PCC
PATIENT & CLIENT COUNCIL

Advocacy Casebook 2026

Your Voice, Our Journey

www.pcc-ni.net

Contents

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 second PCC Advocacy Casebook.

As part of our statutory functions, the PCC provides an independent, professional and free advocacy service to people, their families, and carers, experiencing issues within health and social care in Northern Ireland.

Our Advocacy Casebook for 2026 provides 10 examples of how PCC supports members of the public and works with HSC organisations to seek resolution on their behalf. It demonstrates the positive impact independent, professional advocacy can have on people's lives and how advocacy can support individuals to have their voices heard, uphold their rights, and address inequalities. Advocacy also plays a key assurance role within the Health and Social Care System.

Each year, we support over 600 cases, working to address issues through partnership, mediation and a relationship-based approach. This is reflected in our continued drive towards restorative practice, which has resulted in 58% of all cases in 2025-26 achieving a timely resolution between people calling the PCC and the Health and Social Care Service they had an issue or complaint with. In addition to delivering better outcomes for the public, this approach supports early learning and prevention, increases staff morale, builds trust and confidence, and maximises limited resources in a system under strain.

The Casebook highlights the breadth of the issues supported by the PCC, over the previous year, as well as the wide range of people who access independent advocacy services across Northern Ireland. It demonstrates the different forms of advocacy, including empowerment and representative advocacy, in situations that are often emotionally challenging for both those receiving support and the staff involved.

The Casebook should be of interest to members of the public, public representatives, the voluntary and community sector, clinicians, staff and governance leads within HSC organisations.

I would like to take the opportunity to recognise the commitment and dedication of my team in advocating for individuals across health and social care. I also wish to acknowledge the trust placed in us by those who use our services, as well as the health and social care staff who have worked with us to achieve resolution.

M. Monaghan

Meadhbha Monaghan, PCC Chief Executive.

Note to reader: Case studies included in this casebook have gone through a rigorous anonymisation process. This involves changing identifying elements of the case to protect the anonymity of the person and advocate involved whilst maintaining the accuracy of the case study. The location, age, gender and name of the people in these stories are likely to have been changed.

To support anonymity, feedback quotes do not necessarily relate directly to the case studies included, but reflect feedback received across PCC's advocacy services in 2025-26.

A new Model of Complaints Handling Procedure (MCHP) was commenced on 1 January 2026. Many of the patient's stories within this casebook predate the introduction of the MCHP.

Content warning: This Advocacy Casebook contains content of a sensitive nature, including accounts of death and baby loss that may be distressing, therefore readers' discretion is advised.

WORKING IN PARTNERSHIP FOR POSITIVE CHANGE

BACKGROUND

Following a serious accident, baby Noah attended the Emergency Department with his Mum, Corrina, and Dad, Johnny. Tragically, baby Noah died.

While Corrina and Johnny acknowledged that individual staff showed compassion, they reflected deeply on the environment in which they found themselves. The Emergency Department felt busy, exposed, and unsuitable for parents attending with a critically ill child, a child with a life-limiting condition, or a child who had died. The lack of a private, calm space added to their distress at an extremely traumatic time.

Motivated by their experience and a desire to ensure other families would be better supported, Corrina and Johnny contacted the PCC, not to make a complaint, but to seek advocacy support to work with their local Trust to explore the development of a dedicated family or bereavement room within the hospital.

WHAT WE DID

Our advocate met with Corrina and Johnny to listen carefully to their lived experience and to understand what they hoped to achieve by engaging with the Trust. Our advocate took time to build trust, acknowledge the family's loss, and explain PCC's resolution approach, which focuses on collaboration, learning, and service improvement.

With Corrina and Johnny's consent, our advocate contacted the Trust to arrange an initial meeting involving senior Trust staff and the family. At the request of Corrina and Johnny, our advocate also attended to ensure the family were supported to share their story safely and clearly, and that their ideas were heard and respected.

