



MEDIA RELEASE

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Senses comes to the rescue of a Landsdale family

Caring for a child with a disability can be difficult at the best of times, but when that child is unable to walk, talk or even feed themselves it can put even more strain on a family.

When Lydia Johnson (8), of Landsdale, was born with lissencephaly, or 'smooth brain' as it is commonly known, life changed forever for her parents Jan and Gary and their five other daughters.

The side effects of Lydia's condition are total cerebral palsy, seizures and a complete absence of apparent visual behaviour.

This means Lydia requires 24-hour care. She has trouble maintaining her airways and needs constant suction to remove excess saliva. She also has no swallowing or sucking reflex so is fed via a tube directly into her stomach.

For the first two years of her life Lydia was in and out of hospital to address a number of related health issues, including a highly distressing vomiting disorder.

"On many occasions we thought we would lose Lydia," remembers Jan. "It was a very stressful time."

Just before Lydia's second birthday, Senses Foundation came to the family's rescue offering in-home therapy and respite through its Early Childhood Intervention (ECI) program.

Communication was the first priority and the family quickly learned to think outside the square when it came to interacting with Lydia.

"Senses has taught us that communication is more than just speaking," says Jan.

"We've learned the value of touch and getting up close. Lydia seems to be very peaceful when she is held or cuddled. These little things have become very special to us."

Regular physiotherapy has helped maintain Lydia's range of movement while occupational therapy has assisted with special equipment to make Lydia more comfortable.

Initially bed-ridden, Lydia now has a comfortable new wheelchair which has been modified so she can spend several hours a day sitting up.

Because getting out and about with Lydia is difficult, Senses has also provided respite for the family.

Initially this was for only a few hours a week, however Intensive Family Support funding from the Disability Services Commission has made it possible for carer Leah Windsor to spend three days a week with Lydia.

“Having Leah around has been fantastic,” says Jan. “It has allowed me to return to a more ‘normal’ life, to get out and do simple things like shopping and to spend time with my other children, especially our 10-year-old Kenya who has missed out on so much.

“Just recently we had our first weekend away together in five years, which was marvellous. It gave us time to just enjoy being together and to re-connect as a family.”

Senses has also recently started providing staff support so Jan can take Lydia to hydrotherapy sessions at the new Balga Aquatic Centre.

These sessions have opened up a whole new world for Lydia, who appears to thrive on the relaxing effects of the water.

“She just loves it,” says Jan. “If it wasn’t for Senses there’d be no way I could take her on my own, so I am very grateful.”

Senses Foundation was formed in 2001 when the Royal WA Institute for the Blind - one of WA’s oldest charities - amalgamated with the WA Deafblind Association.

It is now WA’s primary advocate and service provider for people who are deafblind or blind with additional disabilities, providing highly specialised programs and services to improve communication, socialisation, mobility and quality of life for both adults and children.

The ECI program provides therapy services to preschool children who have vision impairment with another significant disability, or who are deafblind, in their own home.

More information: Leanne Pitcher, Media Liaison Officer, 0408 923 249.