



National NoticeBoard

Newsletter of the Australian Association for Families of Children with Disability

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Auspiced by the Association for Children with a Disability

One Day at a Time

Our first son (and thus far, only child) is now ten months old. He was born six weeks premature, by Caesarean, after I had a haemorrhage. Callum was born with more severe complications than should have been the case for a baby who weighed 2.185kg and was only six weeks prem. That should have been an indication of just how wrong things were with him, but it was not something that crossed our minds at that particular time.

Callum had severe respiratory disease. He was intubated a couple of hours after he was born and transferred to the intensive care unit at the Royal Prince Alfred Hospital (RPA) (NSW). Callum's paediatrician at St George hospital assured us that it would only be for a couple of days and then he would be transferred back to St George. He couldn't have been more wrong about things.

Callum stayed at RPA for a month. The first couple of days were the most critical. Callum's life hung by a thread. He was on a ventilator and he had more tubes sticking out of him than I've ever seen in any baby. The doctors worked tirelessly to keep him alive that first week. Even they were baffled by just how sick he was.

On Christmas Eve, he developed sepsis and the doctors suspected meningitis. I think that was the first time that I allowed myself to be truly scared because up until that moment, it had never crossed my mind that Callum would not survive. He was my son; he was tough. Anybody who fought that hard to stay alive had to be all right in the end. It was on



Callum

this day that the doctors noticed that Callum was easily irritable, difficult to handle and didn't like being touched. They thought it was all due to the suspected infection, so they did a lumbar puncture and we spent Christmas Eve in hospital. The results came back negative — he was okay — but it was the beginning of the nightmare for us.

The doctors started noticing abnormal jerks in Callum whenever he was startled or touched or his crib was bumped accidentally. They didn't really show any concern about it because they told me that, overall, he was thriving. They had done various scans of his brain and none of them showed anything. They told us that if they did an EEG at this stage, it would very probably show something, but they would still be in the dark as to what it meant.

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Federal Budget and Federal Election

Both are not that far away! Early in the new year, our Association's advocacy for 2004 will begin by publishing our list of priorities for the Federal Government, based on the 'top 3' policy suggestions submitted to us by parents of children with a disability from across Australia over the past year.

We'll then be looking to the power of 'real-life' parent advocacy to convince politicians and senior government decision-makers to embrace and implement positive policy changes.

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The Australian Association for Families of Children with Disability (AAFCD) is auspiced by the Association for Children with a Disability. For updates and more information see www.acd.org.au



"It was from that day that I started to get a bad feeling about things. I think only a mother has that feeling. The feeling that not everything is right and you can't seem to shake it."

How naive we were. In hindsight, you realise that you place all your faith in what doctors tell you and you take for granted that they know exactly what they're talking about and that everything is going to be all right. In hindsight, you realise that they are just human beings like the rest of us and they don't have all the answers, and that perhaps you should be more demanding where your children's lives and health are concerned.

It was from that day that I started to get a bad feeling about things. I think only a mother has that feeling. The feeling that not everything is right and you can't seem to shake it. It must be instinct where your kids are concerned.

Callum was transferred back to St George a month later. When he arrived at the hospital, his paediatrician was very concerned when he saw him. Something wasn't right. Callum had myoclonic jerks. He ordered an EEG straight away. The news was bad. The EEG showed 'an abnormal background with a burst suppression'. It was only months on, after I'd exhausted every site on the Internet, that I was to learn exactly what that meant. Kids with a burst suppression in their EEG results have a very bad prognosis. We didn't know that then. We were told that it would be severe retardation or cerebral palsy.

"In hindsight, you realise that they are just human beings like the rest of us and they don't have all the answers, and that perhaps you should be more demanding where your children's lives and health are concerned."

A CAT scan was ordered to determine whether the structure of his brain was normal. It was. He was seen by a neurologist who immediately reported that it was metabolic. So we read up on metabolic disorders and found that if they were diagnosed in time, then kids usually led normal lives. There was still a chance. But, we were two months down the track and no closer to determining exactly what Callum had. All the neurologist could tell us (and keep reiterating) was that the prognosis was not good. In fact, it was pretty bad.

