Tracy Oakden tells Jennifer Trueland how Roald Dahl’s Marvellous Children’s Charity is ensuring that young people with rare conditions get the treatments they need.

Nursing care can be marvellous medicine

As a child, Tracy Oakden’s favourite Roald Dahl book wasn’t Charlie and the Chocolate Factory, or the delightful Matilda, now wowing West End audiences as a musical. Rather, she was drawn to The Twits, the story of a humorously vindictive couple who play practical jokes on each other.

‘He had a horrible beard and was always picking food out of it,’ she muses. ‘Yes, it was disgusting, but it’s the sort of thing a lot of children love.’

Like the famous author, Ms Oakden has a good idea of what makes children and young people tick. So perhaps it is fitting that she holds one of the specialist nurse posts created by the Roald Dahl Marvellous Children’s Charity.

Since 1991, the organisation has developed 48 specialist children’s nursing posts, and one allied health professional post, in the UK. Most (31) are in epilepsy, ten in acquired brain injury, seven in haematology and one in palliative care.

The charity gives each post two years of funding, after which time investment is taken on by the host NHS organisation for a further three years at least, guaranteeing the post for five years. According to the charity’s chief executive Richard Piper, all bar one of the posts created so far have then been mainstreamed into the NHS.

Ms Oakden, clinical nurse specialist in paediatric epilepsy with Barts Health NHS Trust, based at the Royal London Hospital, believes that her post makes a difference. ‘I work with the neurology team at the Royal London looking after patients from birth to age 16 years,’ she says. ‘There is still a lot of fear and stigma around epilepsy. Patients, and parents, really appreciate having someone they can contact if they need specialist help and advice. I try to be as accessible as possible, and available to speak to people at short notice.’

Her role includes working in outpatients, helping children and families on admission to hospital, and being an expert source of help and support to other health professionals.

Roald Dahl himself had a high opinion of nurses, says Dr Piper, and the charity was set up by Dahl’s widow, Felicity, partly because of the author’s own experiences of illness. ‘He really appreciated the compassionate care he received from nurses; the personal touch,’ says Dr Piper. ‘And that’s what we try to promote.’

As well as funding the Roald Dahl Marvellous Children’s Nurses, the charity has teamed up with the Burdett Trust for Nursing to fund 12 nurses with a grant of up to £15,000 each to try...
out an idea to help children and young people with a long-term condition to become – and remain – emotionally resilient.

The latest Roald Dahl programme will prioritise projects that aim to help children with a rare or undiagnosed illness, or conditions that otherwise receive little attention. Called the Marvellous Nurse Inventing Room, it is named after the room in Charlie and the Chocolate Factory where Willy Wonka’s new inventions (such as everlasting gobstoppers) are tested out.

‘Nurses know what makes a difference to children,’ says Dr Piper. ‘We are looking for ideas that give support and care to people with chronic conditions, and which can be repeated.

‘It doesn’t matter if it doesn’t work – we want people to have a go, to try something difficult,’ adds Dr Piper.

The programme follows the success of a previous partnership with the Burdett Trust, which funded 22 nurse-led projects between 2010 and 2012, focusing on neurology and haematology (see box). A common element across the programmes, and the specialist nursing posts, is a recognition that healthcare professionals have a vital role to play in the wellbeing of children, as well as addressing their immediate health needs.

**Emotional focus**

‘It is about looking at the emotional and psychological needs of the child and family,’ says Dr Piper. ‘Hospitals can damage the happiness of children. For some, the hospital is their social environment; it’s part of the environment in which they are growing up.’

Nurses per se are conspicuous by their absence in Roald Dahl’s children’s books. But Dr Piper reckons that the characteristics of Miss Honey, the gentle, much-loved teacher in Matilda, are embodied in the charity’s nurses. This year marks the 50th anniversary of Charlie and the Chocolate Factory. Dr Piper hopes that, later in the year, the charity might be able to mark this by announcing its 50th specialist post.

But what of its present nurses – does Ms Oakden see herself as a Miss Honey? She is not sure. ‘It’s important to have that personal side, and to be compassionate,’ she laughs. ‘But when I’m talking to a teenager about the importance of compliance with treatment, then maybe I’m a bit tougher than Miss Honey!’

**SUMMARY**

The Roald Dahl Marvellous Children’s Charity has been funding specialist children’s nursing posts since 1991. The charity, set up by the famous author’s widow, focuses on rare conditions that are often overlooked. Its latest initiative, in collaboration with the Burdett Trust, is supporting nurses to develop ideas to help children become emotionally resilient.

**Author**

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