



Specialist nurses

Changing lives, saving money



Summary

For thousands of people in the UK suffering from long-term conditions, one type of health care professional provides a level of care and support that they couldn't do without – specialist nurses. This report explains all about the role of the specialist nurse, the impact they have on patient care and the financial arguments behind these valuable posts.

Specialist nurses are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases such as cancer, diabetes, Parkinson's, chronic heart failure and dementia.

They provide direct patient care and can play a vital role in educating patients on how best to manage their symptoms, as well as offering support following diagnosis. In many cases the involvement of a specialist nurse can prevent patients being re-hospitalised.

Making a difference

“Stroke patients are more likely to survive (by around 25 per cent), make a better recovery and spend less time in hospital (by six days) if they are admitted to a stroke unit. The role of the specialist stroke nurse is vital within this team to ensure patients receive the specialist care needed to make the best recovery possible.”

John Barrick, CEO, Stroke Association

Today's specialist nurse takes a leading role in making sure patients get the best care possible. Several studies have shown that as a substitute for other health care professionals, including doctors, specialist nurses are both clinically and cost effective. Studies show the direct and indirect benefits of specialist nursing roles can include reducing referral times, the length of hospital stays and the risks of complications post-surgery.

In a national survey of health advocacy groups (RCN/ National Voices, 2009) patients consistently rated specialist nurses higher than any other health and social care professionals in:

- understanding patient needs
- designing and implementing care pathways
- obtaining patient feedback
- being transparent and honest.

A valuable resource at risk

Specialist nurses were one of the groups hardest hit by the NHS deficits crisis of 2005/06. A poll of specialist nurses (RCN, 2008) showed:

- one-in-four faced risk of redundancy
- half were aware of cuts in services in their specialty
- 45 per cent were being asked to work outside their specialty to cover staff shortages in general clinical settings.



Name: Lesley Thomson

Specialism: Breast Cancer Care

Place of work: Nightingale Genesis Centre, Manchester

Lesley, who has a Masters in counselling, is the team leader for the breast care service which she established almost 30 years ago. She now runs a caseload of about 700 new breast cancer patients annually, with six staff including herself, two full-time and four part-time.

She explains her role as principally involving the psychological assessment and support of women who either have or think they may have breast cancer. It also involves doing follow up clinics for women after they have treatment as well as education for schools, the general public and for support groups.

According to Lesley, people react very differently to the diagnosis depending on their age and stage of life. “Older women tend to have a gloomy outlook. Their expectation at diagnosis is of a horrible death. My job is to get them to see the outlook is really quite good and it’s not a death sentence.

“The problem for younger women is the length of the treatment. Younger women tend to have longer

treatment that can go on for as much as two years which interrupts their work, social lives and child care. The knock-on effect of it can be huge and that’s even apart from dealing with people’s body image problems.”

Helen Bailey, one of the patients from the clinic, explains why having her own nurse specialist (Fiona) made such a difference to her when she found out she had cancer. She says: “Fiona was really good. At the time you are bombarded with information but probably the most important thing you get given is a phone number you can actually ring. I called Fiona afterwards and came back a few days later for a chat. She was very clear and what I liked about it was that it was very personal to me. She sat me down and talked about my disease. Going away afterwards I had learnt that there were many different kinds of breast cancer and that it affects women in different ways and it’s found at different stages. But she talked about it personally to me and how it would affect me.”



How do specialist nurses save money?

Specialist nurses add value to patient care, while generating efficiencies for organisations through new and innovative ways of working.

The cost benefits generated by specialist nurses include:

- reduced waiting times
- avoidance of unnecessary hospital admission/readmission (through reduced complications post-surgery/enhanced symptom control/improved patient self-management)
- reduced post-operative hospital stay times
- the freeing up of consultant appointments for other patients
- services delivered in the community/at point of need
- reduced patient treatment drop-out rates
- the education of health and social care professionals
- the introduction of innovative service delivery frameworks
- direct specialist advice given to patients and families.

A number of independent reports reveal the direct and measurable cost efficiencies generated by specialist nurses, including:

Multiple Sclerosis

A PCT will have an estimated 10 patients requiring relapse treatment per year and if an MS nurse could treat them at home, this would save **£17,970**.

The MS Society reports its funded nurse specialists save NHS trusts **£60,000** per year, per trust by treating relapse symptoms at home.

The MS team at the National Hospital for Neurology and Neurosurgery, University College London Hospital Foundation Trust has developed a multidisciplinary specialist relapse service.

Over five years, the service has gone from inpatient to outpatient. This has led to a reduction in waiting times from 6.2 weeks to 6.1 days and this trial also pointed towards an average saving of **£1,797 per patient** who could be treated with steroids at home rather than in hospital.

