastructure, such as video calls and WhatsApp. Nursing homes should have dedicated staff to facilitate communication.
- ▶ Within nursing homes, information and access to advocacy services and mental health supports should be provided. The recommendations from the NHEP report also highlighted the need for people living in nursing homes, both public and private, to have better access to independent advocacy. The Programme for Government⁶ also asked for continued support for the Patient Advocacy Service.
- ▶ There is a need for safe visiting rooms to facilitate visits from family and friends, and access to GPs and health professionals.
- ▶ There should be clear guidance on staffing levels, training and experience in nursing homes. There should be more permanent contracts and less reliance on agency staff to avoid cross contamination.

Key Conclusions in this Report

- ▶ NAS provides a crucial means of support for people with disabilities to ensure the person's voice is heard. The Patient Advocacy Services also offers an important means of support for people who have had a negative experience regarding their care in a HSE-funded public acute hospital or a HSE-operated nursing home and wish to make a formal complaint to the HSE.
- ▶ The Services uphold the person's rights, ensuring fair and equal treatment and access to services. They make certain that decisions are taken with due consideration for a person's unique preferences and perspective, will and preference.
- ▶ The Covid-19 pandemic and the subsequent impact on nursing homes had a significant impact on the lives of the people supported by both Services.



⁶ Programme for Government: Our Shared Future
<https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/>

- ▶ NAS and the Patient Advocacy Service have continued to provide support for those living in nursing homes and their families, working with nursing homes to ensure meaningful communication and visits could take place. They provided support and reassurance to people who experienced isolation, loneliness and fear around the pandemic.
- ▶ Despite preventative measures, there has been an increased risk of infection for people in nursing homes, while the people living in these settings also have a higher risk of transmitting the virus. People in nursing homes are more likely to have existing health issues that increase their risk of contracting Covid-19.
- ▶ People in nursing homes have faced the most extreme restrictions in society, with some having to stay in their rooms 24 hours a day, with no access to friends or family. Due to staffing issues, many people have not been able to receive the care, information and reassurance they need from staff. This resulted in people feeling isolated, fearful and unsure of what was happening.
- ▶ At the beginning of the pandemic, a lack of information, technology and safe spaces impeded communication between Advocates and people living in nursing homes. This was particularly concerning at a time when people had already been exposed to challenging circumstances and events beyond their control.
- ▶ Our Services noted some nursing homes did not have a clear protocol for managing the virus, while family members expressed their fears that care plan were not being followed. Families also raised concerns about Personal Protective Equipment (PPE) availability and usage.
- ▶ NAS has been aware for a number of years of the numbers of people under 65 living in nursing homes. As nursing homes are primarily designed for older people, many people under 65 do not want to live there. NAS has advocated on behalf of these individuals for many years.
- ▶ NAS Advocates also provided advocacy support to people who were participating in the Ombudsman's report "Wasted Lives: Time for a better future for younger people in Nursing Homes⁷," which was published in May 2021.



⁷ Wasted Lives: Time for a better future for younger people in nursing homes, Office of the Ombudsman <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>

Impact of Covid-19 on our Services

Before focusing on the issues Covid-19 has caused for people living in nursing homes, it is important to note the impact of the virus on the services provided by NAS and the Patient Advocacy Service.

The emergence of the Covid-19 virus in March 2020 meant it was impossible for the two services to continue their normal way of office working, including meeting people face-to-face. Overnight, staff moved to working from home, a situation which continues over one year later.

While some organisations struggled to respond effectively to operational changes, NAS and the Patient Advocacy Service continued to manage national phone lines and online methods of enquiry (email, website). This has ensured that NAS has continued to advocate for people with disabilities to ensure that their voices are heard when decisions are being made on public health grounds, and to advocate with them and for them to have access to services and supports at this challenging time.

In addition, particularly at the beginning of the pandemic lockdown, Advocates from both Services provided support beyond their remit by helping people to access services such as shopping, GPs and pharmacies, as well as Covid-19 pandemic unemployment payments.

Meeting the people we support face-to-face also proved challenging as Advocates could not spend time with them to observe and understand their will and preference fully. Responding to these difficulties, Advocates utilised alternative methods of communication such as, phone calls, video calls, emailing and text messaging. To continue with the provision of advocacy for some people, particularly those who communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) Advocates had to rely on the support of families and service providers to aid with continued communication. Despite these communication challenges, NAS worked with the person to ensure their will and preference were carried out.

The Patient Advocacy Service has also continued to provide advocacy support and information to users of its service during the pandemic through its national phone line and online forums. The model of empowerment advocacy has allowed for the Patient Advocacy Service to provide the same level of support to the users of its service without interruption. The use of technology such as Zoom and conference calls as alternative methods of communication worked well for most people supported by the Patient Advocacy Service and for some people has led to increased accessibility with their Advocate.

Covid in Nursing Homes: Responding to the Crisis

“Thank you so much for taking the time to help me, it is kindness such as yours that restores my faith in humanity.”

John, who was supported by our Services in 2021

NAS has a particular remit to work with those who may be isolated from their community of choice or mainstream society, those who may communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) and those who have limited informal or natural supports.

NAS and the Patient Advocacy Service uphold the person’s rights, ensuring fair and equal treatment and access to services. Advocates make certain that decisions are taken with due consideration for a person’s unique preferences and perspective, will and preference.

The Services’ empowerment and representative advocacy involves professional, trained experts in advocacy dealing with specific issues and working with an individual until that issue reaches conclusion. Independent, empowerment and representative advocacy is directed by the people who use it. Where the person communicates differently, the Advocate is still directed by the person.

In ordinary times, the people that NAS works with face rights restrictions and have poorer access to health, education and employment. They have difficulties in accessing justice and decision making and are more likely to experience discrimination.

People with disabilities and those accessing health, nursing and social care supports are a very diverse group and some within this group face even greater marginalisation. These include those experiencing mental health issues, those from different migrant or ethnic groups, and those who communicate differently. During the Covid-19 pandemic, these issues were further exacerbated for people with disabilities and those who are living in a nursing home.



One of the worst hit services has undoubtedly been nursing homes where people living there have dealt with issues such as high rates of transmission, issues around staffing and Personal Protective Equipment (PPE), a lack of communication, isolation, anxiety and fear caused by an unknown and potentially deadly virus.

