Roald Dahl Nurses

A vital lifeline for Children with Medical Complexity (CMC)

Roald Dahl's Marvellous Children's Charity

www.roalddahlcharity.org

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Roald Dahl Nurse Specialists

Roald Dahl's Marvellous Children's Charity provides nurses and support to seriously ill children. The charity was established in 1991 by Roald Dahl's widow Dame Felicity Dahl, and there are now over 200 Roald Dahl Nurses caring for more than 40,000 seriously ill children and young people across the UK.

Working in NHS Trusts and Health Boards across the UK, Roald Dahl Nurses are Clinical Nurse Specialists providing support, information and practical care for seriously ill children and young people. Their dedication in this crucial role delivers **safe, effective, high-quality patient care** and reduces the length of hospital stays.

With complex conditions, care is often disjointed and fragmented, involving a multitude of health professionals in different roles across different contexts. Roald Dahl Nurses bring these diverse strands of care together to provide a holistic and family-centred approach, coordinating healthcare services and therapies, and streamlining the flow of information between families and medical professionals. In addition to this, Roald Dahl Nurses provide emotional and psychological support, as well as expert clinical and technical input. It's no surprise then, that evidence shows **the Clinical Nurse Specialist role conserves resources, leading to greater efficiency and better outcomes.**

Roald Dahl Nurse Specialists are a vital lifeline for seriously ill children and their families.

Roald Dahl Nurses support children and young people affected by complex medical conditions, including rare diseases, sickle cell, neuro-muscular conditions, and epilepsy, among many others. While their specialties may appear extremely diverse, the common thread is that the children and young people looked after by Roald Dahl Nurses are all living with **complex lifelong conditions**. These conditions include progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe, lifelong disability.

> “Honestly, I can't sing her praises enough, she's so fantastic and I feel like she's part of our family.”

> “We were all struggling and then [our nurse] came in and gave us hope again.”

> “It's refreshing to have someone listen to all your concerns, take it all on board and go above and beyond to make sure we're ok.”

> “She's been like a guardian angel.”

The four impact areas of Roald Dahl Nurses[1]

Improved quality and experience of care

One of the main ways in which nurses support those under their care is by **providing families with information** about the nature, prognosis and treatment options relating to their child's condition(s). Roald Dahl Nurses act as the **'one point of contact'** into the service for both parents and health professionals alike.

Parents greatly appreciate the **'coordination of care'** provided by their nurses, with advice and liaison undertaken both within and outside healthcare boundaries.

Roald Dahl Nurses offer families **responsive, intensive, and flexible** services.

Nurses recognise that they can offer practical advice and meaningful reassurance to parents, answering 'quick' questions that would otherwise provoke and feed anxiety: **"small things make a massive difference".**

Overall, families' satisfaction with the care received from their Roald Dahl Nurse is extremely high, with a

mean of 9.47 on a scale to 10

demonstrating the positive impact Roald Dahl Nurses have on quality and experience of care.

Provision of holistic family-centred care

Family-centred care is embraced as a core responsibility and value by Roald Dahl Nurses.

Given the complex needs of children and young people in the caseload of a Roald Dahl Nurse, a traditional patient-centred care approach would be inappropriate. **Family-centred care represents a shift towards the delivery of care that supports individuals within their family unit.** Core components of family-centred care are developing an effective relationship with the family and those health professionals supporting them, working collaboratively together to plan and deliver care for the child or young person.

In the context of working with children and young people with long-term conditions, this type of collaboration is particularly relevant as they are primarily cared for at home, with parents often taking significant responsibility for care decisions and delivering treatments. When parents become skilled and experienced in providing care for their child or young person, they shift from a passive to more active position when collaborating with health professionals.

Over the last twelve months, Roald Dahl Nurses have collectively provided

over 200,000 hours

of holistic family-centred care.

Improved efficiencies and cost effectiveness

Roald Dahl Nurses present themselves as **"active change agents",** introducing a suite of interventions that they feel would lead to reduced waiting times, A&E visits, hospital admissions and duration of stay. They focus on increasing efficiency, reducing resource wastage and parental complaints, and improving patient experience.

Roald Dahl Nurses provide timely access to suitable care, services, and information, for example, providing medication advice (when appropriate) to parents out-of-hours to help stabilise their child, or rearranging appointments so that a child with an emerging concern can be seen by a consultant earlier than scheduled. This helps to reduce risks to young patients' health and relieves the anxiety of patients and families. Moreover, this also improves cost-effectiveness, as these nurses prevent escalation (preventing a major event requiring admission by intervening at an earlier stage) and reduce the number of missed appointments, A&E visits, hospital admissions and duration of hospital stays.