A second EEG came back with the same result. Every single metabolic test that was ordered came back normal, but the specialists still stuck to their guns. They were adamant that there were only two things that could cause Callum to be the way he is — metabolic or structural.

Meanwhile, Callum was still in hospital and we were tired and depressed. We were

commuting to and from the hospital twice a day and we were taking care of Callum's basic needs — feeding him and bathing him.

He was still on oxygen, with no sign of ever coming off it, so we decided to bring him home. The doctors and nurses were not doing anything for him that we couldn't do for him at home.

We demanded a meeting with the paediatrician, social worker and the Nursing Unit Manager (NUM). His paediatrician was blunt with us. Callum would either die of a massive brain seizure that first year of his life or, for however long he lived, he would need 24/7 care. I wanted to bring him home without the oxygen, care for him while he was with us and give him all the love that he deserved. I was adamant. I should have been more so. The paediatrician and my husband were against it. It would make Callum uncomfortable and worsen whatever condition he had. How ironic that it was only months later we were to find out that his condition couldn't get any worse than what it was.

When we brought him home, Callum seemed to thrive for a while. He was feeding well, he had more strength in his head, he was bringing his hands together and he had more focus with his eyes. He responded to our voices and he would look at you if you talked to him. Callum then lost all that. He favoured the right side of his head all the time and his jerks continued.

He was monitored for his oxygen by the neonatologist at RPA and when he went in for one of his monthly visits we were told just how bad things would be for Callum. His oxygen levels weren't improving. He would have severe developmental delays, would never walk or talk and he showed no interest in communicating with the outside world.

After all these months, I asked one of the doctors what would happen if we took away the oxygen. He didn't advise me against it. He didn't know how long it would take Callum to go — his heart would start working overtime to compensate for his lack of oxygen — maybe days, weeks or months. In the end, Callum would go when he was ready. My husband still wanted to wait before we removed the oxygen.

Two months later, on the day we christened Callum, the oxygen was removed. I knew then, as mothers always know, that it would not make a difference to Callum whether he had the oxygen or not. The doctors all believed that he would not live very long, so he was put into palliative care.

Callum is now 10 months old. He is no longer in palliative care because it looks like Callum might live a little longer than the doctors had anticipated. He remains undiagnosed (still suspected metabolic disease). He is still on bottle feeds and he has trouble clearing his secretions. He was in hospital earlier this year because of dehydration from a cold and he has just recently got over a gastro virus.

We've now settled into some sort of a routine and have started planning for the next five years, but always in the back of our minds is that we still don't know when or how Callum is going to go.

We've come to realise there are few resources out there for children like Callum. We take one day at a time because we have already had a few close calls. He is not for resuscitation or any sort of medical intervention, including antibiotics for infections. We also realise that we do better without doctors and social workers interfering in our lives. Not that we don't appreciate their help, but everything we found out with regards to resources has been through research that I have done.

We were going to put Callum in child care next year so that I could go back to work. We were told by the social worker that I would

need to give up my job to take care of him because there really weren't any child care centres that could provide for kids like Callum. It was also reinforced to me that Callum is going to be around a lot longer than anticipated, to which I replied, were they absolutely sure that he would be alive a month or 6 months or a year from now? We do understand that we have to plan for the next few years, but as I said before, always with the cloud hanging over our heads that we don't know when Callum is going to go. He has been incredibly lucky this year and has confounded all the doctors by not catching any infections, considering his low oxygen levels and the fact that he can't clear his secretions.

We have found a facility for Callum that will enable me to go back to work and it will be a great help for us. We have the option of leaving Callum there during the day and bringing him home at night. It's what we want and we know that he will be well cared for there. We have found ourselves completely isolated. Our friends all have healthy children and much as we try to fit in, even with my own family, we do feel different.

I am now seven months pregnant and we did take a chance in having another child. One reason is that we did not want to be left childless after Callum was gone and we weighed up what the doctors had told us. The fact that they can't diagnose it to this day, would indicate that it was a one-off occurrence. If this child is healthy it will be the last chance we take.