Through ongoing engagement, meetings and constant communication, our advocate worked alongside the family and Trust staff to identify practical opportunities for change. A shared commitment emerged to develop a designated patient and family room within the hospital, shaped directly by the family's experience.

In addition, our advocate supported Corrina and Johnny to articulate their wider goal - the development of a hospital protocol, to guide how families experiencing the critical illness or death of a child are supported in Emergency Department settings.

Our advocate also supported the family to engage with the Coroner's Service, the Minister for Health, and the Public Health Agency to highlight the importance of the proposed hospital protocol and wider regional learning.

OUTCOME

With our advocates' support, Corrina and Johnny developed their lived experience into a "Story" and learning tool for professionals. Working in partnership with the Public Health Agency, this was transformed into a digital training resource to support staff education around trauma, bereavement, and compassionate care.

The Trust formally agreed to fund and develop a dedicated bereavement and support room. The room was named by the family in memory of Noah and designed collaboratively with Trust staff, the family, and the PCC.

Corrina and Johnny's lived experience has directly influenced service improvement, helping ensure that families facing trauma and loss are offered privacy, dignity, and compassionate support at one of the most

The names in this story have not been anonymised with consent from the family.
The image of Noah has been used by permission of the family.
In memory of Noah

difficult moments of their lives.

Meadhbha Monaghan, PCC Chief Executive said: *"The PCC is privileged to have supported the family in making their vision a reality, ensuring that families facing the most difficult moments are met with care, dignity and understanding."*

Health Minister, Mike Nesbitt said: *"For any parent to lose a child is unimaginably heartbreaking. I am deeply moved that they would use their own tragic experience to bring about improvements for other families in grief. I want to express my sincere gratitude to them. "My thanks also to Trust and the Patient & Client Council for supporting the development of this important facility."*

The PCC have also reached out to other Trusts to highlight the development of the bereavement and support room, so that other Trusts might reflect on this and consider a similar approach.

TREATMENT AND CARE

BACKGROUND

Nora, who has advanced dementia, was admitted to a care home for short-term respite. Before admission, Nora mobilised with a walking aid. Shortly after admission, the care home removed the walking aid due to behavioural concerns. The care home did not complete a documented assessment or put alternative mobility support in place. Nora subsequently sustained a fall and was taken to hospital by ambulance.

Nora's family were notified but given incorrect information about which hospital Nora had been transferred to. In addition, Nora was registered as an 'unidentified patient' which meant the family were unable to locate Nora and experienced significant distress due to the communication errors.

Nora's hospital assessments failed to identify a fractured hip, and she was discharged back to the care home. Two days later the Hospital notified the care home that in fact a fracture was seen on X Ray which resulted in further hospital admissions, surgery, and prolonged hospitalisation. During Nora's time in hospital, the family were charged care home fees. Sadly, Nora passed away.

Nora's son, Stephen, was frustrated and upset with the mistakes made during his mother's care. Stephen contacted the PCC for support and advice.

WHAT WE DID

Our advocate listened to Stephen, documented the family's concerns and explained the complaints processes across multiple organisations. With consent, our advocate supported the family to submit coordinated complaints to the care home, Health and Social Care Trusts involved, and the ambulance service.

Our advocate was a consistent point of contact, supporting the family to understand responses and pursue further clarification where questions remained unanswered. Information was also shared with the Regulation and Quality Improvement Authority (RQIA) to support learning and oversight.

In addition, our advocate supported Stephen to challenge care home fees charged during the prolonged hospital stay by engaging with Trust Finance Teams.

OUTCOME

All of the organisations involved acknowledged failings in aspects of Nora's care, communication, and coordination. Apologies were issued and learning actions were identified.

Care home fees were waived for the period of hospitalisation, removing a significant source of stress.

FEEDBACK

My experience of working with the PCC has been outstanding and I would not hesitate to recommend your service.

COMMUNICATION AND CHANGES TO CARE PATHWAY

BACKGROUND

Laura had been on a waiting list for over two years following major bowel surgery. She was living with ongoing stoma-related issues and was concerned about the delays in being allocated a new consultant for the ongoing management of her care within the Trust.

