Patient Advocacy Service

INFORMATION | SUPPORT | EMPOWERMENT

Patient Advocacy Service
Casebook 2024

Contents

Foreword by Chairperson

Welcome to our third annual Casebook. This publication contains a selection of the varied advocacy work of the National Advocacy Service for People with Disabilities and the Patient Advocacy Service over the past year.

The National Advocacy Service for People with Disabilities, which is funded by the Citizens Information Board (CIB), focuses on ensuring the rights of people with disabilities are upheld. It provides people with disabilities across Ireland with an independent, professional and free advocacy service that helps people to have their voices heard, make their own decisions and live their lives independently.

The Patient Advocacy Service is commissioned by the Department of Health (DoH) and provided by the National Advocacy Service for People with Disabilities. It is an independent, confidential and free service which provides empowerment advocacy to people who wish to make a complaint about their care in a Public Acute Hospital or a Nursing Home. The service also offers advocacy to people in the aftermath of a Patient Safety Incident.

This year's casebook contains an increased number of case studies providing insight into and detailing the complex case work carried out by Advocates in both services. The Casebook highlights the important role independent, professional advocacy can play in supporting people to have their human rights protected and promoted.

The Casebook shares the lived experience of a diverse range of people who access our independent advocacy services across Ireland.

As you read the case examples in this publication, you will notice that advocacy is generally offered when people need specific and tailored information or support. You will read about the different forms of advocacy, including empowerment and representative advocacy, and you will see that these situations are often very emotive for both the people receiving advocacy and our Advocates. Our Services provide advocacy in relation to issues, for example, issues relating to housing, healthcare, social care and much more, including complex difficulties experienced by parents with a disability.

I hope that these case examples provide you with rich insight into what our Services do, highlighting the importance of independent advocacy, showcasing the positive impact we have had on people and in communities across the country. Advocacy helps breach gaps in systems that leave people in difficult situations, it ensures best practice across public services, and it promotes positive systemic changes when necessary.

Finally, I would like to thank anyone who accessed our Services in 2024. I wish to extend my thanks to CIB for their continued endorsement of the National Advocacy Service for People with Disabilities and their ongoing support of our work. I would also like to thank the DoH for their guidance and support of the Patient Advocacy Service. On behalf of the Board, I would like to thank all the staff of both Services for their work ethic and dedication in providing high quality professional advocacy services.

Rosemary Smyth
Chairperson of the National Advocacy Service for People with Disabilities (NAS), which delivers the Patient Advocacy Service.

Note to Reader: all case studies included in this document have gone through a rigorous anonymisation process which involves changing identifying elements of the case to protect the anonymity of the person and advocate involved. This means that the location, age, gender and name of the people in these stories are likely to have been changed.

1. Accident and Emergency Department

Context

Martin, who is in his mid-sixties, presented at his local Accident and Emergency (A&E) Department after he had a fall at home. He had facial injuries and a swollen arm. Martin was triaged and was told that he would be waiting some time to be seen. Martin spent almost two days in A&E sitting on a chair with no pain relief, food or medical intervention. He asked staff for help and was told that he was on a waiting list but was not told how long he would be waiting. Eventually Martin received an x-ray which showed a broken arm and shoulder. Martin was very disappointed by his experience in A&E. He said that staff were rude towards him and were very dismissive. Martin felt that due to his age, he was being ignored by staff and was not a priority for care or treatment. Martin decided that he wanted to make a complaint about his experience and he contacted the Patient Advocacy Service for support.

Actions by the Advocate

Martin and his Advocate from the Patient Advocacy Service discussed his issues and the Advocate created an Advocacy Plan to support him. The Advocate explained the complaints process to Martin and supported him to draft a complaint letter to reflect his lived experience. Martin's Advocate researched policies such as the HSE's National Healthcare Charter and the HIQA Standards for Better Safer Healthcare to help support his complaint. Martin submitted his complaint to the hospital and when he received a response, his Advocate met with him and supported him to read through the report. The hospital took Martin's complaint very seriously and offered a sincere apology to him for what had happened. The hospital stated that it was providing staff in the A&E Department with specific training in communication to ensure that patients are kept up to date with their care plan. The A&E Department have hired additional healthcare assistants to ensure patient care needs are met while they are waiting to be seen after being triaged. An Emergency Medicine Early Warning Score System is now in place to ensure timely interventions.

