PCC
PATIENT & CLIENT COUNCIL

Advocacy Casebook 2025

Your Voice, Our Journey

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Advocacy can be defined as taking action to support people to say what they want, secure their rights, pursue their interests and obtain the services they need.

Foreword

Welcome to our first PCC Advocacy Casebook.

As part of our statutory functions, the PCC provides an independent, professional and free advocacy service for those that have issues in health and social care in Northern Ireland. Every year we support over 600 cases, emphasising the importance of independent advocacy in addressing issues through partnership, mediation and a relationship-based approach. As well as delivering better outcomes for the public, this approach can offer the opportunity for upstream learning and prevention, increase staff morale, build trust and confidence, and maximise limited resources in a system under strain.

I am pleased that this approach and a focus on restorative practice is reflected in 60% of our cases in 2024-2025 being resolved, an increase from 57% in 2023-24 and 45% in 2022-23.

This Casebook provides a snapshot into the work of our PCC Support Service and provides insight into how independent, professional advocacy can positively impact on people's lives; helping them to have their voice heard, uphold their rights and address inequality. It illustrates the diverse range of people who access independent advocacy services in Northern Ireland and the breadth of issues supported by the PCC.

Advocacy interventions can impact most when people need specific and tailored information or support. The Casebook demonstrates the different forms of advocacy, including empowerment and representative advocacy, in situations that are often emotionally charged for both the people receiving support and the staff involved.

I hope that these case examples provide rich insight into how PCC can support members of the public within health and social care, highlighting the importance of independent advocacy and showcasing the positive impact we have had in people's lives, in communities and across the wider system.

Advocacy helps breach gaps in systems that leave people in difficult situations. It ensures best practice across public services, and it promotes positive systemic change when necessary. I would like to recognise the dedication of my team in advocating for people across health and social care. I would also like to acknowledge the trust placed in us by those who access our services, and the health and social care staff that have worked with us in seeking resolution.

M. Monaghan

Meadhbha Monaghan, PCC Chief Executive.

Note to reader: all case studies included in this casebook 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.

ADVOCACY CASE STUDIES

#1 Resolution

BACKGROUND

Sam was referred for 'red flag' urgent surgery. A pre-operative assessment (pre-op) was completed a year later. However, no date for surgery was received.

Sam was concerned at the lack of communication regarding the surgery and that it still hadn't happened, despite the 'red flag' status. Sam contacted the surgeon's secretary, who said they did not have his medical records following the pre-op, but advised that this assessment would need to be repeated if surgery was not completed within six weeks.

Sam was extremely worried about any delay with his urgent surgery and if his medical records had been mislaid. Sam tried contacting various departments within the hospital to locate his medical notes but was unsuccessful. He felt his concerns were not being taken seriously and became frustrated that systems inside the Trust were disorganised.

Feeling anxious and unable to progress the matter further himself, Sam contacted the Patient and Client Council (PCC) for support and advice about making a complaint in order to get a date for his surgery.

WHAT WE DID

Our Advocate listened to Sam to build an understanding of his concerns. Recognising the time sensitivity of the case, our advocate discussed a resolution approach with Sam - based on partnership, mediation and a relationship-based approach.

Sam provided consent and a plan was agreed that our Advocate would contact the Trust to discuss Sam's concerns with the relevant Service Manager.

Contacts between our Advocate and the Service Manager resulted in the location of Sam's records and these were provided to the surgeon's secretary.

OUTCOME

As soon as our Advocate made the Service Manager aware of the issue, he acted quickly to locate the medical records and progress Sam's treatment. Sam had his surgery 7 weeks later. The Trust apologised for the delay and confusion caused.

Sam was very happy with the support and advice that our Advocate provided to achieve the timely resolution.

#2 Communication

BACKGROUND

Mary, a woman in her late fifties, passed away at home, just eight weeks after a lung cancer diagnosis.

John, Mary's husband, felt confused about her untimely death as Mary had been receiving COPD treatment over the previous two to three years. John felt that due to the number of tests, scans and x-rays that his wife had during that time, the cancer should have been picked up sooner and appropriate treatment provided to her.

When the GP arrived at their home to certify Mary's death, John asked what had happened and was told "sometimes this happens". On reviewing his wife's death certificate, the primary cause of death was stated as "Cancer with primary site unknown".

John rang the Patient and Client Council (PCC) for support to have his concerns addressed. He was upset, confused and wanted help to get the answers he felt he needed for closure.

