

## HSCT and MS



Multiple sclerosis information

# Welcome to this Choices booklet on hematopoietic stem cell transplantation (HSCT) and MS

MS-UK listens to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

**Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis**

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## Introduction

Hematopoietic stem cell transplantation, or HSCT, is a stem cell transplant (known as bone marrow transplant). In simple terms, the procedure replaces unhealthy blood cells with healthy blood cells. Bone marrow (the centre of some bones) produces stem cells. Stem cells have the ability to become different kinds of blood cells. The different blood cells help move oxygen around the body, fight infection and help stop any bleeding. This means that stem cells have a potential to treat a wide range of disorders (1). There are many potential treatments being developed using stem cells, this booklet is specifically about HSCT.

HSCT is also known as autologous HSCT (aHSCT) or allogeneic HSCT. Autologous refers to taking stem cells from the patient and allogeneic refers to stem cells taken from a donor (stem cells from someone else). In most instances, MS will be treated using autologous hematopoietic stem cell transplantation (aHSCT).

AHSCT is a procedure that involves harvesting stem cells from blood, then wiping out the existing immune system via chemotherapy. The stem cells are then transplanted back to the individual which enables the immune system to rebuild (2).

HSCT was originally used as a treatment for bone marrow transplants to treat blood diseases and cancers. It has been used since the mid-1990s to treat MS and other auto-immune diseases in small, but growing numbers of people.

## Treating MS with HSCT

Since the turn of the century, there has been a slowly growing evidence base for HSCT's high level of effectiveness in treating MS and other auto-immune diseases. The treatment has been growing more substantially in use with MS. According to the European Group for Blood and Marrow Transplantation (EBMT) registry there were over 1,400 transplants completed in 2019 for people with MS. Most of the transplants were done in the UK, Italy, Sweden, and Poland. HSCT for MS is organised using a multi-disciplinary approach, meaning it will involve both haematology and MS specialist neurology services (3).



**I had to travel overseas to receive my procedure because of age, EDSS [Expanded Disability Status Scale] of 6.5 and a SPMS [secondary progressive multiple sclerosis] diagnosis. I would suggest that certain bodies will only offer HSCT to young newly diagnosed patients and undoubtedly this is where most benefits can be realised, but there is great potential benefit to others further along the MS road if they can obtain HSCT elsewhere**



AHSCT is a major focus of international research and new learning is emerging all the time, however existing data is enough to know that aHSCT can be used as a treatment for MS. AHSCT has been used for both relapsing and progressive forms of MS.

**As soon as I saw a news story about someone who had received HSCT, I was sure that I wanted to pursue this option. I knew that I was willing to take a chance on HSCT, as it's the only treatment opportunity to potentially halt MS in its tracks**

For approximately 70-80 per cent of people with relapsing remitting MS (RRMS) who had the treatment, complete suppression of

**Do your research and do not just rely on your neurologist. Most neurologists are not that interested in HSCT and you need the expertise of a haematologist**



**HSCT is not a miracle cure, my partner is still struggling, and we don't know if HSCT has made any difference to him, and he has been back 18 months. One of the most worrying parts for us was going against medical advice from his consultant**



disease activity and other neurological improvements have been measured up to five years post-transplant (2).

HSCT thoroughly suppresses the inflammatory activity caused by MS in most cases. Improvements to existing MS symptoms has been noted and although not for all people, there have been improvements to existing disability which is virtually unheard of in other MS treatments developed so far (3).

## **What are the risks and benefits?**

HSCT has historically been seen to present much higher risks than standard MS treatments. In the earlier years of using HSCT to treat MS and auto-immune diseases, there was a relatively high mortality risk (risk of death).

A retrospective, international study looked at 281 patients who were historically treated with HSCT between 1995 and 2006 found that there was a mortality rate of 2.8 per cent (within 100 days of transplant).

**My health was deteriorating rapidly and with PPMS I was not offered any treatment. The risk of doing nothing was greater than the risk of the treatment. Financially it was difficult, but I had inheritance and I fundraised**

Better results for patients treated with HSCT were associated with younger patient age, having relapsing remitting relapsing MS, the patient not having used disease modifying therapies (DMTs) and with a lower Expanded Disability Status Scale (EDSS). The average EDSS score of the patients included in the retrospective study was 6.5. This would be defined as ‘requires two walking aids to walk about 20 metres without resting’, indicating a relatively high level of disability amongst the cohort.

