



THE NETWORK NEWS

FASD-CAN Incorporated

April 2014

A word from the Chair

There has certainly been a bit of media action over recent months and whilst some of it is sad, especially as the story of Teina Pora begins to unfold, we must be grateful that this is causing people to stop and think and talk about FASD and the daily struggles that are reality for many. Some journalists have been in touch to better understand FASD and I take that as a positive sign for change.

On another positive, we were advised back in January by the Ministry of Education that a literature review into FASD was to be carried out. This week I have received confirmation that

the review is complete and has been submitted. Whilst it was a little disconcerting that this review was done in isolation without tapping into our own New Zealand experience and resources, I have made request that the 'parent voice' be heard around the policy setting table. I have suggested that FASD-CAN is the appropriate vehicle for this interaction as the project develops but for now we eagerly watch from the side lines.

After recent events in my own home, I have been searching for ways to 'care for the caregiver' and tips on alleviating stress. What I have learned recently through my own experience is that every day stressful events such as money worries, job security, an ill relative or a pet dying, can easily tip us into hyper-stress zone. I think this is because we are often already living in a pressure cooker raising our sometimes challenging children, that when we add a 'normal' life stressor into the mix, it can blow the whole thing apart and we can find ourselves in dangerous territory.

I have found the following tips on a women's health site (www.womenshealth.gov), related mainly to caring for the elderly with dementia, but I think it is also relevant to all of us who are caring for our FASD children of any age.

In this issue:



- Identifying and reducing caregiver stress
- What the Government is proposing
- What we are doing to educate our communities about FASD.
- aDapt Training Day – a participants perspective
- Celebrating Success – Jackie's Story
- Useful links and resources

How can I tell if caregiving is putting too much stress on me?

Caregiving may be putting too much stress on you if you have any of the following symptoms:

- Feeling overwhelmed
- Sleeping too much or too little
- Gaining or losing a lot of weight
- Feeling tired most of the time
- Loss of interest in activities you used to enjoy
- Becoming easily irritated or angered
- Feeling constantly worried
- Often feeling sad
- Frequent headaches, bodily pain, or other physical problems

Some tips for reducing stress:

- Ask for and accept help. Be prepared with a mental list of ways that others can help you, and let the helper choose what she would like to do. For instance, one person might be happy to take the person you care for on a walk a couple times a week. Someone else might be glad to pick up some groceries for you.
- Say "no" to requests that are draining, such as hosting holiday meals.
- Don't feel guilty that you are not a "perfect" caregiver. Just as there is no "perfect parent," there is no such thing as a "perfect caregiver." You're doing the best you can.
- Identify what you can and cannot change. You may not be able to change someone else's behaviour, but you can change the way that you react to it.
- Set realistic goals. Break large tasks into smaller steps that you can do one at a time.
- Prioritize, make lists, and establish a daily routine.
- Stay in touch with family and friends.
- Join a support group for caregivers in your situation. Besides being a great way to make new friends, you can also pick up some caregiving tips from others who are facing the same problems you are.
- Make time each week to do something that you want to do, such as go to a movie.
- Try to find time to be physically active on most days of the week, eat a healthy diet, and get enough sleep.
- See your doctor for a check-up. Tell him/her that you are a caregiver and talk about any symptoms of depression or sickness you may be having.
- Try to keep your sense of humour.

As with all of these things that are written (usually by someone not under any stress), it can be easier said than done! For example, finding time for yourself and keeping in touch with friends can feel almost impossible at times. However, I like the idea of having a mental 'list of things that can help me'. I'm going to work on that, then I am going to work on finding my Zen. Wish me luck!

Claire Gyde

Government Updates

The Government has agreed to develop an action plan for FASD over the next 18 months. This is a major breakthrough.

In March, the Government responded to recommendations from the Health Select Committee (HSC) on their Inquiry into Child Health Outcomes. Specific FASD recommendations and the Government's response are as follows:

HSC Recommendation 51

We recommend to the Government that the Ministry of Health formulate evidence based guidelines for low-risk alcohol consumption, to be promoted widely, with particular emphasis on alcohol cessation during pregnancy and pre-conception. We recommend that they be formulated within 18 months of this report being published. This could be done by contracting experts in the disciplines of addiction and maternal healthcare.

