Welcome to another edition of ADHD Australia’s the Voice!

In this edition we have a range of articles covering personal experience with diagnosis to an innovative Australian-first program to increase education and shared care for children with ADHD in underserved communities.

As we enter 2018 and more opportunities to further our work in ADHD, we are also proud to announce the transition of THE VOICE to email and online editions to improve access for our readers.

Enjoy!

Caroline Stevenson and Jon Hassall

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In an Australian-first, Children’s Health Queensland is trialling Project ECHOTM as a proposed shared-care model for the management of children with medically stable, uncomplicated Attention Deficit Hyperactivity Disorder (ADHD).

Project ECHOTM (Extension for Community Healthcare Outcomes) is an educational platform, allowing experts in any field to share knowledge with healthcare providers in underserved communities. The platform has been very successful overseas and it will be used to empower Queensland GPs to deliver specialty-level care by providing them with the knowledge and support required to care for patients they would otherwise need to refer on.

ADHD management will be delivered to underserved regions of need, integrating care across health sectors, with greater cost-effectiveness, enhanced quality and safety, and continuity of care provided to patients and their families.

Project ECHOTM creates a virtual community of practice that encourages mentorship and collaboration between primary, secondary, and tertiary specialists, which ultimately provides a more holistic approach to caring for patients and their families closer to their home. The series curricula will also award category one continuing professional development points for participants.

Series one commenced on 2nd May, with subsequent rollouts planed for north Brisbane in the coming months. Each series of 90-minute videoconference sessions last for ten weeks, with ongoing access to virtual resource libraries and specialist advice for case presentations.

Children’s Health Queensland Hospital and Health Service, in partnership with Brisbane North and Brisbane South Primary Health Networks received funding from the Palaszczuk Government’s $35 million Integrated Care Innovation Fund (ICIF) to implement this initiative.

For more information, email ECHO.CHQ@health.qld.gov.au.

Dr Dana Newcomb
Children’s Health Queensland Medical Director – Integrated Care

“When our children were first diagnosed with ADHD my husband and I had very little idea about what ADHD was and how we should be managing it.”
“We relied heavily on our paediatrician for this information and hospital appointments were few and far between.”

Emma Dunlop

“When families will be able to receive the latest, evidence-based care from their trusted family doctor, minimising the disruption to school and work which is often inherent in attending hospital.”

Dr Dana Newcomb
I was sitting in an armchair, supposedly watching a movie but actually trawling Facebook, when Andrew my 22 year old son, leapt in front of me yelling, “Mum! You have ADHD, get some help!” This wasn’t the first time he’d said something similar, but I had always brushed him off. “Don’t be silly, I don’t have ADHD,” I said, “I can concentrate. I’m fantastic at concentrating. I could win concentration competitions!”

“That’s one of the symptoms Mum,” he replied, “It’s called hyper-focus. You are a textbook case.” This was news to me. Although I’d investigated ADHD nearly 20 years ago when one of Andrew’s many therapists had suggested he may have it, I’d never heard of hyper-focus. I did what I always do when I want to know something, and asked Google. Indeed the kid was right. Hyper-focus, the ability to bury yourself in a topic to the exclusion of everything else, is a common symptom of ADHD. “Weird” I thought. But I did nothing.

Some weeks later we were due to move house. Christmas was looming and our house was due to be auctioned two weeks prior. There was no room for slippage. I was standing in the family room looking around me, trying to make a start. I could feel my mind spinning. The panic was rising and I simply could not figure out what to do first. I realized I needed help or things would simply not happen.

My GP was on holidays, so I saw another doctor at the clinic. I explained the situation to her. First she tried to suggest that if I had ADHD, I seemed to be making it work for me. I stared at her, speechless. She knew nothing about my life. She then changed tack. “I don’t think you have ADHD,” she said, “I think you have bipolar disorder, I can give you something for that if you like”. I declined her offer and left.

I went looking online for help, and found an ADHD Clinic that I went to see. They wanted me to try fish oil and diet, and said that I could have a referral to their psychiatrist only after I’d done a lengthy and costly battery of tests, which I found had very little evidential foundation. I had tried fish oil supplements before, so I knew they weren’t going to help.

I went back to the web. Eventually I found a recommendation for a GP on an archived chat forum. I rang his practice and was told that although he wasn’t taking new patients, I could see another doctor there. I would also be sent a link to an online questionnaire, called the Global Mind Screen that I should complete before my appointment.

Dr Ray was the warmest, kindest, most understanding person I have ever met. She listened carefully to my answers to her questions, and understood what I was saying. She showed me my score on the questionnaire, which was high, and told me I definitely had ADHD. She wasn't legally qualified to make an official diagnosis, so she would write me a referral to a psychiatrist who specializes in Adult ADHD.

I saw the psychiatrist just before Christmas. He confirmed Dr Ray’s diagnosis, but required a sleep study to ensure that my issues were not a result of poor sleep, as well as a genetic test. The whole exercise cost over $1600 and took many months.

Meanwhile I realized that in all likelihood my three children had ADHD as well, which explained a lot. Between them, they’d seen and been treated by at least 2 psychiatrists, 4 psychologists, an occupational therapist, a speech therapist, 2 paediatricians, and an audiologist; all of them specializing in children’s care, to say nothing of the half dozen GPs they’d been treated by over the years. And yet none of these health practitioners had been able to diagnose the commonest childhood behavioural problem in any of them. Something needs to change.
How do we remedy the stigmatization of ADHD?

Stigmatization of ADHD - which is fueled by the type of misinformation presented in the mockumentary - requires public education and advocacy.

- It is important that professionals get involved and lobby their local Member of Parliament when negative articles appear in the media.
- Health professionals have a role in educating Teachers and School Principals about the need to provide appropriate classroom accommodations.
- Disability Acts should be used to prevent discrimination. Adults with ADHD may be eligible for adaptations in the workplace such as being appropriately placed in open plan offices, being able to use noise cancellation headphones and/or the ability to use dictation machines in office meetings.
- Education must be provided to families to ensure the benefits of medication are clearly understood.
- Finally, it is important that advocacy groups such as ADHD Australia are supported to ensure policies impacting people with ADHD are fair and non-discriminatory.

As an ADHD community we can all make a difference to the quality of life of people with ADHD.
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