The overall neurological ‘progression-free survival’ was 46 per

**It was a choice of having an independent life I wanted to live or a life dependant on others - it was 100 per cent worth the risk to me**



cent at five years. This means that just under half of the people who underwent HSCT had completely stopped their disease progression for at least five years post transplantation and had not seen any rises in their EDSS score.

**It was a choice of having an independent life I wanted to live or a life dependant on others - it was 100 per cent worth the risk to me**

Neurological outcomes significantly improved for people with relapsing MS. Over 70 per cent of the patients with relapsing MS treated with HSCT had no MS progression or significant disease activity for at least five years post-transplant (4).


Outcomes for people with MS being treated with HSCT have greatly improved as clinicians across the world gain greater experience. Health systems have learned how to improve patient selection, refine transplant techniques, and gained accreditation to help standardise the HSCT process for MS and autoimmune diseases. Transplant related mortality rates have now dropped as low as 0.2 per cent (3).

At Sheffield Teaching Hospitals, one of the most experienced centres in the UK, they tell patients that there is a treatment-related mortality rate of one per cent. This reflects the range of possible associated transplant risks, despite no deaths connected


to someone with MS being treated with HSCT at Sheffield Teaching Hospitals (5).

**We asked GP for referral to Charing Cross hospital who told my partner that he would not be able to get treatment in UK. We then had to re-mortgage our house to pay for treatment abroad. To anyone considering this treatment I would definitely recommend trying NHS first**

Sheffield Teaching Hospitals, along with hospitals from around the world, were part of the 'MIST' trial (Multiple Sclerosis International Stem Cell Transplant). The MIST trial was a relatively small, randomised trial that included 110 people with relapsing remitting MS. The study compared outcomes of HSCT to existing 'best available' treatments. The study was designed to measure the time it took for participants' MS to progress or worsen measured by EDSS and other neurological measures. The trial found that the EDSS score of people receiving the transplantation improved from an average of 3.5 to 2.4, whilst for those using DMTs, their EDSS scores declined from an average score of 3.3 to 3.9. At a follow up point (three years post-transplant) it was found that six per cent of people receiving HSCT had shown worsening of their MS compared to 60 per cent of people using other therapies. Improvements in disability is virtually unknown in other MS treatment trials (6).



**Chemotherapy was tough and so was the recovery process. Be prepared for bumps in the road and developing a secondary autoimmune condition**



Chemotherapy has a host of possible short and long-term side effects. Short-term effects include hair loss, nausea, sickness, tiredness, rashes, and diarrhoea. In the main, these normally last a few weeks and hair regrowth should begin within a few months. Permanent infertility issues are highly likely to arise. If fertility is a concern for you, your team should discuss future possibilities of becoming a parent. If you are worried or concerned about the issue of hair loss, we have included a link from the NHS within the further information and support section at the end of the booklet that may be useful.

Whilst your body is creating healthy blood cells after having your stem cell transplant there will be an increased risk of



**The treatment can be tough. The support of your family and friends can help get you through**



- anaemia (a lack of red blood cells)
- excessive bleeding or bruising (due to a lack of platelets)
- infections due to a lack of white blood cells.

The clinicians will have ways of supporting you if you have any issues and the haematology services should explain the whole process and the associated risks. If fertility is a concern for you, your team should discuss possible ways of having children in the future with you.

There is also the possibility of secondary immune disease occurring post-transplantation. This means that there is the possibility of developing an auto-immune condition, or conditions once you have had a transplant. There can also be transplant-related issues and for a very small proportion of people, may become very unwell and need intensive care due to HSCT. Your transplant team should talk to you about all these risks and how they can be managed (7).

**For me, it was a choice between worsening PPMS which would need a change of housing (expense!) and eventually care (expense!) or having a medical treatment which would most likely stop the progression and prevent the need for those changes**

Cancer support charities Cancer Research UK and Macmillan Cancer Support both have web pages about the side effects of HSCT that may be useful. They list the full range of chemotherapy side effects and the potential support that may be needed if problems arise. The web pages also give information on reducing infection risk, adjusting your diet and self-management tips. We have added links to these web pages in the further information and support section of this booklet.