Earlier in the year, Laura submitted a complaint due to a lack of communication and progress following the departure of her previous consultant. Despite this, several months passed without clarity on who was responsible for her ongoing care, whether she was receiving appropriate follow-up, or who her main point of contact should be. Laura felt anxious that her complaint might have delayed her treatment.

Laura's aim was never to escalate matters, but to gain reassurance that her care pathway remained intact and that her follow-up needs, including colonoscopy surveillance, were being appropriately managed. Feeling concerned, she contacted the PCC for support and advice.

WHAT WE DID

Our advocate listened carefully to Laura and agreed an advocacy plan focused on restoring continuity of care and progressing her complaint to resolution.

With Laura's consent, our advocate engaged over several months with a range of Trust staff, including complaints officers, service managers, and consultant clinicians, to seek clarification on Laura's clinical pathway, her position on the waiting list, and arrangements for allocation to a new consultant.

Throughout the process, our advocate maintained regular contact with Laura, keeping her informed of developments and providing reassurance while the Trust worked through the allocation process.

OUTCOME

Although the issue took several months to resolve, Laura was successfully allocated a new consultant. She attended her first appointment and described the consultation as very positive. Laura reported that she already knew the consultant from previous care and felt confident and reassured being under his management.

FEEDBACK

Right from the outset I found the PCC's service excellent. I received the correct professional advice and was provided the helpful links to the proper procedures.

MATERNITY CARE

BACKGROUND

Emma attended a routine pregnancy scan at 12 weeks. At this scan, Emma was told there was no foetal heartbeat. Faced with limited options, Emma accepted a surgical procedure to remove the foetus. Adding to her distress at an already difficult time, Emma had to repeatedly ask for surgical management rather than medication or natural passing. Emma felt her choice for surgery was not being heard as she needed to repeat this on numerous occasions to several different medical professionals.

The surgical procedure took place and was deemed 'successful', and Emma was discharged home on the same day. Two days later, Emma experienced significant pain and bleeding. Emma attended the hospital and an ultrasound scan revealed that the foetus was still intact and that the initial procedure had not been successful. Emma required a second surgical procedure, resulting in further physical discomfort and compounded emotional trauma.

Emma was deeply distressed by the lack of communication, explanation and involvement in decision-making throughout her care. She wanted reassurance that learning would take place and that her experience would contribute to improvements in care.

Emma's husband suggested speaking to the PCC for support and advice. The Trust decided this warranted Serious Adverse Incident review and the PCC are providing support in this regard.

WHAT WE DID

Our advocate listened carefully to Emma's account, capturing key facts, dates, staff involvement, emotional impact, concerns, and desired outcomes. In addition, our advocate provided advice, reassurance, and clear guidance throughout the review process and maintained regular contact with Emma to ensure she felt supported and informed.

With Emma's consent, our advocate supported her to write to the Trust outlining her concerns and requesting a meeting with senior clinical staff. Our advocate attended the meeting to ensure Emma's questions were addressed directly and sensitively.

During the investigation, significant issues were identified in communication, documentation as well as pre and post-procedure checks. Our advocate maintained contact with both Emma and the Trust to ensure her concerns were accurately reflected and responded to.

OUTCOME

The Trust acknowledged failings in care and communication, and identified learning with commitments to make service improvements.

FEEDBACK

Our Practitioner took time to explain everything in great detail. As a family we have found PCC very helpful in a time of distress.

sands

There is support available if you have been impacted by this story.

For more information visit:
Website: northernireland.sands.org.uk
Facebook: www.facebook.com/sandsnorthernireland

SERIOUS ADVERSE INCIDENT

BACKGROUND

Claire's son, Owen, was involved in a serious incident during a hospital admission. While being treated for a severe illness, Owen, who is neurodivergent, experienced extreme pain during medication administration through a cannula.

