



Submission No. 661.1
(Inq into better support for carers)



3 July 2008

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Committee Secretary,

Carers NSW is the peak organisation representing around 750,000 carers of people with a disability, mental illness, chronic condition or frail older people. Carers are unpaid and are usually family members or friends of those they support to live in the community.

Carers NSW undertook a consultation with its members to inform them of the Parliamentary Inquiry into Better Support for Carers and provided suggestions for carers to participate in the inquiry by writing their own letter.

We also wrote to our young carer members (those aged under 25) and asked them to send us a letter outlining their experiences as a young carer.

A number of letters from young carers were received and we have collated these and enclose them for your information. The letters young carers have written provide detailed information of the individual lives and circumstances of young people that care for a family member or friend.

Carers NSW has also provided a written submission providing evidence of carers needs, of which Young Carers are identified as a specific carer population group in need of support.

If you require further information please contact Colleen Sheen, Executive Manager – Policy, Strategy and Communication on 9280 4744, or colleens@carersnsw.asn.au.

Elena Katrakis
CEO
Carers NSW

From: [REDACTED]
Sent: Sunday, 29 June 2008 11:35 AM
To: policygrp@carersnsw.asn.au
Subject: Parliamentary Inquiry into Young Carers

26th June 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am only 18 years old and my demands as a young carer of my younger brother with multiple disabilities and high medical needs takes its toll on me, physically, emotionally, socially and economically. I have great aspirations as I am presently doing a double degree of astro-physics and history yet the reality is I have a great responsibility at home which often hinders this study and of course restricts my availability to work and my social life.

My brother falls in a category where there is no help available which I just can't understand. This is strange despite my brother can't speak, see, eat so is tube feed, breathes through a tracheostomy and confined to a wheelchair.

He is not considered disabled by DADHC, they call him medical (??). Yet I have not even yet begun to mention all his medical problems as I thought that the above would be enough. Another draw back is he is considered not having an intellectual disability yet he cannot read, write or speak. Therefore due to these labels, we are not entitled to any help or respite.

I do realise it requires special training such as a registered nurse to look after my brother but does this not exaggerate the need for help as the neighbours, friends etc cannot mind him. And we have no extended family. It is not normal for a kid my age to hold him down while mum gives him an injection in his port-a-cath or change his tracheostomy, as this is a two person job. I also shower him, toilet him, tube feed him, and I'm the only one able to lift my brother now and when he collapses there is no time for hoist as he has to be raced to his oxygen.

As there is no help available for me I will just have to learn to cope and what keeps me going is my love for my brother. If I did not help my mother she would never get any sleep or be able to leave the house to buy the food etc. We live on constant red alert as what

3/07/2008

makes his disability different from many other disabilities as we **can never close the door** as it only takes 3 minutes for irreversible brain damage of death to occur.

I have missed out of many things, as for us to leave the house, 5 bags of medical equipment are needed. So simple outings, and of course holidays are out of the question.

I would just like to add the need and importance for the continuation of the Carer \$1600 payment as my mum lives solely on the carer payment (child). And any money we do get goes to towards my brothers medical equipment, which are simply necessities of his life. I want to be out there working, studying, partying but my carer responsibilities don't allow me to do this. If I did not help my mum, she could not do it alone and my brother would be in care and the only place where he could live is The Children's Hospital Westmead (they actually offered). Imagine how much that would cost a day and remember my brother does not have an intellectual disability so imagine how he would feel.

Perhaps there should be a better criteria in determining the severity of each carer's case. As I know our situation is more demanding than most, considering the other people we know who are carers, especially those receiving carer payment (adult). In addition to all of this, I feel as though we are deprived of many other things, including dental care and other medical services. My sister had her jaw pop out of her socket at the start of this year and needed immediate surgery, and we had no assistance for this by Central Coast Health, the only option was private. I am also outraged about the further indexation of my HECS debt of 2.8% which is around \$400 extra this year. I believe that carers need more assistance in these areas. We don't choose to be in this situation of financial difficulty, this is our life.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely,

From: [REDACTED]
Sent: Friday, 27 June 2008 3:19 PM
To: policygrp@carersnsw.asn.au
Subject: Parliamentary Inquiry into Carers Support

Dear Secretary,

I would like to take this opportunity to make a submission about further funding and increased respite, to the House of Representatives Standing Committee on Family, Community, Housing & Youth's inquiry into Better Support for carers, whilst providing you with a remarkable insight into my life as a young adult carer.