HSCT is a treatment that is not suitable for everyone with MS and needs to be considered thoroughly. The short-term risks are substantially higher than other forms of MS DMTs, but the possible long-term impact on MS could potentially stop an individual's MS progression. This 'high-risk high-reward' treatment is a complex decision and journey to make, and only you and your closest people, truly know what is best for you.



**I was put forward for it on the NHS after having Lemtrada (the best available treatment) and still getting slowly worse. I was refused by the NHS and was told they would reconsider in another year if my MRI showed further lesions. I didn't want to get worse so went to Mexico. I had also come into some money so was able to pursue it quickly**



If you are interested in HSCT, it is worth having a shared decision-making conversation with your specialist team. Although there are increasing numbers of MS specialists who are supportive of HSCT, we know that some neurologists are not as engaged. If your specialist is not supportive and you strongly disagree with their view, it may well be that you are still able to get a referral placed by your GP or you can seek a second opinion within the NHS or privately.

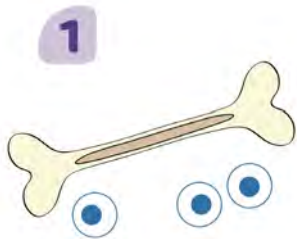


**My neuro put me forward on the NHS and I was turned down. When I told them I was going to Mexico they weren't delighted, but they did agree to support my follow-up and referred me to a haematologist**



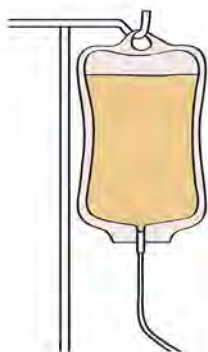
## **What is the transplantation process?**

There is no major surgery involved in the transplantation process. AHSCT will involve a lot of preparatory appointments, approximately 30 days as an inpatient in hospital with many months of monitoring post-transplant. During this time, there will be certain lifestyle adjustments including adjusting your dietary intake and lots of rehabilitation.



1

Mobilise stem cells using growth factor and chemotherapy



2

Stem cells collected from peripheral blood



3

Stem cells frozen until required



4

Conditioning chemotherapy to suppress immune system



5

Stem cells thawed and re-infused




6

Support with blood products and antibiotics (approx 2 weeks)




7

Further follow-up as outpatient for 2-3 months with regular tests and medication



**The process itself was very straightforward, but it does leave you feeling very weak and tired. I did have a stomach upset and some bone pain, but both were looked after by the doctors. Understanding the process will give you confidence as you proceed through the treatment**



### **Stage 1**

Growth factor and chemotherapy medications (delivered by infusion) are given to help stem cells to become mobile and move from bone marrow to the general bloodstream.

### **Stage 2**

When there are enough stem cells present in your bloodstream (usually a few days after the mobilisation), the stem cells are then collected from the blood. This will involve being connected to a machine that will gather and separate your stem cells and return blood to your body.

### **Stage 3**

The stem cells are frozen until needed.

### **Stage 4**

A further, more intensive 'conditioning chemotherapy' is used to



suppress or wipe out the immune system. This chemotherapy can be given at different levels of intensity depending on where you are being treated and which regime the hospital is using.

### Stage 5

Stem cells are thawed, re-infused and ‘transplanted’ back into your system.

### Stage 6

Supported with blood products and antibiotics the immune system will begin to ‘rebuild’, but during this time you are especially vulnerable to infection. You will need to be especially careful of avoiding infection, and you will be monitored closely.

### Stage 7

Follow-ups and monitoring as an outpatient for a few months with regular blood tests and appropriate medication. The follow-up appointments should involve both MS specialists and haematology (8).



