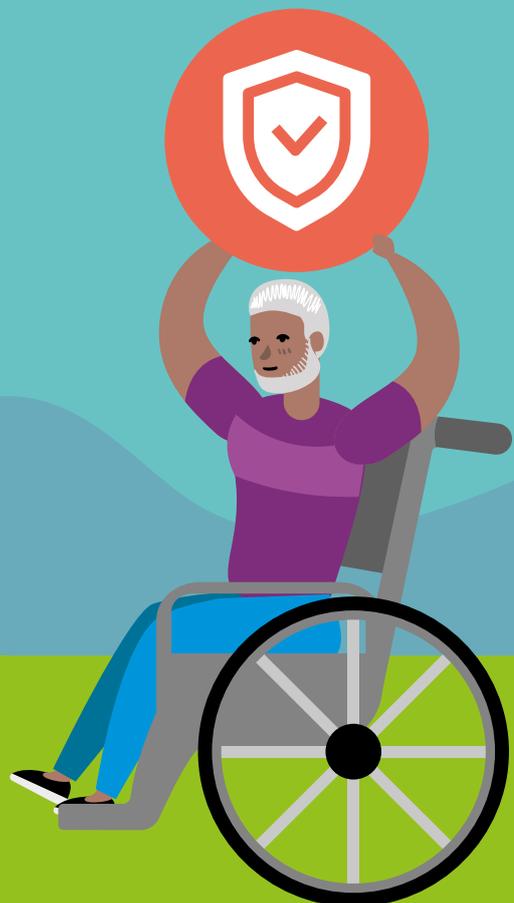




Patient Advocacy Service Casebook



2023



NAS is funded and supported by the Citizen's Information Board (CIB)



The Patient Advocacy Service is funded and supported by the Department of Health (DoH)



An Roinn Sláinte
Department of Health

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Foreword



Welcome to our second annual Casebook. This publication contains a selection of the many advocacy interventions worked on over the past year by the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service.

When we released our first Casebook in 2022, we wanted to share the important work carried out by NAS and the Patient Advocacy Service. Influenced by its success and the positive feedback we have received the Casebook has now become an annual publication.

The Casebook provides a snapshot into the work of both services and provides insight into how independent, professional advocacy can positively impact on people's lives and protect their human rights. It illustrates the diverse range of people who access independent advocacy services in Ireland and the many issues supported by both NAS and the Patient Advocacy Service.

The 2023 Casebook also includes a collection of 'Access to Finance' cases from NAS, which highlight the growth in advocacy issues relating to financial autonomy. These cases are part of a larger body of work carried out by NAS in 2023, including a social policy paper entitled: 'Examining the Barriers to Equal Access to Finances for People with Disabilities in line with their Human Rights', which will be published at a later date.

NAS, which is funded by the Citizens Information Board (CIB), focuses on ensuring the rights of people with disabilities are upheld. We provide people with disabilities across Ireland with an independent, professional and free advocacy service that helps people to have their voices heard, make decisions and live their lives independently.

The Patient Advocacy Service, which is commissioned by the Department of Health (DoH) and delivered by NAS, provides support to people who wish to make a complaint about their care in a Public Acute Hospital or a Nursing Home. The service also offers support to people in the aftermath of a Patient Safety Incident.

As you read the case examples in this publication, you will notice that advocacy interventions generally come when people need specific and tailored information or support. You will be shown the different forms of advocacy, including empowerment and representative advocacy, and you will see that these situations are often very emotionally charged for both the people receiving advocacy and our Advocates. We cover issues relating to parenting with a disability, housing, healthcare, and much more.

In April 2023, The Assisted Decision-Making (Capacity) Act 2015 commenced. The Act aims to achieve key reforms including the abolition of the wards of court system for adults. A core principle of the Act is the presumption that everyone has capacity until proven otherwise. Equally, a person should be fully supported to make their own decisions as far as is possible, emphasising that a person's will and preferences must be considered at all times. Such principles underpin the work of Independent Advocates and while we only touch on the Act in this year's Casebook, it is an area that will develop further in the coming years.

I hope that these case examples provide rich insight into what our Services do, highlighting the importance of independent advocacy, showcasing the positive impact we have had 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 either NAS or the Patient Advocacy Service in 2023. I wish to extend my thanks to CIB for their continued endorsement of NAS 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 the work ethic and dedication of all the staff of NAS and the Patient Advocacy Service in providing high quality professional advocacy services.

Thank you.