According to statistics from the Health Protection Surveillance Centre's (HPSC) Computerised Infectious Disease Reporting System (CIDR), as of 20th October 2021 over 2,100 residents⁸ of Ireland's 576 registered nursing homes have died as a result of contracting Covid-19 since the pandemic began.

Nursing home settings have been particularly vulnerable to outbreaks of Covid-19. There has been an increased risk of infection for people living in these settings who, despite preventive measures, may not be able to socially distance, wash their hands or wear their masks. The people living there also have a higher risk of transmitting the virus⁹.

People living in nursing homes are more likely to have existing health issues which increase their risk if they contracted Covid-19. This has been a cause of great anxiety for many people living in nursing homes and their loved ones. People living in nursing homes have been significantly impacted by restrictions and disruptions to services, with those living in congregated settings such as nursing homes facing the most extreme restrictions to their lives.

Advocates received reports from people they support that in some cases people were asked to stay in their room all day and night. This led to people feeling isolated, alone and fearful of what was happening in the nursing homes and outside.

People in nursing homes were asked to restrict their lives even more so than those in the community to prevent the spread of the virus within the nursing home. Advocates were told that in some cases even as restrictions eased for the public, strict restrictions remained in place in nursing homes.

8 Weekly report on COVID-19 deaths reported in Ireland, produced by Health Protection Surveillance Centre https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/surveillance/weeklyreporton-covid-19deathsreportedinireland/COVID-19_Weekly_Death_Report_Website_v1.5%2019102021.pdf

9 Rapid review of public health guidance for residential care facilities in the context of COVID-19 <https://www.hiqa.ie/sites/default/files/2021-05/Rapid-review-of-public-health-guidance-for-residential-care-facilities-in-the-context-of-COVID-19.pdf>

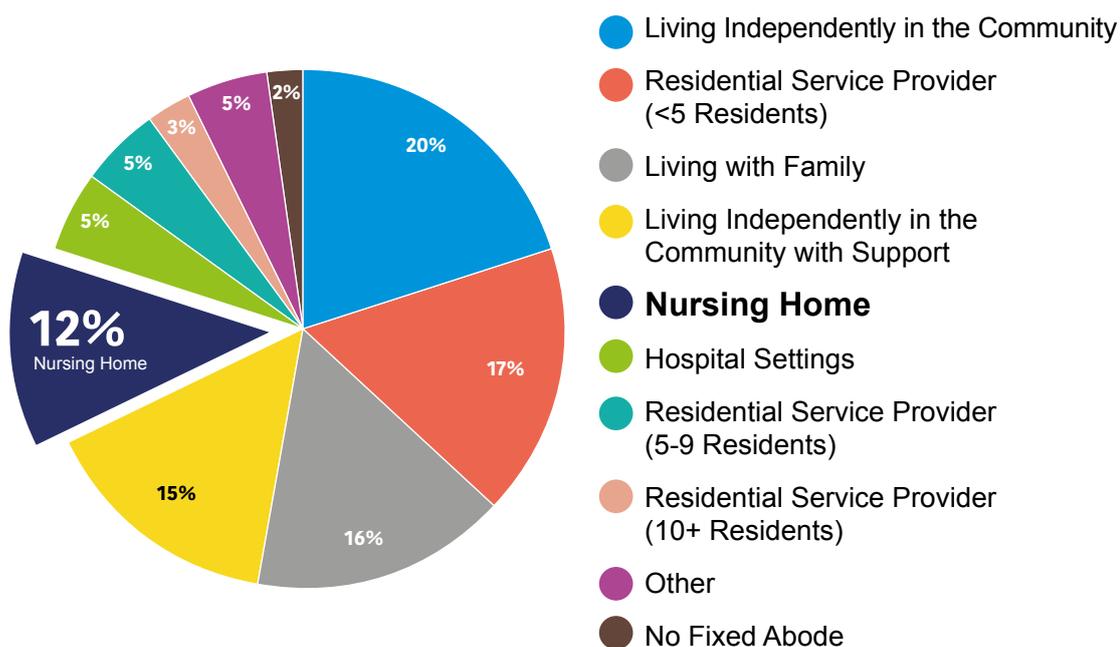
At the beginning of the pandemic, a lack of information, technology and safe spaces impeded communication between Advocates and people living in nursing homes. This was particularly concerning at a time when people had already been exposed to challenging circumstances and events beyond their control.

In the pandemic’s early stages, family members contacted our Services with concerns that some nursing homes did not have a clear protocol in managing the virus. Within the nursing homes some people were placed together in dayrooms due to staff shortages. This included people who were symptomatic of Covid-19 but not tested.

Families also raised concerns to our Services about PPE availability and usage. In one case, a person was symptomatic of Covid-19 and isolating in their own room. The person’s family was allowed to visit, and they observed that there was no signage on the door to the person’s room to flag the person was symptomatic, staff were not wearing full PPE and staff went between rooms. The lack of PPE availability was widely reported in the Irish media¹⁰ during 2020 and led to concerns about infection control.

NAS has provided advocacy supports for people with disabilities living in nursing homes throughout the Covid-19 pandemic on a wide range of issues with 12% of Covid-19 related issues dealt with by NAS relating to this.

Location of Person with an Issue Impacted by Covid-19



10 <https://www.thejournal.ie/nursing-homes-ireland-ppe-5107840-May2020/>

Within nursing homes, Advocates continued to provide support for people living there and their families, working with services to ensure meaningful communication and visits could take place, checking in regularly with the people they support to maintain contact to reduce the isolation they felt, raising any concerns and visiting people when it was possible. NAS provided vital support to people who were experiencing isolation, loneliness and fear around the pandemic.

Through our work in nursing homes, Advocates have observed a range of issues for people living there around four key areas of concern:

- ▶ Communication and visiting
- ▶ Infection control
- ▶ Isolation and mental health
- ▶ Inappropriate placement of younger people in nursing homes

Our Services supported several people at the beginning of the pandemic who were being discharged from acute hospitals and who were then placed in nursing homes.

NAS also provided advocacy support to people who were participating in the Ombudsman's report "Wasted Lives: Time for a better future for younger people in Nursing Homes¹¹," which was published in May 2021. According to the Ombudsman's report, it is estimated that there are 1,300 people under 65 with disabilities inappropriately placed in nursing homes.