**My partner flew through treatment, although he did get an infection and was admitted to the intensive care unit. He had amazing treatment and was better within four days. The care he received was fantastic**



## Access to HSCT in the UK

The Joint Accreditation Committee of the International Society Cell and Gene Therapy-Europe (ISCT-Europe) and the European Society for Blood and Marrow Transplantation (EBMT) (JACIE) is the official accreditation body for HSCT procedures in Europe. All HSCT procedures completed in the UK will be at JACIE-accredited centres. These will all work to the same rigorous standards and will be inspected regularly.

AHSCT for the treatment of MS is available in England, Scotland, and Wales for people that fall into the eligibility criteria. AHSCT is available at specialised NHS centres and is offered to a limited number of people with MS in some areas of the UK.

The NHS says that there is not enough evidence to fully show the treatment's efficacy (compared to other highly effective therapies) to totally incorporate it into the standard MS treatment pathway at this time.

**My neurologist was not helpful and had no interest or knowledge about HSCT. My MS nurse was very supportive, but no one else**

The NHS says that HSCT should be available equally to all people with MS, but currently, they say that it should only be considered for people with relapsing disease, not progressive. They say it should be for people who

- Have tried high-efficacy licensed DMTs and had continued MS disease activity (as evidenced by Magnetic Resonance Imaging (MRI) scans)
- Are prepared to accept the risks of the procedure
- Are eligible under European Group for Blood and Marrow Transplantation (EBMT) guidelines (3).


The NHS recommends that the treatment is offered only by units with expertise both in the management of aggressive MS and the use of HSCT (9).




**My MS nurse was supportive, which was a help. My neurologist was fairly supportive, which is quite rare as far as I can tell**



Health Technology Wales updated their latest guidance in July 2020 and found that evidence supports the use of AHSCT for people with RRMS that have had continued disease activity despite previous DMT use (10).




**My neurology team said it was not advised to have HSCT. My GP was in full support, and I saw another consultant neurologist in London. The consultant put my case forward at the HSCT multi-disciplinary meeting but due to Covid it was held up. I got the funds and went privately for the treatment. When back in the UK, my GP was in full support and did all my aftercare for me and provided my prescriptions**




The Scottish Health Technologies Group (SHTG) published advice in October 2019 saying that AHSCT should be made available via the NHS to people with MS who meet the eligibility criteria. The eligibility criteria would be for people with RRMS who have evidence of disease activity and have not responded to high-efficacy DMTs (11). This advice is yet to be adopted by NHS Scotland and their advice also states that eligible patients must have equal access to the procedures regardless of where they live. In an article about HSCT access in Scotland, the SHTG told the Herald Scotland newspaper that it is unlikely all health boards will be able to provide HSCT (12).

If you are interested in HSCT and feel that you fulfil the eligibility criteria, it is worth discussing this with your MS team or your GP to




**My haematologist was in favour of me getting HSCT and they were very reassuring about the safety of the procedure**




see if they will refer you to an appropriately experienced NHS facility.

If you have tried to gain treatment under the NHS and been turned down, then there is the possibility of private treatment in the UK or abroad. Private treatment can be very expensive, and prices can differ a great deal between different clinics and hospital sites.

AHSCT is available privately in the UK in London (13) and Sheffield



**I didn't qualify for HSCT in the UK, so had to launch my personal fundraising campaign, which I found tiring. We eventually reached my target after 10 months**




(5). There are still eligibility criteria that need to be met by people expressing an interest. The criteria include recent MRI scans showing evidence of new disease activity, along with comparable recent baseline scans. You would need to be referred by your specialist or GP.

## Travelling abroad for HSCT


Many people with MS will feel time pressured over their MS or find they are not eligible for HSCT in the UK and seek treatment abroad. This may understandably feel like the only option to access this high-efficacy treatment for some.

**If you go abroad, you can't get travel insurance and in Mexico you also have to take a 'caregiver' or hire one**


Treatment abroad may have a smaller financial outlay than private treatment in the UK but will still cost many tens of thousands of pounds. Each hospital centre will have different acceptance criteria and may be willing to treat people with relapsing MS and people with progressive MS.




**I went to Russia for HSCT and organised my aftercare before I went. I spoke to my GP, explained what I would need, and met a local haematologist to supervise my recovery. All went smoothly with the aftercare from the NHS**



Treatment abroad may have a smaller financial outlay than private treatment in the UK but will still cost many tens of thousands of pounds. Each hospital centre will have different acceptance criteria and may be willing to treat people with relapsing MS and people with progressive MS.



