



To Senator Patterson, and all other State and Federal Ministers and Shadow Ministers

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July 2004*

I am a 42-year-old mother (and now, without choice, labelled a 'carer') of a precious boy named Ben who has an extremely rare condition called Rubinstein-Taybi syndrome. There are only 600 people in the world with this syndrome. He has also been diagnosed with an autism spectrum disorder.

Ben is severely affected intellectually, is unable to speak, is incontinent, has complex medical problems and is physically challenged in his everyday life.

He recently had his twentieth operation at the Royal Children's Hospital in Melbourne, with no doubt many more to go. Every operation is done at the RCH, without any choice, due to his complexities. This specialised facility is 175 kilometres from our home in Traralgon, Victoria.

Do you have any idea what my daily life entails?

There are many others much worse off than myself but here is a small snapshot to see if you can answer these questions in relation to my everyday life.

Do you know what it is like to have someone be fully dependent on you 24 hours a day, seven days a week, 365 days a year?

Yes, every mother understands this when they are caring for their very dependent newborn baby but, do you know what it is like to have a baby that remains very similar to a baby for the whole of their life, and for the whole of your parenting life?

Do you know what it is like to have to dress someone every day of their life? And usually more than once a day due to incontinence, food spills or just generally getting dirty. Do you know how physically challenging this can be?

Ben is also required to wear a specialised protective suit to bed underneath his pyjamas to prevent him from self mutilating — just another piece of clothing to purchase and wash daily.

Do you know what it is like to have to wake up to a wet bed nearly every day of your parenting life (when your child wets through his night nappies)? And what it is like to have to change that wet bed, wash the bedding, remake the bed, time after time, and how physically exhausting this can be?

Do you know how physically challenging it is to change a nappy every one to two hours every day for the whole of your parenting life? And what it is like to live on very little sleep (three to four hours) every night of your parenting life?

Do you know how much time, energy and money is involved in trying to find appropriate aids and equipment (you would need an extra page to name all the specialised equipment required)?

Do you know how expensive continence items are when caring for an incontinent fully dependent person?

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"Do you have any idea what my daily life entails?"

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*The Australian Association
for Families of Children
with Disability is auspiced
by the Association for
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(www.acd.org.au).*


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“Do you know how painful it is and how it breaks your heart until at times you just can't keep going?”

“Can you, Senator Patterson, and all other politicians, raise your level of empathy and imagine yourself in our role?”

Costs of toilet equipment, change facility, steps, railing, heating and adult seating (required due to the time taken to perform an enema 30–60 minutes each night!), laxative medication (my son requires expensive daily medication, most not available on the PBS), gloves, wipes, specialised creams, adult nappies, inserts (for extra absorbency), tailor made waterproof protective plastic pants to go over nappies, specialised clothing to fit over large nappies and the list goes on!

Do you know how much washing, cleaning, specialised shopping and cooking is involved in caring for your person with a disability? Do you know what it is like to have to prepare a specialised meal every day of your parenting life?

Do you know how time consuming and physically exhausting it is to leave your home when you have to take your physically challenged person with you and organise him/her to get into the vehicle, along with all the necessary equipment and supplies required for the time you are away from home?

Do you know what it is like to feel trapped and isolated in your own home?

To have to seek permission (with minimal choices) for a break with no guarantee that it will happen?

Do you know how much organisation and preparation is involved to finally have that so-called precious respite break — sometimes one hour a week, sometimes a few hours a week — and, if you are lucky, an overnight break might be possible one or two times a year? You are physically exhausted by the time you get to have your break! And often this break is cancelled or shortened due to your person with a disability becoming ill.

Do you know what it is like to have to pay for that entitled freedom (respite) that every man and woman is entitled to and other people take for granted?

Do you have any idea of the costs involved in accessing hospital care for my son?

The lost days of employment, baby sitting, petrol, freeway tolls, wear and tear on my vehicle, car parking and medical costs, just to name a few! (And yes, we have private health insurance.)

Do you know what it is like to have to give up your career and your financial stability to care for your son with a disability for the rest of your lifetime?

No one wants to employ someone for half a day and there are no facilities available to care for Ben after he finishes school at 2.30pm, not to mention how often he is home sick from school.

Are you aware that everything in relation to 'disability' is at a cost? User pays!

Do you know how hard it is to care for someone who cannot express their feelings of pain, anger, sadness, hurt or love?

My precious little man is completely non-verbal and unable to tell me when he is feeling sick, when he is in pain, when he is hungry or thirsty, or when he is unhappy or sad. He has never told me that he loves me and he has never been able to tell me how he is feeling or what he does each day.

Do you know what this is like? Do you know how this makes you feel? Do you know how painful it is and how it breaks your heart until at times you just can't keep going?

Do you know what it is like to have to spend so much time with your child/person with a disability that you can't give your other children the time they need and deserve? This is heart breaking!

Do you know how much grief, pain, loneliness, sadness and lack of support that exists in the everyday lives of parents caring for their child or adult with a disability?

I can only imagine your answers to most of these questions must be 'no' otherwise you would not allow the current inhumane situation to exist the way it does!

Can you, Senator Patterson, and all other politicians, raise your level of empathy and imagine yourself in our role?