11 Wasted Lives: Time for a better future for younger people in nursing homes, Office of the Ombudsman <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>

Covid's Impact on Nursing Homes and their Staff

When the Covid-19 pandemic hit Ireland, our nursing homes and their staff were challenged to respond to a rapidly changing and unknown highly contagious infection. Nursing homes had to adapt how they operated to continue service delivery while keeping the people they care for and staff as safe as possible. Nursing home staff went lengthy periods without leave and often had to isolate from their own families to keep the people they were caring for safe.

We acknowledge the significant impact Covid-19 has had on nursing homes and their staff in Ireland. Many have been left emotionally distressed and frustrated. Concerns of “Psychological distress, exhaustion and burnout” were highlighted in a report ‘The impact of the COVID-19 pandemic and the societal restrictions on the health and wellbeing of the population, on our staff and on health service capacity and delivery: A plan for healthcare and population health recovery’¹², which also highlighted the staff supports available and the need to look after staff so they can continue to care for the people who need it.



¹² The impact of the COVID-19 pandemic and the societal restrictions on the health and wellbeing of the population, on our staff and on health service capacity and delivery: A plan for healthcare and population health recovery <https://www.hse.ie/eng/about/who/qid/covid-19-qi-learning/qi-resources-to-support-learning-from-covid19/covid-19-pandemic-impact-paper-2021.pdf>

Communication and Visiting

“There was great comfort in knowing that your service will be with me throughout the process, talking to me and explaining what was happening.”

Susan, who was supported by the Patient Advocacy Service in early 2021

NAS and the Patient Advocacy Service were contacted by many people we support during the Covid -19 pandemic about arrangements for communication and visiting practices in nursing homes.

The HIQA ‘National Standards for Residential Services for Children and Adults with Disabilities’¹³, ‘National Standards for Residential Care Settings for Older People in Ireland’¹⁴ and the recently published ‘Guidance on a Human Rights-based Approach in Health and Social Care Services’¹⁵ say it is the role of a service provider to ensure that people are supported to maintain and develop personal relationships with family and others. A lack of meaningful relationships and social isolation can have a detrimental impact on a person’s mental health and wellbeing.

Despite these standards, when visiting restrictions were in place during the pandemic, particularly during the first period of lockdown, families said they had no way of communicating with their loved ones and no way of knowing if they were safe from the virus or not.

Families found it very difficult to get updates from nursing homes and were not always told if their loved one was being tested for Covid-19. In some cases, they were only being informed when the result came back as Covid-19 positive.

Communication with families from the nursing home was not always comprehensive and often families were not aware how serious the outbreak was within the nursing home or that an outbreak had even occurred.

13 National Standards for Residential Services for Children and Adults with Disabilities, HIQA, 2013
<https://www.hiqa.ie/sites/default/files/2017-02/Standards-Disabilities-Children-Adults.pdf>

14 National Standards for Residential Care Settings for Older People in Ireland
<https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf>

15 Guidance on a Human Rights-based Approach in Health and Social Care Services, HIQA, 2021
<https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF>

NAS communicated with nursing homes on the importance of family contact for people during this time. Advocates listened to the people they worked with, advocating on their behalf to staff in nursing homes to ensure that contact with families was supported and facilitated by the nursing home. In some cases, this was done via phone call or video call, or as restrictions eased, window and doorway visits took place.

The Patient Advocacy Service encountered family members who were unable to contact nursing homes. Several people told the Service's Advocates that they had received very little communication from nursing homes and were unable to make contact on phone lines.

This resulted in families not having a full picture of what was happening with their loved ones, or the impact that the Covid-19 pandemic was having on staffing levels and level of care. This lack of communication also left many families unaware of the seriousness of their loved one's condition. Family members spoke of the anxiety and distress the lack of communication caused them, while others said they could only see their loved ones through windows.

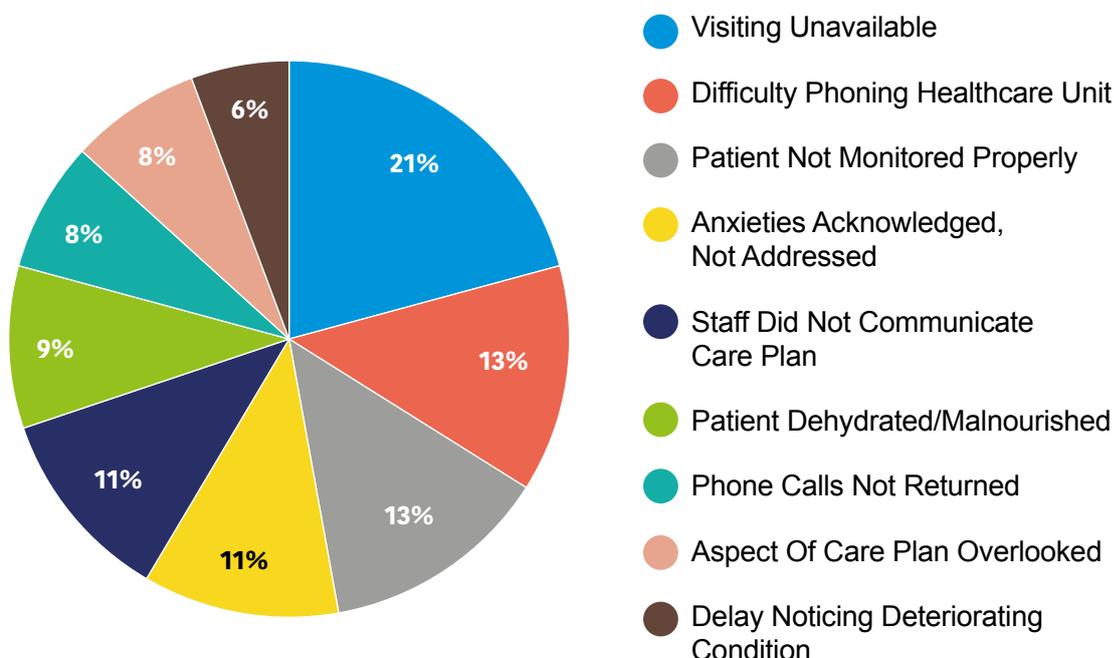
In one case, a person's family was calling them daily, but they were unable to answer the phone in their room as it was out of their reach. There were no staff available to help them to answer it. The person spoke about not being able to reach out and speak with their family and could only lie in bed hearing the phone ring.

Our Services were informed by some family members that care plans were not being followed by certain nursing homes due to the impact of the virus. In addition, when care plans were updated, Advocates were told there was little or no input from the people themselves or family members.

