

Roz makes every moment count with family, friends, and doing the work she loves

10/05/2024, 08:55

Posted on:

4 March 2024

Adelaide dance theatre creative producer Roz Hervey is making the most of every moment.

About 18 months ago, tests showed Roz had motor neurone disease (MND) – and her world came tumbling down.

‘The diagnosis was a shock and my partner and I spent 2 or 3 weeks in total fight or flight mode just dealing with that and having to tell our friends and family and my beautiful kids,’ Roz, 58, said.

‘But then I quite quickly decided, knowing I had a short period left, that I could sit in a corner and cry, or I could just seize the day. And that’s what I decided to do.

‘So, my work life balance has shifted – I now work hard and play hard. I’m spending a lot more time with family and friends, and I focus on every day doing one beautiful thing.

‘That might be lying in the park and looking at the stars or it could be going to watch a sunset, hanging out with my friends. I do something special every day because I know that every day – every moment - is a gift.’

MND is a rare neurological condition with no cure that causes nerve cells known as neurons to die.

For Roz, it means it’s getting harder to move, walk, and make it through the day. In the future, she may lose the ability to eat, speak and breathe on her own.

But for now, Roz is focussed on living her best life.

She says joining the NDIS has made all the difference to staying as active and as positive as she can.

‘Oh, the NDIS has been amazing, that support has just been next level in terms of helping me through this’, Roz said. ‘I don’t think I would still be working if it weren’t for that support.’

Roz joined the Scheme and began receiving supports within a few months of her MND diagnosis in late 2022. She has physiotherapy, neuro physiotherapy, podiatry, and psychology support.

‘It’s having access to the most wonderful therapists, people who really understand the condition, that has been so important for me,’ Roz said.

‘They can watch over me ...and I can work on things physically to keep doing as much as I can for as long as I can.’

Roz also has funding for important home modifications.

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Roz also has funding for important home modifications.

‘Our bedroom was upstairs, so we’ve converted a backyard studio and been able to put in an accessible bathroom. It means I can stay in my home for as long as I possibly can. And I so appreciate that,’ she said.

Roz’s working and creative life has always revolved around ‘making and moving’.

She danced internationally early in her career and later moved into directing and producing.

Now creative producer for award-winning inclusive dance theatre company Restless Dance, Roz has helped guide the company to global success alongside artistic director Michelle Ryan.

Roz says working with Michelle, who has Multiple Sclerosis, and several dancers who have Down syndrome, has helped her to adjust to her own disability.

‘Michelle and everyone at Restless have been amazing, and so supportive. And the benefit of working there was I could really appreciate how wonderful the NDIS could be,’ Roz said.

‘So, I quickly put together my goals and my requests for funding and was able to have the supports I needed in place – and I’m so grateful for that.’

Looking to her future, Roz’s focus now is “friends, family, love and making art”.

‘I have in some ways been lucky because not everybody gets the opportunity to have that finite time, to know the end date,’ Roz said.

‘And so, I’m privileged to go, wow, each day is important to spend time with your friends and family and tell the people you love that they’re really important to you, to really seize the day.’

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