My name is [REDACTED] and I am 21 years old. I have been a young carer for 9 years now. Together with my mum, and my 18 year old brother, we care for my younger 9 year old brother who is one of the very few high medical needs children on the Central Coast. He has moebius syndrome, chronic lung, suffers from cyclical vomiting, hyper tension, is blind, has a gastrostomy, tracheostomy (trachy), is in a wheelchair, in addition to many other things. He requires 24 hour care and can never be left alone, because of his trachy needing constant suctioning to prevent blockage and hence stop breathing.

My care for my younger brother is endless. It consists of feeding him, suctioning him, assisting mum with trachy changes, bathing him, toileting, helping him with his school work. My care also extends to looking after his twin as well (who is not disabled) requiring me getting him to and from school as my other brother is sick, cooking meals, and generally helping mum around the home.

For some reason my brother has, what we now call 'collapses', where he will be fine one minute, the next he gets all sweaty and then the next thing we know we've having to call an ambulance. When he was younger this was happening every two to three weeks, now it is fortunately every few months, but he has to stay in hospital for up to a week at any each time . When this happens we have to drop everything and be there for each other. Most of the time this means missing out on university, classes, exams, I missed out on a fair bit of school, social events, meeting up with friends and going to parties etc. We all have our designated jobs when my brother goes into hospital by ambulance. My mum is the one who usually goes in with him, which leaves me to run the house and look after my other two brothers.

A lot of people say they understand what it's like to be a carer. I find that very hard to believe unless they've experienced it first hand. They couldn't possibly know what it's like to resuscitate your brother in the back seat of the car whilst driving to the emergency department. Or what it feels like to enter the room after you've left for one minute, to find your brother not breathing as a result of him pulling out his trachy (a regular occurrence when he was younger).

I've had to take my brother in by ambulance once, when my mum was looking after my pop in a hospital over 4 hours away. It's traumatic, and I had no support. I was 18 or 19 at the time, and I was left all alone in emergency for around 6 hours while I had to keep suctioning blood and vomit out of my brother's trachy. Sometimes I don't even think people at hospital understand. I had no assistance. We've even found my brother not breathing in hospital, so now mum doesn't leave his side, which means she's been gone for weeks at a time, leaving me in control and caring for my two other brothers whilst still trying to work part time and study. Caring is definitely a full time job. You can't just wake up one day and have a break. It's demanding, tiring, worrying and stressful.

There are only 2 nurses in my area who are qualified to look after my brother, making respite next to impossible. One sits with him all day at school, and the other rides in the taxi. The very few times we've received respite has been when we've booked it months in advance, and it's only been for around 4 hours or so. People can look after him, but hardly anyone is trained enough to solely care for him. This is especially hard on my mum as he wakes 4 - 5 times each night, needing feeding, suctioning, turning. Respite in these circumstances has been almost impossible, and my mum has only been relieved of this 1 or 2 times, at night, in the last 9 years.

For me, the camps held by young carers NSW have helped me a lot. They've given me the biggest insight into the world of caring and disabilities and provided me with, not with relief, but with comfort in knowing

3/07/2008

that there are people out there in similar situations. The young adult carers that I have met are amazing and are truly an inspiration. I believe that these camps provide us with opportunities to do things that we never get a chance to do. Sometimes these are very normal, day to day activities that everyone takes for granted, such as going to the beach or the movies. I will never forget the look in my other 9 year old brother's eyes when we showed him the beach for the very first time, around when he was 5 years old. We'd never had a chance to go because sand cannot get near his trachy. My brother's twin has now been on a few sibling camps himself, and he has had the time of his life. Being taken to the movies, or even to a park, it's just the little things, that he hardly gets a chance at doing.

The government should provide more funding into these types of activities. Giving young carers a chance to have a break, sit back, and be normal, before returning back to their demanding lives.

I would also like to propose that further funding be given to medical equipment and supplies. I've seen a lot of families starve and fundraise for months, just to get a new piece of medical equipment. Despite the costs, medical supplies are also in great demand for families in getting their hands on them. My brother needs to wear a vent over his trachy to prevent dust and dirt from getting into it causing infection, and once we went months without having any because the hospitals could not find any in Australia. We also had to wait months for a nebuliser, which we finally got through sponsorship. But why should children who have life threatening illnesses have to wait so long for treatment and supplies?