Both our Services have worked with families who did not get to see their loved ones before they passed away and were left with the worry that they died alone and scared. Many of these families have expressed their feelings of guilt for not being able to do more and not knowing how seriously ill their loved ones were.

In one case, an Advocate supported a family who had to watch their loved one dying through a window. When their loved one died, a family member had to inform the nursing home staff. This caused deep upset and trauma for everyone involved. The Advocate supported this family to get their loved one's medical records so that they could understand their condition prior to their passing.

Patient Advocacy Service - Most Reported Issues Impacted by Covid-19 in Nursing Homes



NAS and the Patient Advocacy Service were made aware of severe staff shortages in some nursing homes due to the impact of the virus. According to the HIQA report, ‘The Impact of Covid-19 on Nursing Homes in Ireland’, inspectors found that “Due to the number of staff impacted by the virus, the resulting increase in care needs of residents due to the virus, and staff shortages, there were insufficient numbers and skill-mix of staff to care for residents.”¹⁶

People living in nursing homes have said they were not kept up to date on public health developments and that communication was lacking from the staff in these settings. They told Advocates that staff were unable to spend time with, provide them with human contact or give them the information, reassurance and emotional support they required.

Advocates from our Services listened to the people they supported and provided emotional support during this time to those feeling isolated and alone. NAS Advocates made representations to nursing home management on people’s behalf to ensure the person’s voice was being heard during this difficult time.

¹⁶ The Impact of Covid-19 on Nursing Homes in Ireland’ https://www.hiqa.ie/sites/default/files/2020-07/The-impact-of-COVID-19-on-nursing-homes-in-Ireland_0.pdf

When visiting restrictions were lifted at different levels of lockdown Advocates also experienced difficulties in accessing nursing homes and disability services, even though Advocates were deemed to be essential visitors by the HPSC¹⁷ guidance document.

In one case, a person working with NAS was asked to add the Advocate to their list of personal visitors (which is for family and friends). This would have affected the number of personal visitors the person could have if one was the Advocate. The Advocate wrote to the nursing home's director of nursing explaining their role and the person's right to advocacy. They also cited the HSE guidance on essential visitors¹⁸, which gives recognition to advocates, and this addressed the matter.

In some cases, it was difficult for Advocates to communicate with people as appropriate technology was not accessible to meet the needs of people with disabilities. As a result, Advocates asked some nursing homes to buy communications devices, such as tablets and iPads, so those living there could communicate with their families. They also requested that staff support people to use the new technology.

It has taken a considerable amount of time for suitable IT infrastructure and technology to be put in place for people to contact their families. Some nursing homes have worked on developing alternative ways for families to communicate with their loved ones, using video calls and creating specific visiting spaces. Others who need assistance to use technology have said this has impacted on their privacy when talking to their family.

When the IT infrastructure was in place NAS found that services adapted practices to incorporate video calls via Zoom, or aiding Advocates to support and work with people in the most suitable manner possible.

In one case, NAS supported a person with an intellectual disability who was living in a nursing home. The person attended a day service for people with disabilities outside of the home. When the Covid-19 pandemic began, the nursing home went into lockdown and the person's day service was stopped. The person was asked to stay in their room all day and night to prevent the spread of infection and keep safe. All visits from the person's family stopped. The activities that the nursing home provided also stopped.

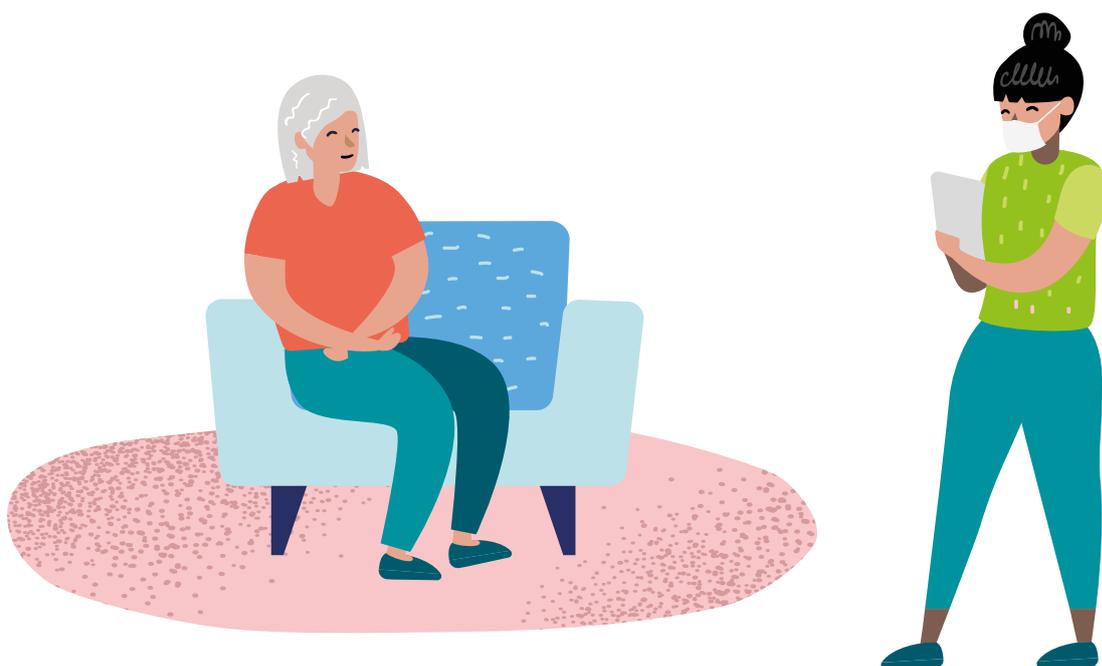


17 COVID-19 Guidance on visits to and from residential facilities for people with disabilities V1.2 15/04/2021

18 COVID-19: Normalising Visiting in Long Term Residential Care Facilities (LTRCFs) V 1.1 10.11.2021
<https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/infectionpreventionandcontrolguidance/residentialcarefacilities/Normalising%20visiting%20in%20LTRCF.pdf>

The person told the Advocate that they felt nothing was being explained to them. They had a lot of fear about what was going on. They were aware of staff shortages due to illness, and this worried them. The person wanted to communicate with their family via video call, but at times the staff were too busy to facilitate this. The person felt alone and isolated. The Advocate listened to how the person was feeling. They wrote to the Director of Nursing in the nursing home and highlighted the case to the Ombudsman. Once restrictions eased, a plan was put in place for the person to meet their family once a week outside of the nursing home. The Advocate also met with the person's family to communicate the plan. The Advocate helped reduce the person's isolation and ensured their voice was heard.