Government Response: Accept

Providing guidance and advice for low-risk alcohol consumption and guidance around alcohol cessation during pregnancy and pre-conception is part of the Government's work programme.

Current and existing work includes:

- *the Health Promotion Agency's evidence-based low-risk alcohol drinking advice*¹¹

- *promotion of alcohol cessation during pre-conception and pregnancy through the Ministry of Health's website*¹²

- *Alcohol and Pregnancy: A practical guide for health professionals*,¹³ which provides guidance for health practitioners around alcohol and pregnancy.

¹¹ This advice can be found at: www.alcohol.org.nz/alcohol-you/your-drinking-okay/low-risk-alcohol-drinking-advice. It is also published in many of the Health Promotion Agency's alcohol publications.

¹² The Ministry of Health's website is www.health.govt.nz.

¹³ Ministry of Health. 2010. *Alcohol and Pregnancy: A practical guide for health professionals*. Wellington: Ministry of Health. URL: www.health.govt.nz/publication/alcohol-and-pregnancy-practical-guide-health-professionals (accessed 16 January 2014).

The Health Promotion Agency is also planning a multi-faceted three year work programme from 2014/15 to address drinking in pregnancy. This will include wider promotion of the message to not drink alcohol while pregnant or when planning a pregnancy and the reasons for this.

HSC Recommendation 55

We recommend unequivocal health warnings that include, at minimum, "alcohol causes brain damage to the unborn child". This should be achieved within two years of this report being published.

Government Response: Noted

The Government supports consideration of mandatory pregnancy warnings on alcohol labels. This is part of the Ministry for Primary Industries' current work programme. The issue comes under the scope of the Food Treaty¹⁴ and was considered by the Australia New Zealand Forum on Food Regulation at their December 2013 meeting.

The Forum on Food Regulation agreed in 2011 to voluntary, industry-led, warning labels to alert women that they should not drink while pregnant. This voluntary arrangement was for a two-year trial period, after which mandatory labelling may be considered.

An evaluation is to commence shortly on action taken by the alcohol industry in Australia to put pregnancy warnings on alcohol products. The evaluation will include an extensive consultation process and consideration of economic impacts. Interim and final reports will be provided to Forum on Food Regulation Ministers in March 2014 and June 2014, respectively.

New Zealand will also be undertaking a quantitative

evaluation of the New Zealand industry's voluntary labelling initiatives. This will be undertaken once the Australian evaluation framework has been circulated to the Forum on Food Regulation.

The Government will await the outcome of the trans-Tasman Food Regulation process that will consider the evaluations planned for 2014.

HSC Recommendation 56

We recommend to the Government that it develop an action plan to combat the harm caused by foetal alcohol spectrum disorder in New Zealand. The plan could be similar to that produced by the Australian Commonwealth Government in 2013, and

should include the WHO international prevalence study to establish reliable data for New Zealand. It should be a whole-of-government plan, and include the whole population but target those at risk, recognise that the disorder is preventable, provide access to services for those affected, and support prevention measures by the health and broader workforce. This should be achieved within 18 months of this report being published.

Government Response: Accept

The Ministry of Health has a range of initiatives that support reducing alcohol consumption during pregnancy and improving responses for people affected by

exposure to alcohol during pregnancy.

The Government is concerned about the impact of fetal alcohol spectrum disorder on the development of young people. It is developing a fetal alcohol spectrum disorder plan of action and will look to complete this work within 18 months of the Report being published.

Read more at

www.parliament.nz/resource/000201850

Noho ora mai

Christine Rogan

Health Promotion Advisor and FASD Project Coordinator



SPREADING THE WORD

I would like to say well done to all the members who have been out and about spreading the word in every way. With us all doing our bit we are making a difference in New Zealand. Last week Jackie and I went to a Local Alcohol Action Meeting to discuss the local alcohol policy for Hawkes Bay. We each told our story and how alcohol has affected our lives. One couple came up afterwards and were truly shocked by what we said saying they had never heard of FASD and didn't know that alcohol can cause such severe brain damage. They then said that they think a child they know in their family may have FASD and what should they do. I gave them the FASD-CAN and FAANZ leaflet and that they should discuss with their GP who can make a referral to the hospital for further investigation by the Neurodevelopmental Paediatrician.

