

in touch

with Senses Australia

Issue 6 | Summer 2015

Andy's dreaming of a good night's sleep

Two and a half year old Andy, is a typical toddler – cheeky and full of energy. He enjoys reading books, drawing, painting, therapeutic horse riding and playing toddler soccer every Saturday morning.

“Sleep is a big thing in our home,” says Andy’s mother Wendy. “Andy has trouble falling asleep and staying asleep.”

Andy was born with CHARGE syndrome, a rare and complex condition that affects various parts of the body and typically involves multiple sensory deficits (such as hearing and vision) plus additional medical and physical difficulties, which generally cause complications with balance, communication and developmental delay. Andy was born profoundly deaf with no sense of balance, due to inner ear anomalies and additional difficulties including feeding and sensory integration issues.

Andy, will soon take part in a trial our therapists are conducting to help Andy sleep well.

“Children and adults with disability often struggle with sleep, as it is difficult to regulate or maintain body temperature and poor postural control can also have an impact,” explains Rebecca Lamhut, Senses Australia’s Coordinator of Children Services.

“It is believed that with the right equipment, including temperature regulating and sleep positioning equipment, our clients sleep could benefit. And, we all know how important sleep is,” says Rebecca.

“We hope by obtaining temperature regulating and sleep positing equipment it will help Andy to fall asleep easier and stay asleep, by dealing with thermoregulation and sensory issues. This aims to get him into a more consistent bedtime routine with more restful nights and deeper sleep so that he can be fully refreshed. It will also mean an improved quality of sleep for us all,” says Wendy.

“We are grateful for all the support of Andy’s therapy team at Senses Australia, which has assisted in his development over the past couple of years and we’ve already seen the benefits of what a piece of equipment can do. Andy already has a fully adjustable supportive chair that we use for feeding and playing.

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Debbie's column

You may recall in the Spring 2015 edition of *In Touch with Senses Australia*, I mentioned our team are busy continuing all services and working on a number of new projects to help support our clients and their families.

We have a number of new projects underway, which I am pleased to share with you. It's been an eventful few months at Senses Australia and we are set for an exciting time ahead.

Senses Australia is set to help end the isolation for many Australians by conducting an Australia wide project – 'Ending the Isolation', which will assist those working in the aged care sector to identify when a person has a combination of a vision and hearing impairment. This will help support older Australians who receive care and give them the support they need (to find out more, please see page 3).

One of our Deafblind Consultants and a Senior Social Worker, is conducting a research study to help better understand the experiences and impacts of having a parent with dual sensory loss (see page 4 if you or you know someone who would like to take part).

We are also delighted that a new sensory therapy room is being developed for us through a Brookfield Multiplex Community Project – this will be a wonderful new edition to a suite of services we offer our young clients and their families (page 6

features the design of the new sensory therapy room).

Finally, we are now offering people with vision impairment an Orientation and Mobility (O&M) Service. Senses Australia has always provided this service to people who are deafblind, but now offers it to people with a vision impairment (to find out more, please see page 7).

With all this happening, I want to hear what you think about our services. It is so important that I receive your feedback so I can ensure we deliver high quality services that meet your needs and those of your loved ones. Please tell us what you think of our services whether it be a complaint, compliment or suggestion by visiting www.senses.org.au/contact-us/have-your-say-on-our-services-and-governance.

On behalf of our Board and all of our staff at Senses Australia, I would like to take this opportunity to wish you and your loved ones a happy Christmas and festive season.

Best wishes

A handwritten signature in black ink that reads "Debbie Karasinski".

Debbie Karasinski, CEO

Getting to know you

There are many different ways to communicate with others. People who cannot rely on speech to communicate, interact with others using a speech device, signing systems, gestures, pictures, body language and facial expressions. They may also still be developing their communication skills.

At Senses Australia we also use a 'getting to know you' or 'about me' document for people who are unable to rely on speech to communicate. This helps us to record in written and photographic form, a person's likes, aversions, preferred activities, ways of communicating and other important information about the people they interact with and the places where they like to spend time. These are also known as communication passports or individual communication guides.

Using Apps on smart phones and tablets is the way of the future in modernising communication passports. We can now incorporate video, audio, photographic and written information and share this vital information with other Senses Australia staff to ensure care is provided seamlessly, while meeting the needs of our clients.