In another case, an Advocate worked with a person living in a nursing home during the first lockdown. The Advocate maintained regular phone contact with the person to offer support and check on their mental health. The person identified concerns about how and when they would see their young children. The Advocate worked as a link between the nursing home and the person and highlighted to the nursing home's staff the necessity for the person to see their children in some capacity. As a result of the Advocate's contact, the nursing home organised window visits/doorway visits for the person to meet with their children.



Niamh's Story: Visiting and Communication Issues

My name is Niamh and my mother Sarah died while living in a nursing home during an outbreak of Covid-19. Before Covid hit I would have visited her twice a day, every day. When the virus reached Ireland, restrictions were put in place and all my visits were stopped.

Throughout the Covid outbreak, communication with the nursing home was an issue. I wasn't allowed in to see my mother, so I relied on the staff to keep me updated on how she was doing because she could not tell me herself. I feared she would catch the virus.

I phoned and emailed constantly trying to get an update but very rarely got to speak to anyone. I was so worried I began to sit outside my mother's room looking in the window to keep an eye on her a few times a day.

My mother became very unwell, and she tested positive for Covid-19. She deteriorated very quickly, and we were allowed some short visits with her. On the day she passed away I had a short visit and was asked to leave. She passed away on her own while I watched through her bedroom window.

This was hugely upsetting as I had been told I could be with her as she passed.

I contacted an Advocate because I had concerns about the care my mother received in the weeks before she died. My Advocate has helped me to get my mother's records and review them to make a complaint.

I was not happy with the response to my complaint from the nursing home and the Advocate helped me to seek an internal independent review. When I got the response to the independent review I was still not satisfied. My Advocate is now supporting me to make a formal complaint to the Ombudsman's office.



Infection Control

Strict restrictions imposed during the Covid-19 pandemic meant that people living in nursing homes were not free to leave their home for any reason. This had a grave impact on the mental health and wellbeing of people many of whom reported feelings of isolation during this time.

People living in nursing homes were no longer free to access activities and or services in their local community. In addition, recreational activities provided in house by external organisations or people also ceased during this period. These restrictions limited opportunities for people living in nursing homes to engage in meaningful day to day activities.

In its report, 'The impact of Covid-19 on nursing homes in Ireland', HIQA says that infection control measures were heightened in nursing homes, and they became more clinical settings. The report says that "After years of moving towards a more homely, social model of care, the pandemic meant the rapid re-introduction of the medical model of care. Some residents expressed a sense of anger and frustration".¹⁹

Advocates were told by some people living in nursing homes that they were largely confined to their own bedrooms due to infection prevention measures. This meant they were not only cut off from their loved ones outside, but they were also cut off from their friends inside their nursing homes.

During the initial stages of the Covid-19 pandemic, particularly during the first lockdown, Advocates from NAS and the Patient Advocacy Service were told by the people living in nursing homes that physical distancing measures were often poor, with some nursing homes not having the capacity for distancing due to shared rooms.

Our Advocates have been told that some nursing homes placed people who tested positive for Covid-19 with people who had Covid-19 symptoms but had not been tested or were awaiting test results. The Patient Advocacy Service was also informed that people in some nursing homes were placed in communal spaces with other residents due to staff shortages. This caused distress to the person living there and their family members as they were concerned about infection control in the nursing home.

¹⁹ The impact of Covid-19 on nursing homes in Ireland
https://www.hiqa.ie/sites/default/files/2020-07/The-impact-of-COVID-19-on-nursing-homes-in-Ireland_0.pdf pg 32

There have also been reports that staff shortages due to Covid meant that some nursing homes found it difficult to maintain proper infection prevention and control standards. Some nursing homes were short staffed when it came to housekeeping and cleaning staff. This impacted on their ability to maintain a clean environment when it was needed most.

In some reports, there were also cases of shortages and misuse of Person Protection Equipment (PPE). People spoke of staff not wearing masks and moving between different rooms, while others spoke of how overwhelming it was to see people wearing full PPE.

Advocates listened to the people's concerns and ensured their view and concerns were heard. They provided emotional support to those living in nursing homes who were experiencing loneliness and anxiety and they spoke to the management of nursing homes to explain how people were feeling and to ask for increased support and care to be given where possible. Advocates also continued, where appropriate, to escalate issues to the HSE's safeguarding teams.

Infection control in nursing homes has improved since the start of the pandemic, with PPE supply issues having been resolved and policy documents developed. However, there continues to be a lack of clarity about the HSE's responsibility and governance within the private nursing home sector. As a result, operational inconsistencies have persisted.

During the pandemic, the Patient Advocacy Service provided empowerment advocacy, information and support for nursing home complaints. The Service assisted family members to access nursing home complaints procedures and provided advocacy support to family members in seeking medical records and drafting letters of complaint.

There have been some cases where Advocates from our Services were informed that people from nursing homes who presented to hospital were severely dehydrated, while others had excoriated skin and bed sores. Advocates supported family members to seek medical records from the hospital to understand how their loved ones were admitted in such a condition.



Isolation and Mental Health

“It was great to have someone there to tell me the truth about the pandemic. Your honesty and reassurance were a big help.”

David, who was supported by NAS in 2020

The impact of the Covid-19 pandemic has had a negative impact upon the mental health of the people supported by NAS and the Patient Advocacy Service.

NAS statistics show that mental health has been the biggest single emerging issue for people with disabilities receiving the Service’s support during the Covid-19 pandemic. For the period March 2020 – March 2021, mental health and wellbeing accounted for nearly 14% of the emerging issues dealt with by NAS.

For people living in nursing homes, issues related to mental health and isolation have been widespread. The associated fear and anxiety of contracting the virus has been a continuous burden. This has been heightened by the high rate of transmission they have experienced.

People in nursing homes have experienced huge isolation throughout the pandemic. Visiting restrictions meant that they were unable to meet their families and loved ones in person. Services adapted by supporting people to make telephone calls and video calls via Zoom and Skype, but this was not a substitute for face-to-face contact.

