

My name is Suzanne Turpie and I'm married to Rob Turpie. Between us we have 5 kids and live on the mid north coast of NSW in a place called Port Macquarie.

In September 2015 our world was turned upside down with the diagnosis of Caleb (9 years at diagnosis) with brain cancer – a medulloblastoma.

Caleb was flown out from Port Macquarie to Sydney the following day and 4 days later underwent surgery to remove the tumour. Most of the tumour was removed, however a small part was too close to the floor of the brain and that had to be left with the hope that radiation would get rid of the rest.

Upon Caleb waking in ICU we noticed that Caleb had a droop to the right hand side of his face and didn't appear to have much control over the right hand side of his body. We were reassured that this would probably correct itself in the next few days and not to be alarmed.

Caleb's recovery went quite well, though the 'droop' never went and he has been left with a complete facial palsy on the right hand side of his face, and he has not got complete control of his right arm and leg. He required the use of a wheelchair to get around and had to learn how to sit, stand and walk again. Even today (March 2017) Caleb requires a wheelchair for school and longer distances.

Caleb's treatment following surgery was 6 weeks of radiation at the Sydney Children's Hospital Randwick followed by 7 months of gruelling chemotherapy.

Radiation was hell. Caleb's head used to be put into a mask face down on the table and that would then be screwed down so that he could not move. Caleb would become hysterical with this and it was a very traumatic experience for us and not one that I would wish on anyone.

Chemotherapy left Caleb so ill beyond belief. He lost so much weight that he required a feeding tube through his nose – with this came added expenses of buying the food needed, syringes, bags etc. Sleeping of a night time was an absolute nightmare with the machine beeping and alarms going off at times and it was a very tiring time.

Caleb finished treatment in July 2016 and whilst we were ecstatic that treatment had ended, nothing really had ended.

In the lead up to Caleb getting ill, both my husband and I worked. From the moment of diagnosis, I have not worked since. I applied for a Centrelink carer's pension for Caleb and was knocked back twice before a friend of mine involved the local Federal member who got onto the case for me and helped it get approved.

The 1st thing I ask you to consider changing is this: Upon diagnosis grant the carer's pension to the parent. The form that is required to fill out I feel is directed more at Autistic kids than a child with cancer. A lot of the questions were not relevant to Caleb and our situation however we did need immediate financial help and we struggled to get this and had to jump through massive hurdles to get it. I understand that there is a process, but we are already going through HELL, please make it easy for us. Why can't a letter from the doctor/specialist/social worker suffice and it be granted. Believe me, it's not a payment I/we want to be on and I'd happily take working over this situation.

This 1st suggestion is a way to help alleviate some financial stress the parents are feeling.

The 2nd suggestion:

Carer Adjustment Payment

What is the Carer Adjustment Payment?

The Carer Adjustment Payment (CAP) is a one off ex-gratia payment providing financial assistance of up to \$10,000 to families in exceptional circumstances who do not qualify for any Government income support payments.

CAP is intended to assist families to adjust following a catastrophic event where a child aged under 7 years is diagnosed with a severe disability or severe medical condition. The event must have caused an adjustment in the care arrangements that cause the family financial hardship that can be assisted by a one-off ex-gratia grant.

Examples of catastrophic events may include (but are not limited to);

- diagnosis of a severe medical condition such as childhood cancer
- childhood stroke
- car accident
- fire
- fall
- poisoning
- near drowning, or
- other type of accident

Note: For the purpose of this payment a claimant must be eligible for and receiving Carer Allowance in respect of the child.

Who may be eligible for assistance?

Families will be able to apply for assistance through CAP where, following a catastrophic event, all of the following criteria are met:

- the child, aged under 7 years, is diagnosed with a severe disability or severe medical condition; and
- the child has significant care requirements – that is, requires full-time care from the carer for a minimum of two months following the catastrophic event; and
- the child's carer is eligible for and receiving Carer Allowance in respect of the child; and

- the carer is not eligible for and receiving Carer Payment; and
- the carer and/or their partner are not eligible for an income support payment; and
- the carer is able to demonstrate a very strong need for financial support during the adjustment period after the catastrophic event; and
- the claim is lodged within 2 years from the date of diagnosis of a severe disability or severe medical condition following the catastrophic event.

Where to claim this assistance?

Your claim for CAP must be lodged with the Australian Government Department of Human Services (Centrelink) within 2 years from the date of diagnosis of a severe disability or severe medical condition following a catastrophic event.