Tracey Jongens is involved in professional development to teams of Early Childhood Educators through an organisation called Footsteps. She is preparing and presenting a series of workshops throughout the year and has travelled to four different regional centres during mid-March to present stage 1 of the series. Stage 2 is being planned for June. This is the very beginning of being able to offer professional development for teachers. Thanks to Christine Rogan who worked hard to set this up.

Claire, our Chairperson contributed to an article about FASD, Teina Pora and criminalizing mothers who drink during pregnancy in the Sunday Star Times and Dominion Post on March 23rd. An excellent article which states that FASD is reaching pandemic proportions and that there are high numbers of people living with this disorder that are undiagnosed. Read the full article here: <http://www.stuff.co.nz/dominion-post/news/9858478/Thinking-of-drinking-while-pregnant>

Lee Tempest, another member has been lobbying the Government on the lack of diagnostic services for FASD in Auckland. Great work Lee and more of us need to do this and put the pressure on for action and support around FASD diagnosis and support.

In my capacity as paediatric nurse, been invited to give a number in-service talks to midwives throughout 2014 on alcohol, pregnancy and FASD within the Hawkes Bay DHB.

Jackie Prichard and Claire Gyde presented a parent perspective via skype at a training day run by Dr Kerryn Bagley. This training was at the request of an Auckland organization called aDapt which run individual parenting programmes.

Lisa Smith



Links with Perinatal Mental Health NZ Trust

Perinatal Mental Health NZ Trust (PMH NZ) is committed to improving the mental health outcomes for Mums & Dads and their whanau in the perinatal period (pre conception to around 18 months post-natally). PMH NZ's mission is to encourage NZ perinatal research, improve professional development for staff around anxiety, depression, co-morbidities like alcohol and drug dependency, and to raise awareness about the importance of perinatal mental health outcomes. Exciting achievements so far include; the delivery of training days and workshops, a three day symposium and networking and awareness events between agencies and individuals committed to improved care for Perinatal Distress (PND). We have an online presence with a website www.pmh.nz and Facebook page.

PND is a treatable condition affecting up to 1 in 4 pregnancies. If left undiagnosed it can lead to ongoing issues including self-medication with alcohol. Hence, our interest in your group and what you are doing.

Recently PMH NZ met with six politicians from the main party's to discuss our concerns around perinatal mental health and the fragmentation of services and few customised pathways of care for these women & families. The hot topic of alcohol in pregnancy was raised, and we will continue to raise it as we meet again with the politicians in this election year. We are excited FASD is publicising that there is no safe amount of alcohol in pregnancy, that there are assessment teams nation-wide now being trained, and that parents are getting answers and being supported with the care of these children. Lisa Smith had raised

with us issues like the disadvantages/discrimination of children being mainstreamed. Each politician went away with a copy of a booklet which included parts of her story and the link between perinatal depression, alcohol use and FASD.

All the politicians agreed that there was cross party support for mental health policy and a need for de-stigmatisation nationally to improve early detection.

National, cited the 18 month research project around alcohol use in pregnancy in NZ to address FASD and the promise of 18 million extra money in last budget to improve facilities for severe perinatal distress in North Island.

Labour is adamant that they will legislate to label alcohol with warnings for unborn babies in their health policy, and is keen to ring fence budget money for perinatal mental health and encouraging early booking of pregnancies.

The Associate Health Minister renewed his emphasis on maternal mental health, and to promote the early detection in pregnancy, of issues especially with adolescents.

We will continue to support FASD CAN, and with links to our website when it is upgraded this year. In the meantime if any of your members are interested in further information about our study days they can learn more at www.pmh.nz and on Facebook.



aDapt Training Day – A participants perspective

aDapt Family Solutions is a service provider funded by the Ministry of Development to run programmes to strengthen families through individual parent coaching and family development programs. These are delivered in the client's home and are customised to meet each family's individual needs. They cover the Auckland region with referrals from numerous sources including self referral. Recognising that some of their clients were presenting with issues similar to those of FASD aDapt took a quantum leap of faith and arranged FASD training in March 2014 with facilitator Kerry Bagley. Having recently completed her PhD in 'An investigation of professional practice in New Zealand' Kerry who is from a social work background is fast becoming known as an international expert in the FASD field. As well as members of the aDapt team, participants included, psychologists, educators and social workers.

