



# MS and Stem Cell

# Stem Cell Treatment for MS in Ireland

## Overview of Stem Cell Treatment

Stem cell therapy, specifically haematopoietic stem cell transplantation (HSCT), is a medical procedure being explored as a potential treatment for MS. This therapy aims to reset the immune system, which plays a critical role in the development of active inflammation and progression of MS. It has been investigated for other autoimmune diseases, such as chronic inflammatory demyelinating polyneuropathy (CIDP) and stiff person syndrome. HSCT offers the possibility of halting disease activity and, in some cases, even reversing some symptoms, making it a topic of growing interest among clinicians and people living with MS.

## History and Development

Stem cell therapy has been under investigation since the 1990's but was initially deemed risky. In the early 2000's, the mortality rate during treatment was as high as 1 in 25. Over time, advancements in treatment protocols and patient selection criteria have significantly reduced these risks. Today, mortality rates are less than 1% in approved centres.

The treatment was previously considered a last resort, often offered to those with advanced disease. Research has shown that HSCT is more effective when administered earlier, particularly in individuals with relapsing-remitting MS (RRMS) who have active inflammation. This shift in understanding has made it a viable option for a broader group of people, provided the timing and criteria for treatment are optimal.

## How Does HSCT Work?

HSCT involves the collection and reinfusion of a person's own haematopoietic stem cells. The treatment comprises of several stages:

- 1. Conditioning Phase:** High-dose chemotherapy is administered to suppress the immune system. This step eliminates the malfunctioning immune cells responsible for attacking the nervous system.
- 2. Stem Cell Collection:** Stem cells are harvested from the person's blood or bone marrow. These cells are then processed and stored.
- 3. Reinfusion:** The harvested stem cells are reinfused into the person. These cells migrate to the bone marrow and begin producing new, healthy immune cells.
- 4. Recovery:** Recipients undergo a critical recovery period, during which their immune system rebuilds. This stage requires close monitoring to manage potential complications. Early complications can occur within the first year of treatment and longer term problems, such as other autoimmune diseases, can emerge at a later date.

This process aims to halt disease activity by resetting the immune system. However, the recovery phase can be physically demanding, often requiring weeks of isolation and ongoing medical support. Recipients are closely monitored for infections, and supportive treatments, such as antibiotics and antivirals, are administered to reduce risks.

## Effectiveness of HSCT

Studies have demonstrated promising results:

- Those with relapsing-remitting MS tend to benefit the most, with up to 83% achieving "no evidence of disease activity" (NEDA) after two years, and over 60% at five years.
- In progressive MS, outcomes are less favourable, though some benefit has been observed in cases with active inflammation.

Research indicates that younger people with active inflammation and fewer mobility issues respond better to HSCT. For those with very aggressive MS, where multiple relapses occur within a short period, HSCT can sometimes be considered as a first-line treatment, although this is rare.

It is important to be aware HSCT is an effective treatment for inflammation in MS but it is not a cure, further relapse or progression can occur at a later date, and it does not result in remyelination or repair to previously damaged nervous tissue.

## Current Research

Ongoing trials such as the BEAT-MS and STAR-MS studies aim to compare HSCT with modern disease-modifying therapies (DMTs). These trials will provide critical insights into the long-term effectiveness of HSCT compared to existing treatments. Earlier research highlighted that HSCT offers better outcomes than many standard treatments, particularly in those with relapsing MS who have failed other high-efficacy therapies.

## HSCT Pathway in Ireland

For Irish people, the pathway to HSCT involves multiple steps:

1. **Consultation:** Individuals discuss HSCT with their neurologist if their current treatment is ineffective. This step often follows evidence of new relapses, disease progression, or new lesions on MRI scans.
2. **Referral:** Cases are reviewed by a multidisciplinary team (MDT) in Ireland to assess eligibility based on NHS criteria. The MDT includes neurologists, haematologists, and MS nurse specialists.
3. **Approval:** Suitable candidates are referred to a further MDT and if approved for treatment are referred to a specialised centre for further evaluation. Both the MDT and specialised centres are located in London.
4. **Treatment Abroad:** Once approved funding is sought via the E112 Treatment Abroad Scheme, candidates undergo the procedure and are monitored closely during recovery. Post-treatment follow-up typically occurs in Ireland.

### Criteria for HSCT include:

- Aged between 18 and 55 (up to 65 in some cases)
- MS duration under 15 years (preferably under 10)
- Evidence of active inflammation
- Prior treatment with high-efficacy DMTs

Candidates must also have adequate family or social support during recovery, as the treatment can lead to significant physical and emotional challenges.