WHAT WE DID

Our Advocate listened to John and discussed some possible options to get the answers he needed, in the most appropriate and timely way.

With John's consent, our Advocate contacted the Practice Manager of the GP Practice to outline his concerns and questions surrounding Mary's diagnosis and treatment prior to her death and requested an in-person meeting with Mary's GP, who subsequently agreed to meet.

At John's request, our Advocate also attended the meeting with Mary's GP to provide support with getting the answers John needed.

At the meeting the GP went through Mary's medical records and explained the tests, investigations and results. The GP explained Mary's recent cancer diagnosis and the cause of death on the certificate. The GP was open in his communication with John and answered all his questions. John was able to see all the reports from various tests and scans and was assured that the information provided by the GP was accurate. The GP invited John to make contact again if other questions came to mind at a later date.

OUTCOME

John received the answers he needed to understand why his wife's death was recorded as "not identified" and was reassured that his wife had received a good level of care.

John felt that a resolution focused approach, that our Advocate facilitated, was the most suitable way of addressing his concerns.

The in-person meeting provided the information John needed in a meaningful way and allowed for questions to be asked and answered without a time delay.

John was very satisfied with the support from our Advocate and appreciated the time and persistence it took to organise the in-person meeting, which gave him clarity and closure to grieve for his wife, Mary.

FEEDBACK

My queries were always dealt with very efficiently. The PCC advocate supported me with advice, guidance, kindness and compassion during a very difficult and stressful time.

#3 Communication

BACKGROUND

Following an accident in January 2020, Rebecca's home required adaptations to allow her to live independently.

In Northern Ireland, house adaptations under the Disabilities Facilities Grant (DFG) are the responsibility of two public agencies i.e. Social Services and the NI Housing Executive.

Due to the involvement of multiple staff and departments, the adaptation process was considerably delayed, impacting on the wellbeing of Rebecca and her family.

Rebecca made a complaint to her Health and Social Care Trust and was subsequently referred to the Northern Ireland Public Service Ombudsman (NIPSO). Rebecca felt disregarded and not listened to.

Rebecca remained frustrated that the house adaptation process was taking so long and contacted the Patient and Client Council (PCC) by telephone for support and advice on how to move the process on.

WHAT WE DID

Our Advocate listened to Rebecca and invited her to meet at a local PCC office. This was to discuss the issue with Rebecca to gain clarity on the situation and establish which aspects of the delay and complaint sat with the Health and Social Care Trust and which sat with the Housing Executive, as PCC cannot provide advocacy support in complaints about the NI Housing Executive.

Our Advocate clearly explained the process to gain house adaptations and the responsibilities of the two public agencies involved in the process.

After discussing the necessity to move the adaptation process along and the urgent need the family had for the adaptations, an advocacy plan was agreed with Rebecca.

Our Advocate suggested a re-engagement with the Trust in an attempt to re-establish communication between Social Services and the family before taking the next step in the complaints process with NIPSO. The aim of this was to establish what was delaying the process and how these delays could be overcome.

With consent from Rebecca, our Advocate contacted the Trust by telephone. The response from the Trust was not as hoped; with the suggestion that Rebecca and her family apply to seek alternative accommodation that may be more suitable. Rebecca and her family did not want to move from their home and again felt like they were not listened to.

With considerable coordination, our Advocate facilitated an in-person meeting with Trust representatives and Rebecca to re-establish communication and to explore the barriers to progress the adaptations. This meeting was very positive. A plan that met the expectations of both Rebecca and the Trust, including an expedited Occupational Health assessment to the Housing Executive, was agreed. Those present at the meeting agreed that adaptations to the family's current home was in their best interest. Rebecca was relieved, as the family support she had nearby was a 'life-line' to her.

Our Advocate suggested that the agreed action plan should include a timeline, so that everyone understood their role and requested that Rebecca received a written copy.

OUTCOME

All staff involved were clear on the process and what was required of each department, by when, in order to move the housing adaptation process along for Rebecca and her family.

A point-of-contact was established for Rebecca to maintain communication.

Rebecca felt content that she was being listened to and that the process had an end date in sight. Rebecca was very grateful for our Advocate's support, advice and intervention to get the process reinstated.

The action taken by PCC prevented this case going to NIPSO and got a quicker resolution for Rebecca.