Cover article continued...

He has had this chair since he was about 10 months old and it has been crucial in helping him overcome feeding issues.

"It has provided him with the comfort of full body postural support to help him learn to eat solid food safely, taking care of his body position and allowing him to focus on his mouth movements such as chewing and swallowing," says Wendy.

"Ultimately this has allowed him to stay on track with eating age appropriate food and feeding himself. It has helped him to develop the skills necessary for greater independence, such that he is now able to attend day care with minimal feeding assistance required," says Wendy.

"We would like to trial this equipment first, as it is very expensive, and if it proves

to be a success, we can support funding applications to purchase these items to help our clients and their families long term," adds Rebecca.

To find out more about our therapy services and how Senses Australia can support you and your loved ones visit www.senses.org.au

Ending the Isolation

“We are calling on aged care providers to join us as we embark on some ground breaking research,” says Matthew Wittorff, Senses Australia’s Manager Deafblind Services and the lead research for this project. “This is a unique opportunity that will add significant value by enabling aged care providers to deliver a more enhanced service, ensuring better quality of life outcomes for older Australians.

Thanks to funding from the Australian Government’s Department of Social Services, the ‘Ending the Isolation’ project will undertake a nation-wide project to determine the impact of a combined vision and hearing impairment amongst older Australians.

“Aged care providers that register their interest will receive the resources that are developed as an outcome of the project. The resources will contain valuable information and advice on how to support and care for people with combined vision and hearing impairment to enable them to lead a better life,” says Matthew.

“Senses Australia has a specialist team that supports people with deafblindness

and this project enables us to support the largest category of people who are deafblind, those who have aged related combined vision and hearing impairment.”

To find out more about Senses Australia’s ‘Ending the Isolation’ project visit www.senses.org.au/i-want-to-know-about/ending-the-isolation

Archer’s kicking goals

This past AFL season has seen five year old Archer, able to participate in a team sport for the very first time and despite having Cerebral Palsy and a vision impairment, he is kicking goals both on and off the football field.

Thanks to his mother, Lisa, his Starkick coach, Rob and his Senses Australia therapists, Aimee, Haylee and Maryke, Archer was able to join his brothers and play football this year, while achieving his goal of being able to walk independently. .

“I am so proud that my three sons all get to go out and play football - Sunday is football day in our house,” says Lisa, Archer’s mother. “Before Starkick, we thought Arch would have to sit on the sidelines and be a spectator. But thanks to Starkick, the fantastic initiative from the Coolbinia Bombers Football Club and coach Rob who is the brains behind this amazing initiative, we all get up in the morning, get dressed and make our way to the oval. Arch gets so excited.”

To enable Archer to play football, he wears an ‘Upsee’, a piece of equipment that Lisa straps around her waist that supports Archer, enabling him to stand and walk with her assistance and without having to hold onto him. Lisa’s movements help Archer to move. Archer also uses his Nimbo walking frame and Motum wheelchair for some football activities.

“Archer receives physiotherapy and occupational therapy as part of our Early Intervention Therapy Program,” says Aimee, one of Archer’s Senses Australia’s therapists. “With this support, as well as participating in extra-curricular activities such as Starkicks, this is helping Archer improve his strength, balance, coordination and physical skills.

“Archer is progressing well, he has learnt to independently transfer in and out of his walking frame and wheelchair, as well as learning how to walk up and down stairs. Archer can stand for short periods of time for play and is learning how to use his core strength for balance so he can take that next step to start walking and playing football more independently,” says Aimee.

2015 was the first season for Starkick, which is an AFL Auskick team started by the Coolbinia Bombers Junior Football Club. It caters specifically for children with disability. Archer was the inaugural team member and he was joined by 46 other children with disability who travelled from all over Perth.

“The football club has made balls with bells inside, so the children with vision impairment, can actively participate in all of

the games and activities with the rest of the group. We also have a number of volunteers who help guide children that need some assistance during activities and games,” says Rob, the Starkick coach

To find out more about Starkicks, visit www.bombersjfc.asn.au or email starkick@bombersjfc.asn.au. To find out more about Senses Australia’s therapy services visit www.senses.org.au/i-want-to-know-about/therapy



Ironman, a lifelong dream

Darren is busy preparing to accomplish a lifelong dream. In 13 months' time Darren will be ready to take part in the 2016 SunSmart IRONMAN Western Australia in Busselton.