Outcome

Martin was satisfied with the apology he received and was happy to see that improvements were being made within the A&E Department. He told his Advocate that the response was very thorough and that he felt he had been listened to. Martin felt empowered by the support provided by his Advocate and felt less alone going through the complaints process.

2. End of Life/Dignity & Respect

Context

Olive's husband Chris was admitted to hospital and sadly passed away a few weeks later. Olive was devastated at the loss of her husband and had concerns about the care and treatment he received while in hospital. Olive felt the hospital did not communicate to her and her family how ill Chris was and they were shocked at how quickly his health deteriorated up until his death. When Olive received Chris's death notification certificate, she was concerned that the information contained was not accurate . Olive had questions she wanted answered and decided to make a complaint to the hospital. She contacted the Patient Advocacy Service for support.

Actions by the Advocate

Olive spoke with the Advocate from the Patient Advocacy Service and shared her story and discussed an Advocacy Plan. Olive said that she felt there was a lack of appropriate and timely diagnostic tests for Chris and this delayed his treatment. She said that Chris had developed complications through pneumonia but that this was never explained to the family. Olive expressed concern that there was a lack of monitoring and supervision of Chris's health and failure to notice his deterioration. She spoke of poor communication between the consultant and the family. Olive said that she was constantly trying to contact the hospital ward for updates on Chris's condition and even requested a family meeting which did not occur. Olive also spoke of poor record keeping, including the mistake on the death notification. She also wanted to highlight issues around infection control as well as concerns about staff shortages on the ward. Olive's Advocate supported her to write a formal complaint letter to the hospital. When Olive received a response to her complaint, the hospital offered a series of apologies to Olive and her family, including, poor communication, the error on the death notification certificate and for the upset caused to Olive and her family. The complaint response identified areas of learning for staff and made a series of recommendations for improvements in the hospital. Staff are encouraged to complete the HSE's National Healthcare Communication Programme and a project is being piloted to improve information sharing with families. Training is also being provided in infection control and hand hygiene. The hospital, in acknowledging issues with record keeping, increased training in incident reporting and record keeping.

Outcome

Olive was satisfied with the recommendations made by the hospital but was disappointed with responses provided in relation to clinical judgement. The Advocate suggested that Olive could write to her husband's consultant however there is no review process for complaints in relation to clinical judgement.

Olive was satisfied with the information and support provided by her Advocate.

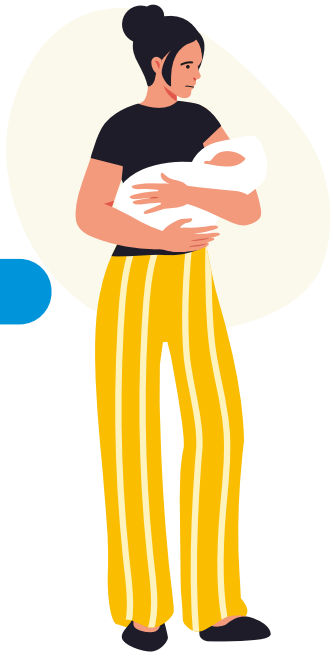
3. Maternity Care & Treatment

Context

Mairead had recently given birth and was unhappy with the care and treatment she had received at her local maternity hospital. Mairead felt that she was not monitored closely enough, including delays in blood tests, which lead to her developing a pregnancy related condition. When Mairead gave birth, she was left alone during induction, was not offered sufficient pain management and suffered a haemorrhage during the delivery of her baby. Mairead was discharged home with her baby but without any explanation as to how her pregnancy and birth had been managed. Mairead submitted a written complaint to the hospital and the hospital wrote to her to acknowledge her letter. However, months passed by and Mairead never received a response to her complaint. Mairead decided to contact the Patient Advocacy Service for support with her complaint.