Many of these nurses also build multi-disciplinary teams from scratch and coordinate the work of different professionals to increase effectiveness, avoid duplication and maximise outcomes.

Families who have averted having to access the following services due to timely contact with their Roald Dahl Nurse

Demonstrating leadership and innovation

Many aspects of the work of Roald Dahl Nurses are synonymous with practice at an advanced level. To improve the quality and experience of care provided, sustainably deliver high-quality holistic family-centred care, and improve efficiencies and cost effectiveness, these nurses execute high levels of clinical reasoning, decision making and critical analysis.

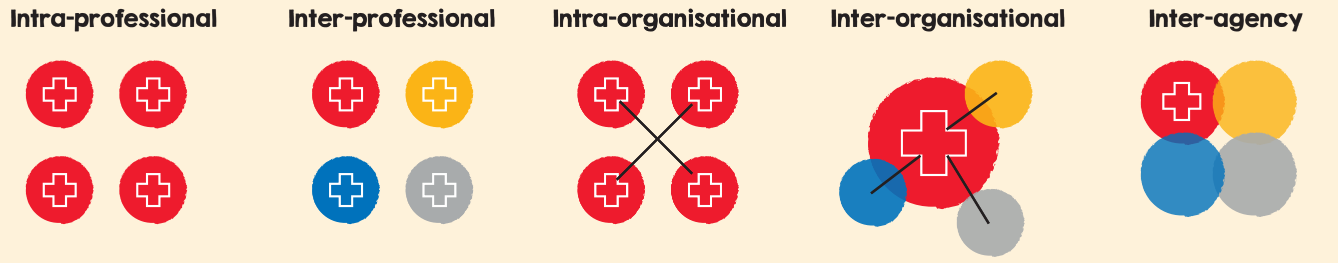
The complex conditions and clinical uncertainty of patients in their caseloads mean that Roald Dahl Nurses cannot always follow standard care pathways or clinical protocols and often depend on their own intuitive leadership and innovation.

Roald Dahl Nurses note that **service development** represents a significant aspect of their role. This involves improving existing services by restructuring care pathways or facilitating access to available resources, in addition to designing and implementing new services by formulating business cases, submitting bids and drawing upon the expertise of different professionals from various fields.

A major distinctive component of the work of Roald Dahl Nurses is situated at a **multi-agency** level.

Although their roles may lie within a particular organisation, their remit encompasses proactively creating connections and facilitating care across organisational boundaries. Improving pathways that span services means that these nurses spend significant time and energy creating and fostering multi-agency and multi-disciplinary links and networks.

This model of practice emphasises nonclinical roles alongside multi-agency work and presents a relatively unique model of nursing practice.



Intra-professional
Nurses working with other nurses

Inter-professional
Nurses working with other professionals

Intra-organisational
Nurses working across different components of their health service

Inter-organisational
Nurses working across different health services

Inter-agency
Nurses working across and between different agencies

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[1] Nightingale J, Urquhart-Kelly T, Saunders L, et al (September 2021) 'Marvellous Nurses' *An independent evaluation of the role, impact and contribution of Roald Dahl Nurse Specialist Nurses*. Sheffield Hallam University, p. 41

Who are the children with medical complexity (CMC)?

We estimate 0.85% of the UK's child population are CMC which equates to 98K - 119K individuals

In an era marked by unprecedented advancements in obstetric and paediatric medicine, we find ourselves at a crossroads where the survival of children with previously unsurvivable or significantly life-limiting conditions is now a reality. This triumph, however, unveils a complex challenge: ensuring these children and their families attain a quality of life that goes beyond mere survival.

While the number of children with medical complexity in the UK is so far unrecorded, we can be guided by other relevant statistics and research to understand this growing patient cohort.

Children with medical complexity (CMC) live with congenital or acquired multi-system diseases, severe neurologic conditions with marked functional impairment, and/or are technology dependent for activities of daily living[2]. These children often face a daily reality that is incomprehensible to many: the inability to walk, talk, eat, or take part in activities that define childhood, coupled with the looming shadow of life-limiting diagnoses.

