‘How team’s holistic care transformed my life’

The Arches team, winners of the Patient’s Choice award, have helped patient Janette O’Connor avoid hospital stays for her rare condition

By Elaine Cole

A team whose clinical excellence and compassionate, holistic care has helped a woman with a rare disease avoid hospital admissions has been chosen by the public to receive one of nursing’s most prestigious awards.

The Arches district nursing team at Belfast Health and Social Care Trust, pictured above, won the Patient’s Choice award at the RCN Nursing Awards 2023, after being nominated by Janette Connor and receiving thousands of votes.

Improved quality of life

The Patient’s Choice award gives the public a chance to thank a nurse or nursing team for exceptional and life-changing care. In Ms Connor’s case, the care provided by the Arches district nursing team has meant an improved quality of life and a vastly reduced amount of time spent in hospital.

Ms Connor, who has a rare disease called Behçet’s syndrome and is receiving palliative care, says the nurses have transformed her life in the past two years. ‘I’m not a complex case when I’m with them, but a person who has good days and bad, hopes and goals,’ she says.

‘My amazing nurses are still here every day, lifting me, being my second mothers. They so deserve this award.’

‘They are my voice when I’m overwhelmed’

People with Behçet’s syndrome, which is characterised by inflammation of the blood vessels, can have a range of symptoms, including blurred vision, swollen joints and ulcers. Ms Connor, who used to work as a teacher with children with special needs, has more than 200 skin ulcers that are dressed daily.

She says: ‘My nurses look after other elements of my physical care, such as my Hickman line. But they also advocate for me – they are my voice when I’m too overwhelmed to speak for myself.’

Before she was under the team’s care, Ms Connor was...
referred to the emergency department for skin infections multiple times a month. In one year, she spent close to 200 nights in hospital, which significantly affected her relationships and mental health.

‘Since this team has taken over, I’ve had one unplanned hospital admission in two years,’ she says. ‘The disease is more active than ever but I can now work from home and spend time with friends and family. When I had to go into hospital, my nurses understood my anxiety and contacted all the appropriate people to ensure a smooth transition.

‘My family are reassured that I’m getting such great care at home. They can see the team has given me back my dignity and self esteem. One friend recently said I’ve got my spark back, which I had lost while spending so much time in hospital.’

Holistic community care
It is the team’s holistic approach that has made such a difference, Ms Connor says.

‘The district nurses have gone above and beyond getting to know me as a person, my needs and what is important to me. Last year was one of the hardest and the nurses listened, gave me space to cry, were a listening ear and even brought me flowers and chocolates after I had a rough week. They have also celebrated my successes and milestones.

‘They have worked past the end of a shift so I could shower after a hospital admission because they knew it would make me feel much better about myself. Life with this disease can be difficult sometimes and people tend to give up, but the district nurses haven’t. Instead, they show up with a smile and a Netflix recommendation.

‘Without them, my only option would be a long-term inpatient stay. Instead,'}

Behçet’s disease: the signs and symptoms

Behçet’s disease, or Behçet’s syndrome, results in inflammation of the blood vessels and tissues. Patients typically experience flare-ups and periods of remission. It is often diagnosed in adults in their twenties or thirties, although it can be found in children.

Symptoms include:
- Ulcers
- Red, painful eyes and blurred vision
- Acne-like spots
- Headaches
- Painful, stiff and swollen joints

In severe cases, there is a risk of serious and potentially life-threatening problems, such as blindness and stroke.

Source: NHS Behçet’s disease tinyurl.com/NHS-Behcets

‘It is quite something to hear the positive impact we can have on a patient’s life and well-being. In these challenging times in nursing, we are still able to provide professional, holistic care’

Orla Glennon, team lead, the Arches district nursing team

that delivers exceptional care in circumstances that can be difficult and highly emotional. To have this recognised is incredible.

‘District nursing is often an invisible workforce, with the public and even our colleagues in hospital not fully understanding what we do, so to raise the profile of district nursing by winning this award is amazing.’

‘My life would be so different without them’

Ms Connor is delighted her nurses have been recognised as a result of her nomination. ‘The nomination was highlighted locally and on social media and it got people talking about district nursing,’ she says.

‘My nurses make such a huge difference to me, and my life would be so different without them.

‘And it has also raised awareness of the disease itself and how we have to live with it, for which I am grateful.’