#4 Patient Safety

BACKGROUND

Hannah's father, Michael, experienced a stroke and was admitted to his local hospital. Whilst in the hospital he contracted sepsis, resulting in renal failure. Michael was discharged alone seven weeks later, suffering from delirium.

Michael was very confused at the time of his discharge, he didn't know his address nor remember the entry code to his home. He could not use his phone, get access to food or look after himself.

Hannah was unhappy with her father's care whilst on the ward and was concerned that no assessment had been carried out in his home ahead of discharge, so she made a complaint about the staff to the Trust.

Hannah highlighted multiple failings to the Trust, which they acknowledged initially through a face-to-face meeting. However, Hannah still had a number of outstanding concerns and felt like she needed support to continue with her complaint. Hannah contacted the Patient and Client Council (PCC) for advice.

FEEDBACK

I can't thank you enough for all your support and kindness. You gave me so much strength at such a difficult time.

WHAT WE DID

Hannah discussed her concerns with our Advocate and they agreed an advocacy plan to address her issues. As Hannah felt that the hospital did not fully acknowledge what had happened to her father, our Advocate suggested that they ask the Trust for a meeting to discuss her concerns in detail. The Trust agreed to meet with Hannah, but didn't confirm a date. With Hannah's consent, our Advocate followed this up with the complaints department to agree a date for the meeting.

Our Advocate supported her to prepare for the meeting, helping to put together the questions she wanted to ask. Our Advocate went to the meeting with her to offer support. There were several senior hospital staff members including a Consultant, Head of Service and senior nursing staff at the meeting who listened to Hannah's concerns about the discharge planning and lack of communication with family members ahead of the discharge. There was agreement that a proper discharge assessment had not been completed.

OUTCOME

The Health and Social Care Trust;

- apologised to Hannah and her father with regards to their experience at the hospital.
- undertook to feedback to the hospital social work team and medical team on the ward regarding communication and discharge planning.
- offered to answer any further questions Hannah might have and sent a copy of the meeting notes.

Hannah stated that she felt empowered by the support provided by our Advocate and that she felt both her and her father's voices had been heard. Hannah was happy that the Trust had taken on learning.

#5 Nursing Home

BACKGROUND

Martina's mother, Eleanor, lives in a Residential Care Home. Due to her medical condition Eleanor experiences regular falls.

For Eleanor's birthday, Martina fitted a smart TV in her bedroom at the Care Home, which had video call technology. In addition to Martina's daily face-to-face visits, she would also call her mother virtually, as and when she wanted to, via the video call technology on the television.

During a late evening virtual visit with her mother, Martina noticed that her pressure floor mat wasn't plugged in. The mat would alert staff if Eleanor had got out of bed and support could be provided. She was anxious about Eleanor falling so she rang the Care Home, five times, but was unable to get speaking to anyone. Martina drove to the Care Home, after some time gaining entry to the Care Home, and a heated verbal exchange ensued with a member of night-shift staff. Martina was subsequently asked by the Care Home Manager to remove the video call technology immediately.

Martina was very unhappy as she felt this was an important way for her mother to be connected with her family and to check all was well with her. Martina rang the next day to speak to the Care Home Manager who advised that it was a policy decision not to have virtual recording devices in residents' rooms.

Martina asked if she could have the video call technology on at pre-agreed times, arguing that staff had been aware of it being in use previously without any issue and that she had been unaware of this policy. Management did not accept this compromise and Martina had to remove the video call technology from the television in her mother's room. Martina was insistent on getting it reinstalled.

Martina contacted the Patient and Client Council (PCC) for advice and for support to submit a complaint to the Care Home's responsible Health and Social Care Trust.

WHAT WE DID

Our Advocate listened to Martina and explained the complaints process and the different stages of making a complaint.

Our Advocate helped her to write a complaint letter to the Trust, that requested a meeting with the Care Home's Regional Manager to discuss the removal of the video call technology.

A date was arranged for Martina to meet with the Care Home Manager and the Care Home's Regional Manager. Our Advocate supported her to prepare for the meeting, helping to put together the questions she wanted to ask. Our Advocate also went to the meeting with her to offer support.