These children are not only under the care of multiple specialists, frequently spanning diverse NHS Trusts and healthcare organisations, but they also face extensive needs beyond traditional healthcare. This reality makes navigating the healthcare system and coordinating their comprehensive care an extraordinarily complex and exhausting endeavour for their families.

Percentage of families under the care of Roald Dahl Nurses recognising that:

81% "Sometimes I feel like we live on a rollercoaster: we are in crisis when my child is acutely ill. But coping well when things are stable"

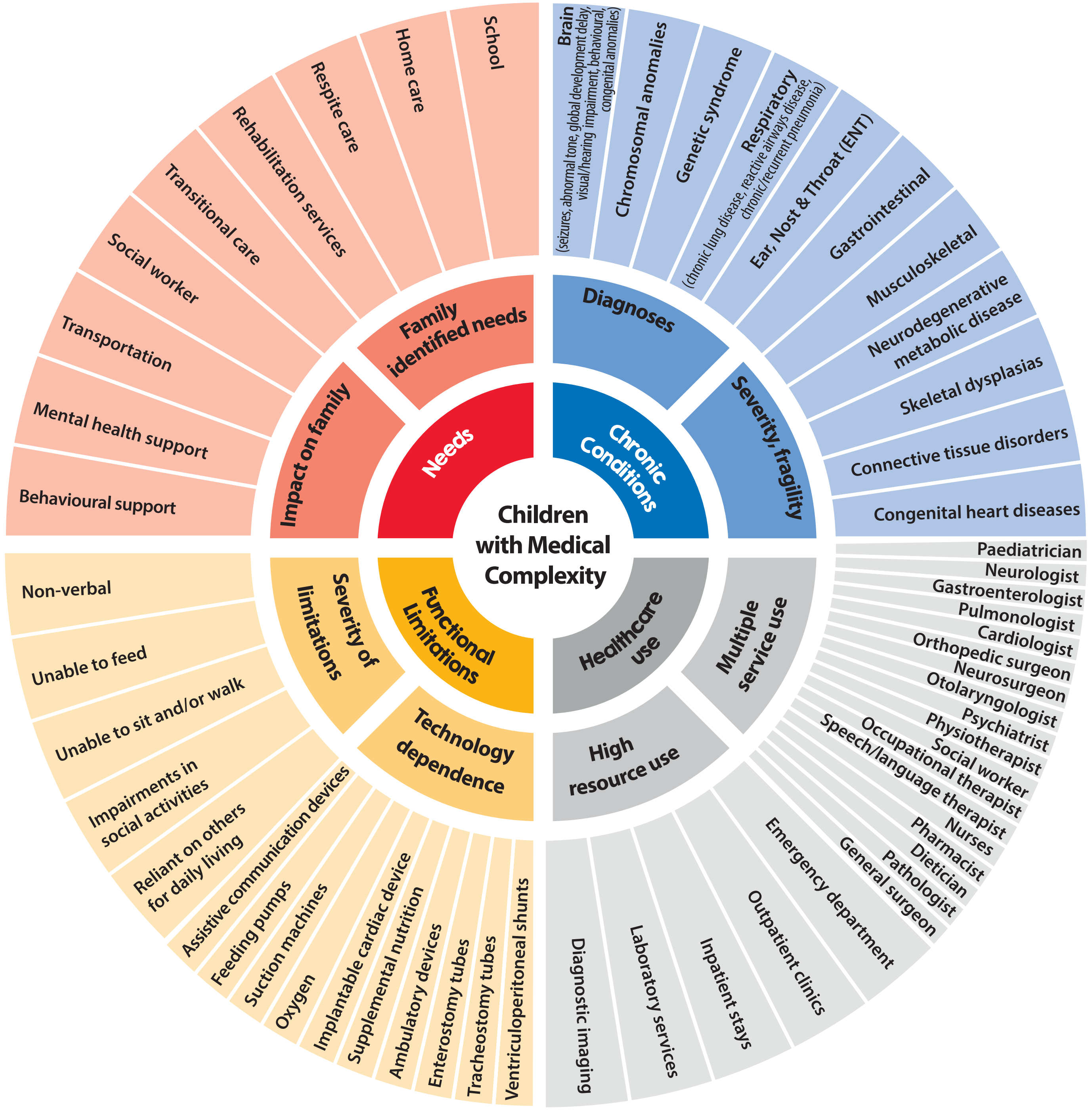
80% "Our family gives up things because of child's illness"