When will politicians see it how it really is and ensure government supports families of children with a disability at all times?

A great deal more support is required immediately! Listen to parents and provide this support! Seek opinions and solutions from the people who live this situation every day of their lives!

What would government do if every person who cared for their child with a disability had a mass walk out? What would you do? Where would you find the funding to look after all these children/people?

I cannot believe that the Federal Budget promise to provide a guaranteed four weeks respite break for parents/carers is only targeted to parents aged over 70 years of age. Seventy! So, I've only got to wait another 28 years! You must be joking! (And 70-year-olds should not be caring full-time, they should have the opportunity to choose a normal retirement. Are you saying us parents cannot plan for retirement, ever?

The four weeks respite promise should be for all parents/carers of a child or young adult with a disability. Other respite breaks should also be available when parents need them.

I can't believe that the \$600 budget 'bonus' to Carer Allowance (and the \$1,000 Carer Payment bonus) is restricted to a once-off payment, whereas the other \$600 family

payment bonus (for 'normal' children without disabilities) is ongoing, every year.

Why did disability miss out again! Why did you give us a token once-off payment, but not make it a payment every year?

Begin to understand the reality of our lives and start making sensible and appropriate decisions to adequately support families.

You, and everyone else in government, need to realise that parents/carers are one of your greatest assets.

We don't expect governments to do everything for us, but we do expect a decent level of support.

I am very interested to receive all policies developed from all sectors of government in regards to carers and disability leading up to the election to allow me to determine who should win my vote along with many others living in this unique world of unpaid caring.

Helen Johnson

(Unpaid, very confused and frustrated parent/carer.)

"Do you have any idea the costs involved in accessing hospital care for my son?"

The lost days of employment, baby sitting, petrol, freeway tolls, wear and tear on my vehicle, car parking and medical costs, just to name a few! (And yes, we have private health insurance.)"

Our Federal Election Priorities

In March 2004 National NoticeBoard we published a list of Federal Policy Priorities. Taking into account the Federal Budget in May 2004 (which included several disability/family related initiatives) our updated 'Top 5' list of policy priorities for the Federal Election are outlined below. How will the election platforms/policies of the major parties stack up against these priorities?

1. Carer Allowance (\$600) and Carer Payment (\$1,000) 'bonus' payments

Make these 'bonus' payments to families of children and adults with a disability (or an equivalent increase in regular fortnightly payments) recurrent (ie. ongoing, every year) rather than a 'once-off' payment only. Also, reform the ridiculously narrow definition of profound disability used for Carer Payment eligibility for children under 16.

2. Continence Aids and Assistance Scheme (CAAS)

Increase the maximum rate of CAAS assistance with continence aids (eg. disposable nappies) for families of young adults with a disability to \$2,000 per year, recognising that not all families will require this level of assistance (eg. families whose young adult needs night nappies only will be likely to require less assistance). For Budget costings, expect the average cost per client to increase from the current \$470 to \$1,000 (with indexation thereafter every year).

3. Vehicle Modifications

Pilot a new 'Business Partnerships' initiative to assist 500 families of children and young adults with a severe physical disability to purchase or lease a modified vehicle to transport their child.

4. Respite and Family Support

Extend the promised 'four weeks per year respite/family support' guarantee to all parents/carers of children and young adults with a disability, not just those aged 70 or older! Increase flexible respite funding available to families of children and young adults with a disability through regionally based Commonwealth Carer Respite Centres.

5. Family Self-help Information, Support and Advocacy

Provide funding to increase access to self-help information, support and advocacy for families of children and young adults with a disability at the national level and in every state/territory.



www.aafcd.org.au

Keep an eye on our web site for any breaking news on the election and election policies. The site also includes details of a new one-off \$40,000 grant to our association from the Federal Government.

Awakenings Festival 16-24 October, 2004

An exciting community celebration of ability. Performing arts, workshops, visual arts and more! see the Awakenings site <http://awakenings.horsham.net.au> for more details.

Postcard Campaign!

Thanks for your enthusiastic response to our 'Disability is important to me when I vote' Postcard Campaign (launched in May 2004 NNB). Unfortunately, some of the replies from politicians have been a bit uninspiring, but maybe the best is yet to come with election policies!

The Postcard Campaign is not a short-term gimmick. It is designed as a long-term, sustained campaign throughout 2004 and 2005 to demonstrate to decision-makers, at both the federal and state/territory level, that disability matters to many people beyond those individuals and families directly impacted.

If you haven't yet got your head around the campaign, check our web site www.aafcd.org.au or ring us on 1800 222 660, 1800 654 013, or 03 9500 1232 for a Campaign Kit.

Your Story?

Do you feel inspired to write your story for National NoticeBoard? Send your story with a photo to The Editor, National NoticeBoard, AAFCD, c/ 590 Orrong Road, Armadale, 3143 or by email to (mail@aafcd.org.au).

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.'

AAFCO Committee Members

Australian Capital Territory

Karen Connaughton
Cheryl Patrick

New South Wales

Sue Griffin
Kylie Ramstadius

Northern Territory

Bruce Young-Smith

Queensland

Christine Saunders
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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.

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 (or ring/email us with your details). 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
590 Orrong Road, Armadale, Victoria, 3143 or Fax to (03) 9500 1240