"I have conquered a lot of challenges in my life," says 23 year old Darren, who has a vision and hearing impairment, "but one challenge I have been wanting to do for a long time is an Ironman 3.8km swim, 180km bike ride and a 42km marathon run."

Darren, who lives in Bunbury, is looking for people to help him train.

"Of course, having a vision impairment makes this a bit tricky, which is why I am seeking out some people who would be interested in helping with my training and keeping me motivated. I plan to do the Ironman in December 2016, so keeping motivated for so long can be tough on my own," says Darren.

Darren's training is in full swing, he's swimming at the public pool, riding his tandem bicycle and running and he will eventually do some beach swims. "I will swim with a partner at the beach, who will have a rope that will be attached to me while we swim together.

"I ride a tandem bike when cycling. I am always happy for people to have a go on it, if they've never been on one before and I need to get some kilometres into my legs," says Darren.

"The running, I have a lead rope which we tie on each other's wrist and it's about a metre long, which enables us to run together. Running is probably my strongest.

"I am also working out at the gym, trying to bulk up my arms a bit, especially for the swim, so a gym buddy is also welcome as well."

Although taking part in an Ironman event has been a dream of Darren's for some time, he was encouraged to take part in the event next year, with the help of Senses Australia's Deafblind Youth Leadership Program.

"Darren truly is an inspiration to us all," says Matthew Wittorff, Senses Australia's Manager, Deafblind Services, "he has set a goal as part of our Deafblind Youth Leadership Program to participate in the Ironman event next year and he's been working hard to ensure he can give it his best.

"We are proud to be able to support and encourage Darren and with the support of others helping him train, we know he's going to do well," says Matthew.

If you live in the Bunbury area and would like to help Darren train, please email Darren djs.1991@yahoo.com or to find out more about Senses Australia and the Deafblind Youth Leadership Program visit www.senses.org.au or www.deafblindinformation.org.au.

Calling for research participants



Are you over 18 years of age? Are the child of a parent with Usher syndrome or dual sensory loss? You could provide us with vital information for a research study that will build on our previous research on parenting and Usher Syndrome and help us better understand the experiences and impacts of having a parent with dual sensory loss.

"Being the child of a parent or parents living with Usher syndrome or dual sensory loss presents some unique challenges and opportunities," says Karen Wickham, a Senses Australia Deafblind Consultant and Senior Social Worker. "Through this research, we hope to identify particular themes and issues that are commonly faced by children of parents with dual sensory loss, with a view to comparing and sharing experiences and helping to raise awareness about this unique journey."

Karen, who is conducting the project and working in collaboration with Edith Cowan University's School Exercise and Health Sciences says the research will provide long term support to families, guidelines regarding how to best develop strengths within these families and advocacy for more relevant support services for those in the community who are deafblind.

To find out more about this research study visit www.deafblindinformation.org.au/news or contact Karen Wickham, a Senses Australia Deafblind Consultant and Senior Social Worker via email karen.wickham@senses.org.au.

Orientation and Mobility



Did you know we can provide Orientation and Mobility (O&M) services to people of all ages who have low vision or are blind, helping get them to where they would like to go and travel there safely?

“My role as an O&M Specialist provides one-on-one instruction that can help you develop or relearn the skills and concepts you need to travel safely and independently within your home and in the community,” explains Paul Garwood, Senses Australia’s Senior Orientation and Mobility Instructor.

Senses Australia’s O&M services can help you develop your senses to help you where you are and where you want to go, by using your senses in combination with self-protective techniques and sighted guide to move safely through indoor and outdoor environments.

“We can assist you to learn how to use different types of white cane’s and other devices to walk safely and efficiently. We support you in finding destinations with strategies that including following directions and using landmarks and compass directions. Techniques for crossing streets, such as analysing and identifying intersections and traffic patterns while enabling you to develop problem solving skills to determine what to do if you are disoriented or lost or need to change your route as well as using public transport,” says Paul.

To find out more about Senses Australia’s O&M service visit www.senses.org.au/i-want-to-know-about/assistance-for-me-in-the-community/orientation-and-mobility

Update - NDIS and WA NDIS My Way

The last few months has seen more clients and families accessing our services through NDIS and WA NDIS My Way.

