The Care Bridge Team were lucky enough to be in the audience as Dame Stephanie Shirley spoke about her book 'Let It Go' at the Oxford Literary Festival. She is truly in incredible, not only as a business woman and a philanthropist but as the mother of an autistic child.

Here is a woman who has done so much to improve the lives of autistic people and as always is the case when we are inspired by the great work in our sector to respect and protect humanity, her commitment, contribution, love and understanding have galvanised our passion to do more.

It is so important to remember that every family touched by autism has a story to tell if we can simply take the time to listen.

Dame Stephanie Shirley has had an amazing life. One that took her from a childhood fleeing Nazi Germany as an unaccompanied refugee, to coping with the obstacles facing women workers post-war, to setting up an IT company in the earliest days of computers that incorporated flexible home working for its many employees.

But it is her love and devotion for her autistic son Giles that punctuates her story and makes it so very poignant. Indeed, it is to her credit and honour that by devoting herself to seek solutions to the challenges and burdens of autism that she has become one of the greatest philanthropists of our time.

Recently our Care Bridge Specialists team were lucky enough to sit in the audience when Dame Stephanie Shirley spoke at the Oxford Literary Festival and we have reflected and spoken about it ever since. We all concurred that 'Let It Go' is an inspiring, vibrating, painful, and at the same time peaceful read and for many reasons that stay with you long after its final chapter.

As readers one cannot help but admire Dame Shirley for her generosity of both wealth and wisdom. Not least because by her own admission she was inspired to give away much of her fortune by Andrew Carnegie's dictum- "The man who dies rich dies disgraced".

She established 'The Shirley Foundation', founded 'Autistica' and created both Priors Court, a residential school for 90 children and young adults with profound autism, learning disabilities and complex needs and Kingswood, which provides supported-living and outreach services to over 130 autistic people across Berkshire, Oxfordshire, Buckinghamshire and Wiltshire.

But though noble, her journey to such crowning achievements was an intensely challenging one and a test of her strength, courage, valiance and undiminishable love for her child. It took her to the lowest lows and in 1976, as a result of Giles' condition, work, a lack of sleep and other stresses Dame Stephanie broke and was admitted into a psychiatric hospital.

She writes in such elegant prose that "All those years of fighting, all those years of accumulated scar tissue, seemed to fragment and break and fall away from me, leaving me as vulnerable and helpless as the five-year-old child I had been the last time my life changed irrevocably at the railway station thirty-seven years earlier".

At this point in her story the families of children with severe autism will find a quantum of solace in her words. This is a lady, a mentor and role model who truly recognises the daily hardships and emotional agonies that go hand in hand with unconditionally loving an autistic child.

Fellow parents of autistic children will read passages that only they will be able to feel in their bones. Never more so than when Giles tragically passes away after a seizure in his sleep, which caused "the inner howl of despair that reverberates through the rest of your life. An ache that bites and gnaws and never heals" It is certainly not Dame Shirley the refugee, or business women that describes, "It was like a light going out. Nothing I can write can begin to convey the desolation. The beloved, mysterious, tormented, beautiful being who had been at the centre of my life for thirty-five years was suddenly and irrevocably absent". These are the words of a bereft mother who has gone through the unimaginable, through suffering too terrible to name.

Dame Stephanie reflects that while Giles was living the problems seemed both intractable and endless. He suffered from severe epilepsy, he could not speak, he would not function autonomously and he would always be dependent on others' care. He was strong, often violent and suffered aggressive outburst after aggressive outburst. His condition quite literally drove her marriage to breaking point. It meant that life was a continual struggle and that every day ended in miserable exhaustion. "We had long since given up any pretence of a normal, happy family life. We snatched food when we could, rather than sitting down together for meals. Derek and I resorted to sleeping in shifts. (You can imagine what that did for our relationship). But what really frightened me was how the strain was changing me as a person. Emotions and ideas that I neither recognised nor approved of seemed to pop up in my head without prompting."

These ordeals took such a toll on Dame Stephanie's mind that she even contemplated suicide to "bring this miserable parody of a life to an end."

It is a worrying truth that desperate thoughts such as these are not entirely uncommon in families besieged by severe autism but when you see it there in black and white, when such honest words leap off the page and offer you a glimpse into the world of caring for an autistic child, it is a stark reminder of the experiences and burdens that we must all share and learn from.

You cannot raise any child – and especially not an autistic child- alone. It takes a village. A network of people – siblings, extended family members, specialist practitioners, physical and occupational therapists, speech therapists, doctors, and teachers. And while it can feel challenging at times, keeping the lines of communication open with all these important people will help to protect and safeguard the wellbeing of any parent of an autistic child.

Dame Stephanie's story is truly a testament to that. She recognised the need to adopt an “oxygen mask” principle. She lived in a perpetual state of high alert and needed to look after her own welfare if she were to retain any meaningful capacity to care for her son.

All too often parents suffer undiagnosed PTSD, high anxiety and poor health. All too often isolation, seclusion and depression are commonplace. Parents and families desperately need our understanding, respite and support so that they can continue to live with autism and foster loving relationship