75% "Fatigue is a problem for me because of my child's illness"

> **"It's exhausting trying to navigate through it [...] I am his voice, which means knowing when something isn't right, when he's not well or something is agitating him, so I push to be heard [...] These children are unique and don't follow the rulebook, they write their own and you have to listen to them."**

The risk of premature death for mothers of a child with a life-limiting condition is more than 50% higher compared to mothers with children with no long-term health conditions[3]

This infographic[4] aims to illustrate the multiple facets of medical complexity, detailing the wide range of conditions that could affect a child. It also highlights the diverse areas of daily life that are influenced by these conditions, showcasing the profound impact on both the child and their family. By visually representing these interconnected elements, the infographic seeks to provide a comprehensive understanding of the challenges faced and the significant adjustments required in day-to-day living.



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[2] Cohen E, Kuo DZ, Agrawal R, *et al*. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics* 2011;127:529–38.

[3] Johnson, M. (2021). *Mothers caring for seriously ill children at greater risk of serious health problems*. [online] Together for Short Lives. Available at: https://www.togetherforshortlives.org.uk/mothers-caring-for-seriously-ill-children- [Accessed 25 Jun. 2024].

[4] Adapted from Jarvis S, Richardson G, Flemming K and Fraser LK. *Numbers, characteristics, and medical complexity of children with life-limiting conditions reaching age of transition to adult care in England: a repeated cross-sectional study* [version 1; peer review: 2 approved]. NIHR Open Res 2022, 2:27 using data taken from Appendix of Cohen E, Kuo D, Agrawal R, et al (March 2011) *Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives.* Pediatrics, Official Journal of the American Academy of Pediatrics

The inadequate care provision for children with medical complexity

In the face of such complexity, **the traditional healthcare framework, often fragmented and siloed, falls short of addressing the multifaceted needs of these children and their families.**

Navigating the healthcare landscape for parents of CMC presents an array of daunting challenges, magnified by the complexities of their children's conditions. Central to these challenges is the pronounced lack of coordinated care. This lack of cohesion not only exacerbates the logistical and emotional challenges of managing their child's condition but also generates a feeling of abandonment as their requests for comprehensive support are ignored.

Parents feel abandoned: parents of CMC do not always feel emotionally supported beginning from the diagnosis period and continuing as they move through the health system. Parents find themselves isolated and fighting for coordination of their child's care. Parents need services to provide them with emotional and physical support.[5]

The emotional ramifications for these families are profound. The clinical emphasis on addressing the medical issues of the child's condition(s) frequently neglects the equally crucial need for emotional and psychological support for the family. This imbalance fosters a **sense of neglect and isolation** among parents, amplifying the distress associated with their child's complex needs. **They are left to confront harrowing diagnoses without adequate support.**

Given these factors, **the value of continuity of care cannot be overstated.** Parents of CMC need stable and enduring relationships with healthcare professionals. Such relationships, built over time, offer a semblance of stability and reassurance amidst the turmoil. However, the reality for many of these families is a constant cycle of re-explaining their child's complex medical history to an ever-changing roster of consultants and healthcare professionals, with frequent, disorienting trips to emergency departments disrupting the fragile continuity they strive to maintain.

> **“I'm not just a mum looking after a child, I have to be a doctor, a nurse, a physiotherapist, every person [...] It's a constant battle for the right care.”**

> **“Our child is currently under 24 teams between several Trusts.”**

Poor continuity of care

Child is diagnosed with a medical complexity

This could lead to a fragmented care system

and unsuitable care for the child and family

> **Children with medical complexity have been described as “Everybody's patient, Nobody's responsibility”[6]**

> **‘On an institutional level, the UK health system [is] viewed as a perceived barrier to high-quality care as it was not believed to be designed to meet the needs of children with medical complexity.’[7]**

The current healthcare system was primarily designed for acute care, resulting a fragmented care model that lacks holistic coordination. This not only leaves families feeling unsupported but also clinicians feeling frustrated by the inefficiencies and limitations in care delivery.

The absence of a unified care lead for CMC contributes to a ‘silo' mentality, where care is compartmentalised, leading to gaps in communication and continuity. This not only complicates the treatment pathways for these children but also diminishes the quality of care they receive, impacting their overall wellbeing and quality of life.