## Risks and Considerations

HSCT is an aggressive treatment with potential complications, including:

- Short-term: Hair loss, infections, nausea, and fatigue are common. People may also experience a temporary worsening of MS symptoms during the recovery phase.
- Long-term: Thyroid issues, shingles, and rare cases of infertility or increased cancer risk have been reported. While these risks are low, they highlight the need for careful patient selection and monitoring.

Fertility preservation is an important consideration, as the treatment may impact reproductive health. Options such as egg, embryo, or sperm freezing should be discussed prior to treatment.

In Ireland, fertility preservation options for non-cancer patients remain limited, adding to the complexity of planning for HSCT. Even if funding for HSCT itself is approved, fertility preservation may have to be self-funded.

## Lived Experience and Quality of Life

While HSCT has shown significant potential, experiences vary. Short-term recovery can be challenging, with many reporting fatigue, cognitive issues, and emotional struggles. However, long-term quality of life can improve, particularly for those who achieve disease stabilisation or remission.

Neuropsychological studies have shown that people frequently report an improvement in overall quality of life after treatment, despite initial difficulties. Key factors influencing recovery include age, the severity of MS before treatment, and the presence of supportive care during recovery.

## Raising the Topic with Your Neurologist

Those considering HSCT are encouraged to discuss it openly with their neurologist if this is something they are interested in learning more about.

Things to discuss with your neurologist include:

- Your understanding of HSCT and its potential benefits
- Specific reasons you believe you may be a suitable candidate
- Any new relapses, lesions, or progression despite current treatment

Neurologists may recommend further assessments or refer the case to Ireland's MDT for review. It may be the case that other interventions (such as other DMT's) would need to be explored before HSCT could be considered.

Even if HSCT is not immediately suitable, it may remain an option if circumstances change.

## Flexible Eligibility Criteria

While the criteria for HSCT generally require less than 15 years since diagnosis, flexibility exists in certain cases. Candidates with clear inflammatory activity and relapses, even beyond 15 years, may still be considered. However, the absence of new lesions or inflammatory activity significantly reduces eligibility, particularly for progressive forms of MS.

## Commercial Access to HSCT

Some people explore commercial HSCT options abroad. This can be very costly. It is essential to ensure the chosen facility adheres to recognised standards, such as JACIE accreditation. You should:

- Understand the specific protocols used at the centre
- Confirm the safety data and outcomes of the facility
- Coordinate follow-up care with their local healthcare providers

While Irish neurology clinics are generally supportive of those seeking HSCT abroad, it is crucial to have a clear understanding of the treatment and any follow-up requirements before proceeding. Please speak to your neurologist before making any plans to access stem cell therapy commercially. It is very important that a haematologist based locally to you in Ireland also agrees to continue your care and monitoring when you return after a transplant to prevent or identify potentially serious complications.

## Long-Term Effectiveness

There is limited data on the long-term efficacy of HSCT beyond five years. Some people experience sustained remission, while others may see new disease activity after several years. Research indicates variability in outcomes, highlighting the importance of individualised care and ongoing monitoring.

## The Future of HSCT in Ireland

Efforts are underway to establish a HSCT service within Ireland, reducing the need for people living with MS to travel abroad. A comprehensive Irish service would focus on:

- Adequate staffing and infrastructure
- Individualised patient care
- Monitoring both clinical outcomes and quality of life measures

Establishing a service in Ireland would not only improve accessibility but also reduce the financial and logistical burdens on people living with MS and their families.

## Conclusion

HSCT represents a significant development in MS treatment, offering hope to those with active and highly aggressive forms of the disease. However, it is not suitable for everyone. People living with MS who wish to pursue HSCT for MS should discuss their options thoroughly with their healthcare team to determine the best course of action.

## Further Reading

BEAT-MS Trial - <https://clinicaltrials.gov/study/NCT04047628>

STAR-MS Trial - <https://mstrust.org.uk/a-z/star-ms-trial-hsct-ms>

## 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."

## Multiple Sclerosis Ireland

T: (01) 678 1600 | MS Info Line: 0818 233 233

E: [info@ms-society.ie](mailto:info@ms-society.ie) | W: [www.ms-society.ie](http://www.ms-society.ie)

Charity Number: 05365 | CRA Number: 20007867



Multiple Sclerosis  
Ireland



@msireland



multiple\_sclerosis\_ireland



MSSocietyIRELAND