



Jen shows off some moves during a dance session



**You are AMAZING**

By Carole Richardson

# 'We want to teach the world to dance'

When recently asked if she was the mum of the 'Queen of DanceSyndrome', Sue Blackwell had to smile to herself. Of all the roles that she could have imagined herself fulfilling at the age of 63, this definitely wasn't one of them. Just as she'd never dreamed that at the age of 26 she'd be the naive mother of a daughter with Down's syndrome...

"It was a total and absolute shock," Sue admits when recalling the moment she and husband Malcolm (now 63) learned that their first precious baby, Jen, had arrived in the world with an extra chromosome that would restrict her ability to learn.

"It was suggested to us within five hours of her birth and we had no inkling prior to that. We were totally unprepared and we knew absolutely nothing about Down's syndrome or learning disabilities. We had no starting point and not one shred of knowledge about what life would hold for us."

What they did quickly learn was that life's full of surprises. They embarked on a journey that has led to Jen (now 37) becoming the founder (or 'queen' as she's known) of the multi award-winning charity DanceSyndrome

Mum Sue, left, says she has grown into a much more assertive person because of Jen, who has Down's syndrome

which encourages people of all ages and abilities to dance and train as leaders.

Along the way, Jen's been named as one of the most influential people with a disability in the UK and recognised as an inspirational volunteer by Prime Minister Theresa May who honoured her with a Points of Light award last October.

"It didn't happen overnight though," Sue is quick to point out. "It's been one step at a time."

And it's been a path that has hit "many brick walls and many barriers" right from the start.

Fortunately, Sue, who has a music degree, and Malcolm, who has an engineering degree, knew how to research and their immediate response to their new baby's issues was to head for the library to learn as much about Down's syndrome as they could.

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Even when their findings were scoffed at by a medical professional, they pressed ahead with a pioneering regime of extensive daily exercises that they hoped would help to neurologically 'pattern' and develop Jen's brain.

"My whole philosophy in life has been about love and if you love someone you have to support them," adds Sue, who, although she does not actively practice the faith today, was brought up with fundamental Quaker values.

From the time she could toddle, it was evident that Jen's own love was dancing which she did at every opportunity. Dance classes followed - as much initially for fitness and health benefits, as people with Down's are so prone to obesity and weak muscles.

"Jen sometimes struggled to keep up, but she loved it," recalls Sue.

Sharing her passion: Jen, the 'Queen of DanceSyndrome', demonstrates her skills



Jen's passion just continued to grow. "Dance is Jen's relaxation; her coping mechanism; her safety valve. It always has been," she adds.

As Jen says herself: "If I feel stressed or anxious, I just dance. When I dance I feel like I am flying."

When she left her mainstream school at 18, she had one burning ambition - to become a community dance worker. "We travelled the length and breadth of the country for ten years looking for dance training but there were no opportunities that suited Jen and that wanted Jen," Sue says.

There was only one solution - to create one that did suit her. With both her parents' support and initial funding from UnLtd, The Foundation for Social Entrepreneurs, in 2009 Jen set up DanceSyndrome. The following year she found 14 dancers to work with, half of whom had learning disabilities.

Today, DanceSyndrome is a registered charity that provides training courses for people with and without learning disabilities to become dance leaders. They can then help deliver the charity's workshops and performances across north-west England and beyond.

Jen, lives in her own home in Chorley, Lancashire, with round the clock support, where she dances six days a week in her own space/ dining room. She is also lead flautist in a group sponsored by the Royal Northern College of Music for people with disabilities after picking the instrument up at 11. It also helped with her rehabilitation from

pneumonia at 13 which doctors had feared would kill her.

Sue meanwhile can now take a back seat while Jen and the DanceSyndrome team get on with the day job, which includes spreading the charity's work further afield.

"We want to teach the world to dance," adds Jen confidently.

So is Sue proud of what Jen's achieved with her parents' unstinting love and support?

"I am proud of her but I don't really look at it like that. Jen's also made me the person I am. It really is a two-way street.

"I was really shy when she was born. She has made me assertive because she had no ability to be assertive. Within six months of her birth I was putting up a photo display in the village hall to explain to people what Down's syndrome is.

"If somebody closes a door in your face you find another road. It's about not being prepared to give up and not taking no for an answer. It's about Jen's right to have a life of her choosing.

"My wish for both my children is exactly the same." (Sue and Malcolm have a younger son Anthony, 35).

"I want them both to be as happy and healthy as they can be. It is just the way they achieve it that is different. Everybody has their own talents and attributes. You just have to listen..."

■ If you would like to find out more about the incredible work of DanceSyndrome, visit [www.dancesyndrome.co.uk](http://www.dancesyndrome.co.uk)



Tiny dancer: Jen performing aged seven