



**NATIONAL ADVOCACY
SERVICE**

FOR PEOPLE WITH
DISABILITIES



**Patient
Advocacy
Service**

INFORMATION | SUPPORT | EMPOWERMENT

Advocacy Matters:

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



Executive Summary
December 2021

Executive Summary

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.

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.

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

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.

Covid in Nursing Homes: Responding to the Crisis

Findings

One of the worst hit services has undoubtedly been nursing homes where residents 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 and the inappropriate placement of people under 65 in nursing homes.

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.

NAS has provided advocacy supports for people with disabilities living in nursing homes throughout the Covid-19 pandemic 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.

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

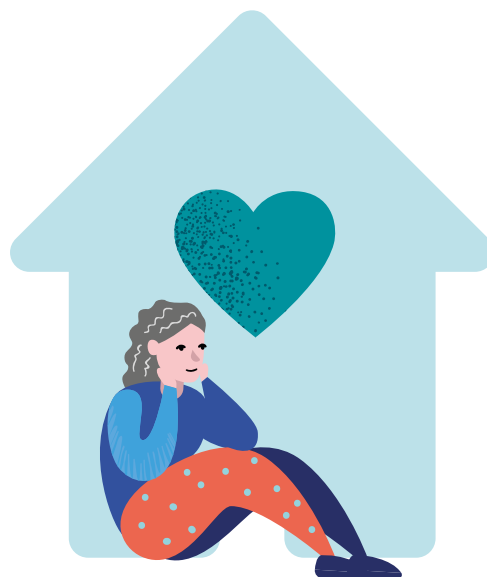


Covid's Impact on Nursing Homes

Findings

When the Covid-19 pandemic hit Ireland, 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.

We acknowledge the significant impact Covid-19 has had on nursing homes and their staff. 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’¹, 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.



¹ 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

Findings

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.

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. 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.

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.

Both our Services have worked with families who did not 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.

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.

NAS advocated on people's behalf to nursing homes to ensure that contact with families was supported and facilitated, and to make sure the person's voice was heard. Advocates provided emotional support during this time to those feeling isolated and alone.



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 HPSC² guidance document.

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. 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.

Infection Control

Findings

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. People were unable 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.

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 our Services 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.

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

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.

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 status of the private nursing home sector and inputs by the State as a response to the pandemic. As a result, operational inconsistencies have persisted.

Isolation and Mental Health

Findings

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.

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 personal circumstances.

Inappropriate Placements: People Under 65 Living in Nursing Homes

Findings

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 had 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.

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.

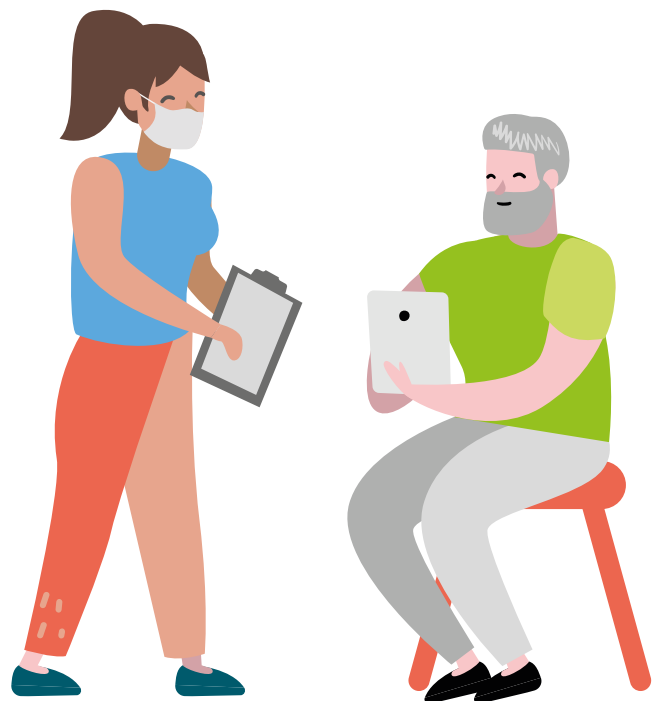


Many months later, people supported by NAS and the Patient Advocacy Service say they have found themselves inappropriately placed in a nursing home setting without the adequate supports to enable them to move their own home and live in the community.

Due to the restrictions, they have continued 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.

Advocates also supported people to make complaints to the Ombudsman as they had no access to funding for appropriate community and disability specific services. Advocates supported people to record their experiences to inform the Ombudsman's 'Wasted Lives'³ report.

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.



3 Wasted lives. Time for a better future for younger people in nursing homes. An investigation by the Ombudsman
<https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>

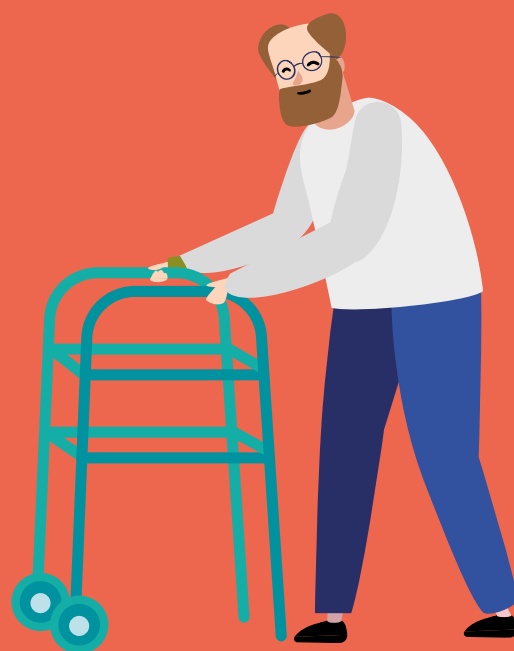
Key Recommendations in this Report

- ▶ 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) Report⁴ 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.



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

- ▶ 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 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'⁵, 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 project⁶ 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.



⁵ Your Service Your Say <https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/ysys2017.pdf>

⁶ <https://www.thejournal.ie/younger-people-in-nursing-homes-report-5428570-May2021/>

- ▶ 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 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 Government⁷ also committed to 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.



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

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.
- ▶ 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 Homes⁸," which was published in May 2021.



8 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>