It later emerged that the cannula had been incorrectly placed, resulting in medication entering surrounding tissue rather than a vein. This caused a significant burn injury to Owen's hand, muscle damage, scarring, and long-term trauma.

Claire wanted to understand how this kind of mistake could happen. She sought reassurance that lessons had been learned, and confidence that her child would receive necessary follow-up care. Claire contacted the PCC for advice on how to achieve this.

WHAT WE DID

Our advocate listened to Claire and arranged to meet her in person to develop a detailed timeline of events. Our advocate also supported Claire to receive Owen's medical records and reviewed them with her, to identify concerns.

With Claire's consent, our advocate liaised closely with the Trust's Serious Adverse Incident (SAI) team and attended a meeting with the SAI panel and Claire to ensure her concerns were accurately recorded. When meeting minutes did not reflect what had been discussed, our advocate challenged this and amendments were made.

OUTCOME

The SAI report acknowledged that errors had occurred, explained how they happened, and identified learning and service changes to prevent recurrence.

Claire received confirmation of appropriate ongoing care for Owen, including plastic surgery, and Owen is recovering well.

Owen's case has since been used by the Trust as a training example to improve practice.

Claire also recommended the PCC to her friend who has come to the PCC for support.

FEEDBACK

My advisor showed great empathy and support. She gave me the courage to continue the process, as I was debating with myself whether to proceed or not.

ACCESSING SPECIALIST CARE OUTSIDE NORTHERN IRELAND

BACKGROUND

Pat experienced prolonged delays accessing specialist surgical treatment. His health issues had been ongoing for six years and involved complex care needs. Initially under the care of one Health and Social Care Trust, his care was later transferred to another Trust.

As part of his treatment plan, Pat required specialised surgery that is not available in Northern Ireland. Pat was advised by the Trust that a referral to a specialist consultant in England had been made, two years earlier. Pat was told by the Trust that the consultant in England was waiting on test results from the Trust in Northern Ireland before progressing his care.

Meanwhile, Pat continued to experience significant health problems, including recurrent infections. Over time, these infections became antibiotic-resistant, increasing his anxiety and concern about the impact further delays would have on his health. Pat felt lost in the system.

Uncertain about where responsibility lay and unsure how to move the situation forward, Pat contacted the PCC for advice and support.

WHAT WE DID

Our advocate listened carefully to Pat's concerns and reviewed the information he had been given. With Pat's consent, our advocate contacted the Trust to clarify the status of the referral and outstanding actions.

The Trust confirmed that all requested information and test results had a been provided to the consultant in England. To prevent further delay and ensure clear communication, our advocate requested and obtained direct contact details for the consultant's secretary.

Our advocate contacted the consultant's secretary directly, clearly outlining Pat's situation, the length of time he had been waiting, and the urgency of his clinical needs.

OUTCOME

Following our advocate's contact, Pat's case was reviewed promptly and the consultant's secretary made direct contact with Pat to offer him an appointment with the specialist consultant in England.

Pat was relieved that progress had finally been made after years of uncertainty and waiting.

FEEDBACK

Your service has provided me with impartial advice and steps how to manage the situation. My Practitioner was a great representative of your service [who] gave clear and concise advice and information with no judgement.