In the Northamptonshire PCT, an MS specialist nurse saved **£65,773** by treating 34 patients at home rather than in hospital and also freed up secondary care neurology appointments by half, saving **£16,402**.

Parkinson's disease

The Parkinson's Disease Society report (2006) found that community-based services for people with Parkinson's could save the NHS an estimated £56 million – or **30 per cent** of the money spent on supporting people in care homes – and that Parkinson's specialist nurse care – as part of a multidisciplinary team – reduces hospital admissions by **50 per cent**.

In Harlow PCT, a Parkinson's specialist nurse reduced patients' length of stay and reversed the upward trend in admissions which delivered a saving of **£80,000**.

Heart disease

A report by the British Heart Foundation (2008) revealed that close monitoring of patient symptoms by a nurse specialist reduced readmission rates by **35 per cent**, saving PCTs **£1,826 per patient**. Furthermore, patients in contact with a heart failure specialist nurse experienced less impact from their condition on their daily lives.

Epilepsy

Epilepsy Action estimates that by reducing waiting times to see a specialist or general neurological consultant, epilepsy specialist nurses save health trusts **£80,000** per year.

In Surrey PCT, a new specialist epilepsy nurse reduced attendances at A&E by **nearly half** in 2005. This represents a saving of **£17,136** a year.

Epilepsy misdiagnosis (which happens in 20-31 per cent of cases, or over 100,000 people) in England costs £23 million and the non-medical cost was £111 million. A specialist epilepsy service could help combat this and a randomised controlled trial (**NHS National Workforce Project**) found that patients consulting a specialist nurse and a neurologist were less likely to visit their GP, which led to a saving of **£184 per patient** per year.

The Secondary Breast Cancer Taskforce

The taskforce reported that clinical nurse specialists will see around 13 follow-up patients per week in outpatients. According to Department of Health tariffs, this represents **£53,040** in income and frees up **13** slots to new patients per week.



Name: Carrie Dobson

Specialism: MS Nurse Specialist

Place of work: Southampton University Hospitals NHS Trust

Carrie Dobson provides support for patients with Multiple Sclerosis (MS) in the Wessex region including co-ordinating their drug therapies.

Carrie and her colleague have a caseload of 350 patients on drug treatment. “But we see more than that on a more sporadic basis. We also have a patient helpline so anyone can phone in with a problem. We do several clinics a month including two outpatient clinics a week for symptom management and drug follow up, a newly diagnosed clinic every other week and a drug information session once a month. We also get involved with the MS charity groups offering support for their patient group meetings.

“Even if they don’t want regular contact they know someone is there, so if they have a problem they know there’s someone they can call.

“We take the pressure off the doctors because we co-ordinate the drug treatments. We’re also able to spend more time with the patients, give them a bit more education and get involved a bit more, for example, if they have problems at work.”

One of Carrie’s patients, Linda McGuinness, explains why the service means so much to her: “Unless you’re going through it you don’t know how it will affect you. When you’re sitting there and suddenly your feet don’t work or your legs don’t work it’s very frightening and you want help there and then. You can’t always get the doctor, although he’s very good, you need to have somebody there you can ring up and say ‘help, this is happening, what should I do about it?’ It’s like a safety rope, like a lifebelt to know there is somebody there.”





Name: Carolyn Noble

Specialism: Parkinson's Disease Nurse Specialist

Place of work: The City Care Centre, Peterborough

Carolyn Noble works in Peterborough and the surrounding areas. Her work involves seeing people soon after they have been diagnosed with Parkinson's and supporting them throughout the course of their condition.

Carolyn explains: "I aim to reduce any fears people may have by helping them to understand what is happening to them and to enable them to resume control over their lives.

"I usually get called to see people who have run into problems such as falling or getting an infection which, if left untreated, can bring about a deterioration of their symptoms and they might have to go to hospital."

In Carolyn's experience most people want to remain as independent as possible for as

long as possible and she can help them achieve this by helping them understand how to manage the condition. However, some people with Parkinson's go on to develop dementia which adds to the difficulty of being able to remain at home.

One of Carolyn's patients, Tim, has both and is being cared for at home by his wife of 46 years Lillian. "Tim's had Parkinson's for 30 years and he's marvellous. Some days he'll talk to me but some days he'll only come out with one word but still he's my husband.

"He's got dementia now connected with the Parkinson's but he's very happy.

"I want to have him at home as long as I'm well and able to do it. I love him very much and he's my number one boy.

"Carolyn is a star and I really mean it. I wouldn't know what we would do without her."





Name: Paulette Winchester-Joseph

Specialism: Admiral Nurse (specialising in dementia care)

Place of work: North East London NHS Foundation Trust and For Dementia, London

The main focus of Paulette's role is to look after family carers of people with dementia by supporting them at home. However anyone affected by dementia can come to Paulette for practical support and advice.