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. Maternity Health Care



Context:

Katherine attended her local maternity hospital, there were no complications during her pregnancy, and everything progressed well. When Katherine's labour started, she went to the hospital to deliver her baby. Katherine became distressed during the delivery and asked the staff if she could have a Caesarean Section. Staff told Katherine that this was not possible due to the late stage of her delivery. Katherine gave birth to a baby girl, however, there were complications. Katherine's baby was transferred to the neo natal intensive care unit where she stayed for several days. Katherine's baby became increasingly unwell and sadly passed away.

The coroner was notified of the death and a postmortem was carried out. Katherine and her partner were informed that there would be an inquest into their baby's death. The hospital contacted Katherine and her partner to offer them a meeting to discuss what had happened. Katherine and her partner were processing their grief, following the traumatic experience of losing their baby. Katherine felt that she might need independent advocacy support during the hospital meeting and contacted the Patient Advocacy Service.



Actions by the Advocate:

Katherine spoke to her Advocate from the Patient Advocacy Service about the death of her baby and the impact this had on her family. Katherine expressed concerns around poor communication from the hospital around the death of her baby and the lack of maternity bereavement support. Katherine asked her Advocate what she and her partner could expect from the hospital meeting and if there might be an investigation.

Katherine and her Advocate agreed an advocacy plan to address her concerns. Katherine's Advocate supported her to prepare for the meeting with the hospital. The Advocate explained the HSE's Open Disclosure process, Katherine's right to full knowledge about her healthcare and to be informed about what had happened. The Advocate explained how the HSE's Incident Management Framework (IMF) process is used following an incident causing harm or the death of a patient in hospital. Katherine's Advocate explained the types of reviews that can take place, how they are conducted, and timeframes involved.

Katherine's Advocate attended the hospital meeting with her and her partner in a supportive capacity. The Advocate helped them put together a list of questions they wanted answered in advance of the meeting. With the Advocate's support, Katherine was empowered to request a review of her care and the death of her baby. The hospital agreed to commission a review.

Katherine wanted to prepare for the review and asked her Advocate if she could access her medical file from the hospital. Katherine's Advocate empowered her to access her file from the hospital through a Freedom of Information request.

Katherine's Advocate supported both her and her partner to prepare for the review, this included drafting a communication plan with their hospital liaison person, submitting a timeline of events to the review team, contributing to the Terms of Reference of the investigation, and submitting Katherine's list of questions. The Advocate also attended subsequent meetings that Katherine and her partner had with the review team.



Outcome:

A year after the review began, an initial report was issued to Katherine and her partner, with outcomes and several recommendations. Katherine's Advocate supported her to read through the report. This was helpful for Katherine as the review reminded her of the trauma that she had been through after losing her baby.

A final draft of the review report will be issued to Katherine and her partner, with recommendations for the hospital going forward. Katherine hopes that this will result in quality improvement at the hospital and will improve patient safety there and the patient experience.

Katherine feels supported by her Advocate, who will continue to work with her during these ongoing processes.



2. Nursing Home Facilities/Quality of life



Context:

Michael is a resident in a nursing home for several years. Michael likes to take part in activities and enjoys spending time talking to other residents. Michael likes to take a walk outside, enjoying the fresh air, even on days when the weather is not great. Michael is, however, very unhappy with the outdoor facilities at the nursing home. The nursing home does not have any sheltered areas outside, and if the weather is not good, residents are encouraged to stay indoors. Michael made several verbal complaints to staff about the lack of sheltered areas outside. Michael asked if anything could be done to create a sheltered area outside for residents, but nothing was being done to address this. Michael felt he was not being listened to and not being able to get out whenever he wished was having an impact on his quality of life.



Actions by the Advocate:

Michael spoke to an Advocate from the Patient Advocacy Service about making a formal complaint to the nursing home about the lack of outdoor facilities. Michael asked his Advocate how he could make a formal complaint to the nursing home and if they would help him to write the complaint letter. Michael was hard of hearing and asked his Advocate if they could visit him at the nursing home rather than phoning him. Michael's Advocate agreed an advocacy plan with Michael that included his request for in person visits. His Advocate explained the nursing home's complaints policy to him and the different stages of the process. Michael's Advocate visited him several times to support him to write his complaint letter. In his letter, Michael outlined his concerns that there was no suitable outdoor area for residents, and he highlighted the impact this was having on his quality of life. When Michael was happy with the letter, his Advocate, with his consent, gave the letter to the Person in Charge of the nursing home. Michael's Advocate was copied in on all correspondence received from the nursing home, which helped the Advocate to keep up to date with the complaint and how it was progressing.

