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Howden, the new name for Endsleigh charity and not-for-profit. HOWDEN

Charlotte Fairall: Leading with lived experience

By Charlotte Fairall 24/10/2025

When Charlotte Fairall lost her daughter Sophie to cancer, she turned grief into action. Now, through Sophie's Legacy, she's reshaping hospital care and policy with lived experience at the heart.

When my ten-year-old daughter Sophie was diagnosed with rhabdomyosarcoma, an aggressive childhood cancer, our family's life was turned upside down. Watching her go through treatment, I witnessed not only the brutal realities of cancer but also the gaps in the support available to children and families. Sophie's experiences, her courage, and her voice became the driving force behind what would later become Sophie's Legacy.

Before this, I was a children's social worker as well as a mum to three wonderful children. My professional life had always centred around advocating for children and families, but I had no formal background in healthcare or running a charity. I found myself stepping into an entirely new world - working alongside hospitals, NHS trusts, and government which is driven by Sophie's vision of what needed to change. Leading with lived experience has taught me lessons no qualification ever could, and I'd like to share some of them.

Purpose overcomes fear

Starting something new without a professional background in healthcare or running a charity was daunting. I often wondered if people would listen to a mother and former social worker without credentials. But I quickly realised that authenticity and passion are powerful. I wasn't approaching this work as an outsider; I had lived the experience and seen the gaps first-hand. The "why" was so clear it gave me the courage to work out the "how."

Listening is leadership

Sophie inspired much of the charity's vision. She believed children should be fed properly in hospital, that parents should never go hungry while staying by their child's bedside, and that play should always be central to a child's care, even during treatment. After she passed away, I carried her words with me and listened deeply to other families too.

Leadership, I've discovered, is less about having the answers and more about creating space for voices that deserve to be heard. Families, nurses, play specialists, and young patients themselves have shaped Sophie's Legacy every step of the way.

Building bridges, not barriers

Coming from outside healthcare could have left me feeling like an outsider. Instead, I chose to approach professionals with openness and respect. Sophie's Legacy was never about criticising the NHS; it was about partnering with it to improve the experience for families. By working together rather than against one another, we've built strong relationships across hospitals, NHSE, and government.

Being invited to contribute to national conversations on children's cancer has been both humbling and vital. Working with government allows Sophie's voice to reach decision-makers and ensures that the realities families face are influencing policy, not just practice on the ground.

Small acts have big impact

At first, I sometimes worried that unless we changed the whole system, we weren't doing enough. But I've seen the extraordinary power of small, thoughtful interventions. A simple pack with toiletries doesn't change a cancer diagnosis, but it restores dignity and comfort for a parent at their child's bedside. A hot meal for a mum or dad sitting through long nights in hospital can bring strength and hope. These small acts ripple outwards to create wider cultural change.

Lived experience is expertise

Too often, lived experience is treated as secondary to professional knowledge. My journey has shown me the opposite: lived experience is not only valid, it is vital. Families know the emotional, practical, and systemic challenges of childhood illness better than anyone.

I've come to embrace my position not as someone lacking a healthcare background, but as someone bringing a different, essential form of expertise; as a mother, a former social worker, and now, as Sophie's voice in the world.

Looking forward

CHARITY TIMES VIDEO Q&A: IN CONVERSATION WITH HILDA HAYO, CEO OF DEMENTIA UK



Charity Times editor, Lauren Weymouth, is joined by Dementia UK CEO, Hilda Hayo to discuss why the charity receives such high workplace satisfaction results, what a positive working culture looks like and the importance of lived experience among staff. The pair talk about challenges facing the charity, the impact felt by the pandemic and how it's striving to overcome obstacles and continue to be a highly impactful organisation for anybody affected by dementia.

CHARITY TIMES AWARDS 2023



MITIGATING RISK AND REDUCING CLAIMS



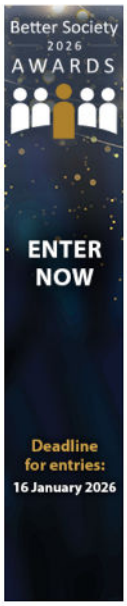
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The cost-of-living crisis is impacting charities in a number of ways, including the risks they take. Endsleigh Insurance's* senior risk management consultant Scott Crichton joins Charity Times to discuss the ramifications of prioritising certain types of risk over others, the financial implications risk can have if not managed properly, and tips for charities to help manage those risks.

* Coming soon... Howden, the new name for Endsleigh.

BETTER SOCIETY

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Sophie's Legacy was born from heartbreak, but it is sustained by hope. Every initiative we deliver carries Sophie's spirit and determination. Leading this charity has taught me you don't need clinical credentials to drive change; you need purpose, perseverance, and the courage to listen and collaborate.

For anyone thinking of starting a purpose-driven organisation without the "right" background, I would say this: your lived experience is your strength. Use it. Partner with others, keep your purpose at the centre, and never underestimate the difference you can make.

Sophie believed children and families deserved better. Carrying that vision forward, whether through direct support in hospitals or working with government on children's cancer policy, has been the greatest honour of my life.

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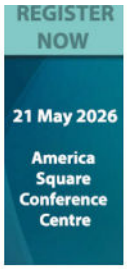
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London Marriott Hotel, Grosvenor Square
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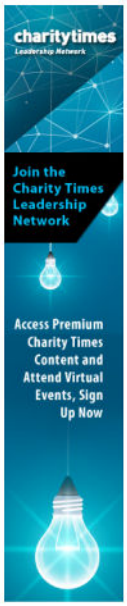
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