Currently, Paulette and her colleague running the service in Barking and Dagenham are actively dealing with about 80 people in various stages of their treatment.

"I would try to see four carers a day at home. And though I don't give medical advice per se, I do monitor the side effects if they are on a particular medication for dementia.

"I saw a lady recently who has just been made redundant at 60 and has that to deal with as well as looking after her partner

with dementia. Her work was her lifeline and I am supporting her in getting back to work while helping her balance being at home with her husband and her feelings of self worth."

One of Paulette's carers, Jim Hook, has spent the last few years looking after his wife who had several health problems including dementia. She died two weeks before Christmas. Jim is 90 this year and had been married to his wife for 64 years.

"When I needed to know who to contact or what I needed to do, I phoned Paulette and she did it for us. That's where her strength came in. She was someone to turn to. Your nearest and dearest relatives haven't got any idea what it's like to be a carer and it isn't something you can train for. The stresses and strains I've been through the past years have been made a lot easier by Paulette's continued presence and her ability to see the overall picture and give me the support I've needed even if I haven't always asked for it. She's been marvellous and I'll appreciate it for the rest of my life."





Name: Joan Grogan

Specialism: Craniofacial Neurological Nurse Specialist

Place of work: Alder Hey Children's Hospital, Liverpool

Joan runs the craniofacial surgical unit at the well known Liverpool children's hospital and was central to setting up the unit in the 1990s.

The unit started by doing two major craniofacial surgeries a year. They were funded by the Department of Health to do 49 major cases four years ago. They are now funded for 101 major cases and last year carried out 136.

The patients will typically be seen by the hospital over a period of years since many of them (Apert's or Crouzon's patients for example) will need a lot of surgery over a long period of time. "We offer a total service from birth to 18 so we act as a comfort blanket for our patients. They can phone us if there is anything wrong and we can get them referred on quickly to whoever they need to see."

Joan also co-ordinates the pre-operative surgery meetings for patients and aims to bring all the professionals together in one room to make it more

convenient for the patients and their families. "Many of our patients come from far away and when they come they will need to see a range of specialists. They might need to see up to 14 professionals and we try to get them all in the room at the same time so they can see everyone at once which is intimidating the first time but ultimately saves them so much time and bother that they really like it once they get used to it."

Claire Prior, the mother of one-year-old Cian who had major surgery recently at the unit, explains what extras Joan added to the process. "We met Joan for the first time at the initial meeting and then again afterwards. She gave us time and explained things in simple terms even though the consultant did do it in blatant terms. Joan went over things as well and just gave us a bit of time to absorb everything."





Name: Sarah Doyle

Specialism: Advanced Paediatric Nurse Practitioner Urology

Place of work: Alder Hey Children's Hospital, Liverpool

Sarah is an autonomous practitioner for patients who don't require surgery. She takes patients' histories, undertakes physical examinations, compiles differential lists, orders relevant diagnostic investigations as needed and devises treatment



plans. As an independent prescriber she is also able to write prescriptions. Currently, Sarah is working a four-day week so she can begin her PhD.

“The hardest thing about my job is that there isn't enough time to do all I want to do or as well as I would like,” she explains about the job which sees her dealing with children who have bladder and related urinary problems.

“We take referrals from GPs, consultants from other hospitals and within the Alder Hey. Most patients are referred to us from neurosurgery and nephrology.”

“I also deal with children before and after urological surgery and the most important thing here is that they understand what's going to happen and what will happen afterwards. Even at their pre-operative meeting I'm starting to build a relationship with the family.

“But there are many benefits to having nurse specialists/advanced nurse practitioners. Financially we're value for money because we can do many of the tasks that doctors do but we're cheaper. We also add value in the relationships we build with the families, their communities and schools.”

She adds: “As a nurse I believe I'm approachable and am happy to help when people come to me with a problem, sometimes even it's just by knowing who to contact.”

Her patients and their families can testify to this. Louise, whose young son, Glen, was receiving care for a bladder problem said: “If I've got any problems at all I speak to Sarah and she's very helpful. It's very nice to have her here.”



Examining the threat

As we enter another period of constrained public spending, many specialist nurses now face serious organisational and funding challenges that are inhibiting their ability to deliver high quality care, tailored to the needs of patients.

The potential of specialist nurses to drive the safety and quality of care, and to improve patient outcomes is under threat.