Clinicians recognise the current disjointed nature of the care provision for CMC and the urgent need for reform in how their care is conceptualised and delivered. **Clinicians are calling for a more structured, integrated approach to care that transcends traditional service models.**

Recognising the gap in care provision for children with medical complexity, Roald Dahl's Marvellous Children's Charity took a pioneering step in 2023 with the launch of a dedicated programme. The establishment of a groundbreaking network of Roald Dahl CMC Nurses will improve the care provided to CMC and their families.

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[5] McLorie EV, Hackett J, Fraser LK. *Understanding parents' experiences of care for children with medical complexity in England: a qualitative study.* BMJ Paediatrics Open 2023;7:e002057. doi:10.1136/ bmjpo-2023-002057

[6] Cass, H. (2020). *The child with medical complexity: Everybody's patient, Nobody's responsibility*. Developmental Medicine & Child Neurology, 62(3), pp.265–265. doi: https://doi.org/10.1111/dmcn.14430

[7] McLorie EV, Hackett J, Fraser LK. *ibid*.

Life without a Roald Dahl CMC Nurse Specialist

River's story

River is 3 years old and loves light-up toys, TV and hydrotherapy. He is in the care of 21 different specialisms for his medical issues including, but not limited to, Hypoxic ischemic encephalopathy (HIE), dyskinetic cerebral palsy, refactory epilepsy including tonic seizures, non-epileptic myoclonus, laringolmayacia, neurological gut dysfunction, moderate hearing loss and cortical visual impairment.

The last couple of years have been hard on the family as River's conditions have been identified. His mum, Alison, says, "It's very difficult… because of his complex needs we don't get a lot of reaction from him. Not having your child smile back at you is heart-breaking. It's been very, very slow progress. He's just started smiling this year. He's still got a high seizure burden and if he smiles or starts to focus on something he'll have a seizure and it's back to the beginning."

Managing River's medications is challenging, as Alison describes, "He's been sick since he was born, and we have to micromanage it with medication. He was on 16 meds a day and 2 nose sprays, which added up to 40 doses every day. Every couple of hours he needs medication and he's tube-fed, so we're very much governed by the clock. I think he's more or less under every department, it's exhausting. He has botox every 3 months to help his salivary glands, plus a dietician, occupational therapist, physiotherapist, and lots of consultants involved because it's just so complex."

> **“When River's not well it's never just one thing, it's always a multitude of things, so trying to figure it out you'll speak to one doctor and they'll make a decision, then another doctor needs to see you, but they'll make a decision that doesn't work with the first one. We need somebody to communicate between them all.”**
>
> **Alison**

Patrick's story

8-year-old Patrick is a twin who loves music, swimming and going to school. At two weeks old, he was diagnosed with the rare condition, pontine tegmental cap dysplasia; he is only the 19th person to be diagnosed with it in the UK.

His mum Vicki explains, "Patrick has it on the more severe end of the spectrum. I've found families across the world now with the condition and some children can walk with aids, whereas Patrick is in a wheelchair. He can't walk or talk and is delayed in almost everything."

Vicki continues, "We can understand some of his body language and that's how he communicates with us, he's nonverbal. He also can't eat by mouth, he's got a gastrostomy and he has a super pubic catheter. He was born with two kidneys, but one has disappeared and the remaining one is not 100%, but it does the job. He does get quite a few urine infections. His condition also affects him when he gets ill, like a chest infection, as he doesn't have the ability to cough very well and that's one of the big dangers. I never realised how important a cough was until I had Patrick."

Patrick's condition means he has to be under the care of multiple consultants and medical care teams. Vicki goes on, "He's under the neurologist and the renal team, and he has an eye condition where there are no nerves in his eye, in fact his face and whole body don't feel pain. He can just feel pain inside his body, like a tummy ache. He also has epilepsy and another condition to do with his kidney that causes swelling and pain in his joints, which he can feel. We have to juggle all the appointments, it hasn't got less as he's got older, but they're more spread out. You just have to get on with it."

Vicki says, "We nearly ended up in hospital with him recently because he was breathing funny, then we were in again two days later with his catheter. "

> **“We would really benefit from [a Roald Dahl CMC Nurse]; it would be amazing. It's hard to put into words, it would be helping so many families and children that are in the hospital and have to make so many trips there. That extra support would be amazing because it's hard, it's like you're living in a completely different world when you have a child with additional needs and when you're in hospital you're even more alone. To have a person to help vouch for your needs or to even just say it's alright would make a massive difference.”**
>
> **Vicki**

> You get support for more than just the illness and it's invaluable for a child with complex needs, as there's no clear process and you need help to navigate that. It's a huge benefit, I cannot say how useful and worthwhile this role is; every hospital should have a Roald Dahl Nurse.