Actions by the Advocate

Mairead spoke with an Advocate from the Patient Advocacy Service and discussed her issues and preferred outcomes and they drew up an Advocacy Plan. Mairead's Advocate from the Patient Advocacy Service explained the Your Service Your Say Complaints Policy to her and made her aware that the complaint response had fallen outside of the timeframe. The Advocate highlighted options to Mairead including escalating her complaint to the Hospital Group and the Ombudsman. Mairead's Advocate supported her with this and she eventually received a response from the hospital. Mairead was unhappy with the response issued by the hospital. The Advocate discussed some options with Mairead, including attending a meeting with the hospital or making a Stage 3 complaint. Mairead wanted to have a meeting with the hospital and the Advocate supported her to contact the hospital and she was offered a meeting. Mairead and her Advocate attended the meeting with the hospital's Clinical Director and Complaints Manager. The hospital staff listened to Mairead's concerns and they explained improvements that had been made within the hospital. Mairead felt assured that positive changes had been made and that her concerns had been taken seriously.



Outcome

Mairead was satisfied with the outcome of her complaint and the support offered by the Advocate. She felt that her Advocate helped her to get the complaint processed and resolved to her satisfaction. She felt reassured and empowered that if she attended the hospital again, she would receive the appropriate care and treatment.

4. Nursing Home

Context

Craig has a long-term health condition and due to his medical and care needs, he lives in a nursing home. When Craig moved into the nursing home, care plans were created with him to reflect his needs and will and preference. However, he felt that the staff were not following these care plans. Craig needed support to get dressed in the morning and he was sometimes left for hours before staff came to help him. He felt that staff were sometimes very rough when they supported him with personal care. Due to his medical condition, Craig was on a specific diet and on many occasions, he was provided with meals that were not safe for him to eat due to the consistency and texture of the food. He was once provided with a meal that led to a choking incident and he had to call staff to help him. Craig spoke about being fearful and feeling unsafe. Craig wanted support to raise his concerns and contacted the Patient Advocacy Service.

Actions by the Advocate

Craig spoke to an Advocate from the Patient Advocacy Service and asked if they could come to the nursing home to meet him. The Advocate met with Craig and listened to his concerns. The Advocate developed an advocacy plan with Craig, including a communication plan that reflected his will and preference. The Advocate requested a copy of the nursing home's complaint policy and met with Craig again to discuss the policy with him and making a complaint. Craig decided that he would like to make a verbal complaint, which was Stage 1 of the nursing home's complaints policy. The Advocate supported Craig to request a meeting with the Director of Nursing (DON) and the Assistant Director of Nursing (ADON) to make the complaint. At the meeting, Craig outlined his concerns regarding the poor quality of care he experienced, how he felt unsafe at mealtimes and that staff were not familiar with his care-plans. During the meeting, the DON acknowledged Craig's concerns and apologised for the poor care he had experienced. The ADON offered to review Craig's care plans with him and make any necessary changes that were needed. The updated care plans would be discussed with all staff with an emphasis on the importance of following them. Craig was happy with the outcome of the meeting.

Outcome

The Advocated contacted Craig to check if improvements had been made with his care. Craig informed the Advocate there has been an improvement in the meals that are provided, and that he feels safe eating them now. Craig said that his care had improved as well. Craig felt listened to and decided not to make a formal complaint as his issues were fully resolved. Craig felt empowered by the support his Advocate had provided to him and knows that support is there if he ever needs it again.

5. Care and Treatment

Context

Marion was admitted to hospital after she had developed issues with her swallow. While she was in hospital, there were aspects of her care that she was unhappy with. Marion felt that communication with staff was poor throughout her stay in hospital. She had asked hospital staff to keep her family informed about her care and treatment, but this did not happen. Due to issues with her swallow, Marion required a feeding tube but there were delays in inserting the tube. A Do Not Attempt Resuscitation order (DNAR) was put in place for Marion without discussing this with her or seeking her consent. Marion asked that this be removed from her file which took some time to do. When Marion was discharged, she decided to make a formal complaint to the hospital and contacted the Patient Advocacy Service for support.

Actions by the Advocate

Marion met with an Advocate from the Patient Advocacy Service and discussed her issues and created an Advocacy Plan to support Marion's complaint. Marion's Advocate provided her with information on the Your Service Your Say Policy and supported her to draft a Stage 2 formal complaint letter. There was a lengthy delay in the hospital issuing a response to Marion, and the Advocate supported her to escalate the complaint to the Hospital Group and to the Ombudsman. Marion received a response to her complaint but was unhappy with it. She felt that there were several inaccuracies in the response and that it did not address some of the issues she had raised. The Advocate supported Marion to request a Stage 3 Internal Review of her complaint and the response she had received. Again, there were delays in receiving a response and once again the Advocate supported Marion in escalating her complaint to the Hospital Group, which led to a response being issued. The Internal Review Team provided a sincere apology to Marion and provided a series of recommendations for improvements within the hospital. The hospital stated that it would make improvements in staff communication, especially when a patient raises a concern with them. The National Health Care Communication programme would be made available to all staff. The hospital stated that it would provide pathways for staff to escalate ongoing issues and that it would provide training on the Your Service Your Say policy and timeframes.

