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National Disability Insurance Scheme (NDIS) participant Andi has always worked hard and never liked the word “can’t”.

From Victoria’s Bellarine Peninsula, Andi, 55, has Bethlem myopathy, a form of muscular dystrophy, weaking every muscle in the body. ‘My father had it and out of 6 of us kids, 5 of us have it,’ Andi said. ‘It just makes doing everything much harder.’

Andi trained as occupational therapist and worked in forensic and child mental health. Later she led a commercial unit at a Victorian university. As her mobility declined, she had to give up work.

‘It was hard going from working 7 days a week to nothing,’ she said.

In 2010, Andi moved from Melbourne to the Bellarine to start a new chapter. With a love of fashion and homewares, she opened a small shop close to home. She built it from scratch, employed staff and ran it for 13 years.

‘My Bethlems’ started to affect my breathing, further impacting my mobility,’ Andi said. ‘I had to make the difficult, heart-breaking decision to close the shop. I just couldn’t do it any more.’

Today, Andi is grateful for NDIS support which has given her the ability to continue to work and follow her passion. She’s enjoying a life filled with creativity, connection, and purpose.

Andi is now making resin bowls that turn into cake stands, sewing decorative bows and creating balloon garlands to mark all sorts of special occasions. She sells them online and at her local market when she can.

Andi said the NDIS has really helped to improve her life.

‘I couldn’t do what I do without NDIS support,’ she said. ‘I’m so grateful for it.’

While Andi has support to help her manage daily household tasks and to safely access her community, it’s the smaller things most take for granted, that’s reignited her spark.

‘My support workers help me with things like getting my sewing machine out, so I can work. They lift it up onto the table, help me gathering the materials I need. It makes setting up much easier for me,’ she said.

‘I can’t always move things around or carry equipment. My support makes it possible to create the beautiful items I sell online and locally.’

Andi also has support for an hour of an evening.

‘I have a support worker who comes in to help me make dinner,’ she said. ‘They also help me set up everything I need to make breakfast the following day. I don’t have any morning support, so it makes me feel like I still get to enjoy a little bit of independence.’

Andi also works regularly with an exercise physiologist. Every activity is adapted to what her body can do.
‘Strength work is key to maintaining my mobility,’ she said. ‘We always focus on what helps me function. Even 5 minutes of the right exercise makes a difference.’

Every 6 weeks, Andi shares her lived experience via the National Disability Insurance Agency’s Participant Engagement Capability Panel, where she meets with 15 other panel members to help improve staff and participant resources.

‘I enjoy contributing to these meetings,’ she said. ‘As an OT, I can draw on my knowledge from having worked in the field and my own lived experience.’

Andi’s day and even weeks can be unpredictable, but with the right supports she continues to create, connect and contribute.

‘My supports help me live my life,’ she said. ‘I love creating. I just want to make things that help people feel happy.’

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