

Stories help describe what services do.

Every-day and ordinary, or life changing and extraordinary?

Jackie's story July 2023	
Service name: Colo-rectal and Stoma Nursing	
Main purpose of service: The specialist nursing service offers advice, support and guidance to people living in South Kirklees who are living with a stoma. Patients are seen in their own homes and are often recovering from recent surgery.	
<p>About the person: Jackie is 40 years old and has cerebral palsy. She was born prematurely and developed a bowel infection. At 2 weeks old she had surgery and wasn't expected to survive. "I lost almost all my large intestine and had a colostomy which was then reversed when I was 9 months old."</p> <p>Jackie read 'Disability Studies' at University and passionately believes that "disabled people must be seen and heard". She is regularly invited to meet with student Medics and shares her own lived experience to help them understand approaches to patient centred care. "It helps future health professionals, so it helps future patients." She believes that the best way for health care students to learn, is to work together with patients and families. "It's important to remember that health professionals are human too."</p>	
<p>Surgery: Jackie takes up her story, "I lived with a shortened gut until I was 25 years old. The bowel I was left with was kinked and twisted." She was told she needed further surgery and would have "a bag for life". She says, "It was devastating. It was overwhelming. I wondered how I could deal with it. How was I going to be able to stand up to deal with a stoma?" Jackie explains that because of cerebral palsy, her mobility and balance is compromised. Jackie has now lived with a stoma for 15 years and has developed a 'parastomal hernia'. This is when the intestines push through the muscles around the stoma.</p>	
<p>Complications: In 2014, Jackie's bowel strangulated. The surgeons thought it was too risky to operate. "I self-advocated. I was in so much pain. I asked them to proceed." Then 1 week post op, Jackie's bowel ruptured. She was told, "We've got an hour to save your life." Jackie woke up in intensive care 5 days later. "There were more complications. If there was a complication to get, I got it!" She remained in hospital for 12 weeks.</p>	
<p>Keeping healthy: Having a shortened gut, a stoma and a hernia is challenging. Jackie explains, "It's about keeping a metre of bowel and the stoma and my skin as healthy as we can. It's about keeping me out of hospital in terms of blockages – reducing the need for further surgery." About 7 years ago, Jackie decided to leave her flat and move to a care home. She says, "It was fundamental for my quality of life. When I moved in, it was a relief to finally have 24/7 help with stoma care." Keeping hydrated is vitally important to avoid bowel blockages, but not easy when you live in a warm environment. The last blockage was August 2021, "in part because the care home staff have worked with me on a low residue diet as requested by my doctors [food that is easier</p>	

for the bowel to digest, and the stoma to expel]. **Food gets monotonous, but eating this way is something else that keeps me out of hospital.”**

Specialist nursing: “I first met Cheryl 7 years ago. She was new in her role, and I was new to my care home. I met her due to skin problems. The peristomal skin [skin around the stoma] was raw. Cheryl said, ‘We have to get that looking better’. It’s been trial and error ever since. Trying new seals, new bags. Some don’t fit or work.” Jackie has recently been re-referred to the service. Cheryl’s team has expanded and so her colleague Emma now also visits Jackie. “They’ve been visiting me again since September 2022. We’ve struggled to get the skin healed and stay healed.”

Lotion: “Cheryl isn’t afraid to ask questions and involve other people if she needs to. Because of Cheryl’s experience, she can advise my GP on medication. She’s talked a lot to the ‘Medicine Management’ team and found a lotion that is usually used on scalps. There’s a steroid in it.” Jackie explains, “Many creams [to help the skin heal] stop the bag sticking to me. This new lotion dries, and the bag can still attach.” Jackie understands that the Stoma Care team have reduced their visits because they’ve found something that works. “Due to further concerns, I sent Emma a photo of the stoma and surrounding skin. I’m thankful that Emma was able to visit that same day. The skin around the stoma had healed enough, but we agreed to change how the stoma bags were cut to size.” Due to the success of Jackie’s treatment, she explains it is now clearer what is stoma and what is skin. This means the bags can be cut to a smaller size. Jackie feels this illustrates the need for and the success of the Community Stoma Team.

Holistic: Jackie values Cheryl and Emma’s clinical expertise and also their supportive, personalised approach. Jackie feels that many people – health and care professionals included – can too easily undermine or ignore her opinions and concerns. “If what was wrong was seen on the outside, I wouldn’t be dismissed. Cheryl and Emma get it.” She continues, “The stoma and skin and medical minutia – both Cheryl and Emma have taken a more holistic view. When you have health professionals that are good at making you feel seen and heard, it’s a relief. Cheryl and Emma just get it. They see the whole person. Like the mental health effects - they see all of that.” Jackie says that ongoing research exploring the aging process for people with Cerebral Palsy suggests that pain and fatigue may come from ageing more quickly. “The pain is draining.” Jackie’s mobility fluctuates. “Some days I’m exhausted.”

Advocacy and self-advocacy: Jackie describes how the hernia around the stoma has got bigger, but there isn’t enough bowel to operate. The hernia is uncomfortable, “It’s heavy.”

Jackie’s bag needs changing daily to protect her skin. She explains that at times the stoma works continually, and this makes cleaning the area and reattaching a new bag difficult. It can take 5 minutes or up to an hour.

“Emma and Cheryl have shown many different carers what order things go, for example, extra seals under the bag and explain to them why we are experimenting. It takes effort off me. The staff listen to Emma and Cheryl. Emma and Cheryl are my back up. They advocate on my behalf, or they help me self-advocate. Partnership working - that’s important.”