Throughout the pandemic, NAS adapted their advocacy practice to ensure support could be maintained for those we work with living in nursing homes. Advocates quickly began linking with people via phone and video call. In some cases, Advocates provided emotional support and listened to those in nursing homes who were the most isolated and fearful at one time. We continued to advocate for people’s right to dignity, independence and wellbeing to service providers and to maintain contact with families and friends where applicable.

People living in nursing homes have spoken of their fear of catching Covid-19 and how they have been impacted by watching so many people they live with die. Others have said they felt like they were forgotten about and found that their mental health was affected by the constant discussion of risks and even death.

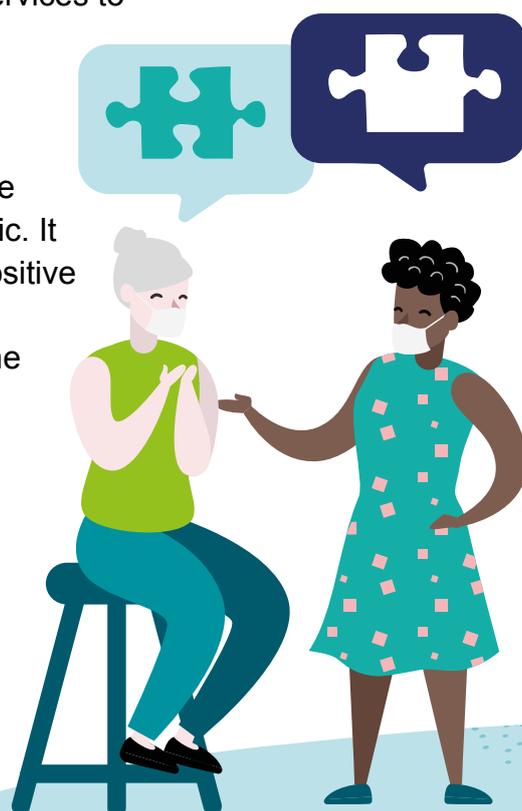
In one case, a person with an intellectual disability living in a nursing home was required to remain in their bedroom due to Covid restrictions. The person did not understand what was happening and was very confused. The person's Personal Assistant (PA) was not allowed to enter the nursing home as they were external staff. The Advocate requested that internal staff be supported to provide PA supports to the person so that their normal support service could be maintained, and the person would spend less time alone in their bedroom. This increased the person's quality of life at a very difficult time.

In another case, NAS advocated for a person in a nursing home who had still not returned to day service, even as Covid-19 restrictions eased. The person told their Advocate how much they missed the routine of the day service and spending time with their friends. The Advocate contacted the day service centre and was informed that because the person was living in a group facility and not in a private home, they could not return to the service at that time.

With the person's consent, the Advocate wrote a letter to the Service Manager highlighting the negative impact the unnecessary restrictions were having on the person and stressing the need for rights restrictions to be proportionate to public health guidelines. Within a couple of weeks, the person returned to their day service for one day a week, with the plan for this to increase gradually over time.

Our Services also helped people to access other organisations that could offer them support and guidance. Advocates researched support mechanisms and helped people contact the Services to explain their person circumstances.

An example of this involved a case where an Advocate supported a person to link in with a mental health organisation **Headsup**. This gave the person an outlet during part of the pandemic. It involved a 12-week programme focusing on positive mental health, setting goals and taking action. The person reported that they really enjoyed the programme, where they met new friends and learned new skills.



Mary's Story: Isolation and the Impact on my Mental Health

My name is Mary I have been living in a nursing home for several years. An Advocate was working with me before the Covid pandemic to support my wish to move to the community as I had been inappropriately placed in a nursing home.

I attend college a couple of times a week. This is the only opportunity I have to meet people and socialise outside the nursing home. It really helps with my confidence and mental health.

In September 2020, during the Covid-19 pandemic, the manager of my nursing home said I was not allowed to leave the home to attend my college course. The manager said this was due to infection control and posed a risk to the other residents. I found this very difficult, and I knew it would leave me very isolated.

I discussed the situation with my Advocate and together we decided they would organise a meeting with the manager. With the support of my Advocate, I stressed that there were controls in place at the college which made it a safe place for me to attend, and I made it clear I would stick to all public health measures while out of the nursing home.

My Advocate and I acknowledged it was a difficult time for the nursing home, who wanted to protect all residents from the virus, but we made it clear that it was important for my mental health and wellbeing that I continue to attend college. I would not have put myself at risk as I was also scared of contracting the virus.

My appeal was successful, and the manager acknowledged she had no right to detain me. I went back to college, where I continue to attend, and I feel fulfilled.



Inappropriate Placements: People Under 65 Living in Nursing Homes

“I don’t know what I would have done if it hadn’t been for my NAS advocate. They supported me to have my wishes heard.”

Tom, who was supported by NAS in 2020

NAS has worked with people under 65 with a disability who were inappropriately placed in nursing homes before the Covid-19 pandemic began. These people have been living in the community or had a stay in an acute hospital setting. Due to a change in their circumstances the necessary home support packages are no longer available to support them at home, or not available at all.

According to the Ombudsman’s ‘Wasted Lives’ report, it is estimated that there are 1,300 people under 65 with disabilities inappropriately placed in nursing homes. The Ombudsman describes the situation of younger people living in Nursing Home as follows:

“Living in a nursing home for older people can affect the quality of life of a younger person. Usually, this is not related to the quality of care provided by an individual nursing home but rather the appropriateness of placement. Younger people have a particular set of needs, which are often different to those of older people.

Nursing homes in Ireland are largely designed for older people and this is their main focus of care. This means that staff training and the nature of the service provided are more focused on this age group.”



During the pandemic, NAS experienced an increase in the number of people under 65 finding themselves placed in a nursing home. People have reported that social workers or discharge coordinators from hospitals have helped them to sign up to the Fair Deal scheme for nursing homes without alternative options being discussed or knowing the long-term consequences.

People explained that they thought a nursing home was a short-term alternative to hospital as they recovered from an illness, as the hospitals were cleared in early 2020 to make room for the large number of Covid-19 patients expected. Nursing homes were initially viewed as a safer environment than a hospital setting.

Many months later, people supported by NAS and the Patient Advocacy Service say they have found themselves inappropriately placed in a nursing home setting without the adequate supports to enable them to move to their own home and live in the community.

Due to the restrictions, they had to continue to live in the nursing home. They also lost other supports like day services, personal assistance hours and all access to the community which has impacted their mental health negatively and led to feelings of isolation. In one case, the only visit a person received for over a year were window visits from their key worker.

