



THE HEART OF THE MATTER

Heart Failure Nurse Specialist Jill Nicholls knows the difference that her advanced role makes to patients and their carers in NHS Tayside. She wants to see even more being done to support heart failure services across Scotland



Royal College
of Nursing
Scotland



Sylvia Adamson sits in her front room, surrounded by holiday mementoes. Her travelling days are over, she says. "I used to love getting about, seeing new things, meeting people. But my condition has put a stop to all that – or so I thought, until I met Jill."

Jill Nicholls is a Heart Failure Specialist Nurse, and she is visiting Sylvia at her home in Dundee to check on progress. Having suffered a heart attack in 1993 Sylvia, now in her 70s, has recently been fitted with a pacemaker and Jill is keen to see how she is getting along.

The last time they met, Sylvia had been breathless, struggling to sleep, and in pain. "The new tablet worked a wee treat, and the breathing has settled," says Sylvia. "In fact, I've been able to get out to the shops, which is a real breakthrough."

During their first consultation, Jill asked Sylvia what she would most like to be able to do. Sylvia said she wanted to get out of the house and buy a new coat, but she had no real hope of being able to manage that. "I did it," she says triumphantly. "I bought that coat. I'm going to the shop on my own, walking about on my own, making choices on my own. I've achieved that!"

Helping people who live with heart failure to manage their symptoms and enjoy life again is Jill's aim, and she brings all her skills, knowledge and considerable experience to the task. "It's

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ALLAN KEILLOR, PATIENT, NHS TAYSIDE

like talking to a friend," says Sylvia. "She knows about my anoxia and my blood pressure, and she's brilliant at putting all the bits together. Because of her, my confidence has improved. If it wasn't for Jill I'd have been back in hospital again, and who knows whether I'd ever have got out."

Jill works for NHS Tayside's Heart Failure Nurse Liaison Service, which offers specialist outreach to a growing number of people who are living with the consequences of a failing heart. "We have patients who are aged from 16 to 100," she says. "Heart failure frequently comes with co-morbidity, so care can be extremely complex."

There are many causes of heart failure – ischaemic heart disease, hypertension, genetics, poor diet and smoking, alcohol and drug misuse and viral infection among them. It is imperative to identify the cause, which is done by the cardiology team. "But finding the reason for ongoing symptoms is central, and that means I have to rely on clinical assessment and decision



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JILL NICHOLLS, HEART FAILURE SPECIALIST NURSE, NHS TAYSIDE

making,” says Jill. “Problems can sometimes be down to reactions with medication. It is my job to sort that.”

Originally from Dundee, Jill joined the Queen Alexandra Royal Naval Nursing Service at 18 and trained as a nurse during service in Portsmouth. She specialised in cardiac nursing, became a specialist practitioner, and worked in critical care aboard the hospital ship RFA Argus during the 2003 Iraq war before leaving the Navy to start a family and progress her career as a civilian.

In 2003, and back in her home town, Jill saw an advert for posts to develop a new service for patients with heart failure. “I knew it was for me,” she says. “There was massive unmet need, and it was going to be quite a challenge addressing that.”

The development of the Tayside service was driven by the fact that patients with heart failure suffer significant symptom burden – breathlessness, fluid retention, reduced physical capacity and mental health issues are common. It is one of the top reasons for unscheduled admission to hospital in Scotland: good community-based care keeps people at home, improves the patient and carer experience, and helps to ease pressure on beds.



With strong support from their management, Jill and two other specialist nurses established a nurse-led service protocol and set about persuading clinical colleagues that it was safe to refer patients to them. “There was concern among some doctors that we would be changing their treatments and making autonomous decisions,” says Jill. “We had to reassure them about our skills, communicate with them, and involve them in developing our clinical guidance.”

Over time, good relationships were built with the cardiologists working in Ninewells Hospital and doctors across Tayside’s 73 GP practices, and referrals started to grow. The Heart Failure Nurse Liaison Service team now manages around 600 patients a year, and awareness of the service is increasing.

Because heart failure can present and progress in very different ways, the nurses must maintain links with a wide range of services. “We are there from diagnosis through to the end of life for many of our patients,” says Jill, who says that heart failure nursing is in a rare position, bridging clinical boundaries between primary and acute care. “We need to work with lots of people to achieve the best for our patients.”

The team operates out of an office in Ninewells, and covers the whole of Tayside, an area that encompasses both urban and remote communities. “We visit the majority of patients at home, undertake telephone consultations, and continue to expand the nurse-led clinic service,” says Jill. “This is about focusing care



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JILL NICHOLLS

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The service aims to see patients within 10 working days of referral. "It is a slow and steady process getting the drug treatments right," says Jill. "It can be a delicate balancing act, reaching the optimal dose for an individual."

Initially, that might mean home visits every week, stretching out as things stabilise, and picking up again as patient needs grow more acute. "We liaise closely with GPs, district nurses, pharmacists and social care, and link with specialist palliative care colleagues too," says Jill. "An informed, supported collaborative approach is the best way of working."

Part of the service's role is to promote self-care, and there is a strong focus on partnership with patients and their family carers. "They live with their symptoms and can learn to monitor and identify deterioration to prevent exacerbation," says Jill. "With support, most patients can be willing and active partners in their care."