Outcome

Marion was satisfied with the response she received from the hospital and the recommendations for improvements. She was very appreciative of the support provided to her by the Advocate. Marion felt listened to and found the information and guidance provided by the Advocate empowering and very helpful in supporting her to navigate the complaints process.

6. Nursing Home

Context

Sylvia is in her late 70s and lives in a nursing home. She moved into the nursing home as she could no longer live at home by herself. Sylvia had settled in well and made good connections with her fellow residents and staff. One day, a staff member came to Sylvia's room to collect her washing. The staff member did not check the clothing and did not notice that Sylvia's watch was in the pocket of one of her cardigans. The watch was put into the washing machine by mistake and was broke beyond repair. Sylvia was very upset when she found out the watch had been broken. The nursing home purchased a replacement watch, but Sylvia wanted her watch back. Sylvia wanted to make a complaint and a member of staff supported her to contact the Patient Advocacy Service.

Actions by the Advocate

Sylvia's was contacted by an Advocate from the Patient Advocacy Service to discuss her complaint. The Advocate spoke to Sylvia over the phone and it was agreed that they would meet in person to discuss her complaint. The Advocate met Sylvia and discussed the complaints process with her and agreed an Advocacy Plan. Sylvia told her Advocate that she would like an apology and assurances that staff would be more mindful with her personal belongings. Sylvia consented for the Advocate to discuss the issue with the manager of the nursing home. The Advocate spoke to the nursing home manager who confirmed that a replacement watch was provided to Sylvia and a verbal apology was made. Sylvia wanted to make a formal complaint. The Advocate supported Sylvia to submit a formal complaint to the nursing home. The manager accepted Sylvia's written complaint and stated that they would investigate the issues raised and provide a written response in line with their complaints policy. The nursing home manager responded to Sylvia's complaint within 2 weeks.

The manager provided Sylvia with a sincere apology and acknowledged an error had been made. The manager stated that employees should always check residents' clothes to ensure they are empty before washing them. The complaint response stated that all staff were being made aware again of housekeeping policies to reduce the risk of this happening again. The response stated that efforts were made to fix Sylvia's watch, but as it was irreparable, it was disposed of. The nursing home stated that a replacement watch was purchased for Sylvia and that every effort was made to buy a watch like the one she had. The response letter advised Sylvia if she required support with using the watch the staff would support her.

Outcome

Sylvia was satisfied that the nursing home had offered her an apology and had acknowledged that a mistake had been made. While she wanted to have her old watch back, she understood that the nursing home had made every effort to fix it and had provided her with a replacement watch. Sylvia felt her voice had been heard and was happy with the support provided by her Advocate.

