



Media reports about autologous haematopoietic stem cell transplant



There are many stories in the media about autologous haematopoietic stem cell transplant, also known as bone marrow transplant, AHSCT or HSCT, as a treatment for MS.

In particular, we are aware that the 60 Minutes program this weekend will provide a report about a patient's AHSCT treatment experience in Russia. MS Research Australia was available to interview for this story, however, 60 Minutes declined our involvement.

Media reports often describe AHSCT as being a 'miracle cure' for MS and include personal stories of how it has given people 'a new lease of life'. While the results of this treatment have been life-changing for some people, it is important to recognise that this is unlikely to be a treatment that is appropriate for everyone.

The media reports rarely discuss the full details of the treatment, which is very intensive and carries significant risks. The reports also do not provide a full picture regarding other people who may have received the treatment but had a less positive response. To understand how this treatment option may sit within the range of other treatments available, it is important to look at the results for a broader group of people who have been followed up for longer periods of time. MS Research Australia understands that people with MS will wish to explore all potential avenues of treatment. Every person's situation and experience of MS is unique. However, we do encourage all decisions about any MS treatments especially anyone considering travelling overseas for any form of treatment, to always consult with their Australian health care providers, including their neurologist. Health care providers take into consideration the potential benefits, risks and side effects for an individual's particular circumstances. If considering treatment overseas they can ensure that the individual is fully informed about the range of treatment options available in Australia, the nature of the treatment overseas and the providers of that treatment, what can and can't be expected from the treatment, what other health conditions they may have that may impact on the treatment and management of their MS, and what medical care they may need prior to or during travel, or on their return. It is also important to note that not all countries share the same regulatory standards that apply within Australia. The National Health and Medical Research Council have also produced a guide on overseas treatment considerations.

AHSCT has been used in the treatment of blood cancers for several decades, but its use for severe autoimmune disorders has developed relatively more recently. As the safety and efficacy has not yet been tested in sufficiently large randomised controlled trials specifically for MS and in comparison to currently available MS therapies. Therefore globally it is considered experimental for the treatment of MS.

AHSCT is primarily an immune-suppressing chemotherapy treatment combined with reinfusion of blood stem cells to help re-build the immune system. It aims to regenerate a new immune system that is less likely to attack the brain and spinal cord. Further details on the steps involved in this treatment can be <u>found here.</u>





Generally, the outcomes have shown that people who are younger and who still have active inflammatory disease (new lesions on MRI scans and/or relapses) may achieve better outcomes for reducing or halting disease activity. Studies also suggest that AHSCT does not halt or reverse more long-standing disability, or progressive forms of the disease, and it is therefore unlikely that AHSCT would be recommended as a treatment for patients with secondary progressive or primary progressive MS.

Currently, this treatment is provided in Australia through two observational clinical trials, at St Vincent's Hospital, Sydney and Austin Health, Melbourne and by a small number of other centres on a case by case basis. These centres have strict eligibility requirements that have been set by the hospital ethics committees and may only apply to limited numbers of patients with MS who have failed to respond to other standard MS treatments. It is for this reason patients need to be referred to these centres by a neurologist, who can provide a detailed clinical history and MRI findings.

AHSCT is playing a role in the range of treatments available to treat MS in Australia, however, for this to become a standard therapy in Australian hospitals for people with MS, further rigorous evidence for the effectiveness, safety and most appropriate use of AHSCT is still required. While some clinical trials of AHSCT for MS are ongoing, there is also consensus amongst MS organisations globally, as well as researchers and clinicians who are involved in the use of this treatment for MS, that a large scale, 'gold-standard' clinical trial is required.

MS Research Australia together with MS Australia have been actively advocating, and will continue to advocate, to the federal government for accessibility to all suitable treatment options for people with MS in Australia. We have also been encouraging dialogue between hospitals, state health departments, haematologists and neurologists to ensure that AHSCT treatment can be provided in Australia for those who need it.

As research continues to determine the safety and long-term effectiveness of AHSCT and for whom the treatment is most likely to be appropriate and effective, MS Research Australia will continue to actively review all AHSCT studies as they become available and report on them via the MS Research Australia website and other communication channels. We have provided a full overview of what is involved in the AHSCT treatment, and a review of research to date, <u>on our website</u>.