Michael's complaint was upheld by the nursing home, which he was very happy about. The nursing home set out a plan to build a sheltered outdoor area so that residents could spend more time outside. However, the nursing home did not give a timeframe for when building work would start or finish. Michael was unhappy with this and wanted more information on when the building work would be completed. Michael's Advocate suggested that Michael could write to the Person in Charge of the nursing home and ask for more detailed information on expected timeframes for each action and expected date of completion. Michael received a response to his letter, which gave a timeframe of when the sheltered outdoor area would be completed.



Outcome:

The nursing home built the sheltered outdoor area for residents. Michael was satisfied with the outcome of his complaint and with the support from his Advocate. The nursing home now has a sheltered area that all residents can enjoy.



3. Care & Treatment and Discharge Planning



Context:

Sophie's mother, Dolores, passed away in hospital with sepsis. Dolores had been in hospital for a few months and during this time, Sophie had concerns about the level of care her mother had received.

Sophie was concerned that staff did not always treat her mother with dignity & respect when she received personal care. Dolores was sometimes upset at how staff spoke to her and that she was not listened to. Dolores had a bad fall on the ward one day and was left with cuts & bruising. Dolores told staff that she was very sore, but staff did not treat her injuries until sometime later. Dolores was discharged but was readmitted to hospital within a few days. Dolores became very sick with sepsis and passed away in the hospital.

Sophie wanted to raise her concerns with the hospital and wanted to access more information about the care & treatment her mother Dolores had received. Sophie wanted to know how her mother's fall was managed and wanted information on the discharge plan. Sophie contacted the Patient Advocacy Service.



Actions by the Advocate:

Sophie and her Advocate from the Patient Advocacy Service discussed Sophie's concerns and agreed an Advocacy plan to address her issues. Sophie's Advocate helped her to request her mother's medical file from the hospital and supported her to read through it. The Advocate explained the complaints process to Sophie and the different stages of making a complaint. The Advocate helped her to write a formal complaint to the hospital.

Sophie was unhappy with the response to her complaint. Sophie felt that the hospital did not fully acknowledge what had happened to her mother and that there was no learning for the hospital. Sophie's Advocate suggested that she ask the hospital for a meeting to discuss her complaint in detail. The hospital agreed to meet with Sophie.

Sophie's Advocate supported her to prepare for the meeting, helping her to put together the questions she wanted to ask. The Advocate went to the meeting with her to offer support. There were several senior hospital staff members at the meeting. They listened to Sophie's story. Sophie told staff how devastated she was after the death of her mother. She told staff about how upset her mother had been while she had been a patient in hospital. Sophie told them about the fall her mother had, and said how worried she was when her mother had been discharged. Sophie told them how sick her mother became with sepsis.

The staff took time to explain Dolores's discharge plan with Sophie. They spoke about Dolores's care plan and explained the treatment & care that she had received. The staff said that because of Sophie's complaint, members of staff who treated Dolores had received additional training. The staff acknowledged the trauma that Sophie had been through, and they apologised on behalf of the hospital for how Dolores felt while she was in hospital.



Outcome:

Following the meeting Sophie stated that she felt heard by the hospital. Sophie felt that staff had taken on board the devastating impact losing her mother had on her and they acknowledged and apologised for any mistakes made. Sophie stated that she felt empowered by the support provided by her Advocate. She stated that she felt both her and her mother's voices had been heard.



4. Poor Communication



Context:

Jonathan, who is in his late forties, was experiencing severe back pain when he decided to go to the Accident and Emergency (A&E) Department in his local hospital. While he was in the A&E Department Jonathan experienced a lengthy delay in being admitted. An oversight by the triage team led to further waiting times. Jonathan's extreme pain was dismissed by medical staff and, he felt very unhappy with the care and treatment that he had received there. Jonathan described being spoken to in a rude manner by A&E staff and felt that some staff who were treating him were not acknowledging his medical needs. Jonathan felt quite vulnerable as he needed medical attention and was in constant pain. Jonathan decided that he wanted to make a formal complaint about his experience, and he contacted the Patient Advocacy Service for support.



Actions by the Advocate:

Jonathan and his Advocate from the Patient Advocacy Service discussed his concerns and agreed on an advocacy plan to address his issues. The advocacy issues from Jonathan's experience in A&E included poor communication, oversight by medical staff, anxieties acknowledged but not addressed, lengthy delays, rude behaviour by staff, no pain relief, very little monitoring of his medical needs and long wait times. Jonathan was discharged without sufficient examination and never accessed a specialist.

Jonathan's Advocate helped him to write a formal complaint letter, identifying the issues he wanted addressed and the questions that he wanted answered. Jonathan submitted his complaint to the hospital and waited for a response. Jonathan did not receive a response from the hospital about his complaint. Jonathan's Advocate advised that he follow up with the hospital to find out why his complaint had not been addressed. On follow up from Jonathan the hospital issued a response. However, he felt the response was not adequate and did not address his concerns.