The training was over a two day period, with the first day focusing on the impact alcohol has on the developing brain and how diagnosis is made. In New Zealand, (as in most countries) there is no national policy or strategic plan to address FASD. There are no funded health or community programmes either. This means that those individuals and families living with FASD are isolated from accessing appropriately developed programmes. The second day focused on intervention using the Neurobehavioral Logic model developed by another of the leading experts in the world of FASD - Diane Malbin. This model provides a framework for understanding FASD and brain function.

Neurobehavioral Logic requires a shift in thinking from concentrating on behaviour and learning based interventions to using behaviours as cues for recognising brain difference, and making accommodations for this. It is about questioning whether all those traditional parenting/teaching/judicial strategies such as consequences, time out, lecturing and shouting 'fit' with what we know about the child's brain function. Most don't, and are ineffective tools because they focus on changing the person rather than considering and adapting the environment. As a result, secondary disabilities often emerge that get the diagnosis of conduct disorder, oppositional defiance disorder, reactive attachment disorder and the list goes on. This is due to the intense frustration of the child who cannot regulate their emotions, has sensory processing issues and cannot function in a world that has not adapted to their needs.

Strategies include managing the environment to avoid behaviour problems, using language and non verbal communication that the person understands, having realistic expectations, using diversion tactics, identifying stressors and avoiding them, shifting our perception from the child who 'won't' to 'can't'. So.....

- they are not annoying they are frustrated
- they are not lazy they are trying hard and tired of failing
- they are not lying, they are confabulating to fill in the gaps in their memory
- they are not refusing to sit in class they are just over stimulated.

Let me give you an example. This a typical picture of a junior school class right?



To most (not all) FASD kids, this class is their worst nightmare and will give them sensory overload leading to behavioural problems. Jeez, imagine being stuck in this environment 6 hours a day. I can imagine that many FASD children will process this environment in a way similar to this:

'Arrgggh too much information on the walls to process, where do I start, what do I look at first arrrrghhh. Too many bright colours stimulating my brain in an unkind way. Fluorescent lighting hurting my eyes with its brightness when all I want to do is wear a cap to shield myself from all this stimulation. Imagine having to sit on the floor when all I want to do is move around in order to learn? Who is the teacher talking too???? Is it me or is it Johnny over there and who is supposed to answer, I am so confused so I may blurt out inappropriately.

The desks placed all together so I have to sit with other children and I cannot filter out the noise of their pencil writing or the scraping of the chair so I cannot concentrate. I just want to sit on my own to learn, facing a blank wall where there is no outside noise. I am a visual learner and I learn by doing not by

watching somebody wave cards around at the front of the room. I cannot cope with my environment it needs to be adapted to suit my special needs. I am going to have a meltdown because I cannot cope. I will now get labelled a child with behavioural problems'.

The Neurobehavioral model addresses issues like the classroom environment and seeks to adapt it so the child can function better. This seems logical to us parents raising our FASD children but it is still seen in the 'too hard basket' for many schools to implement. They want to change our child rather than adapt the environment. aDapt family solutions as part of their parenting support programme will be able to work alongside the parents advocating for adaptations to be made in the school environment if necessary. The Neurobehavioral model is a good fit when working with all people who have brain differences such as FASD, Autism and ADHD. Working with the child's strengths is imperative. So this all sounds so logical and easy huh?

Implementing it on a daily basis when you are tired and your 8 year old has just called you a turd because you did not jump up immediately to get their dessert can prove somewhat challenging after the 20th time. It still does not account for your own personal feelings when you want to tip that dessert over said child's head in protest at being called a turd - but in the quieter moments you can reflect on what may cause this reaction and be better equipped to deal with it the next time it occurs.