During the meeting, the Regional Manager explained that their policy prohibited the use of video call technology in residents' rooms as it was viewed as a monitoring device. However, Martina maintained that she had been using it as a means of connecting her mother with family and for herself, to ensure that she was not at risk of falling. Martina described several instances that had left her uneasy about the frequency of staff checks but insisted that she was not using the video call technology as a means of monitoring the staff. Martina again offered to only use the feature at pre-agreed times if it was reinstalled. However, the Regional Manager insisted that their policy was not negotiable and that it could not be reinstalled. As an alternative, the Regional Manager suggested that Martina could FaceTime with her mother on an iPad, provided by the care home at an agreed time every night. Martina was not keen on this as a solution initially but eventually agreed to a trial period of the FaceTime option.

Our Advocate contacted Martina during this trial period to see how things were going. Martina said that there had been some issues with connectivity at the beginning but difficulties had been ironed out.

OUTCOME

Martina felt happier with the compromise and accepted that she was unable to get the video call technology reinstalled in her mother's room.

Martina's relationship with the Care Home staff was back on good terms having had the opportunity to talk over the matter in full context.

Martina was satisfied with the outcome of her complaint and with the support from our Advocate.

The lines of communication that were established during the meeting, have ensured that Martina and her mother have secured regular contact while adhering to the care home policy. The complaint was resolved and did not need to progress.

#6 Treatment and Care

BACKGROUND

David, who is in his early forties, has been living in pain with a medical condition. David's pain was so unbearable that he attended his GP over twenty-six times in a six-month period as well as attending his local Emergency Department, sometimes by ambulance. He was told he was on the waiting list for a procedure but didn't have any further information as to when this would happen. David was frustrated with the lack of treatment and felt he was being bounced between services.

David was concerned that he now had a fractured relationship with the healthcare professionals because of the many attendances and reported a breakdown in communication with the consultant. It was at this point David made a complaint to the Trust.

David received a response to his complaint but felt it did not address his concerns. As time went on, David began to feel depressed, he spent most of his day in bed which impacted his family life and he lost touch with his social circle, leading to a decline in his mental health.

After seeing an advert for the Patient and Client Council (PCC), David made contact for advice.

WHAT WE DID

Our Advocate listened to David and agreed an advocacy plan. With David's consent, our Advocate re-established contact with the services to find out what treatment pathway he needed to be on to manage his condition until the surgical procedure took place. Our Advocate contacted David's consultant to emphasise the deterioration in David's condition since David was last seen.

OUTCOME

David was seen by his consultant and together they are working on a treatment plan, which includes David having regular direct contact with the service and a programme of re-education and changes to his medication, working alongside his GP and Primary Care Team.

David said the change to his life has been great and that he and his family are grateful for the support received from the PCC.

FEEDBACK

You were my rock, a light in the dark. At a time when I was at my lowest, you were there, you listened and did everything to help.

#7 Safeguarding

BACKGROUND

Jason is a wheelchair user who lives in a three bedroom, specifically adapted, bungalow owned by a Health and Social Care Trust. Jason shared the house with another tenant who is also a wheelchair user with one other room being vacant. Without consultation another tenant came to live in the vacant room. The new tenant was not a wheelchair user. Within a very short period of time Jason became upset that the new tenant was purposefully obstructing corridors in the house, blocking doorways and causing general disruption. Jason had also experienced some physical abuse from the other tenant and had cause to contact the police. Jason had become fearful and was spending an increasing amount of time in his own room with the door locked. The Police attended the home on four separate occasions due to noise complaints from neighbours as the new tenant insisted on playing loud music late at night.

Paula, Jason's sister, contacted Jason's social worker to raise her concerns and felt unheard. The social worker advised that she had no power over who is allocated the tenancy. Paula didn't know what to do next so she contacted the PCC for support and advice.

WHAT WE DID

Paula contacted the PCC helpline and immediately spoke to an Advocate. Consent was sought from Jason for the PCC to provide support. Our Advocate felt that Jason's safety was at risk and recognised that a safeguarding referral should be made to the Trust.

An urgent referral was made to Adult Protection Gateway Services which prompted the Trust to undertake an immediate investigation.