**Financially it's a lot of money - £40k minimum. But health is wealth so hopefully, with a strategic plan with good money management I should be ok**



The EBMT and JACIE published general information for people considering HSCT. It says that although they recommend seeking treatment in your home country, if travelling, it is better if you have the full support of your MS specialist, a transplant specialist, or your GP.



**My mind was pretty blown with the visa application, but we paid an agency to help us which was worth every penny for peace of mind that it was done properly, and this was very easy in the end**



Follow-up monitoring and aftercare medications will be needed once at home and this will need arranging and facilitating carefully. The EBMT, therefore, recommend that before arranging treatment abroad



**Both my neurologist and MS nurse refused to treat me on return from Mexico. Thankfully my bloods were monitored by an open-minded GP**





people explore follow-up care arrangements in their local health services (8).

Hospitals outside of Europe offering HSCT may not work with the same regime as the EBMT suggests. They may belong to other accredited bodies in their home nations and work to different protocols. If you are considering treatment abroad it may need careful consideration and planning to ensure you get the best care possible. It is worth investigating the experience of the clinic and clinicians in question, speaking with people who have been through the process and making sure you have anticipated and planned for as many of the potential issues as possible. Just because the clinic is not in the UK does not necessarily mean that it will not be able to deliver good quality transplant procedures.



**A private MRI was required by Mexico. It was very straightforward. Most of the people that have had HSCT belong to Facebook groups, and they have a wealth of first-hand experience. I also had a private appointment with an experienced haematologist who is doing HSCT in London**



The charity Auto Immune and Multiple Sclerosis (AIMS) has been set up to specifically support people with MS and

autoimmune diseases with an emphasis on HSCT. They can offer travel grants and peer support. There is more information and links in the further information and support section of this booklet.

## **Trials and studies using HSCT for MS in the UK**

Researchers and advocates hope that through larger trials, with higher numbers of people, evidence can be gathered to show health systems that HSCT should be a treatment option for all people with MS.

Star-MS is a trial that is currently recruiting in the UK. They have participating hospitals in England, Wales, and Scotland. In total there are nineteen hospital sites across the UK taking part in the trial. It aims to recruit 198 participants and will be testing HSCT in active MS. The trial will be comparing the efficacy and safety of HSCT against Ocrevus (ocrelizumab), Lemtrada (alemtuzumab) or Mavenclad (cladribine) which are the highest efficacy approved DMTs available via the NHS.

The trial is for people that have a diagnosis of RRMS, are aged between 16 and 55 years old, have tried a high efficacy DMT and had continued relapses and disease activity in the last year, are able to walk 100 metres (with or without an aid) and have not taken the medications proposed to be used in the trial (14).

BEAT-MS or Best Available Therapy vs. Autologous Hematopoietic Stem Cell Transplant (AHSCT) for MS is a

trial based in the United States of America. However, Imperial College in London will be joining as a trial site soon. This randomised trial will compare existing high-efficacy DMTs against AHST and capture data over six years. The trial will look at efficacy and safety, and make a cost comparison against existing drug therapies. Part of the eligibility criteria for BEAT-MS is to be 18 to 55 years old, be able to walk 100 yards without using an aid, have highly active MS that has been resistant to treatments and have evidence of recent disease activity (15).

If you are interested in becoming part of a trial in the UK, you can find all the details you need by searching on the Be Part of Research [www.bepartofresearch.nihr.ac.uk](http://www.bepartofresearch.nihr.ac.uk) website. This resource is part of the National Institute for Health Research (NIHR). You can use Be Part of Research to search for clinical trials by keyword (treatment name, for example), location or by condition. All open and recruiting trials will show the individual trial's eligibility criteria, referral route and location. If you need to be referred by a health professional, they will normally tell you who it should be (such as a specialist or GP).

## HSCT in the press

In recent years HSCT for MS has made it into the news, with articles with standout headlines about the potential high efficacy and the difficulties people with MS have in accessing the treatment.