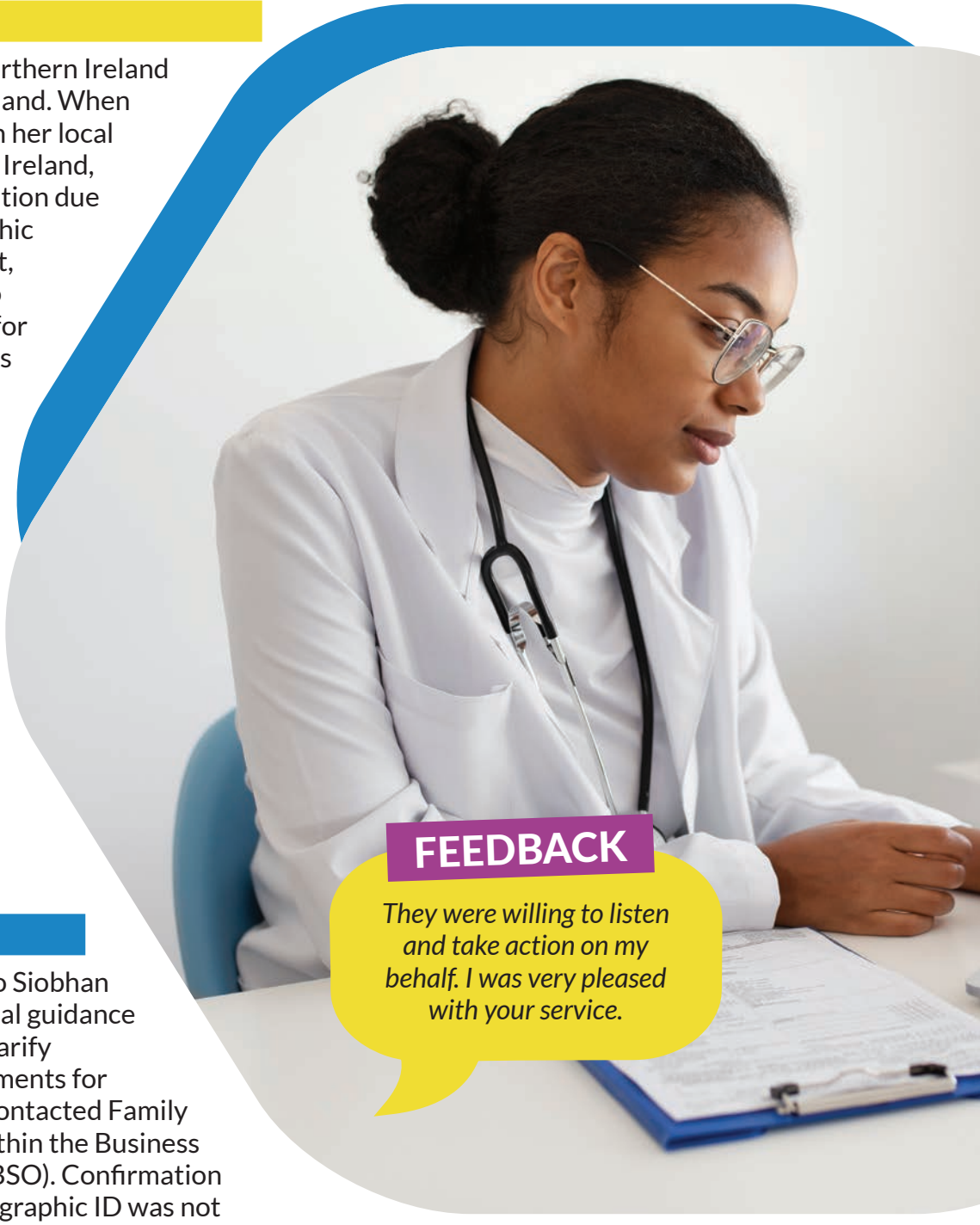
GP REGISTRATION RESOLUTION

BACKGROUND

Siobhan relocated to Northern Ireland from the Republic of Ireland. When she tried to register with her local GP practice in Northern Ireland, she was refused registration due to not having photographic identification. As a result, Siobhan was left with no other option but to pay for private GP appointments and medical care.

Siobhan felt excluded from primary care services and unsure how to challenge the decision.

Whilst visiting her local library, Siobhan came across a PCC Support in the Community session and used this opportunity to get advice.



FEEDBACK

They were willing to listen and take action on my behalf. I was very pleased with your service.

WHAT WE DID

Our advocate listened to Siobhan and reviewed the national guidance on GP registration. To clarify the registration requirements for Siobhan, our advocate contacted Family Practitioner Services within the Business Services Organisation (BSO). Confirmation was received that photographic ID was not mandatory and that a birth certificate was sufficient.