7. Patient Safety

Context

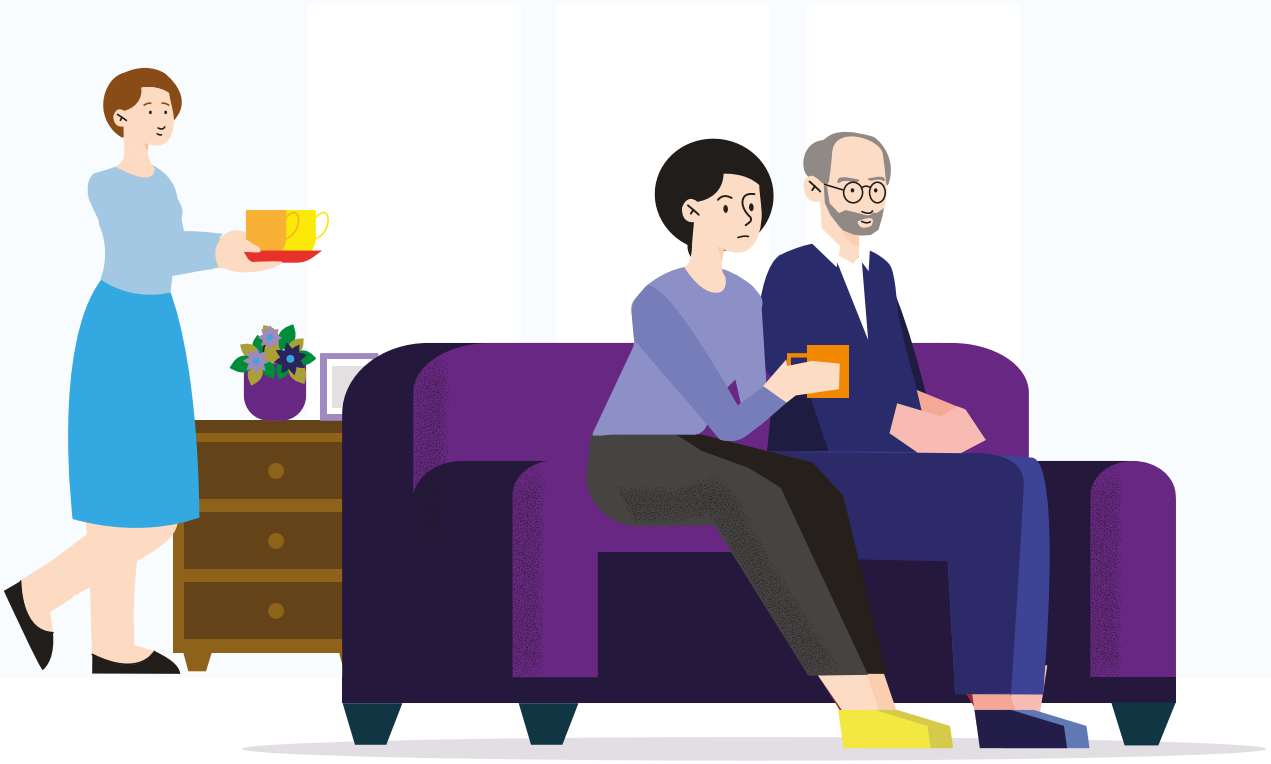
Julie's father, George was feeling unwell and she brought him to their local hospital. George was living with dementia and had several underlying health conditions, for which he required regular medication. George was in hospital for almost a week when it was discovered that the hospital had not been giving him his regular medication. As a result, George became very unwell and spent the following week in the Intensive Care Unit (ICU). After he was released from ICU, George spent several more weeks in hospital and was discharged to a nursing home. George had been living at home with the support of his family but as his dementia had progressed while he was in hospital, he could no longer be cared for at home. Julie contacted the hospital to find out why there had been an error with her father's medication and was told that the hospital would investigate the incident. However, after months of waiting, Julie never heard anything back from the hospital. Julie decided to make a formal complaint to the hospital and contacted the Patient Advocacy Service.

Actions by the Advocate

Julie's spoke with an Advocate from the Patient Advocacy Service and explained what had happened with her father's care while he was in hospital and agreed an Advocacy Plan. The Advocate explained the HSE's Your Service Your Say policy to Julie and went through some options, including requesting her father's records through Freedom of Information. Julie decided she would like to access the records and the Advocate supported her to make the request. When the records arrived, Julie's Advocate supported her to read through them. The Advocate then supported Julie to write a Stage 2 formal complaint letter to the hospital. When a response was issued, the Advocate supported Julie to read the letter. Julie was not satisfied with the response and the Advocate supported her to request a Stage 3 Internal Review of her complaint. The hospital responded stating that they would review the complaint and offered Julie a meeting to discuss her concerns in further detail. Julie was nervous about attending the hospital meeting and the Advocate put her at ease, supporting her to prepare for the meeting and offering to attend the meeting with her. Julie wanted a full explanation from the hospital and assurances that this would not happen to another family. The Advocate supported Julie to draft questions for the meeting that reflected her expectations.

Outcome

Julie hopes that once the complaint process is complete it will lead to quality improvement at the hospital and will improve patient safety there. Julie feels supported and empowered by her Advocate, who will continue to work with her during these ongoing processes.