People under 65 also spoke to Advocates about their fear of contracting the Covid virus and the lack of PPE worn by nursing home staff. There were several cases reported to NAS where people under 65 living in nursing homes had contracted the Covid virus and were scared for their own lives having witnessed the deaths of other people living with them.

NAS also found that nursing homes had a higher level of public health restrictions than disability services. As restrictions began to ease, under 65s were often not supported to return to community supports and day services, due to the perceived risk posed to other people living in the nursing home. One person reported they did not have “permission” to go and meet friends for walks and felt they could not have any independence.

NAS continued to ask the management of nursing homes to address these issues on behalf of the people we were working with throughout this time. We had beneficial outcomes for many of the people we worked with.

By communicating with nursing home management/decision makers, Advocates ensured the voice of the person they were working with was heard and listened to. NAS also advocated for the rights of people with disabilities and stressed that restrictions to people's rights should be balanced proportionately with public health guidelines.

NAS also continued to support people to engage with the Ombudsman in preparation for the Wasted Lives Report, which highlighted the issue of people with disabilities aged under 65 who are living in nursing homes due to a lack of community supports available.

Advocates also supported people to make complaints to the Ombudsman as they had no access to funding for appropriate community and disability specific services. The Ombudsman investigated the complaints and began working on their report.

Advocates supported people to record their experiences to inform the report. NAS also supported people to be kept up to date on the report and the publishing of this.

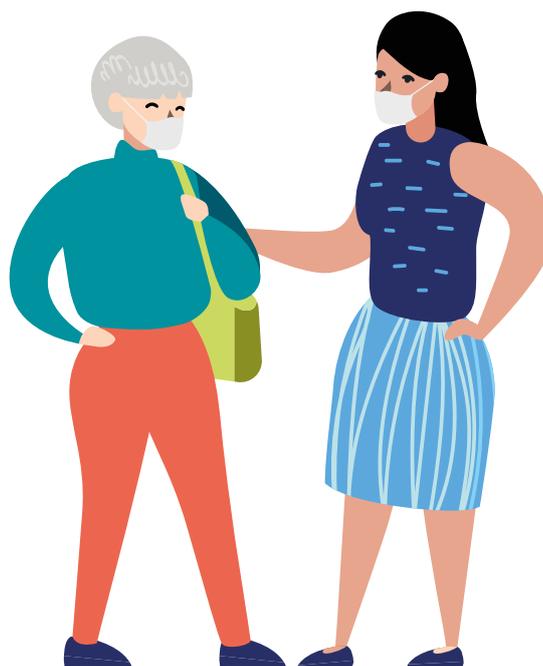
In one case, NAS supported a young person where a support package had been agreed for them to return home to live. Due to the impact of Covid-19, the new support staff were not allowed into the nursing home to spend time with the person and get to know them. The person passed away without having the opportunity to return to live in their own home.



NAS also supported another young person who had accepted a nursing home placement on a short-term basis and found they were there far longer than they had anticipated. During Covid-19, the person was confined to their bedroom 24 hours a day. The Advocate linked this person with the **Irish Human Rights Equality Commission** and the person was enabled to return to their home, with 24 hour supports, 7-days per week, which was required by the person to live in their own home.

In another case, NAS supported a person with a disability in their 40's. The person went into hospital during the pandemic for treatment. The hospital suggested that the person be discharged to a nursing home as the discharge plan. The person was clear they did not want this. They wanted to return home, with appropriate home care supports and continue to live in the community. The Advocate worked with the person's Multi-Disciplinary Team (MDT) and supported the person's will and preferences. The person was discharged home with an appropriate support package.

Access to specialist multi-disciplinary support was also an issue for those under 65 in nursing homes. People requiring specialist Speech and Language Therapy, Occupational Therapy (OT) and Physiotherapy often rely on community-based supports. As these services could not access nursing homes, this led to several issues for people, including problems with their physical and mental well-being, ability to communicate and mobility.



Robert's Story: Inappropriate Placement

My name is Robert. I suffered an injury just before the Covid-19 pandemic and I had an operation. It took months to heal, and I had to spend that time in a nursing home.

I couldn't go home as my bedroom there is upstairs. I worked very hard to get walking again and practised going up and down stairs in the nursing home with my physiotherapist. I missed my freedom, and I was really excited when the physiotherapist said I was well again.

Then the Covid pandemic and its restrictions happened. The nursing home was boring, and I couldn't leave my room for most of the day or take part in activities. I missed being able to go for walks by myself.

My key worker explained that a meeting would be organised between my family, the nursing home and the HSE to plan for my future. I was encouraged to sign a Fair Deal form as they said this would be the best opportunity for me to get a fair outcome.

I thought this was a chance to have my views heard but I was very upset when they told me I would be staying in the nursing home. I was told it was a fair outcome because I probably wouldn't manage the stairs in my house much longer. But it wasn't fair, I wanted to go home.

The staff in the nursing home helped me organise a meeting with a NAS Advocate. I told the Advocate all the things I missed because I was stuck in the nursing home. She really listened to what I wanted. She spoke with my nurse who told her I had signed the Fair Deal form and the nursing home would be moving me to a long stay ward.

My Advocate explained I had every right to be fully involved in any plans about my life, but I told her no one listened when I said I wanted to go home. She said she would help me explain to everyone that this was what I wanted.

We had to go to meetings with different people. Due to the Covid-19 pandemic, everyone had to wear a mask, use hand sanitiser and practice social distancing. My Advocate explained to my family and staff that I had a right to return to my home.

Some people argued that I wasn't as able to manage now, so my Advocate asked if I would like to have some 1:1 support for a few weeks until I got settled back at home. That sounded good to me, and a plan was put in place for my move home.

I had to have a negative Covid test and undertake a two-week quarantine period on returning home. I am happy to be home again and am enjoying my freedom.

Conclusions and Recommendations

NAS provides a crucial means of support for people with disabilities to ensure the person's voice is heard. The Patient Advocacy Services also offers an important means of support for people who have had a negative experience regarding their care in a HSE-funded public acute hospital or a HSE-operated nursing home and wish to make a formal complaint to the HSE.

The Services uphold the person's rights, ensuring fair and equal treatment and access to services. They make certain that decisions are taken with due consideration for a person's unique preferences and perspective, will and preference.

