

Mother of disabled boy, 16, who died after 71-day health battle in hospital reveals the shocking words doctors wrote on his death certificate

- Rachel Browne said doctors wrote Down syndrome as a cause of her son's death
- Her son Finlay died in 2016 after a 71-day fight in hospital including 12 surgeries
- Finlay was hospitalised with severe abdominal obstruction in 2016
- He died after 12 surgeries, and doctors put his condition on his death certificate
- Ms Browne wants policy changed so disability can't be a default cause of death

By AUSTRALIAN ASSOCIATED PRESS AND JACKSON BARRON FOR DAILY MAIL AUSTRALIA

PUBLISHED: 16:54 AEDT, 19 February 2020 | UPDATED: 16:54 AEDT, 19 February 2020

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The mother of a disabled boy has revealed the shocking words that doctors wrote on her son's death certificate.

Rachel Browne told the the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in Sydney that Down syndrome was listed as a cause of death on her son Finlay's death certificate.

The 16-year-old from Bathurst in New South Wales died following an agonizing 71-day fight in hospital in 2016 which included 12 abdominal surgeries and 65 days spent in the paediatric intensive care unit.

Finlay lived with autism and Down syndrome and fell rapidly ill in September 2016, suffering terrible pain, vomiting and had blood in his faeces and was rushed to Bathurst Hospital.

As Finlay left the house for what would be the last time, his mother and father were on either side of him.

'He put an arm around each of us and he looked up and said, I love you mum, I love you dad,' Ms Browne told the hearing.

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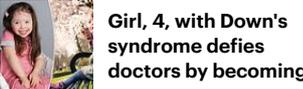
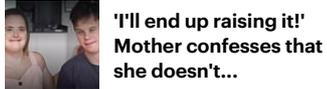
Rachel Browne (pictured) told the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in Sydney that doctors wrote 'trisomy 21,' or Down syndrome as the cause of her son Finlay's death

Finlay collapsed on arrival at the hospital, with a CT scan revealing he had significant abdominal obstruction which would require surgical intervention.

Later that night, Finlay was taken into theatre and the next morning was flown to the Children's Hospital at Westmead where he underwent further surgery.

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Following his 12 operations, the majority of Finlay's small bowel was removed, and the family was told he would never eat or drink again.

As a result of his injuries, Finlay's liver and kidneys were shutting down.

'He kept saying, Mum, I want to go home ... I wanted to get him home but it became evident that if he did recover he would have no quality of life,' Ms Browne said.

Mother reveals words doctors said on her son's death certificate

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'My biggest regret'

After a final surgery, the decision was made to withdraw treatment, and he died in December 2016 with his family around him.

On Finlay's death certificate, which was shown to the commission, 'trisomy 21,' or Down syndrome, is listed among the causes of death.

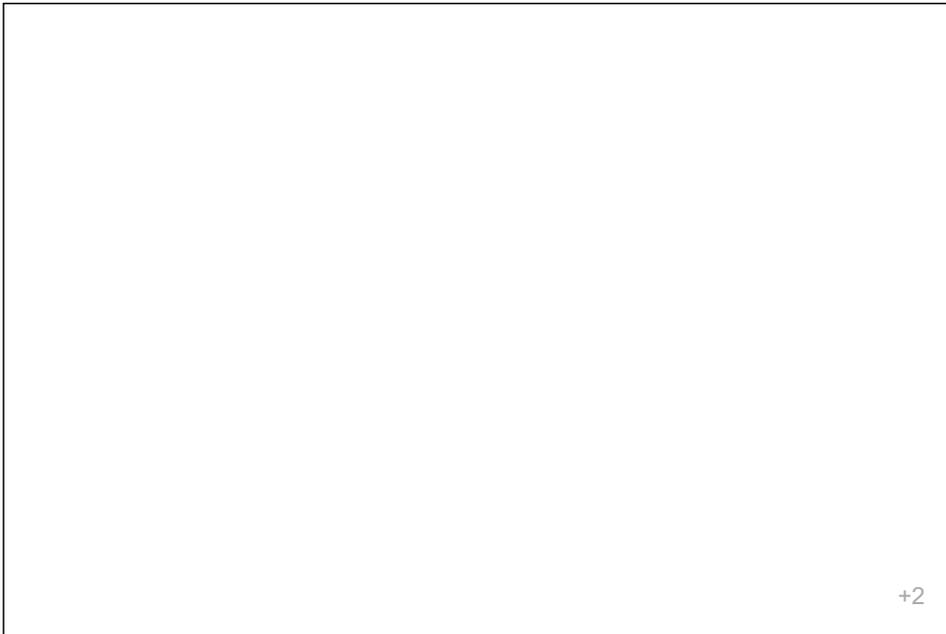
'(This) indicates that one of the causes of Finlay's death is in fact his Down syndrome,' Ms Browne said.

Ms Browne would like to see policy changed to ensure it is not ordinary course to identify a person with intellectual disability, and their disability, on a death certificate if it was not part of the cause of the person's death.

She had received questionable comments from medical professionals throughout Finlay's life, including from a doctor in hospital the day he was born.

'The doctor said that he felt there was something wrong with Finlay and I had commented that I knew, I'd felt that he had Down syndrome, he said to me that it was okay because I was young and I could have more children,' Ms Browne said.

Six months after Finlay's death, Ms Browne addressed Bathurst Hospital staff.



Ms Browne approached Bathurst Hospital (pictured) staff after Finlay's death and lodged complaints with them and the NSW Healthcare Complaints Commission

'I wanted clinicians to know what the ramifications of their inaction were to not only Fin, but to his family, to his friends,' she said.

'That this young man had a life, a life well lived - he was just not a person with a disability, he was a human being.'

Ms Browne has also lodged complaints with Bathurst Hospital and the NSW Healthcare Complaints Commission.

The commission indicated the matter should not go to formal investigation but have suggested engaging in a conciliation process.

Ms Browne has written to the NSW Health Minister and is currently awaiting a decision on whether a coronial inquest will be held into Finlay's death.

The commission continues.

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Down's syndrome is a genetic condition that typically causes some degree of learning disability and certain physical characteristics.

Symptoms include:

- Floppiness at birth
- Eyes that slant down and out
- A small mouth
- A flat back of head

Screening tests can uncover Down's syndrome during pregnancy but are not completely accurate.

It is caused by an extra chromosome in a baby's cell due to a genetic change in the sperm or egg.

The risk increases according to the age of the mother.

A 20-year-old woman has around a one in 1,500 chance of having a baby with Down's syndrome.

Women in their 40s have a one in 100 chance.

There is no evidence women can reduce their risk.

Down's syndrome does not have a cure.

Treatment focuses on supporting the patient's development.

People with Down's syndrome are more at risk of health complications such as heart disorders, hearing problems, thyroid issues and recurrent infections.

Source: *NHS Choices*



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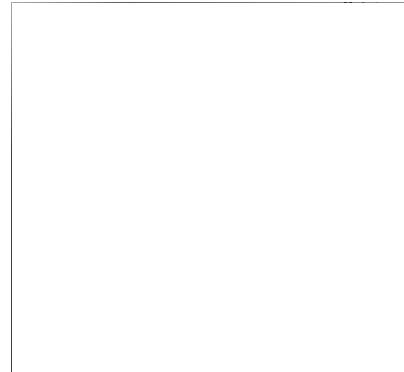
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