

Maria's story October 2023

Service: Heart Failure Nursing

The team work with patients who have been confirmed as having heart failure following a heart scan. The team monitor signs and symptoms of heart failure and advise patients and their families on how to manage these symptoms. Through guidance and support, the team enable people living with heart failure to be as confident and skilled as possible in managing their symptoms. This is often called maximising independence or self-care.



About the person: Maria is an administrator and is planning to retire soon. She chatted with Joanne from Locala's Engagement team to talk about her experience with the Heart Failure Nursing team. Maria lives with both cardiomyopathy – a condition that affects the heart muscle - and asthma. She explains that both made the other worse and by summer 2021 every day activities were a struggle. She says, **"I couldn't even walk across the room."** She continues, **"Michelle from the team had discussed me with the Consultant and told me that I met the criteria for a pacemaker. I thought that she must be over egging it! I was shocked – it felt like a last resort. Like your dying!"** Maria discussed her options through with her partner. **"We decided I should go for it! I decided I'd be stupid if I said no to it. Within 3 weeks, I'd had it done!"**

Getting used to a pacemaker: Maria continues her story, **"I will admit, I felt stranded when I came home. It was just there. You can see it – it's a raised bump. You know it's highly beneficial, but it's all new and you don't know what to expect."** She explains that 18 months later, she attended a 'meet and greet' organised by the hospital at a local hotel, which fully explained the background of pacemaker development and what to expect when living with one. **"It was very enlightening and reassuring, but it would have been good to have gone sooner."**

Shocks: Maria describes how her pacemaker 'kicks in' when she has an 'arrhythmic shock'. **"It's preventative, it keeps you going on an even keel."** The first time this happened Maria was asleep and knew nothing about it. **"I was amazed."** The Heart Failure team – and Maria's Consultant – can read data downloaded from the pacemaker over night, and this helps them to monitor Maria's health on an ongoing basis. **"Michelle is vigilant – she's always asking for data to be run off."** This attention to detail has become crucial in recent months as Maria has now been diagnosed with colitis. This gut condition, causing episodes of diarrhoea and loss of appetite, results in Maria's potassium levels dropping. This in turn, triggers further arrhythmic shocks. During two consecutive days in August 2023, Maria had 21 shocks and was admitted to Intensive Care. **"My gut doesn't work in the way it used to. It doesn't take in the nutrients in the same way."** Her GP practice keep a very close eye on Maria's potassium levels.

Support: **"It is frightening to have shocks, but with a pacemaker you've got a chance of survival. Without my pacemaker, I would have died. It's saved my life at least 21 or 22 times! I can't thank Michelle enough – she took the time and went the extra mile when she talked with the consultant. She wasn't over egging it! I am so grateful that Michelle mentioned the pacemaker. Michelle is always approachable. The team are always bending over backwards to help. I can't praise the whole team enough. If Michelle isn't there for whatever reason, I know I'm not left stranded. My advice to anyone who is offered a pacemaker – consider it very seriously!"**