GIVING GRACE A VOICE!

LITTLE GRACE FOUND THE POWER OF SPEECH THANKS TO A VERY SPECIAL DEVICE

The bubbly 4-year-old is happier than ever.

Fran teaching Grace how to use Frasil.

Fran has given Grace the power of speech.

When Emma Maly gave birth to a beautiful baby girl named Grace in December 2015, she thought her newborn was perfect.

Everyone was besotted, especially her two big brothers, William and Oliver.

The first few months of little Grace's life were a dream – but at around the 4-and-a-half month mark, something seemed very wrong.

"Grace developed a virus and from that time she started to go floppy," Emma, from Sydney, NSW, exclusively tells New Idea.

"We had no idea what a journey we were about to endure. At around 6 months, Grace was unable to even sit up and she was clearly behind in all her important milestones."

Emma and her husband, Adam, spent the next agonising few years in and out of hospital before a neurologist suggested in 2018 they do some genetic testing.

It wasn't until Grace was 3 years old that she was finally diagnosed with a genetic movement disorder called ADCY5-related dyskinesia. Fewer than one in a million people live with this condition.

It means Grace's movements and speech are severely limited, despite having an otherwise full cognitive ability. She faces significant daily struggles as she can't sit, stand or walk independently and needs full assistance with personal care with eating.

Grace's parents are so proud of their little girl.

"Her intelligence is not affected, it's purely her body," Emma explains. "So she's a very clever, bright and social little girl."

The most frustrating part of Grace's disorder for her loving parents was watching their little girl struggle to communicate even the simplest desires. Most 4-year-old girls are starting to pick their own pretty dresses and what cartoon they'd like to watch.

But for Grace, the power of speech we all take for granted seemed to be a faraway dream.

That is, until now.

A woman named Fran Killoway has changed the Maly family's lives in the most incredible way. With the invention of an AI app named Frasil, Grace has found the voice her parents thought was lost forever.

The technology works as a sort of 'motherboard' which allows Grace to communicate her thoughts, needs and desires to her family – it has options such as, 'I am cold', 'I am hungry' and can even help Grace to choose what she wants to watch on television.

"Grace is able to express her wishes and needs to us with sentences she constructs in 'my voice', for example, with just one click of a button she can say, 'I love you, Mummy,'" Emma says. "This is absolutely phenomenal for us! Grace will be able to have more choice in what she wants to eat, wear, and activities she wants to do. It means she can be her own person, can say what she wants to say and how she feels.

"IT'S SO WONDERFUL TO SEE THE DELIGHT ON HER FACE"

"If she is feeling cranky or feeling just ordinary, the app will ask why. It uses artificial intelligence to customise to exactly her personality, too."

Having physical autonomy has made a world of difference for little Grace. Frasil founder Fran says if Stephen Hawking had this device, his own quality of life would have improved enormously.

"Why wouldn't I help someone like Emma and little Grace? Everybody deserves this," Fran tells New Idea.

"I get so upset when I see how much other technologies like this cost. It can be $20,000 or $30,000 and some families just can't afford it. But Frasil basically costs a $1 per day."

Fran is working hard with her developers on the app to give Grace and other people with speech disabilities a real, unique voice that matches their personality.

"We have sophisticated algorithms that will make her voice sound almost real. "Within a few months, we think Grace will be able to hear the sound of her own voice," Fran adds.

With the help of Frasil and therapy, Grace is able to attend a mainstream preschool and is working hard on developing her natural speech skills.

Emma says with a smile: "As a parent, it's just so wonderful to watch Grace and see the delight on her face when she's able to say exactly what she wants, quickly and easily.

"It makes me emotional; it's so amazing. Frasil allows people with disabilities to have a voice and that is so empowering."

By April Glover