Through anticipatory care plans, patients are given advice and guidance on self-monitoring and assessment, and have a rapid response number to contact the service during the week. "That gives people the reassurance that they are not on their own," says Jill. "Unless an acute event occurs, out-of-hours calls shouldn't be necessary."

Properly managed, the progression of heart

failure can be considerably delayed. In the past, hospital readmission rates were running at 30%; now it's 8% and reducing all the time. Prior to the widespread introduction of heart failure services, 50% of patients died within a year of diagnosis: now, 50% of patients are alive at five years. "That's a considerable improvement," says Jill. "We are giving patients hope."

And hope is a precious commodity for people living with heart failure. Businessman Allan Keillor started developing atrial fibrillation and breathlessness late last year. He underwent electrical cardioversion at Ninewells to still his heart rate, and Jill has been visiting him at home since he was discharged from hospital.

Allan's wife Elizabeth sits in on the consultation as Jill measures his blood pressure while he is standing and sitting, and reviews his overall progress. They talk about test results, warfarin management, and heart rate monitoring. Jill asks about how he is tolerating his drugs and they discuss potential side-effects such as vivid dreams and lightheadedness. Together they conclude that things are going well. "It's extremely reassuring," says Allan. "Jill is a specialist. I would far rather see her than a GP or a junior doctor."

In addition to regular audit of clinical practice, the Tayside service has sought patient and carer satisfaction using the Consultation and Relational Empathy (CARE) measure tool, and it scores highly. "We're extremely happy with the service," says Allan. "I would advise anyone to jump at the chance of seeing a heart failure nurse if they get the chance."

Because of concerted work by the professional forums and charities such as Chest, Heart and Stroke Scotland and the British Heart Foundation, most health board areas in Scotland now have a heart failure nursing service. The current exception is NHS Orkney. "Heart failure can be a very scary diagnosis, and the carer burden is significant," says Jill. "Everyone who needs it should have access."

Jill is closely involved in the development of specialist heart failure nursing across Scotland. She is seconded one and a half days a week to serve as one of the Scottish Government's Heart Failure Hub Co-ordinators; she chairs the Heart Failure Nurse Forum in Scotland, and sits on the Scottish Intercollegiate Guidelines Network (SIGN) heart failure review group.

In addition, Jill tutors on the NHS Tayside 'Current Perspectives in Cardiac Care' course and lectures on the University of Dundee's School of Nursing masters programme. Today, 12 nurses who are in training to become autonomous clinical decision-makers are attending her session on the heart failure advanced nurse practitioner role.

Perched on the edge of a lecture room desk, Jill describes her job. She outlines the aetiology of heart failure, the complexity of the case mix, and the necessity for early intervention. "Continuity matters," she tells her students. "Ours is subjective assessment. It's about putting all your education, experience and instinct to good use. If I avert one hospital admission, I feel satisfied."

Jill talks about how she admits a patient to the service, draws up a treatment plan and secures agreement to it from the patient, their carers, GP, district nurse and consultant. There are multidisciplinary team meetings every three months. "It is vital that we have confidence in our own skills and clarity in our support networks," says Jill. "If there are no existing guidelines for practice in your area, go out there and create them."

Building confidence in decision-making takes time and experience, says Jill. "In our role, being a nurse prescriber enhances the ability to be a successful clinical decision-maker. It is hugely rewarding, but that doesn't mean you don't worry about your decisions: that doesn't get any easier," she says. "As long as you are doing what your colleagues would do under the same circumstances, you will be OK. Don't let it be scary – nurses are perfectly equipped to do this."

Jill's patients are in full agreement with that. On another of the day's home visits, she calls in on Arthur, who has been living with type 2 diabetes for the past 35 years. He has a long history of angina, undergone a heart bypass, had a leg amputated and recently suffered a heart attack. For most of his life, he has been in and out of Ninewells Hospital. "Since Jill started coming, it's been just great," he says. "She's keeping me at home, which keeps me happy."

Jill says the unmet psychological needs of her patients is considerable. "There's a long wait to see a clinical psychologist, so it is important for our service to do what we can to support people in distress. We can empathise, but sometimes that's not enough," she says. "We seem to be the only constant for many of our patients, who can be terribly isolated by their illness. Right now, a diagnosis of heart failure does not trigger a routine GP review. This should be improved."

With growing numbers of patients needing specialist heart failure support, service sustainability is a concern. Jill can foresee networks of professionals coming together, under ANP leadership, to keep more people stable. "Community pharmacists are increasingly involved in monitoring blood pressure and titrating medication; social workers and home carers could be supporting patients with daily monitoring such as weighing and alerting us to changes; practice nurses could be reviewing more patients and keeping an eye on their progress," she says. "Heart failure has long been considered difficult to manage. But now we can offer the expertise to support new ways of delivering high-quality care."

Jill has a list of further improvements that she would like to see: earlier access to specialist palliative care; better IT systems and processes that allow patient information to be shared across all care sectors; the resource to support intravenous treatment in the community, as happens in England, and an end to postcode provision of service; and heart failure specialist nurses to work within the hospital. "If we were on the wards as well as in the community there would be increased opportunity to identify more patients and improve their prospects," she says.

Driven by passion for positive role models within the specialist nursing field, Jill is determined to further the development of heart failure services across Scotland. "Our opportunity to influence the future is huge," she says. "I am still as excited as I ever was about this role."



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