My mother and I both receive carer payment (child) from Centrelink because of the nature of my brother's condition. We are a part of the small minority of Australia, around 2000 or so who are receiving this payment, and the government decided to cut off our bonus payment. Why cut this payment for such a minimal number of people, whilst still giving away baby bonuses left, right and centre? Carers would use that money for a much needed cause, for getting medical supplies for Australia's high medical needs children, is just doesn't seem fair.

I appreciate you taking the time to read my submissions, as part of the committee's inquiry, and I certainly look forward to hearing about the outcomes that will hopefully improve the lives of young carers Australia wide.

Yours sincerely,

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From:
Sent: Monday, 30 June 2008 8:23 AM
To:
Subject: FW: RE Parliamentary enquiry

27 06 08

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO BOX 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into Better Support for Carers

I am a young carer. The people I care for are my two sisters.
One of them has the disability of cerebral palsy and she has hearing and visual loss as well.

She cannot talk but uses a book to communicate as well as some signing.
My other sister has a mental illness and she recently had to go to a hospital 80kms away for nearly 10 weeks.

This meant we had to do a lot of travelling just to visit her. Mum said the petrol and tolls cost a lot.

I feel that my role as a young carer is important to be there for my sisters whenever

they need me.

In my caring role I help make one sister cups of tea and play cards and stuff with her. With my other sister, i just worry a bit about her and make sure i play with her when she doesnt have a friend.

Some problems I have is that i miss out on a little bit of school when mum has a migraine or she just has too much to do.

Things that stress me about being a carer is that it takes some of my play time and also i worry about if my sisters will get

worse as they get older and that mum and dad wont be able to care for them.

The things that i reckon help me are that our family gets the support they need and i am getting some tutoring now

which should help me with my school work.

I think the government can better help young carers if they continue to have the camps the young carers organise.

I am going on my second one and i am really looking forward to it. Sometimes i feel like i dont have a lot of time with my mum

because she is always helping my sisters and taking them to therapies and counselling, but she always tries to give me special time.

Thank you for taking my views into consideration as part of the Committee's inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

(13 years)

Example of letter to Inquiry

{Insert date, your address and contact phone}

23rd Monday June
Committee Secretary
Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my..... brother Tremayne

I feel that my role as a young carer is... to get tremayne ready for school ect.

The things I do in my caring role are... Getting Tremayne's Tablets from Pharmacy.

I face the following problems... that tremayne punches, kicks, swears (and bashes my)

I miss out on social things because... I have a need of Family (need help) caring for my

I have difficulty attending school/work because.... I am sick and brother tremayne is aswell.
Tremayne might grow up bashing me.
cuts, bruises ect.

The things that stress me most about being a young carer are.... Tremayne not taking his tablets, not doing what he is told/ bashing me.

Things that would help me are.... Getting the pharmacy to provide Tremayne tablets so we don't have to pay they are alot of \$

I think the government can better help young carers by.... help pay perscriptions, help by food, ~~clothes~~ ect

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

{Sign your name here}
{Type or clearly print your name here}

I have made another page, I thought i would add a little bit more.

Dear Secretary.

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into better Support for Carers.

I am a young carer. The person/s I care for is/are my brother Tremayne

I feel that my role ~~is~~ as a young carer is to get tremayne ready for school, packing his lunch ect. I face the following problems Tremayne punches, kicks swears and bashes my family (well the people who live with me, Deanna, Mum, Tremayne, me. I really need help with that.

I miss out on social things because I have no time looking after Tremayne. I have a need of caring for my brother

I have difficulty attending school/work. because actually I don't miss out on school because mum makes me go I worry about my future because I may grow old and still be caring for ~~the~~ ~~him~~ tremayne I would like a carer for him when he gets older = elderly

The things that stress me most about being a young carer are When tremayne doesn't take his tablet of a morning and gets ~~secho~~ pschic at school.

things that would help me are: Getting Pharmacy to provide percriptions his tablets are ~~is~~ expensive \$\$\$\$
~~I think~~ I think the government can do better to help carers by helping look after their mentely person. ect.

Next Page.

Thank you for taking my views into consideration as part of the committee's inquiry. I look forward to hearing about the outcomes that will improve the lives of young ~~ones~~

Your ~~sincerely~~
sincerely
signature

two movie tickets
I would take
Tremayne if I won.

Committee Secretary

Standing Committee on Family, Community Housing and Youth

Po Box 6021

House of Representatives

Parliament House

Canberra ACT 2600

My name is . I am 10.

the people I help mummy care for are
Jeramee and daddy and my big brother
Shannen and also my two sisters.
Jeramee and daddy have problems
with their brains they bothe get mad
and go crazy. My sister Ciralee has
epilepsy. I feel that I have to help my
mummy, when she is cooking and cleaning it
is my job if mum is busy to bath
and dress my two sisters. I carry dads
tea to him, cook breakfast sometimes.
and find clothes for my brothers.