Despite the evidence of positive impacts in terms of patient care enshrined in national guidelines, no other group has been targeted to such a degree in the wake of NHS financial pressures. As an RCN (2008) survey highlighted, the scale of the potential loss of specialist nursing expertise is significant:

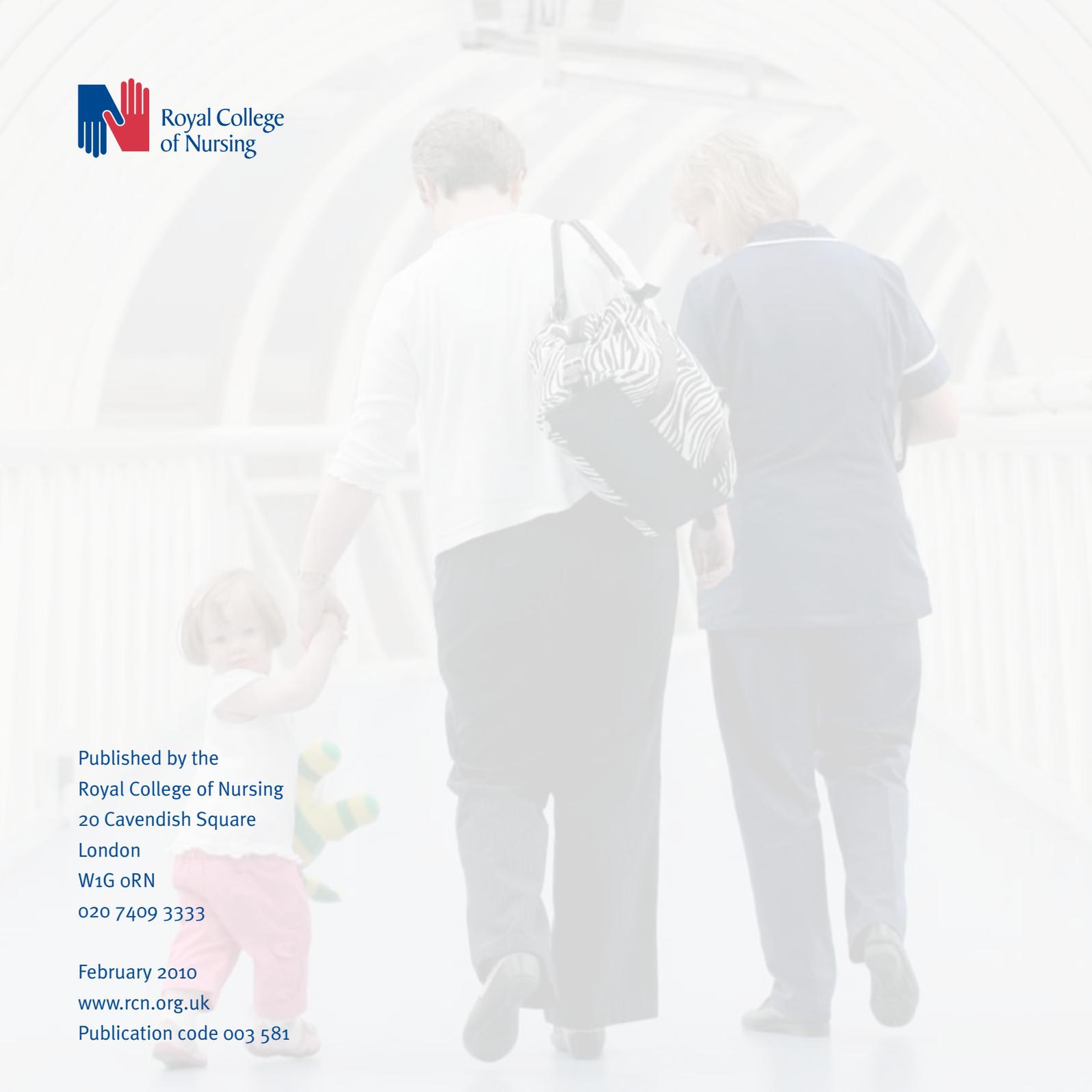
- more than one third of specialist nurses reported their organisations had a vacancy freeze in place
- 47 per cent reported they were at risk of being downgraded
- 68 per cent reported having to see more patients.

What is the RCN calling for?

To enable specialist nurses to continue to deliver high-quality care, tailored to patient needs, the RCN has identified three key recommendations.

- 1 Every patient with a chronic or long-term condition should have the right to specialist nursing care.** Local decision makers should map the number and type of specialist nurses required. This information should be linked to service and workforce planning to ensure that sufficient specialist nurses are in post to support this patient right.
- 2 Specialist nurse posts should be supported through robust long term funding.** Short-term funding of up to two years makes these posts vulnerable to cut backs. Where funding is provided by a charitable or voluntary organisation this should be underwritten by the NHS. Specialist nurse posts must not be targeted for cut backs when health spending is under pressure.
- 3 Specialist nurses need time to fulfil the key aspects of their role.** Job descriptions and workload should recognise and allow time for the core elements of the role, which include providing clinical expertise, leadership, and education and training.





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