



Speech by

**Hon. Annastacia Palaszczuk**

**MEMBER FOR INALA**

Hansard Wednesday, 3 June 2009

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## **HUNTINGTON'S DISEASE; BUCKLEY, MS E**

**Hon. A PALASZCZUK** (Inala—ALP) (Minister for Disability Services and Multicultural Affairs) (9.39 pm): As local members, often we meet people in our community who leave a lasting impact upon us. Over the past year I have been working very closely with my constituents Colleen Woodcock and her daughter Ellen Buckley of Carole Park. Initially they approached me because Colleen wanted some assistance to modify her home so that Ellen, who had Huntington's disease, could remain living with her.

The first Colleen learned about Huntington's disease was when a doctor arrived on her doorstep from the Herston Medical Research Centre. It was there that she was informed that her two children, Ellen and her brother Andrew, were at risk of Huntington's disease because their father had the disease, which meant that there was a 50 per cent chance that they would both contract the disease between 30 and 45 years of age. Andrew, the younger of the two, was diagnosed in 2006 and passed away in January this year. Ellen was diagnosed with Huntington's disease approximately four years ago. Within 12 months she was wheelchair bound and two weeks ago Ellen passed away, five months after her brother.

I have chosen to share this story with the House because, firstly, it raises awareness about Huntington's disease, which was the wish of both Ellen and her mother. Huntington's disease is a genetic brain disorder that progressively affects the body, mind and emotions, inevitably leading to death. In Australia 1,200 people have Huntington's disease and another 6,000 are at risk. From when the symptoms first appear, day-to-day tasks begin to become increasingly more difficult. After time, involuntary jerking movements of the limbs, face and torso make walking impossible without an aid. Before long it is impossible to walk and it is difficult to chew and swallow. A person's brain behaviour, personality and reasoning are affected, making communication more difficult. The memory begins to fail, as does the capacity to learn and to think, and the emotional state becomes more erratic and unpredictable. Family members and carers can only try to help sufferers to maintain their lifestyle as the symptoms progressively take hold. The disease literally, bit by bit, takes away the person's life and there is no known cure.

In the face of this disease Ellen showed immeasurable courage. 'Don't live the disease, live life' was her and her mum's favourite saying. She continued living her life for as long as possible, socialising, painting and doing the things she loved most. I thank former minister Lindy Nelson-Carr, who provided \$34,000 for renovations to the bathroom and the widening of the deck of the family home, which enabled Ellen to live her final months at home. Her mum, Colleen, was there for her daughter every step of the way. Ellen was loved by her stepfather, Greg, her carers Jenny Pszezonska, Sharon Hughes and Tina Pederson, who often went beyond the call of duty, as well as her best friend Maree, who provided her with strong support. My life is richer for having known Ellen Buckley. God bless you.