8. Delayed Referrals

Context

Christopher's son Noah is four years of age and has a disability. Christopher had been attending regular appointments at his local hospital with Noah. At their most recent appointment, a consultant paediatrician assessed Noah to see what clinical and community supports he might need. During the appointment, the consultant made a referral for physiotherapy and occupational therapy for Noah. A follow up appointment with the consultant was also scheduled. Christopher waited for the appointments to be made for Noah but never heard anything from the hospital. He made several calls to the hospital to ask about the referrals but could not get any information. Christopher made a verbal complaint to the hospital, but this did not resolve the issues he was having. Christopher decided to make a formal complaint to the hospital and contacted the Patient Advocacy Service for support.

Actions by the Advocate

Christopher spoke to his Advocate from the Patient Advocacy Service and agreed an Advocacy Plan. His advocate provided him with information on the HSE's Your Service Your Say policy and how to make a formal complaint. The Advocate supported him to write the complaint letter and submit it to the hospital. Christopher received a response to his complaint; however, it did not fully answer the questions that he had raised. The hospital stated that the referrals had been made for Noah eventually but did not explain why they were delayed and advised Christopher that his son was now being discharged from the care of the consultant. Christopher was not provided with any information on seeking a new consultant and was told that his complaint was resolved. He was not offered a meeting to discuss his complaint or provided with any information on how to request a review of his complaint. Christopher was very unhappy with how his complaint was managed and his Advocate provided him with several options, including writing to the Ombudsman for Children. Christopher decided to make a complaint to the Ombudsman for Children and his Advocate supported him to write the letter.

Outcome

The Ombudsman for Children investigated Christopher's complaint and found in his favour. The hospital apologised to Christopher for how his complaint was managed and stated that they were reviewing their complaint management system. They also apologised for the delayed referrals that were made for Noah. The hospital provided Noah with a new consultant who has regular appointments with him to ensure his care plan reflects his ongoing needs. Christopher was satisfied with the outcome of his complaint and felt fully supported by their Advocate throughout the complaints process.

9. Open Disclosure/Incident Management Framework

Context

David visited his GP as he had not been feeling well. The GP carried out an examination and made an urgent referral on David's behalf for an MRI at the local hospital. David did not hear back from the hospital but presumed that the scan was being scheduled for him. Some months later, David and his GP had still not received information about the referral. David's symptoms became worse and he decided to go to his local A&E. Several tests were carried out, including a scan. David was sent for urgent surgery and was diagnosed with cancer. David was shocked at the diagnosis and asked why his scan had been delayed. The hospital told David that an error had been made processing the referral made by his GP and that it had been marked non urgent instead of urgent as had been requested. David was concerned that his cancer could have been detected at an earlier stage if he had received the urgent scan his GP had requested. David decided to make a complaint to the hospital about the delay in his diagnosis and contacted the Patient Advocacy Service for support.

Actions by the Advocate

David's Advocate from the Patient Advocacy Service listened to his story with empathy. The Advocate provided him with information on the possible routes the hospital could take in relation to David's late diagnosis including the HSE's Your Service Your Say complaints pathway and the HSE's Incident Management Framework for a more in-depth review of what had happened. The Advocate explained the HSE's Open Disclosure policy to David and highlighted that the error with his scan and his late diagnosis should have been managed through that process. The Advocate supported David to submit a letter to the hospital highlighting the missed diagnosis, missed opportunities for when the diagnosis may have been picked up and a request for a full investigation. The hospital wrote back to David and informed him that his case would be investigated under the Incident Management Framework. The Advocate explained to David what he should expect from the process and supported him to have input into the investigation to ensure that he was kept at the centre of the process and that his voice was heard throughout.

Outcome

The investigation process into David's late diagnosis is still ongoing and the Advocate continues to support him. The Advocate supports David when he attends meetings with the hospital and has helped him to submit particular questions he wants answered. The Advocate supported David to draft an impact statement which has been submitted to the review team. David has said that he feels empowered, informed and supported through the review process as he has an independent advocate helping him to navigate this route. The Advocate will work with David until the investigation process has concluded.

National Advocacy Service
For people with disabilities

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An Roinn Sláinte
Department of Health

Patient Advocacy Service &
National Advocacy Service for
People with Disabilities
Level 3 Rear Unit
Marshalsea Court
Merchants Quay,
Dublin DO8 N8VC

PAS National Line: 0818 29 3003
patientadvocacyservice.ie
info@patientadvocacyservice.ie

NAS National Line: 0818 07 3000
advocacy.ie
info@advocacy.ie