Estela Merif, NSW

"I am now seven months pregnant and we did take a chance in having another child. If this child is healthy it will be the last chance we take."

Your Story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories.

Send your story and a photo to Fiona Gullifer, Editor, National NoticeBoard, Association for Children with a Disability, 590 Orrong Road, Armadale, Vic, 3143 or email (fionag@acd.org.au).

Centrelink Service Issues

Our Association is represented on two separate Centrelink 'Customer Reference Groups' — one for 'disability' and one for 'carers' — which aim to improve the quality of Centrelink services. Please let us know your experiences of Centrelink and any suggestions for improvement.

Not another survey!

A new Federal Government advisory group — National Family Carers Voice — is distributing a survey to all types of 'carers', including families of children with a disability, to assist them to advise the Government about policy issues. While we understand the problem of 'survey fatigue', we would encourage you to fill in the survey. We are represented on the National Family Carers Voice Committee.

Carer Allowance Review

If you missed the December 5 deadline to make a submission to the Review of the Lists of Recognised Disabilities for Carer Allowance, you can still have some input via our Association. We are represented on the Reference Group for the Review which will be meeting during January/February.

To contact our Association phone Barbara Alexander on freecall 1800 222 660 or Diane McCarthy on freecall 1800 654 013 (calls from mobiles are not free).



Mary-Ann with her son, Nick.

Mary-Ann Murphy (SA)

I'm Mary-Ann, mum of Nick and Rachel and partner to Andrew. Nick is now 14 years old and has Down syndrome. Nick does not find life easy, having difficulties with communication, being with people and understanding what 'our' world is all about. As Nick matures, we hope he can make more sense of our world. Nick enjoys swimming, animals (especially dogs), watching videos and like all teenagers, loves going to the movies. I have been to Harry Potter's latest movie twice and slept through another (three times is definitely enough!).

Coming from a rural background, I understand the issues which arise from a lack of services for children with disabilities. I am currently involved in a new association for families of children and young adults with disabilities in South Australia. We will lobby at a state level to maximise the best opportunities for children and young adults with disabilities.

The AAFCD has already lifted the profile of issues at a federal level for families of children with a disability. This is a great start for the future of our children. As a state rep, I hope to help families in South Australia to be heard at a national level.

Mary-Ann Murphy



Australian Association for Families of Children with Disability National NoticeBoard Membership/Subscription Form

If you're not already on our mailing list to receive National NoticeBoard, you need to register as a member/subscriber by sending in this completed form.

It's free for families and service providers.

I would like to be put on the (free) membership/subscription list for information from the Australian Association for Families of Children with Disability, including National NoticeBoard.

I am a: Parent/Carer A young person with a disability
 Service Provider Family friend/Concerned person Other

Name:

Organisation & Title:

Postal Address:

Town/Suburb: Postcode:

Phone: () Mobile:

E-mail:

(Optional) If parent/young person, child's name/your name, DOB and disability:

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Send this completed form to:

Australian Association for Families of Children with Disability
8 Grubissa Court, Benalla, Victoria, 3672 or Fax to (03) 5762 7000

What is the AAFCD?

Our Association is a 'grass roots' organisation, run by parents/families for parents/families. Our Association includes all types of disability. Our formally defined purpose is:

'To provide information, support and advocacy to families of children aged 25 and under with disability in all States and Territories of Australia. The advocacy role includes provision of information to the Federal Government about family needs and issues and advocacy for changes required to Federal policies and programs to address these needs and issues.'

AAFCD Committee Members

Australian Capital Territory

Karen Connaughton
Cheryl Patrick

New South Wales

Sue Griffin
Julie Brunsdon
Kylie Ramstadius

Northern Territory

Bruce Young-Smith

Queensland

Christine Saunders
Leonie McKnight

South Australia

Mary-Ann Murphy
Cale Dalton

Tasmania

Cheryl Shuttleworth
Diane Fugslang

Victoria

Barbara Alexander AO
Jan De Witte
Lyn Kemperman

Western Australia

Clara Harris
Cherie Shaw

Contact Barbara Alexander AO on 1800 222 660 to be put in contact with your State/Territory rep.