Posted on:
10 December 2021

Burnie NDIS participant, Louise Morse is a fighter. She’s just completed 100 Burnie Parkrun’s and she’s not letting an unknown rare neurological disease stop her in her tracks. She’s soldiering on, driven to still get the best out of life.

Louise, 37, has a rare disease, which in the last four years has seen her speech and mobility rapidly decline to the point she now has limited speech and uses a wheelchair.

Parents, Sheree and Paul, said Louise’s disease has stunned everyone and left her Royal Melbourne Hospital specialist team puzzled to what it is, but the closest disease with similar symptoms is Kufs – a neuronal condition, affecting the nervous system.

With no diagnosis, and devastated witnessing Louise’s decline, the couple said their middle daughter is not a quitter, nor are they, and with support from the NDIS they can afford to continue to make each day in Louise’s life the best it can be.

“We are so proud of Louise. She got 100 Burnie Parkrun’s, or shuffles, up and then two more Parkrun’s later she was in a wheelchair, but we got her there,” Paul said proudly.

“Louise would do one lap of the circuit, which was 2.5 k, and Sheree would do it with her, but as her mobility declined, we started to slowly cut the distance back.

“Now she’s still participating in her wheelchair and she just thinks she’s it on a stick,” Paul said with a laugh.

“She’s full of smiles, everyone congratulates her, and now she’s got all these men pushing her around. We think it’s a bit of a guy magnet,” he added with a laugh.

All jokes aside, it’s been a daunting four years for Louise, Sheree and Paul, with COVID preventing them from travelling to Melbourne for Louise to undergo more tests and treatment, but they said they’ve been able to stay connected via telehealth.

“Now boarders are reopening we’re hopeful we can continue to work with Louise’s specialist team, but for now we are treating her as palliative, trying to keep her as comfortable and content as possible,” Sheree said.

While the couple said they would have moved heaven and earth to provide the right supports and equipment for Louise, they both admitted financially it would have tough without support from the NDIS.

“Louise’s Local Area Coordinator, Leanne, has been absolutely wonderful,” Paul said.

“One weekend Louise’s condition just changed overnight. She couldn’t walk anymore and she went from being tentatively mobile to using a wheelchair.

“Zoe our amazing Support Coordinator contacted Leanne. Leanne got things moving, and within 48 hours Louise’s new plan was all in place, and all the equipment she needed started arriving.” Sheree said Leanne was so supportive and knowledgeable.

“We’re very grateful to Leanne,” she said. “In our review, she went through everything – speech, occupational therapy, wheelchair, hospital bed and even support workers to ensure Louise stayed connected to her community.”

“Her plan also included Supported Independent Living with Multicap, which Louise is living in now,” Paul added.

“It’s only 10 minutes around the corner from us. It’s brilliant. Instead of being her carers we can relinquish that role and concentrate more on being her parents.”

“We’re big fans of the NDIS. It’s really helped to support Louise, and us, through this incredibly difficult journey,” he said.

Related Stories and videos

Peace of mind provides a positive path to Paris and beyond for wheelchair rugby champion

NDIS support helps spur Chris on to Post-Tokyo challenge

2 November 2021
With NDIS supports, Louise has a new sense of identity and purpose

Louise’s mosaic art delivers powerful message about mental health disability

8 December 2021
Kerri wants to share her story about psychosocial illness to help others

Kerri’s mental health improves despite Stage 4 lockdown

27 October 2020
More stories and videos