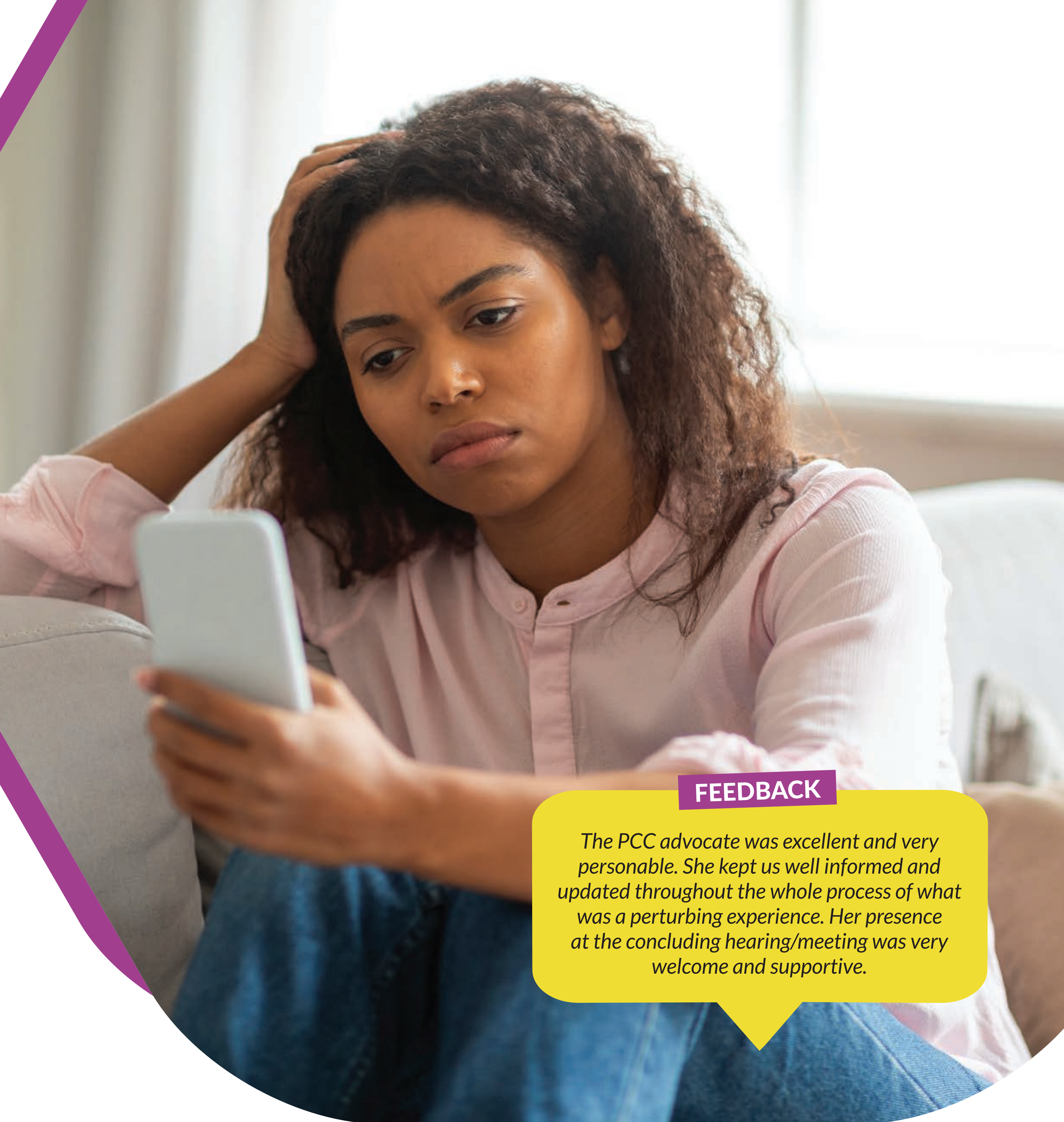
Jason, Paula and our Advocate were invited to a meeting where Jason and Paula were able to outline their concerns about Jason's physical and emotional safety. The Head of Service, who was in attendance, had agreed to the offer of the tenancy to the third tenant but had not been updated on the assessed needs of the third tenant, which were at odds with the original purpose of the adapted property.

Jason received an apology from the Head of Service for the anxiety this situation had caused. Jason was offered alternative accommodation in the meeting which he refused as he had lived in this accommodation since it was adapted 10 years previously and it was his home. The accommodation allowed Jason to socialise with his friends nearby, attend his part time employment and use the public transport which was frequent. During the meeting our Advocate highlighted the need to safeguard Jason in his own home and as the victim in this case Jason should not have to move. During the meeting the Head of Service agreed to make immediate contact with his counterpart in another service in the Trust to discuss the need to resettle the third tenant. Our Advocate insisted that Jason's need for protection was paramount. It was agreed that Jason would be accommodated temporarily in a local hotel until the third tenant could be accommodated elsewhere.