MS-UK's magazine *New Pathways* has covered HSCT in many articles and features including those written by Scott McCormick (from Channel 4's *Gogglebox*), who shared his journey and

experiences with MS-UK in regular columns and vlogs (available on MS-UK's YouTube channel). Scott had these thoughts to share

**“I feel lucky to have had HSCT. I want to spread the word because I think it is an incredible procedure. In my case, I went to Hammersmith hospital and met my haematologist Dr Gabriel. He’s a man who when you meet him, you feel immediately reassured by the knowledge and confidence he has in the HSCT procedure.”**


HSCT was also in the mainstream media in 2016 when the BBC Panorama documentary followed trial participants in the Sheffield arm of the International MIST trial. The programme was titled Can you stop my multiple sclerosis?. Many of the people featured in the show had stories picked up in the national press, greatly raising awareness of HSCT for MS.

When the Hollywood actress Selma Blair was diagnosed with MS in 2018, she sought out HSCT. In 2021 she released a discovery+ original documentary titled Introducing, Selma Blair, which explored her diagnosis and shared her thoughts on trying to slow the progression of her MS, including through HSCT. The documentary is available to watch through streaming services (16).


Caroline Wyatt is a long-standing and recognisable BBC correspondent and journalist. She was diagnosed with MS in 2015 and found that she did not meet the criteria for HSCT trials, so she travelled to Mexico to have the treatment. Caroline has spoken and written, openly and honestly about her thoughts and experiences. (17).

## Life after HSCT

MS-UK asked veterans of the HSCT process to share their thoughts and insights about life after HSCT. We asked if people had any adverse reactions to the therapy, whether their MS was in remission (or halted) and whether they had any improvements to their symptoms.



I was 66 when treated and now, nearly six years later, I have had no new MS symptoms. I believe that I am generally weaker. I was at EDSS 7.5 when treated. Generally, I am very well. I had a very uneventful recovery and I have not seen a neurologist since my return from Mexico in 2016! The main improvement for me was that the fatigue has gone. My mobility has deteriorated slightly



To date, my MS is in remission, and I am hopeful that this will continue. I have not had any disease activity for two years post-HSCT and I've not been on medications. I don't feel many improvements (other than my brain fog is better), but my MS has not gotten any worse, which is a massive bonus. My MS was becoming pretty aggressive before I had HSCT



The progression of my PPMS was stopped in its tracks and I remain in remission, almost eight years after HSCT. I have been lucky enough to have many symptomatic improvements too - bonus! However, there have been unfortunate side effects from the treatment. I now have extensive avascular necrosis and immune deficiencies. However, I am still glad that I had HSCT



My MS has definitely halted. No new lesions on MRI since my return. I still have previous damage, but it's intermittent, and I would say still changing for the better, even three and a half years later. All in all, I live a totally normal life. Any ongoing symptoms are minor and manageable. I had no side effects after treatment except trying to grow my hair back, which seemed to take forever



I'm 86 days post-transplant, so I'm not sure about disease activity – I've no new symptoms anyway. But I have had a lot of joint pain arise and it seems to have put me in early menopause and I'm suffering a lot with that

## Further information and support

Whilst writing this booklet we asked people with experience of HSCT to tell us where they went for extra support and to get information. They told us that online forums and social media (particularly Facebook groups) had been useful.

**I turned to HSCT Facebook groups initially, then the Panorama programme that was aired in January 2016. Then a private appointment with a UK haematologist**

People told us that they had variable experiences of getting the support of their clinical teams, with some people telling us that they had good support and some people saying that their MS team

**The road to HSCT is long travelled. I would suggest that anyone interested should do their homework, understand the pros and cons and make their personal decision from there**

were not positive about HSCT.

We know that getting good support is very important, please remember the MS-UK helpline team is here if you need someone independent and impartial to talk to.

## **AIMS**

Autoimmune and multiple sclerosis (AIMS) is a charity that has been set up to support people living across the UK looking to seek HSCT as a treatment for MS and other autoimmune conditions. They offer peer support, signposting, and grants.

**[www.aimscharity.org](http://www.aimscharity.org)**

## **Scottish HSCT Network**

A not-for-profit organisation offering information and support to people in Scotland considering HSCT as a treatment. They have a Facebook group and are led by people with experience of MS and HSCT.

