

The **core** of our being

The brain makes us who we are, so when disease strikes it affects the very core of our humanity. We need to know more about brain tumours, how to treat them and how to treat those who suffer them, say members from both sides of the House of Representatives. Story: Peter Cotton Photos: Getty Images

Open a copy of *Hansard*, the official record of what's said in parliament, and at first glance it may seem a dry and legalistic document. A closer look will show that it also chronicles life stories which by their telling can greatly impact on the way we, as a nation, deal with an issue.

Hansard for the afternoon of May 31st this year records a speech by the Member for Blaxland (NSW), Michael Hatton, during which Mr Hatton told the House of Representatives how both his uncle Lenny and his stepson Robert died from brain tumours.

His account of suffering and loss not only evoked great empathy, it may help boost research funding and change treatment protocols for brain tumours.

Mr Hatton was one of six speakers who gave bipartisan support to a motion, sponsored by the Member for Shortland (NSW), Jill Hall, which sought to raise awareness of brain tumours.

Mr Hatton told the House that 25 years ago his uncle Lenny was a 38 year old who was running 20 kilometres a day to prepare for a marathon. One day after a run he noticed his foot uncontrollably “flop and flap around a bit”.

His doctor assured him he was well, but the problem persisted. Then it got worse. Lenny was found to have a slow-growing, untreatable brain tumour.

“He just had to live with the fact that, inexorably, this is what would take him out,” Mr Hatton told the House. “Eventually, he got to the point where, if you sat on the edge of his bed in the hospice, or even touched the bed, the pain was so intense that it was like pins and needles throughout his whole body.

“I had to be the one to tell him just to give it up and to accept the fact that he was dying and that he could not keep going and trying to push forward to beat this thing because it was harder than he was. It was a very long, slow, difficult death.”

Continued page 16 ►



1,400 Australians are diagnosed with brain tumours every year.

Then, 14 years ago, Michael Hatton's stepson Robert was diagnosed with a brain tumour. "It was a very quick death," Mr Hatton told the House. "He had an original operation which took out a blastoma. He then expected that it was successful and that he would be able to live. He and his wife had a child. But just after the birth of their child the blastoma returned and, because it was so aggressive, Robert was dead [within] nine months."

Mr Hatton says when a loved one is struck down with a serious illness, family members rush to see if there is an off-the-shelf cure. "Part of the great trauma when it comes to brain tumours," he told the House, "is that there is no ready cure that can be brought in off the shelf. Glioblastomas are so rapid, so high-grade, that the probability of getting over them is very small."

An effective response to brain tumours requires more than beefing up support for carers and extra research, says Mr Hatton. "If people can have a relationship with their doctors and health professionals, where the nature of what is facing them is better explained, they can deal with those realities on a surer footing. [A brain tumour] is one of the great unknowns, the great dangers, and that actually increases the suffering."

Mr Hatton says he's not surprised that his speech in support of brain tumour awareness had an impact. "If people were moved by what I had to say, it's because what I said was true and it's real and I feel very deeply about it. I'm still moved by those experiences. They were quite shattering."

Jill Hall's motion asked that the House acknowledge the distress caused by brain tumours. It asked the House to note that 1,400 Australians are diagnosed with brain tumours every year and that these tumours are responsible for more child deaths annually than leukaemia.

The motion also asked the House to note that while brain tumours rank 13th on the list of the most common cancers to afflict Australians, they rank 4th on the table of years of life lost to cancer.

The motion noted that there was not a single known cause of brain tumours, nor

was there a cost effective, safe and efficient way to screen for them.

The motion called on the federal government to recognise the need for a specialised response to the problem of brain tumours and to recognise the need for more research, as well as the development of better treatment protocols that might lead to longer survival and a better quality of life for those afflicted.

Ms Hall told the House there are 40 major types of brain tumour and these could either be the so-called benign tumours, or they could be malignant. The treatment required for brain tumours has an impact on both a sufferer's physical and cognitive functioning.



"Brain tumours can affect a person's memory and their emotional behavior," says Ms Hall. "They attack the core of a person and sufferers can become very different people."

Jill Hall is patron of the Hunter Branch of the Australian Brain Tumour Network. She says while motions such as hers don't attract media attention, they can bring change. "Once you've got awareness," she says, "these things take on a life of their own. This motion also helps pressure the people who make decisions about research grants to increase the funding for brain tumour research."