How much will be paid?

CAP is a one-off non-taxable payment available to families in exceptional circumstances. The amount payable depends on the family's individual circumstances. The amount available to any family is up to \$10,000 for each child in a single catastrophic event.

Making a Case

All eligible applications for CAP are considered on a case-by-case basis based on the families individual circumstances. Carers will need to present their case by setting out their circumstances and the ways in which the family needs extra support and assistance during the adjustment period.

This may include disruptions to things like the carer's capacity to work and/or the care arrangements for the child or other children in the family.

The Department of Social Services (DSS) CAP assessor will provide a recommendation to a senior officer in DSS. The recommendation will be considered and a final determination made by a DSS senior officer.

<https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carers-adjustment-payment>

Open this payment up to these families. Quite often you will find that these families are regional families. They've had to leave work immediately, leave their home and friends and family behind and suddenly they find themselves in a massive city, often alone, terrified and broke. We are so

scared by the prospect of our child's fate but at the same time we somehow have to cope with the lifestyle that has now been thrown at us, with no choice given.

Our own experience was our family was separated. We had my husband stay in Port Macquarie with 4 kids and Caleb and myself were in Sydney. This meant 2x groceries each week on one limited income, savings all used and struggling to make ends meet whilst dealing with a tragic medical event.

The 3rd thing to address that we personally dealt with was income protection: What a great thing to have – when it pays. My insurance company refused to pay my own income protection as it was a dependant child of mine ill, and not myself. Income protection should cover your dependants if this leaves you unable to work. As their mum, it's my job to care for my kids, they are the priority.

You will notice that the 1st 3 points are all financial – it has a massive impact on the family and I think there is a huge gap in supporting parents financially that needs to be filled.

My next areas are treatment:

4: Relapse options – we have been told that if Caleb's brain cancer comes back that there is nothing they can do, and he will require palliative care. However, from research done on my part this is not necessarily the case and that there are options. Yes, from the USA and UK, however it's not correct to say, we've done everything, there's nothing more we can do after the 1st initial treatment. Bring these drugs to Australia, allow testing to be done, research these options because there are options – don't give up on our kids – we aren't and we ask you not to as well.

5: Cannabis oil – I believe that there can be a benefit to using cannabis oil with radiation and chemotherapy. Research this, look into this, direct funds into what are the benefits and how can this help our kids. Will it help them keep their appetite, not to throw up 24/7, keep them comfortable? We were desperate to get Caleb to put weight on and not to be throwing up and to be comfortable. I think we need to explore this option in much more detail.

After treatment:

6: After treatment never have we felt so alone then what we do now. It's like your kicked out on the street and told to swim. There needs to be more support put into place for families. Even a simple phone call to ask how are you, how is Caleb doing, is there anything you want to ask? Redkite has a counselling service but I can reassure you that I won't pick up the phone and ring as I'm too 'busy' but someone should make the time for these families to follow up and see how they are going. Ask them directly are you ok.

7: Mental health. There is a huge gap here. My son desperately needs to talk to someone however in my regional hometown there is no one available. This should have been arranged during treatment so Caleb could come home to immediate support. Families can't always (if they can even find one) afford to pay someone privately for mental health help and this needs to all be included in the overall care and treatment of the child. Treatment shouldn't just cover, surgery, radiation and chemotherapy – there are so many more things than just that.

Overall the statistics of brain cancer is terrifying. The survival rate for Caleb to make it to 5 years is terrifying and pretty much requires a miracle, yet it seems as though brain cancer has been put into the too hard basket and barely any funding is being allocated to fund research. Why?

Our children are real victims to this horrendous disease and we are real people showing you how easy it could be you and not us. Caleb didn't do anything to increase his chances of getting brain cancer, and he hasn't abused his body or done anything wrong, yet before he's given a real proper chance – the Australian government have already given up on Caleb and many other kids and adults by 1st not providing adequate funding into research and secondly failing all my above points.

We are struggling families, emotionally, physically and financially and there is such a HUGE gap that needs immediate addressing.

I have emailed many politicians recently including a member of the Senate with trying to raise the profile of brain cancer and I've only 1 reply. 1 reply out of around 6, and that reply was generic and not very understanding or personal. Is that acceptable? Is that Australian, is that how it's seen as it doesn't affect you??? I promise you – this could so easily be you and not me.

Please direct some urgent funding into brain cancer research and consider all my other points.

Kind Regards,

Suzanne