With Siobhan's consent, our advocate contacted the GP practice manager to explain the guidance and share the advice received from BSO.

OUTCOME

The GP practice accepted the guidance and registered Siobhan as a patient.

Siobhan felt relieved and grateful that our advocate had resolved her issue, preventing further financial and emotional strain.

TREATMENT AND CARE

BACKGROUND

Michael's mother, Margaret, died while she was an inpatient in hospital. Margaret had a complex medical history which included several diagnoses and a previous surgical procedure to remove an organ. Over time, she developed further serious health conditions, including cancer.

Michael had concerns about delays with his mother's diagnostic tests, uncertainty surrounding diagnoses, and what he felt was a lack of clear communication throughout Margaret's care.

During Margaret's final hospital admission, Michael learned that his mother had been given an unnecessary treatment intended for another patient due to an administrative error.

Sadly, Margaret died and Michael was left distressed and confused.

Michael had unanswered questions about his mother's care and the circumstances surrounding her death. He wanted reassurance that his concerns would be properly examined and that learning would take place to prevent similar incidents happening again. After seeing an advert for the PCC, Michael made contact for advice.

WHAT WE DID

Our advocate listened to Michael and supported Michael through the complaints' process and discussed additional options for raising his concerns. With Michael's consent, our advocate helped him to submit a complaint to the Trust and request Margaret's medical records. When the Trust's initial response did not address all of Michael's questions and contained inaccuracies, our advocate contacted the Trust to highlight these issues and requested clarification. Disappointingly, further responses had inconsistencies. Our advocate challenged these on Michael's behalf and attended two senior-level Trust meetings with Michael to ensure he had the opportunity to raise all of his concerns directly, correct inaccuracies and receive explanations.

OUTCOME

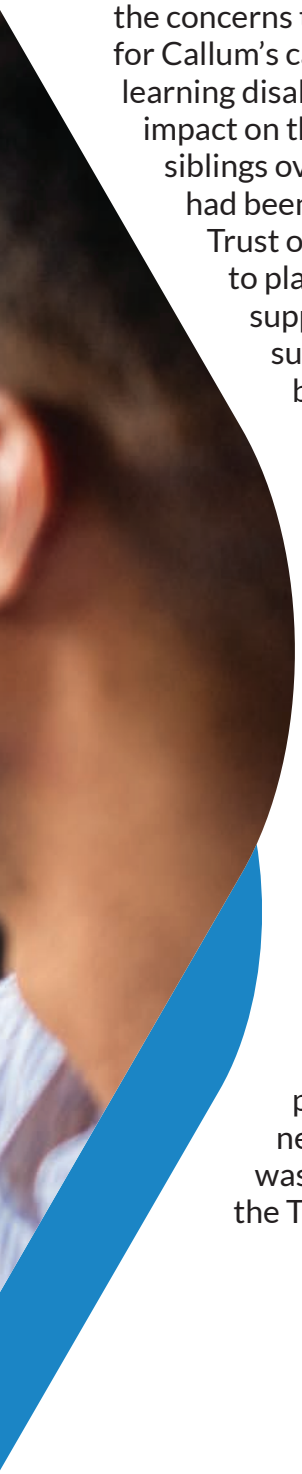
The Trust acknowledged failings in care and communication and outlined actions taken to reduce the risk of similar incidents occurring again. The Trust also offered Michael's family screening for a familial health matter

Michael said that he valued having an advocate present to help him navigate the complaints' process to ensure accountability and learning.

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.

COMMUNICATION AND FUTURE PLANNING



BACKGROUND

Callum's family contacted the PCC to seek support. Callum is a 19-year-old young man with significant mental health and learning disabilities' diagnoses. The family outlined the concerns they had about future planning for Callum's care, as his mental health and learning disabilities has had a traumatic impact on the whole family and his younger siblings over many years. The family had been engaging with their local Trust over the preceding year trying to plan. Accommodation in a local supported living service had been suggested but the family had not been connected to the ongoing discussions within the Trust and the supported living service. The family were extremely anxious that the proposed plan would not proceed and asked the PCC to to support them to communicate and engage with the Trust. They asked for help to solidify the planning to ensure the proposed accommodation would still be available to them as the accommodation was within easy reach of the family to maintain strong links with Callum. The family were frustrated by the perceived delays and prolonged negotiations and what they felt was a lack of communication from the Trust.