Home work is hard to do on time because I
am always busy. I don't want to die
because I want to help my mummy.

I always have to do things for people I
only have one friend. If you could
help me it would be good to have
someone else to help mum. Young Carers
should be given money or a party for
a reward. Camp would be fun, fun day
trips would be greift

from

Example of letter to Inquiry

{Insert date, your address and contact phone number here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my.....Mum and elderly nanners

I feel that my role as a young carer is... To take care of the elderly and family and friends.

The things I do in my caring role are... Taking care of the people I do.

I face the following problems... by just doing something that I love right after

I miss out on social things because... I have to work overtime for extra credit

I have difficulty attending school/work because... I always am late for school because I try to sleep in because

I worry about my future because... I don't know how its going to turn out. I stay up to try and finish my carer work.

The things that stress me most about being a young carer are... I never get a little holiday all to myself.

Things that would help me are.... to have some holiday time and more sleep

I think the government can better help young carers by.... giving some time of school to help them all.

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

{Sign your name here}

[Type or clearly print your name here]

Example of letter to Inquiry

{Insert date, your address and contact phone number here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my..... Brother

I feel that my role as a young carer is... To protect him

The things I do in my caring role are... Baby sit sometimes, Play sometimes

I face the following problems... stress, No personal time

I miss out on social things because... he can't go

I have difficulty attending school work because.... No difficulty

I worry about my future because.... I don't know what's going to happen in 10 years

The things that stress me most about being a young carer are.... My brother might get hurt, and he can't think for himself

Things that would help me are.... To have a place to go when I feel stressed like my own room

I think the government can better help young carers by.... providing better services for people with disabilities

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

[Sign your name here]

[Type or clearly print your name.....]

Example of letter to Inquiry



RECEIVED

{Insert date, your address and contact phone number here}

26 JUN 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my..... *mother*

I feel that my role as a young carer is... *help my mum*

The things I do in my caring role are... *clean the house*

I face the following problems... *every day*

I miss out on social things because... *because my mum get sick*

I have difficulty attending school/work because.... *because my mum can't help me*

I worry about my future because....

The things that stress me most about being a young carer are.... *all the job I have do and school work*

Things that would help me are.... *help with school work*

I think the government can better help young carers by.... *more camp meet friend my age*

(Remember it will be helpful for people to understand if you can write down examples of your own experiences). *people dont understand my mum illness*

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

{Sign your name here}
{Type or clearly print your name here}

19/6/08



RECEIVED
23.6.08

Committee secretary
Standing committee on family, community, housing and youth
PO Box 6021
House of representatives
Parliament house
CANBERRA ACT 2600

Dear secretary,

I wish to make a submission to the House of Representatives standing committee on family, community, housing and youth's inquiry into better support for careers.

I am a young carer. The people I care for are my... mum (epilepsy), dad (anger, speech), step dad (anger), step mum (not sure), step brother (not sure). I don't live with all of them but I do care for them whenever I can.

My role as a young carer is taking care of them all in the best possible way. Sometimes that's not the easiest thing to do and I don't have much time for myself and it does take up a lot of my time but I think that although things do get hard sometimes, it's worth it.

Some of the things I do in my role is taking care of my mum when she has a seizure, I know what to do because I have been doing it since I was five or six I am now fifth-teen, I have had to take care of my sister, cook meals, clean house, get ready for school, and basically be the mum of the family.

Which I have to say is hard and has been hard but it's the only life I have known. I have faced many problems along the way such as my step dad thinks he knows what to do when mum has a seizure but really he has no clue and my mum cant get a job because the place she was working at (kelianna) at a laundry service with people with disabilities working at it, was to hot for her in the summer and the business couldn't facilitate for her 'special needs' as they call them. So she had to quite, and as you can imagine has put a strain on the income into the household. My sister went to a privet school, my great grandma left my mum quite a lot of money for my mum in her will before she died. Now it has run out and mum cant live off the trickle of money coming in, she finds it



RECEIVED
23.6.07

Example of letter to Inquiry

{Insert date, your address and contact phone number here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my.....sister

I feel that my role as a young carer is... sometimes good.

The things I do in my caring role are... Help shower, clean up, help get to sleep, help feed. and help teach my sister.