Jonathan's Advocate recommended he contact the hospital again to let them know how inadequate their response was and to request an in-person meeting to try resolve the complaint concerns. Jonathan was offered a meeting, which took place seven months after he made his complaint.

Jonathan's Advocate attended the meeting and provided moral support to him. During the meeting, the hospital apologised to Jonathan and acknowledged that there had been failings in his care. The hospital made assurances to Jonathan that they would make improvements in the Accident and Emergency Department.



Outcome:

Jonathan received the apology that he had wanted with clear recommendations from the hospital in relation to communication and assurances that other patients in A&E would be treated with care and respect. As a result of advocacy support Jonathan felt his complaint and experience was validated. Jonathan felt he received a genuine outcome for himself and for future A&E patients. Jonathan was empowered by the whole experience and is now a patient representative improving the quality of care in the same hospital.

Jonathan was very satisfied with the support from his Advocate and with the outcome of his complaint and felt that through the process the hospital had listened to him and taken on learning.



5. Dignity & Respect/End of Life



Context:

Louise's sister Cathy unexpectedly passed away in the Accident & Emergency (A&E) Department in hospital. Louise expressed that the hospital did not communicate fully to Cathy the seriousness of her symptoms following triage. Louise felt Cathy should have received better clinical & nursing care. Louise believed that Cathy's dignity and respect were overlooked by staff. When Cathy sadly died, Louise said that the hospital did not provide follow-up communication with her family, showing very little empathy towards them. This was very upsetting for Louise and her family.

Louise wanted to make a complaint and felt she needed additional support in order to engage with the hospital's complaint process and contacted the Patient Advocacy Service.



Actions by the Advocate:

Louise met with an Advocate from the Patient Advocacy Service and agreed an advocacy plan to help address her concerns. The main advocacy issues for Louise centred around communication with Cathy and Cathy's family during her stay and following her death. Also, inadequate standards of clinical and nursing care provided during Cathy's time in hospital, as well as, during end of life. Louise felt that Cathy was not treated with dignity and respect and when personal items went missing staff did not help the family to find them and showed little empathy towards them.

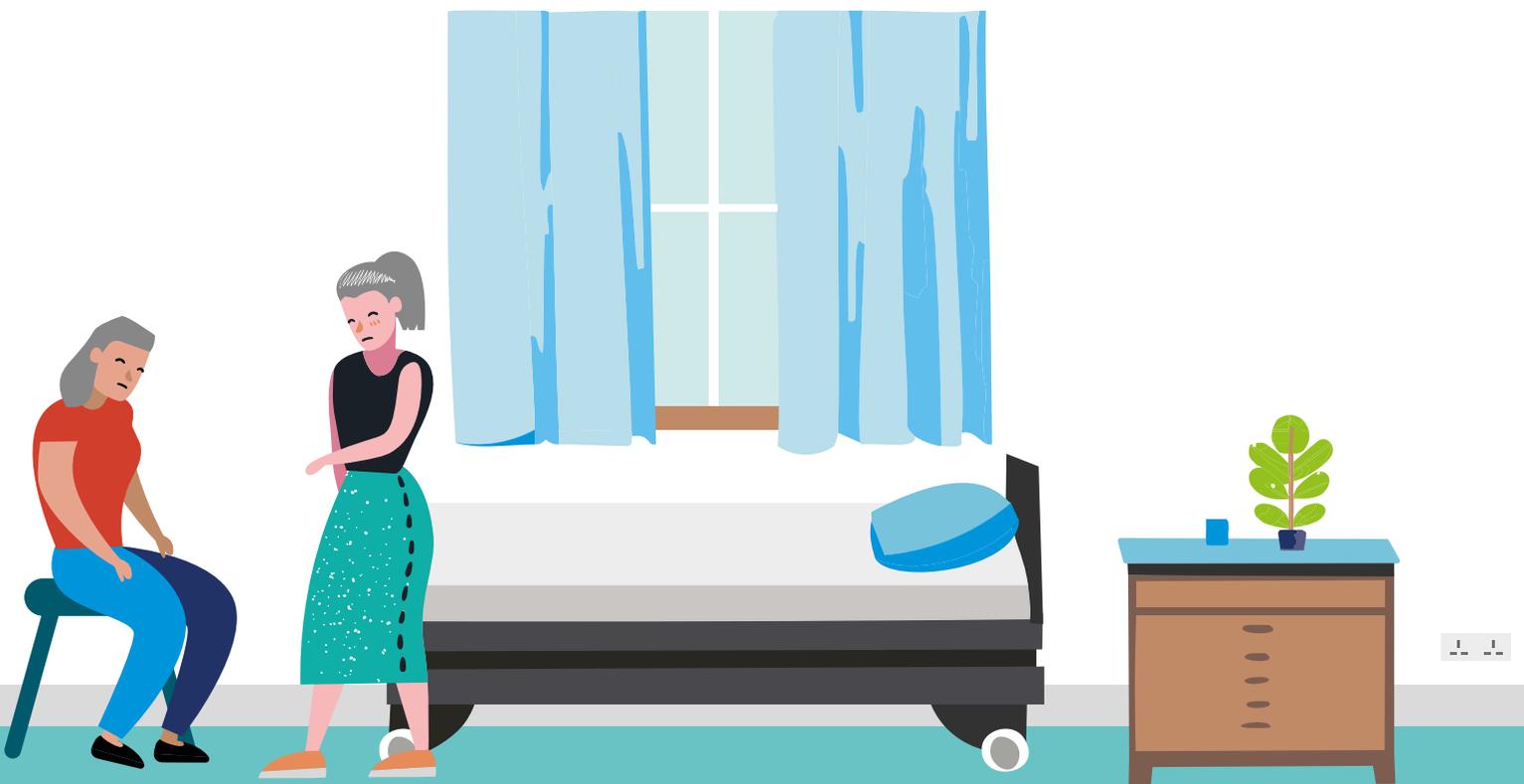
Through the Patient Advocacy Services' Trauma Informed Care approach, an Advocate was able to encourage Louise along the complaint pathway, including submitting a formal complaint to the hospital. The Advocate helped Louise to write a timeline of what happened but also to pinpoint the questions that she wanted answered. Louise's Advocate explained the complaints process at each stage to her and helped to research certain policies for her complaint.