WHAT WE DID

A senior manager and a PCC practitioner arranged to meet the family to explore their concerns. The family felt frustrated that they could not communicate effectively with the Trust and were denied access to more senior managers in the Trust to discuss the matter. During that meeting a plan was agreed that the PCC would contact the Trust to open lines of communication and mediate between the family and the Trust. When the PCC contacted the Trust, the Trust quickly arranged to meet the family alongside the PCC practitioner. The Trust provided the family with a detailed outline of the current planning and the applications that had been made to secure the funding for the proposed accommodation and the required care package. The family felt reassured that actions were being taken to secure the proposed care arrangements for the future. The PCC will continue to support the family going forward until the proposed care arrangements are in place.

OUTCOME

The family have been assured that planning for Callum is on track. The Trust responded quickly to the PCC when the matter was raised with them. The PCC will continue to keep the lines of communication between the family and the Trust open until such times as the planning for Callum is concluded.

FEEDBACK

My Practitioner was helpful and understanding. We really appreciated all her help and guidance. From start to finish you handled our enquiries perfectly.

NAVIGATING A PATHWAY

BACKGROUND

Andy, a 47-year father of 3 employed in a role that required significant driving experienced a four-inch clot in his leg 2 years previously. He had waited 2 years for surgery to remove the clot, during which time his life and work were severely impacted. Following surgery, at a follow up appointment he was told by his surgeon that the procedure was not successful and that no further intervention was available. The consultant advised Andy that a further monitoring appointment would be provided in 6 months' time. In effect Andy's life and work were on hold as the clot restricted his ability to drive, due to significant pain and swelling. The situation caused considerable stress as he continued to have the worry that the clot would cause the vein to rupture. Two months later, Andy was admitted to hospital due to a sudden and painful expansion of his already swollen leg. The clot had become infected. Andy's surgeon in a regional hospital was contacted but advised that no surgical option was now available. Through a friend Andy and his wife heard about the PCC.

WHAT WE DID

Andy's wife contacted the PCC and explained the current circumstances. The PCC advocate discussed with them a possible second opinion and an Extra Contractual Referral (ECR). This option had not been mentioned to them previously. The PCC assisted Andy to secure a telephone call with his current consultant to discuss the possible ECR, the Consultant agreed and suggested a surgeon in England. Andy researched this surgeon and found that the surgeon was extremely specialist regarding vascular clots. The PCC liaised with Andy's current consultant to ensure an ECR was completed and brought to the ECR panel to agree funding. When the ECR funding was agreed the PCC engaged directly with the consultant's team in England on Andy's behalf who accepted the referral and the PCC developed a contact for Andy in the Strategic, Planning and Performance Group (SPPG) who would be providing the administrative backup for the referral transfer and funding arrangements. Andy and his family are now extremely relieved to be in a process that may result in a more positive outcome for Andy, which might allow him to return to his work full time and participate more fully in family life once more.

OUTCOME

Andy was offered an appointment with the consultant in England. The consultant discussed with Andy a new clinical trial using an innovative procedure that would restore the vein to full use. Andy is one of only 100 patients who will be on this trial. Andy is hopeful this procedure will take place in the Autumn and that he will be able to resume his normal life.

FEEDBACK

Calling the PCC helpline was a refreshing experience. The initial call handler was patient and informed. A practitioner called back within the hour and was of great support! Their ability to listen and relate made the world of difference and I felt assured I could come back to the PCC for support when required. The kindness and compassion of the staff shone through and offered a beacon which was needed.

PCC
PATIENT & CLIENT COUNCIL

Phone: 0800 917 0222
Email: info@pcc-ni.net