I face the following problems... I miss out on sports, school trips, and having friends over alot. We dont get many new things like clothes alot.

I miss out on social things because... we dont have very much money and erbe is always sick.

I have difficulty attending school/work because.... I'm tired. And sometimes my sister vomits over my work so I have to do it again.

I worry about my future because.... I might not get to go to university. And I might have to help look after my sister.

The things that stress me most about being a young carer are.... Mum and Dad are tired and grumpy sometimes. I think they need a holiday. My sister has alot of attention. And she is messy.

Things that would help me are.... I dont know.

I think the government can better help young carers by.... looking after the families more.

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Example of letter to Inquiry

e/



RECEIVED
23/6/08

Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person I care for is/are my..... ~~brother~~ brother

I feel that my role as a young carer is... help Mum & Dad care for my brother

The things I do in my caring role are... Play with my brother, take him to the shops and I look after my little sister

I face the following problems... My brother throwing tantrums (he is very strong and hard to handle)

I miss out on social things because... My Mum & Dad have to stay home with him, he some times refuses to go places, he won't let us go places.

I have difficulty attending school/work because... I sometimes have to help take care of my family and ~~some~~ most of the time I am too tired to get up from a night of tantrums

I worry about my future because....

I wonder if my brother gets the care that he needs

~~and~~ If a group home The things that stress me most about being a young carer are....

Mum can't cope with my brother by her self
My brother might do something terrible like burn down the house
or hurt some one badly.

Things that would help me are....

~~A~~ Knowing my brother has been given the care & help he needs

I think the government can better help young carers by....

Doing something about the above.
Provide more respite & find a group home for my brother to help my family

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

Isign your name here!

[Type or clearly print your name here]

Example of letter to Inquiry

{Insert date, your address and contact phone number here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person(s) I care for is/are my.....

brother and sister

I feel that my role as a young carer is... to support my parents and help them with my siblings

The things I do in my caring role are... babysit all the time, always looking after making sure there safe, feeding and bathing, looking after all there needs such as hygiene, hunger, safety, clothing etc.

I face the following problems...

that I cant go out with my friends, cant get to places, cant study, having breaks, going on holidays away, going out as a families.

I miss out on social things because... I cant get many plates as my artistic siblings need 24 hour 7 days

I have difficulty attending school/work because.... sometime my siblings bus is late and when I get to school late. I also have to rush home from school too.

I worry about my future because.... I am worried about who is going to support them, when my parents cant.

The things that stress me most about being a young carer are.... that I always have to look after my siblings and dont get to have much of my own time or holidays

Things that would help me are.... more respite for longer times so my family and I could go on holidays

I think the government can better help young carers by.... been more organised with facilities and payet more

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Example of letter to Inquiry



RECEIVED
246-08

[Insert date, your address and contact phone number here]

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my.....

Brother, Clint, who suffers from Autism

I feel that my role as a young carer is...

sometimes frustrating & on the odd occasion, demanding.
The things I do in my caring role are... Sometimes I miss out.

~~watch~~ Play games with him, read to him, help him on the computer.

I face the following problems...

Occasional outbursts when he is frustrated. Medical issues that he sometimes has affect my sleep.

I miss out on social things because...

Only if his occasional medical issues get in the road. This doesn't occur often.

I have difficulty attending school/work because....

I don't.

I worry about my future because....

Sometimes I worry about money. Clint's appointments cost a lot of money & the carers payments are only small & don't help much.

The things that stress me most about being a young carer are....

Clint's constant need of attention, financial issues.

Things that would help me are....

A higher amount of money for the carers pension would make things easier on my parents & me.

I think the government can better help young carers by....

Possibly making a pension for young carers because if we ~~take~~ borrow our parents money it makes it hard for them. I can't (Remember it will be helpful for people to understand if you can write down examples of your own experiences). Some examples are - borrowing my parents money for social gatherings which, as a teenager, there are a lot of.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

Example of letter to Inquiry

{Insert date, your address and contact phone number here}

25 JUN 2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my..... *mum*

I feel that my role as a young carer is...

The things I do in my caring role are...

Clothes Food Vaccins dress

I face the following problems...

being away from school

I miss out on social things because...

Stay home

I have difficulty attending school/work because....

Knowing my mum hurting

I worry about my future because....

I Love my mum

The things that stress me most about being a young carer are....

When my mum doing things

Things that would help me are....

Cubby house to get quiet, sleep

I think the government can better help young carers by....