Brendan O'Connor, the Member for Burke (Vic), has had no personal experience of brain tumours, but he says he took the

opportunity to speak on Jill Hall's motion after being contacted by Ms Hall and by a family with a loved one with a brain tumour.

Once he was on the list of speakers for the motion, community groups which focused on brain tumours sent Mr O'Connor reading material. The reading clearly had an impact, which no doubt was part of Ms Hall's intention.

In the House, Mr O'Connor spoke about the physical and emotional strain that brain tumour sufferers and their families endure. He says we should be doing more to ensure care and support is provided in a holistic manner, especially following an operation.

"When you discuss an illness in this way in the parliament and show an understanding of the associated problems for those affected, it gives comfort to those people," says Mr O'Connor. "After the speech, family members of sufferers contacted me to thank me for my support for the motion."

Mr O'Connor agrees that talking about brain tumours in the House could have a profound impact on the issue.

"If you get a handful of members across the political divide supporting a particular view on an issue such as this," he says, "when party committees come to discuss the issue in the context of budget expenditure, you've already got the support of a significant number of members of

parliament. In effect, you've created a very effective lobby group to operate on your behalf."

The Member for Eden-Monaro (NSW), Gary Nairn, also considers himself an advocate for people with brain tumours, and their carers.

Mr Nairn says his awareness of brain tumours was raised when a married couple from the NSW south coast contacted his office after the husband was diagnosed with a brain tumour. "It made me wonder how many other people in my electorate might be similarly affected," he says.

"When the motion came before the parliament, I thought it was something I should be more

more likely it is that others will take notice of them. It's then that you get action. The old squeaky wheel syndrome comes into effect. There are reverberations right down the line when a matter such as this is raised in a motion in the parliament."

Brendan O'Connor says, having spoken on the brain tumour motion, he too feels an attachment to the issue. "When there's an issue such as brain tumours discussed in the House and there's no conflict surrounding it, the media don't usually give it much coverage," he says. "However, coverage is not necessary to get decisions.

"The speeches supporting the motion inform members of parties who are either in

"We can lose our fingers or even an arm or a leg and still function, even flourish in this life. But the brain is central to our humanity and that's why I think there's something taboo when it comes to talking about these tumours."

Mr Johnson says that speaking to such motions in the House is an opportunity for members to learn about issues in a very direct way. "I've read about it and thought about it and that's made me well informed should the matter ever come up in a committee or in the party room."

Another government member to support the motion, the Member for Moore (WA), Dr Mal Washer, was a medical doctor for



"It's not the sort of affliction that's commonly spoken about. It's somehow too private, too personal to bring out publicly."

26 years and in that time treated children with brain tumours.

"Although the incidence of brain tumours increases with age and is more common in the elderly, brain tumours are the most common solid tumour of childhood," Dr Washer told the House.

He says a discussion in the House on an issue such as this helps the people who have a tumour, as well as their family and friends. "It means they don't feel so alone," says Dr Washer.

"It also raises political and medical awareness of the problem. You've put it on the public record, interest groups can then put an account of the parliamentary motion into their publications, and when constituents come into the electorate office of their local member to discuss the issue, the politician can look up *Hansard* to see what was said in support of the motion.

"Some of the most important issues that come up in the parliament aren't controversial, they don't get the publicity and that's sad," says Dr Washer. "But it's an important part of our job to add to the knowledge and the complexity of the parliament by talking about different issues such as this." ■

The House of Representatives debate on brain tumours is available at www.aph.gov.au/hansard for 31 May 2004.

aware of so I went off and did some research and acquainted myself fully with the issue. I then decided I'd like to speak on it.

"Having spoken to a motion like that means you're in a better position to help," says Mr Nairn. "It may even mean you raise the issue in the party room. Each year in the lead-up to the budget there are various policy discussions in the party room where members stand up and push a particular issue that they've spoken about in the parliament.

"The fact that several of your colleagues have learnt about an issue by participating in a motion means that they too may become advocates. The more people who have information and take a position, the

government, or who could form government, and a lot of things happen in this place without the media making any comment upon them."

Another government member to support the motion, the Member for Ryan (Qld), Michael Johnson, has a neurosurgeon brother who helped his understanding of brain tumours.

"While anyone can get a brain tumour," says Mr Johnson, "it's not the sort of affliction that's commonly spoken about. It's somehow too private, too personal to bring out publicly. Maybe it's because it's a disease that attacks the brain and gets sufferers at the very core of their being.