“Our services and supports have continued to grow in the NDIS Hills trial site and in the two WA NDIS My Way sites – Cockburn/Kwinana and the Lower South West to meet demand,” says Elvira Edwards, General Manager Services.

“Senses Australia is locally based in the trial sites having offices in the Hills and in Busselton – we think this is key to ensuring we meet the needs of the communities and are able to provide a variety of services and support to individuals and families.

“We have been busy recruiting a professional and experienced team in the Lower South West to help meet the demand for our services. This is an exciting time for Senses Australia and the Lower South West community as it gives people more choice in which services they want to access,” says Elvira.

To find out more about how Senses Australia can support you or the NDIS and WA NDIS My Way visit www.senses.org.au/i-want-to-know-about/ndis-and-my-way



Senses Australia receives much support from our clients, donors, community groups, corporate organisations and as a beneficiary of family trusts and bequests for which we are very grateful. Thanks to this support, our community helps us to make a difference to the lives of our clients, their families, carers and ultimately the Western Australian community.

We couldn't do it without you!

Senses Australia would like to acknowledge some of our recent contributions including:

- | | | |
|--|--|------------------------|
| > The Rotary Club of South Perth. | > Jacaranda Gardens Craft Ladies. | > Mr J Simpson. |
| > Cunderdin Community Mission Op Shop. | > Marcus and Molly Stone Charitable Trust. | > Mr and Mrs M Elphick |
| > Cecil Andrews SHS Armadale Police Rangers. | > Helen Parsons Charitable Trust. | > Mr R Branchi |
| | > Estate of Harold Redcliffe. | > Mr S Dunn |

New sensory therapy room

Senses Australia would like to especially thank Brookfield Multiplex and their Graduate Program for designing and constructing a new sensory therapy room at our Kitchener Avenue office, Burswood.

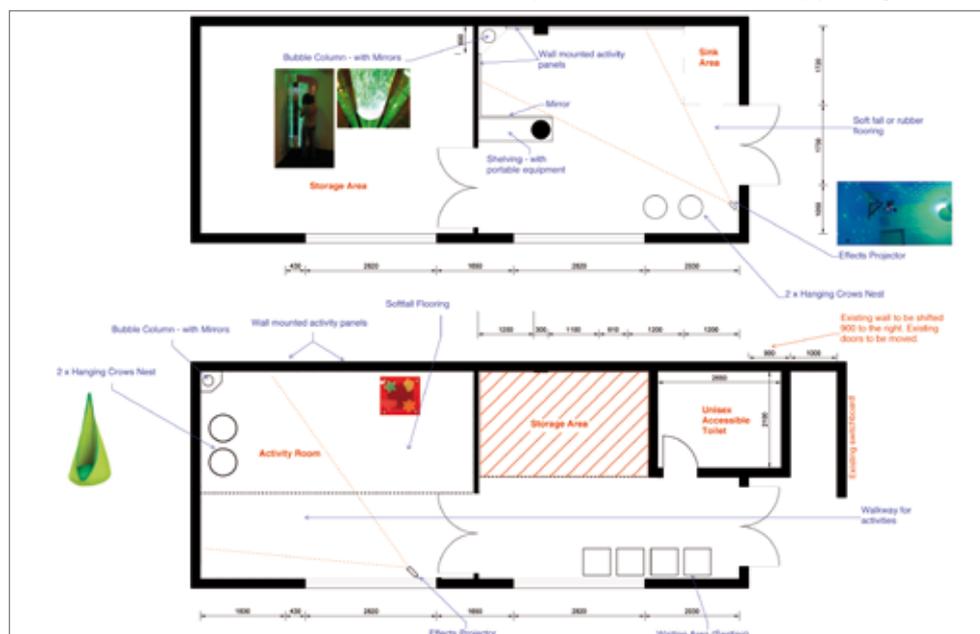
With the kind help of Brookfield Multiplex's contractors and suppliers, the graduates have been busy working on this wonderful project which will support our clients, their families and carers.