The hospital provided a response to Louise's formal complaint offering a sincere apology to her and her family for what had happened with Cathy's care. The hospital stated that there had been learning from the complaint, and they would make improvements in how they made clinical care plans and nursing care plans. The hospital stated that they would prioritise end of life communication training and improve clinical training for staff. The hospital agreed to introduce a family room on each ward so that families could have privacy and a space to go to when their loved one was sick. The hospital said that it would introduce supports for families after a person had died and would introduce a system for the management of personal items.



Outcome:

Louise was satisfied with the advocacy support received and the outcome of her complaint, including the apology. Knowing that other patients and their loved ones would experience a better standard of care during end of life was paramount for Louise.



6. Patient Safety Incident



Context:

Síle's husband Eamon had contracted Covid-19 in hospital and passed away. Eamon, who was in his 60's, had been unwell and presented to his local Accident & Emergency (A&E) Department. He was admitted to hospital and was told he would need a procedure. Eamon was on a ward for a few days before his procedure was going to take place. During this time, there was an outbreak of Covid-19 on the ward. Síle and Eamon were unaware that he had contracted Covid-19 when he had his procedure. Síle decided to make a complaint to the hospital based on her experience. She contacted the Patient Advocacy Service for advocacy support.



Actions by the Advocate:

Following discussion with her Advocate from the Patient Advocacy Service, an advocacy plan was agreed to address Síle's concerns. Síle outlined several issues she and her husband Eamon had with the hospital. Firstly, there was the management of the Covid-19 outbreak on the ward. Eamon had been sharing a room with others and Síle thought Eamon should be on his own as he prepared for surgery. There was a delay in telling Eamon that he had contracted Covid-19. Síle also found communication with her was poor when Eamon became very sick with Covid-19. Eamon was not able to communicate with Síle and she felt the hospital could have managed this better. Síle had difficulty getting to visit Eamon prior to his death and felt that the hospital should have allowed more visits on compassionate grounds.

Síle's Advocate helped her to write a complaint letter to the hospital, supporting her to write a chronology of events and to write her questions and expected outcomes. When Síle was contacted by the hospital to inform her they were going to hold an investigation into Eamon's care, her Advocate was able to help Síle with this process, explaining the relevant policies and procedures to her. Síle attended several meetings with the hospital during this time and her Advocate was able to attend these meetings with her.



Outcome:

When the investigation was complete, Síle received a full report which highlighted where errors occurred in relation to Eamon's care. Síle's Advocate was able to help her read through the report. Síle felt that she had been listened to and that her concerns were taken seriously. While the investigation was very traumatic for Síle, she felt that the hospital took on learnings and implemented improvements so that no other family would have to go through what she and Eamon had. Síle felt empowered by the advocacy support provided.





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