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More than 6 years since she was diagnosed with a rare, life-threatening condition, Darwin first grader Aviana (Avi) McElwee is thriving – and so is Avi's mum, Bethan.

Thanks to supports, funded through the NDIS, Avi has increased her mobility and independence and mum Bethan has returned to work.

'When Avi was diagnosed, I basically dedicated my whole life just to caring for her, and I wouldn't change that,' Bethan says.

'But it was exhausting and all consuming, and I lost my whole sense of identity, and it was just really hard. After not working for 3 years, I lost a lot of confidence.'

Avi has spinal muscular atrophy Type 1 (SMA1), a neurodegenerative disease that destroys motor nerve cells. It affects the muscles Avi uses to breathe, eat, and move.

Doctors didn't expect Avi to live to her first birthday. But today Avi is doing well at school, enjoys spending time with friends, and loves being active.

She dances, learns piano, swims, and plays wheelchair basketball and tennis.

'Avi is so much happier because she's so much more independent,' Avi's Mum Bethan says.

'All the home modifications and supports have been so important for that. She can even dress and shower herself now too, which is amazing,'

A former professional dancer, Bethan says Avi's NDIS-funded support workers helped build Avi's independence and allowed Bethan to start working again, teaching dance.

'NDIS support workers were a game changer for us,' Bethan says. 'They allowed Avi to trust people other than myself and Jonny with her care and to have much more autonomy. Without that support I don't know when I would have been able to work again. Things would be very different.'

Bethan now runs her own ballet school and teaches dance and drama in primary schools.

'It's so important for me to be working again,' Bethan says 'I'm really proud I've managed to get back to myself, to being me, and doing things I enjoy beyond being a carer.

'I'm a carer, yes, but I'm also a person with a career as well. And I think it's OK to admit that that (working) makes you happy.'

Bethan is a proud role model for Avi and younger brother Hugo.

‘Working is not just good for me, it’s good for my kids,’ Bethan says. ‘If you ask Avi what she wants to do when she grows up now, she says “I want to be a ballet teacher”.

‘Avi said to me “Mum, you love your job. When you’re teaching ballet, you’re so happy, you’re so funny, and I think I could do that in my chair.

I could just tell them what to do and do the arms, and I can still do it.” It just fills my heart with joy. She’s such an amazing kid.’

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