"We are very appreciative of Brookfield Multiplex's kind support and that too of the graduates who are part of the Brookfield Multiplex Graduate Program. The graduates have been working tirelessly to ensure this new purpose fit out will allow us to adapt the room to ensure we meet the needs of our clients – so people of all ages can benefit," says Elvira Edwards, General Manager Services.

"The new sensory therapy room will allow us to hold individual and group therapy sessions including our Little Explorers Play Group and Social Skills group. The room will also enable us the opportunity to trial specialised sensory equipment to see if it is beneficial before looking into purchasing options.

"The room will provide a safe and confidential space for our clients and their families who prefer to have their therapy sessions and meetings outside of their home," says Elvira.

We are looking forward to welcoming our clients, their families and carers to our new sensory therapy room very soon. Stay tuned to find out more or like Senses Australia on Facebook and keep up to date with what's happening.



Summer safety

Summer is a great time of year to get outside and active in the sunshine! Here are some ways you can help keep everyone safe:

- > When outside wear a wide-brimmed hat, sunglasses and loose, comfortable clothing with long sleeves.
- > Remember to use SPF30+ sun-screen every two hours.
- > Drink lots of water and carry water with you when you are out and about.
- > Never leave people or pets in an unattended car on a hot day (temperatures inside a car can rise to 50 degrees within a few minutes, leading to serious illness or death).
- > Be careful to ensure intruders cannot enter your home if you are leaving doors and windows open to allow airflow.



Friendly reminder

If your child is unwell at the time of their appointment with our therapists, please reschedule the appointment at a time when your child is back to good health. Please help us stop the spread of infectious diseases and illnesses, together we can ensure our staff and our clients maintain good health.

Did you know?

Senses Australia holds a number of different support groups throughout the year to meet the needs of our clients as well as their families and carers. To find out more, visit www.senses.org.au/i-want-to-know-about/therapy-and-support-groups



COMPETITION

Win a luxury cinema experience



Thanks to Officeworks and Event Cinemas, we have a \$100 voucher to give away to experience the movies in luxury at Gold Class Innaloo.

With wall to wall screens, full reclining arm chairs and food and drinks delivered to your seat throughout the movie – there is no other movie experience like it!

Question: name the equipment Senses Australia would like to trial and are raising funds for in our summer 2015 appeal.

The competition closes Friday, 15 January 2016 and will be drawn Monday, 18 January 2016. Winners will be notified by mail and telephone.

To be in the draw to win this great prize, simply write the answer to the question below on the back of an envelope along with your name, address and telephone number and post it to:

**Senses Australia, Communications and Marketing Department,
PO Box 143, BURSWOOD, WA 6100**

Fighting fit, staying healthy

Our gold sponsors, PKF Mack, who have kindly supported our 120 year celebrations this year, know the importance of keeping fit, maintaining a healthy lifestyle and supporting one another to do so.

Recently, they competed in a corporate netball day, hosted by Netball WA which featured players from the West Coast Fever.

And, we would also like to thank a team of seven of our staff who took part in the 2015 Chevron City to Surf in August, as well as the Gold Runners and Walkers who supported us as a Gold Charity taking part in this year's WAToday Swan River Run in July! It really was fantastic to see everyone come together, not only to help us raise funds but also to support one another

prepare and train for the fun runs and be there together on the day, encouraging one another every step of the way.

We're looking for a team of people to take part in next year's HBF Run for a Reason to help us raise vital funds that will be used to support our clients. To make Senses Australia your reason to run save the date – Sunday, 22 May 2016 and simply visit www.hbfrun.com.au to register. Registrations will soon open!



How you can help

Making a donation to Senses Australia will make a real difference to people's lives. Your gift will assist us to provide essential services and support to those in your community living with disability.

Donating to Senses Australia is easy, you can donate:

Online

One of the most efficient and cost effective ways to donate is with a credit card through our website via our secure online facility. A receipt is sent to the email address provided and your donor record is updated. To make an online donation please visit www.senses.org.au and select the donate button.

Mail

Alternatively donations can also be made by including your payment and the donation coupon in the reply paid envelop supplied (no stamp is required) with each edition of *In Touch with Senses Australia*.

Phone

Or, you can make a donation over the telephone with a credit card by calling Senses Australia during business hours on **9473 5400**.

All donations of \$2 or more are tax deductible. If you would like to find out more please call Senses Australia on **08 9473 5400**.



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