Jason was visited at home the following day by the Director of Adult Social Services who apologised on behalf of the Trust for the upset that had been caused to him and his family. The Director said that full consideration of Jason's needs and that of the other tenant should have been take into consideration by the Trust prior to the third tenant moving in. He explained that the decision had been made in an emergency by the out of hours service and that this would not occur again.

Our Advocate engaged with Victim Support NI on Jason's behalf.

The PCC sought advice from a housing rights organisation which, when shared with the Trust, it was agreed that the third room in



the shared house was too small to be legally considered a permanent bedroom. The room will be no longer suitable for another tenant. Jason is relieved that he can be content and relaxed in his own home once more.

OUTCOME

Jason was able to return to his home and felt more secure and safe. Jason and Paula thanked the PCC for initiating the safeguarding referral which they believe was critical to the resolution of the matter.

Following PCC's 'Positive Passporting' referral to Victim Support NI, Jason continued to avail of their services.

#8 Dignity and Respect

BACKGROUND

Sophie was referred to Ophthalmology Services at her local Health Trust regarding problems that had been discovered during a regular eye test. Due to the swelling found in her eyes an appointment was arranged for a lumbar puncture the next day. On arrival the Neurology Consultant brought Sophie and her mother into a small room and a diagnosis was confirmed very quickly. They were told that "there was nothing that could be done" and that Sophie had developed the condition due to being overweight. The Consultant didn't provide any information on the condition nor explain that the condition was rare. Sophie was handed a prescription for medication and discharged without any opportunity to ask any questions. Sophie felt judged for her appearance as she was never informed about other aspects of the condition.

In the following weeks, Sophie's health deteriorated significantly and was advised to go to the Emergency Department (ED) by her GP, where she was admitted for observation. Again, Sophie felt judged regarding her weight as the Neurology Consultant spoke to her in an abrupt and unpleasant manner and advised her to "go home and lose weight."

Sophie's condition continued to deteriorate and she was readmitted to hospital. During this 3 week stay, Sophie became fearful of medical professionals. She said she experienced a lack of empathy for her deteriorating sight, aggressive mannerisms and dismissal of her pain and symptoms.

Eventually an appointment for Sophie to attend the Eye Casualty was made and she was diagnosed with Optic Neuritis. Despite the diagnosis, the Neurology Consultant continued to dismiss Sophie's symptoms and delayed the commencement of her treatment for some time.

Sophie was later discharged following treatment, still with impaired vision and was offered no help or consideration for care within the community. Sophie said that she was told in an abrupt tone to "just go home, the Neurology department did not want to see her again." Sophie requested for the Neurology Consultant to explain the discharge to her Mother. This didn't happen.

In addition, incorrect information regarding her medication was provided to Sophie's GP.

Sophie wrote a letter of complaint to the Trust and received a phone call from the deputy Medical Director offering a meeting to discuss the complaint. Unsure of what to do, Sophie contacted the Patient and Client Council (PCC) for support and advice.

WHAT WE DID

Our Advocate listened to Sophie and asked her how PCC could best support her. Sophie said she was unsure whether she should attend the meeting with the deputy Medical Director. Our Advocate advised that attending the meeting may help to address the issues quickly as opposed to waiting for a written reply, and that attending the meeting would not affect the complaint process, and they would still be entitled to request a written response after the meeting.

Following this advice, Sophie decided to meet with the deputy Medical Director.

With Sophie's consent, our Advocate contacted the Trust to arrange a time and date for the meeting and supported Sophie to prepare for the meeting, helping her to put together the questions she wanted to ask. Our Advocate went to the meeting with her to offer support.

OUTCOME

The Trust apologised for what was said to Sophie as well as how she was made to feel and thanked her for bringing the matter to their attention, acknowledging also how difficult the experience had been for her.

The deputy Medical Director said that learning from the matters discussed would be shared at the clinical and nursing staff team meetings and also advised Sophie to speak with the Nurse in Charge of any department if she has any future difficulties. This provided Sophie with reassurance.

Sophie thanked our Advocate for the guidance and support she received.

FEEDBACK

The PCC advocate was extremely helpful. From when my case was opened and until it closed he was courteous and offered excellent advice on how to proceed with my issue. I would like to pass on my thanks and appreciation to him for the manner in which he helped me through the whole process.

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