**[www.scottishhsct.net](http://www.scottishhsct.net)**

There are a variety of Facebook support groups with a wealth of personal insights and experiences. Three of the more popular and active groups are listed below.

## **UK HSCT Facebook group**

**[www.facebook.com/groups/ukhsct](http://www.facebook.com/groups/ukhsct)**

## **HSCT Hematopoietic Stem Cell Transplant - MS & Autoimmune Diseases Facebook group**

**[www.facebook.com/groups/hsctworldwide](http://www.facebook.com/groups/hsctworldwide)**



## **HSCT Veterans Support Group For Autoimmune Diseases**

[www.facebook.com/groups/172430049818483](https://www.facebook.com/groups/172430049818483)

## **Other organisations**

### **Cancer Research UK**

Web page on the side effects of a stem cell or bone marrow transplant.

[www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/bone-marrow-stem-cell-transplants/side-effects](http://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/bone-marrow-stem-cell-transplants/side-effects)

### **Macmillan Cancer Support**

Web page covering the side effects of Autologous Hematopoietic Stem Cell Transplant.

[www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment/stem-cell-and-bone-marrow-transplants/autologous-stem-cell-transplant/side-effects](http://www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment/stem-cell-and-bone-marrow-transplants/autologous-stem-cell-transplant/side-effects)

### **EBMT Position statement providing general information for patients and carers considering HSCT for severe autoimmune diseases**

Members of working parties across the EBMT have created a position statement providing general information for patients and carers considering HSCT for severe autoimmune diseases.

[www.ebmt.org/ebmt/news/position-statement-providing-general-information-patients-and-carers-considering-hsct](http://www.ebmt.org/ebmt/news/position-statement-providing-general-information-patients-and-carers-considering-hsct)

## **Chemotherapy, cancer, and hair loss**

The link below is from the NHS and gives support relating to hair loss through use of chemotherapy. The web page gives hints and tips for planning for hair loss and signposts to further support.

**[www.nhs.uk/conditions/chemotherapy/cancer-and-hair-loss](http://www.nhs.uk/conditions/chemotherapy/cancer-and-hair-loss)**

## **Be Part of Research**

A resource for finding information about clinical trials in the UK. You can search by keyword and by condition.

**[www.bepartofresearch.nihr.ac.uk](http://www.bepartofresearch.nihr.ac.uk)**

## **MS-UK's YouTube channel**

Scott McCormick recorded a series of exclusive videos all about his journey with HSCT, you will be able to find them all on our YouTube channel.

**[www.youtube.com/c/Ms-ukOrg/videos](http://www.youtube.com/c/Ms-ukOrg/videos)**



# About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

## The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



## New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

# About MS-UK

## Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more [www.ms-uk.org/peer-support-service](http://www.ms-uk.org/peer-support-service) or email [peersupport@ms-uk.org](mailto:peersupport@ms-uk.org).





## Online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

## E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

## Sources

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# What will your legacy be?

By leaving a gift to MS-UK in your Will, you will be giving hope to people with MS for generations to come.

No matter how big or small, every gift makes a huge difference.



For more information, visit  
[www.ms-uk.org/Gifts-and-Legacies](http://www.ms-uk.org/Gifts-and-Legacies)

Registered charity number 1033731

 **MS-UK**  
Supporting your MS journey

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## Stay in touch

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[www.ms-uk.org](http://www.ms-uk.org)

✕ @MSUK6

f [www.facebook.com/MultipleSclerosisUK](http://www.facebook.com/MultipleSclerosisUK)

▶ [www.youtube.com/c/ms-ukorg](http://www.youtube.com/c/ms-ukorg)

in [www.linkedin.com/company/ms-uk](http://www.linkedin.com/company/ms-uk)

📷 [www.instagram.com/multiplesclerosis\\_uk](http://www.instagram.com/multiplesclerosis_uk)

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**Registered Company Name**

Multiple Sclerosis-UK Limited, trading as MS-UK

**Company Number** 2842023

**Registered Charity Number** 1033731

**VAT Number** 632 2812 64

**Registered Office** D3 Knowledge Gateway,  
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