I have decided that parenting my children in two different ways is in the too hard basket and is leading to my other child becoming very resentful that he has consequences whilst his sibling literally gets away with what he perceives as mass parental abuse. I am going to be using the Neurobehavioral model with both of my children as it makes so much sense. Many will see me as a slack arse parent rather than a dedicated mum who is doing a bloody good job in more challenging circumstances than they could ever imagine or be faced with in parenting.

In an ideal world every parent, service provider, clinician and educator would be trained in the Neurobehavioral Logic model as it is a logical approach to fit our children's diverse needs. I highly recommend Kerryn as a FASD trainer; she was able to deliver the programme in an easy to understand format, is a great advocate for our children and very knowledgeable about everything FASD. I was going to write in just a professional capacity about our recent training but as I am a mum to an 8 year old girl with FASD I am living the daily roller coaster with you all, unable to get off or stop for a breather. Therefore, I have written this article as both a professional and a mum who can struggle to get through each day. I too am frustrated at the paucity of services available to support us in our journey. However, I am excited at the prospect of a service provider who has committed to implementing appropriate strategies that take into account our child's difference. The FASD wave is gaining momentum in its recognition.

Thank you to aDapt Family Solutions for taking the initiative and thank you to Kerryn Bagley for providing us with the tools to become better parents and service providers.

Lee Tempest, Member of FASD-CAN

Celebrating Success



*This is a brief summary of Jackie Pritchard's story so far. Her son Alex had a full neuropsychological assessment done early at the age of 8yrs and subsequently as a result is succeeding well in all the schools he has been at due to a good Individual Education Plan suited to his needs plus schools that are welcoming for all children with disabilities. He has since had another one which will help plan his transition to high school next year. Last week he received a Merit Award from the school to say **"Well done for having a great start to his learning and getting on with others"**. This is fantastic and shows that our kids can achieve with the right supports in place.*

Well where do I start? I guess with hindsight lets go back to when I got pregnant, just quickly.

I found out I was pregnant quite early as we had been trying. Went to the Doctor, got a midwife and started the journey. Was given so much info I skimmed most of it and was strongly talked to about my smoking. Never was I asked if I drank or told anything about it nor do I remember seeing anything on it. Went to antenatal and again wasn't mentioned. Hubby said he did ask about it but they quickly answered with a non-answer and moved on.

My son was about a week late, although scans had said my dates were out by 4 weeks so who knows. He was, as far as we knew, a normal healthy child and no one was alarmed. He was the perfect baby. He slept for hours and I had to wake him to feed him, he ate like a trouper even having to do solids early. Move forward couple years and I was little concerned with his lack of speech so I mentioned this to the Plunket nurse and was told to wait till 2 and we will go from there if no progress. Hit 2 and we were referred to speech therapy, had one assessment then moved towns so started again. Now we are at 3 starting kindy and found he had delayed speech and kindy noticed some strange behaviour due to "delayed speech" and so GSE was involved. He would start with the trains every time and 'watch out' anyone else coming to play with them, they were his and it had to be done his way. He couldn't handle touch or someone being too close on the mat, if anyone brushed past or bumped him it was an all-out blow out because they had hit him and hurt him. He never really played with the other kids. The focus was on his delayed speech and so everything seemed to stem from that even when I mentioned his eyes looked further apart, all I got was "he doesn't have Downs". (Mmm, that wasn't what I was asking.)

Did a parenting course to help with his behaviour which was interesting. Then we hit school and that's where the journey really picks up speed. They decide they want to asses him for ADHD. Mmm, that got my back up but talking to a support worker they had there at the time, we decided it would be fine and they were going to look at a lot of things, and it's just ADHD the school are thinking. Had assessments done at 6yrs old and came back with "we don't know" he was a few markers of Aspergers (Syndrome) and a marker or two of ADHD. So we waited in limbo for two years to start the process again and hope some extra things would come up that would explain my child's ways. I will add I did mention at a

paediatrician appointment that I had smoked and had a few drinks with the girls over yhatzee a night or two a week but never getting drunk. It was decided not enough to worry and therefore not written down.

