

Sorcha's MS and Stem Cell Story

In April 2014, at 33 years old, Sorcha Boyle was diagnosed with MS. Her diagnosis came through a private consultation, though she later moved back into the public health system. Looking back, she recalls how symptoms had already been troubling her for a year before that, but early consultations had left her feeling dismissed. By the time she finally received clarity, there had already been significant delays, and her MS had quickly begun to show an aggressive course.

From the beginning, treatment was difficult. Her first medications caused severe reactions or simply did not work, and within a short space of time she had already cycled through three DMTs. Each attempt was followed by new activity, new relapses and fresh complications. One of the most devastating relapse led to a ten-week hospital stay followed by a further eight weeks as an inpatient in rehabilitation. Even when higher-efficacy medications were trialed, the disease activity did not relent, and in the midst of this she also developed thyroid problems that required surgery.

The COVID-19 pandemic only made things more complicated. Her treatment was paused during this period, and when it resumed, she tried yet another DMT. But still the pattern continued: every four months she relapsed, with new symptoms each time. By 2021, it had become painfully clear to her that her MS was unresponsive and highly aggressive.

In August of that year, her neurologist suggested her case should be put before a committee determining access to stem cell treatment in London. To her surprise, by September she was told she met the



NHS criteria and had been approved for HSCT. "I was sick of constant relapses," she recalled. "We're all looking for the silver bullet when it comes to treatment for MS. When HSCT was suggested, I didn't expect anything, but it felt like a chance. Life had become punctuated by relapses. So when I was accepted, it was good news. What did I have to lose?"

Fertility was an important part of the discussions at this stage. While she already had a child and did not intend to have more, she understood that for many others this is a crucial consideration, and she encourages women to explore options such as egg freezing before beginning treatment. At the same time, she was forced to step back from her work, another reminder of how MS was stealing parts of her life.

Her HSCT treatment began in January 2022 in London. The first phase involved a series of outpatient assessments, scans, and a priming dose of chemotherapy. At home, she gave herself twice-daily injections to stimulate stem cell production in her bloodstream, ultimately harvesting between eight and nine million cells, well above the three million required.

Two weeks after her first chemotherapy, she began losing her hair and decided to shave her head before returning to London. During this period, she also had to be vigilant about avoiding infections such as COVID-19 or chickenpox, which could have proved devastating.

In March 2022, she was admitted for the second phase: a more intensive course of chemotherapy followed by reinfusion of her stem cells. Recovery was closely monitored, involving daily blood tests, antibiotics, and antivirals. Sorcha recalls that on St. Patrick's Day her neutrophil count, a type of white blood cell that fights infection, had returned to a safe level. This signalled the first signs that her new immune system was taking hold. She remained in hospital for a further week and a half before being discharged, returning home to follow-up care with a haematologist in Beaumont and eventually resuming the care of her neurologist.

Since undergoing HSCT, her MS has been stable. Sorcha describes it now as "in hibernation." While she was told not to expect improvements, she has noticed changes and sees those as a bonus. "The goal is to stop MS in its tracks," she said. Looking back, she sometimes struggles to reconcile the fact that she is the same person who went through so many hospitalisations and relapses. "That feels like someone else's story."

Her experience has not been without challenges. She was the first patient from her hospital to undergo HSCT for MS through the NHS, which meant there was no peer support to draw on. A dedicated stem cell nurse became an invaluable source of guidance.

Financially, the process was extremely difficult. Although her treatment was approved under the Treatment Abroad scheme, reimbursement for flights and other expenses never materialised, and she had to rely on fundraising to cover the costs. Returning to Ireland also brought hurdles. Some healthcare professionals were unfamiliar with HSCT for MS and questioned why she would undergo such a procedure, leaving her feeling she had to defend her choices.

Reflecting on the transformation, she describes an important shift in identity. "Instead of being the girl with MS who can't do this or that, I am just Sorcha again." While her career had been taken from her by the relentlessness of relapses, she now feels as though her condition is asleep and hopes it will remain that way. For others considering HSCT, she is honest: it is a serious undertaking with risks attached, and it demands self-advocacy, especially in countries like Ireland where it is not yet available. Everyone responds differently to chemotherapy, and while her side effects were manageable, that will not be the case for all. Fertility, family planning, aftercare and long-term supports all need to be thought through carefully.

Despite the financial strain, the gaps in understanding within the Irish system and the uncertainty of what the future holds, Sorcha believes HSCT has been life-changing for her. Above all, she feels it has given her hope, more presence in her daughter's life, and the chance to reclaim her identity. As she puts it "My MS is asleep now, and long may it stay asleep."