In normal times, the support offered by both services is of huge importance. People with disabilities already face discrimination and marginalisation in many aspects of their lives, while people who have had a negative experience in a public hospital or nursing home can often feel they have nowhere to turn for support to have their views and complaints heard.

The Covid-19 pandemic and the subsequent impact on nursing homes has had an even greater impact on the lives of the people supported by the Services.

Despite preventative measures, there has been an increased risk of infection for people in nursing homes, while the people living in these settings also have a higher risk of transmitting the virus. In addition, people in nursing homes are more likely to have existing health issues that increase their risk of contracting Covid-19, which has been a cause of great distress and anxiety for people and their loved ones.

People living in nursing homes have faced the most extreme restrictions in society, with some having to stay in their rooms 24 hours a day, with no access to friends or family. Due to staffing issues, many people have not been able to receive the care, information and reassurance they need from nursing home staff. This has resulted in people feeling isolated, fearful and unsure of what was happening in their nursing home and the outside world.

At the beginning of the pandemic, a lack of information, technology and safe spaces impeded communication between Advocates and people living in nursing homes. This was particularly concerning at a time when people had already been exposed to challenging circumstances and events beyond their control.



Some families told our Services they had no way of communicating with their loved ones and no way of knowing if they were safe from the virus or not. They found it very difficult to get updates from nursing homes and were often unaware how serious the outbreak was within the nursing home or that an outbreak had even occurred.

Our Services noted there were concerns that some nursing homes did not have a clear protocol for managing the virus, while family members also expressed their fears that care plans were not being followed. Families also raised concerns about Personal Protective Equipment (PPE) availability and usage.

Within nursing homes, Advocates from NAS and the Patient Advocacy Service have continued to provide support for people living there and their families, working with nursing homes to ensure meaningful communication and visits could take place, checking in regularly with the people they support to maintain contact to reduce the isolation they felt, raising any concerns and visiting people when it was possible. They provided support and reassurance to people who experienced isolation, loneliness and fear around the pandemic.

NAS has been aware for several years of the number of people under 65 living in nursing homes. As nursing homes are primarily designed for older, many people under 65 did not want to live there. NAS has advocated on behalf of these individuals for many years. People reported to NAS that social workers or discharge coordinators from hospitals helped them to sign up to the Fair Deal scheme for nursing homes without alternative options being discussed or knowing the long-term consequences. NAS ensured they were able to explore their options to make a choice about where they live.

NAS Advocates also provided advocacy support to people who were participating in the Ombudsman's report "Wasted Lives: Time for a better future for younger people in Nursing Homes," which was published in May 2021.

It is crucial that nursing homes reflect on, review, and continue to improve their service delivery, adapting to the evolving situations arising from the ongoing pandemic. As a result of the extensive advocacy work carried out by NAS and the Patient Advocacy Service in the period March 2020 - March 2021, we have developed several recommendations which should be given consideration to improve the lives of people living in nursing homes in Ireland. It is imperative that people living in nursing homes are supported to lead fulfilling lives and to have their voice, will and preference heard.



There is an over-reliance on the nursing home sector to provide care to a wide range of the population. The only statutory funding available to people is the Fair Deal Nursing Home support scheme. This severely limits the choice people have to access services.

There should be increased government funding for alternatives to nursing homes such as rehabilitation, supported accommodation and home care hours. Less emphasis should be placed on the Fair Deal Scheme, especially in cases following a stay in an acute setting.

It is crucial that the Nursing Home Expert Panel (NHEP) report recommendations are implemented regarding the integration of private nursing homes into the wider framework of public health and social care.

In private nursing homes there is a need for a suitable structure and process for external oversight of individual care concerns arising in nursing homes, once internal processes have been exhausted without satisfaction as recommended by NHEP recommendation 15.3.

Recommendation 13.1 of the NHEP report should be implemented which provided for support and communication for residents and their families to be a continuing priority.

Recommendation 15.4 of the NHEP report which provides that HIQA and each nursing home provider should continue to highlight and promote independent advocacy services available to resident should be implemented. However, there should be regulatory or statutory requirement for access to advocacy.

A more robust standardised complaints policy, like the HSE's 'Your Service Your Say', should be put in place across all private nursing homes to ensure there is good governance over the complaints process. The recommendations from the NHEP report also highlight the need to better governance in Private Nursing homes and these recommendations should be implemented.

There must be a standardised consultation, planning and handover process involved in the discharge and transfer of people from acute hospitals to nursing homes. People who need personal care or nursing support should have a choice about where they are moved to. There are several cases of people being placed in nursing homes when another form of care, such as home support, would be more appropriate. For those people who are inappropriately placed in nursing homes, additional staff are required to provide one-to-one support for these people to engage in meaningful activities.



The proposed HSE pilot project to support people under 65 living in nursing homes must be instigated and properly funded. Longer term, a cross departmental group that also includes people living in nursing homes and families, the nursing home sector, the HSE and other stakeholders should be established with the aim of moving all people under the age of 65 out of nursing homes into accommodation of their choice.

There is a need to review the bedroom and communal space capacity of nursing homes. All people living in nursing homes should ideally have single rooms with ensuite bathroom facilities, smaller numbers in communal areas, and outdoor space for activity in isolation. This offers the ability to contain infection in one area should the need arise.

Recommendations 13.3 and 13.4 of the NHEP report stress that nursing homes should develop plans to improve their communication with those living there and families by providing information in an accessible format and establishing IT infrastructure, such as video calls and WhatsApp. Nursing homes should have dedicated staff to facilitate communication.

Within nursing homes, information and access to advocacy services and mental health supports should be provided. The recommendations from the Covid-19 Nursing Homes Expert Panel report also highlighted the need for people living in nursing homes, both public and private, to have better access to independent advocacy. The Programme for Government also commits to continued support for the Patient Advocacy Service.

There is also a need for safe visiting rooms to facilitate visits from family and friends, and access to GPs and health professionals.

There should be clear standards and guidance on staffing levels, training and experience in nursing homes. There is an urgent need for more permanent contracts and less reliance on agency staff to avoid cross contamination.

Given the ever-changing situation with Covid-19, it is crucial that nursing homes reflect on, review, and continue to improve their service delivery, adapting to the evolving situations arising from the ongoing pandemic. Nursing Homes should also consider the experiences of people supported by NAS and the Patient Advocacy Service, along with the learnings of our Advocates, to improve service delivery. It is imperative that people are supported to have their voice, will and preference heard and are included in decisions that impact on their lives.