Two years later age 8, we start again and in the team was a new social worker who wanted to get to know us and in questioning it was brought up I smoked and had a few drinks.... (well, that was jumped on!) I was asked, in more depth, about this and the next thing I'm being asked how I would feel if it came back FASD. I'm thinking FASD what? Never heard of it and had no idea how I would feel until I had the diagnoses. Well with all the testing we had done and this final piece of the puzzle it all was clear to them he had pFAS (yeah, like the P makes it easier to take!) ... with a hint of ADHD.

And so our journey begins fully during a meeting with Christine Rogan in Auckland a month after I found out. Talk about throw yourself in there ... LOL! Ever since I have been out there when needed and waddling my way through this world of FASD. We have been very lucky with our journey so far and things have fallen into place when needed, even when there were some school supports that didn't think he should be on their book, we were quickly sorted and back on. Intermediate has been wonderful but that is due to those that went before me (thanks Lisa Smith), who helped educate them in the world of FASD and they were willing to learn and implement what was needed. As we move on towards the next chapter of high school I really hope my luck holds up, but I am willing and strong enough (I hope) to take whatever comes my way and with FASD-CAN and all the wonderful people I have met I know I can do anything.

Jackie Prichard

Fundraising

We are in the process of registering with the Charities Commission which may help with regard to obtaining funding. However we really need to focus on raising money if we are going to increase our profile and to look at feasibility of having a seminar in September. If every member does their bit we will be able to do more. Hold a coffee morning, garage sale, supermarket collection. Every little bit helps. If each of us were to fundraise \$100 then that would be about \$3000 which would allow us to do much more.

Useful Information

A fantastic resource for IEP meetings. The website is: www adayinourshoes.com

This is a list of printable strategies to help with your child's IEP – there are over 500 which can be ticked off specifically for your child. Very thorough and means that nothing is missed.

Some new books on the market:

Fetal Alcohol Spectrum Disorders , Interdisciplinary Perspectives. Edited by Barry Carpenter, Carolyn Blackburn and Jo Egerton.(2014) Our members Andi Crawford and Christine Rogan have a Chapter called "Building a community of care through diagnosis of fetal alcohol spectrum disorders in Aotearoa, New Zealand".

<http://www.fishpond.co.nz/Books/Fetal-Alcohol-Spectrum-Disorders-Barry-Carpenter-Edited-by-Carolyn-Blackburn-Edited-by/9780415670166>

Cost: \$62.34 free postage in NZ

Preview Dr. Rod Densmore's 2013 eBook edition of "FASD Relationships—For a general audience" here:

<http://LivingWithFASD.com/rodbook1/>

You would be amazed at the time and effort Dr. Densmore spent researching and writing, even going back to summer school (medical) several times! His eBook is only \$15 and really, it's worth ten times that much.

The Perfect Love Story – Healing the Scars of FASD with our Love by Claire Gyde

This publication was designed as a 'quick read' (just 73 pages) for service providers, educationalists and health professionals and those living with FASD. It is an intensely personal story written by Claire Gyde to provide insight into family life when Fetal Alcohol Spectrum Disorder is part of the journey. The author acknowledges that many of the issues they have personally experienced are not unique in the adolescent world of FASD, and many other parents and caregivers will instantly identify with much of what has been written. The story includes disrupted school experiences, substance use, criminal activity and mental health issues. But, as the title suggests, woven through this personal recount is a love story, how one mother's love for her son keeps her on an impassioned path to make the world a brighter place for him and those like him. This is a story based in New Zealand.

Available through our own web-site for \$12 with all proceeds going to FASD-CAN. www.fasd-can.org.nz

The following poem was compiled by Claire from the words that parents used to describe their child with FASD on our FASD Network NZ facebook page a few months ago.

What we see

As sweet as a box of chocolates,
You're our delight, a soft centre full of goo!
Precious child, this is how we see you

As innocent as a puppy
You're trusting and accepting of others too
Precious child, this is how we see you

Teaching us to view the world differently
You're artistic and creative too
Precious child, this is how we see you

A loving, kind soul
Who needs a kiss goodnight too
Precious child, this is how we see you

Looking at things through your lens with the wonder of a child
Your gift is to start each day anew
Precious child, this is how we see you

A beautiful smile and infectious laugh
You're interesting, funny and take us there too
Precious child, this is how we see you

A brain damaged before birth
But you shine on this earth!
You are not defined by FASD

You are what we see!