ABC News

Radical treatment gives MS patient his life back

By Matt Peacock and Jacquelyn Hole

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A new stem cell treatment has saved the life of a young Australian with multiple sclerosis, but MS Australia still warns the procedure is "experimental".

Ben Leahy, 20, was diagnosed with MS. The first sign something was wrong was when his leg became sore.

"My legs started going numb, probably from my feet up - one leg feet up and my other leg from the waist down," the Canberra student told The 7.30 Report.

"It was probably over a week but I thought nothing was wrong. Then in a week it probably got really bad."

So bad that his family, including his step-father, GP Dr Don Curtotti, rushed Ben to emergency at Canberra Hospital, fearing a brain tumour.

Ben Leahy ... 'I've got a life again' (ABC News)

- ***Map:** Canberra 2600*
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For his mother Prue, the diagnosis of multiple sclerosis was the least-worst outcome.

"I was relieved, believe it or not. I am sorry if it sounds stupid but Don had warned me that he could have had a tumour," she said.

"I wouldn't have thought MS in a boy because it's extremely rare, and so I was relieved. I just thought, 'I am not going to bury my son in the next six months from bone cancer'."

However, the family's respite was short-lived.

MS - a disease that attacks the protective sheath around the nerves in the brain and spinal column - is generally a long-term degenerative process.

But the MS lesions in Ben's brain were multiplying fast, dangerously pressing on areas that controlled his key bodily functions.

In a matter of weeks, Ben's body started shutting down.

Rushed back to Canberra Hospital, consultant neurologist Dr Colin Andrews assessed Ben's cascading physical impairments.

"The onset was over a matter of days, with weakness in his legs and then it progressed to weakness in his arms," Dr Andrews said.

"Eventually his limbs were totally paralysed and he couldn't breathe without assistance."

In medical terms, Ben's MS is known as "rapid onset", but the swiftness with which the disease robbed the teenager of his core functions was shocking.

Dr Andrew's assessment was blunt: "If he wasn't in intensive care he would have died."

Ben's life was reduced to mere survival.

"I couldn't talk or move," Ben recalled. "My eyes were opened but no-one would notice that I was still alive."

The young man's chances of survival were nil and Dr Andrews decided to attempt a treatment he had only heard about from overseas - an autologous stem cell transplant.

The experimental procedure had never successfully been performed in Australia and required the co-operation of the neurological department at Canberra Hospital. The answer was no.

"I remember having to go and say [to Ben's parents], 'I'm sorry, I can't get consensus from my colleagues, so what are we going to do now?'" Dr Andrews said.

'A step in the dark'

But the Curtottis had undertaken their own research.

"We had read about a fellow in Athens who had [this] stem cell procedure done well. I was all for it at this stage, it was all we had," Ms Curtotti said.

Dr Andrews went back to the hospital and this time haematologist Dr Michael Pidcock said yes.

"It was a step in the dark, " Dr Pidcock recalled. "We hadn't done something like this before."

The procedure is akin to rebooting the patient's immune system. The first step was to extract some of Ben's stem cells from his bone marrow.

"Following some chemotherapy and administration of marrow stimulating drugs, the patient's own bone marrow stem cells are harvested from the bloodstream on a machine during a narrow window of time," Dr Pidcock explained.

Ben's extracted stem cells were stored in Canberra Hospital's liquid nitrogen tank, waiting for his body to be ready to receive them back.

For this to happen, Ben was subjected to a second dose of chemotherapy to knock out his immune system and remaining bone marrow cells.

"The marrow cells were reinfused a day afterwards and following a period of reduction of the cells in the blood due to chemotherapy, the normal marrow regenerated like seedlings in a garden and produced normal blood cells after about 14 days," Dr Pidcock said.

Within weeks of the treatment, Ben was out of intensive care and walking - something he had not been able to do for more than nine months.

A year later, MRI scans of Ben's brain revealed almost all the life-threatening lesions had disappeared.

The result is the best in Dr Andrews's long career.

"It is the most dramatic change that I've ever seen in someone with MS," he said.

However, for the Curtottis, the decision to proceed with the radical stem cell treatment was taken against the advice of the respected MS Australia.

"[They told us] we don't do it in Australia and probably won't for another 10 years because there is just not enough information around," Ms Curtotti said.

MS Australia's consultant, Professor Bill Carroll, justifies this precaution in the interests of protecting vulnerable patients against false hope.

"I must say however it still is very experimental," Professor Carroll said.

"The case of Ben Leahy is terrific for Ben, but may not be translatable to all people with MS."

For Ben the outcome is straightforward.

"I've got a life again," he said.

Canberra Hospital advises the treatment is not suitable for everybody with MS. Should you have any questions in regard to this line of treatment, in the first instance please contact and discuss with your treating doctor. Further information can be obtained from the ACT Health Department and MS Australia.

For the full story, watch The 7.30 Report tonight on ABC1.

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