Roald Dahl Nurse Specialists are a vital lifeline for seriously ill children and their families.

> It's about having someone who's familiar with you as a family [...] you don't get continuity and people that know your children. Somebody familiar with their needs and what's been happening, who's involved and able to co-ordinate, is just enormous, it means a huge amount. It would be amazing if this was available everywhere for complex children. I don't think the words cover it; it would just make such a huge difference.

Better care for children with medical complexity

Roald Dahl CMC Nurse Specialists emerge as central figures, with the potential to embody the gold standard in care for CMC.

These specialist nurses extend their care beyond the conventional medical framework, weaving a comprehensive network of support that addresses the medical, emotional, and social fabric of each child and their family's lives.

By fostering collaborative relationships that bridge multiple healthcare disciplines, Roald Dahl Nurses ensure that care is not only seamless and family-centred, but also holistic, encompassing all aspects of health and wellbeing.

Roald Dahl Nurses stand as indispensable allies to CMC families, offering guidance through the healthcare maze and ensuring that no family has to face their journey alone. Their deep understanding of the unique challenges these families encounter – from managing intricate care regimens to interfacing with social services and education – allows them to provide support that is tailored to the specific needs of the conditions they help manage.

Roald Dahl Nurses embody the essence of hope and advocacy, offering not just clinical care but also a compassionate presence that accompanies families through every challenge and milestone. This commitment to excellence, empathy, and holistic support reflects the very mission of Roald Dahl's Marvellous Children's Charity and its vision for a more integrated, empathetic approach to paediatric healthcare.

From initial diagnosis through to transition into adult services, these nurses offer a steady, reliable and reassuring presence, embodying the qualities of passion, empathy, and resilience that define the gold standard of care for CMC patients. Through their dedication, and pathfinding care model, **Roald Dahl Nurses are redefining what it means to support families facing the profound challenges of medical complexity, ensuring that every child has the opportunity to thrive.**

Good continuity of care

Information continuity

Management continuity

Relationship continuity

Every child with medical complexity deserves a Roald Dahl Nurse

As Roald Dahl's Marvellous Children's Charity continues to expand its network of Roald Dahl Nurses, the vision is clear: to ensure that no seriously ill child, or their families, are left without the specialist care they desperately need and unequivocally deserve.

Through dedicated support, advocacy, and care coordination, Roald Dahl Nurses can help to improve the lives of children with medical complexities and their families, making more time for memories to be made.

Investment in Roald Dahl CMC Nurses is a necessary step to provide a comprehensive model of care for this forgotten cohort of children. Roald Dahl Nurses can ease the pressure on these families during an overwhelming and stressful time, alleviating the burden facing parents of CMC and allowing them time to enjoy as a family.

Acknowledging the critical gaps in the current healthcare provision for CMC is paramount. **Roald Dahl's Marvellous Children's Charity is striving for more structured support that will safeguard exceptional standards of care and a holistic approach; a crucial step towards addressing the existing health inequalities that CMC endure.**

It is beyond dispute that Roald Dahl Nurses meet the unique care needs of CMC patients. With a strategic focus on establishing more Roald Dahl CMC Nurse Specialists, the charity is confronting the health disparities these children face head-on. Roald Dahl's Marvellous Children's Charity envisions a future where the care and support provided is seamlessly co-ordinated, ensuring that CMC receive structured, comprehensive care and advocacy that safeguards their wellbeing and allows them to thrive.

> "We are so grateful for the charity, the impact the nurses have on families is amazing. [Our nurse] is just a support in every way. If we didn't have her, I think I would be broken. She's part of the family to us, she is caring, healing and definitely inspirational."

> "It's such a lifeline, our Roald Dahl Nurse really does mean a lot to us. I'm so grateful there are people funding Roald Dahl Nurses because it's vital. I wish everybody had a [Roald Dahl Nurse]."

Fund a Roald Dahl Nurse

Roald Dahl's Marvellous Children's Charity needs your support to establish more Roald Dahl CMC Nurse Specialists. Your donations can help us to ensure that more children with medical complexity have access to the vital specialist care of a Roald Dahl Nurse.

To find out how you can get involved and make a difference to seriously ill children and their families, please visit:

www.roalddahlcharity.org/donate

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