Stein to stop si lying

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

[Sign your name here]

[Type or clearly print your name here]

Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600



RECEIVED

26 . . . 2008

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my..... brother tremayne

I feel that my role as a young carer is... to look after him if no help is around.

The things I do in my caring role are... look after, take care, Cook, make sure gets medication

I face the following problems... punching, kicking, swearing, name calling.

I miss out on social things because... can't go anyway because we can't take him anywhere always starts fights on people he doesn't know!

I have difficulty attending school/work because... he is always getting in trouble. I feel I don't need him there. I feel I'm in a prison.

I worry about my future because... I'll have to look after him he eats everything.

The things that stress me most about being a young carer are... I feel that I do everything.

Things that would help me are... just asking for help.

I think the government can better help young carers by... reaching out to us and not ignoring us.

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

[Sign your name here]
[Type or clearly print your name here]

Example of letter to Inquiry



26 JUN 2008

{Insert date, your address and contact phone number here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my..... *Sister & Mom*

I feel that my role as a young carer is... *important because we are family*

The things I do in my caring role are... *help out with household chores
Look after my sister
let my mom rest*

I face the following problems...

I miss out on social things because... *- my mom doesn't have enough energy
- helping in looking after sister*

I have difficulty attending school/work because....
- I get tired

I worry about my future because....
because I worry about my sister

The things that stress me most about being a young carer are....
being worried

Things that would help me are....
Camps where I can roam more freely

I think the government can better help young carers by....
*providing money to help out in the homes
and for camps*

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

{Sign your name here}
{Type or clearly print your name here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth.
PO Box 6021
House of Representatives
Parliament House
CANBERRA .ACT. 2600.

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into Better Support for Carer's.

Yes, to tell you the truth, I am a young carer at the age of ten, caring for my little sister. She has Autism. Although, it's sad to see her not like the other kids, but, she is the way she is, and no matter what, I love her.

I feel my role as a carer is to attend to my sisters' needs and wants. For she has a disadvantage in life and it's my duty to help her with nearly everything like; getting her shoes, finding her brush and clothes, helping her into bed, making her lunches, helping to prepare her dinner and much more.

I am both her sister and her best friend as well as her carer, as sadly she does not have many friends. Sometimes people hear her being loud and forcedly tell her off. I tell them that she has a disability, but they don't understand or empathise for some strange reason.

The problems I face are: embarrassment for my sister, most of the time people tell me she is she annoying, when we are in a public place and she is making noise. They think just because she is disabled she's annoying and strange. She can be annoying but, normal people can be just as annoying.

I miss out on social occasions because I must consider my sister's needs. I can't always have my friends over or go to visit them, as my sister may get upset or angry if I am away from her for too long, or does not understand why she can't come along as well, as she doesn't have many friends of her own.

I have difficulty attending school, as I have to be responsible for my sister,

even at school, my parents want me to oversee what is happening with my sister because she needs someone to look out for her. She cannot tell them if anything has happened to her at school, so I need to be aware of what is going on with her. I am not free to do my own thing.

I worry about the future because my sister isn't capable of living on her own, so I would have to look after her, if my Parents are not around or anything was to happen to them. I would not be able to have a life of my own. This puts a lot of pressure on me to live up to this.

Things that stress me about being a young carer are the endless duties I have to perform to help my sister, as she can't do things on her own.

The things that would help me would be to have my own Laptop or Computer Notebook, so I could catch up on my school work. As, I am falling behind because I don't have a lot of time to spend for myself. I need a computer to assist me with assignments, projects, school work and give me access to the Internet, and services that may help me with my Caring role. It would also allow me to maintain social friendships with my friends, even though I may not be able to get out to see them as much as I would like.

I think the government can help young carers by funding families to be able to go away together on a weekend or a weekly holiday. My parents don't always have enough money to afford family vacations, the cost of living, petrol prices, feeding a large family, all take away any money for luxuries like a holiday.

A holiday together can be the glue that keeps families together, it gives you good memories to help survive the hard times.

The Government needs to keep the Sibs website going and keep the phone hotline service available for all young carers to use when they need to. There is something that also needs to be addressed too, there needs to be more community awareness about the role young carers play for their families and for their sibling who has a disability. Too many people are still rude and ignorant and fearful about people who have a disability, and they need to be educated so they do not stress and upset the families and people with a disability.

I would like to thank you for taking my views into consideration, as part of the committee's inquiry. It helps to tell someone what my life is really like, it isn't discussed much at school or elsewhere in the community.

I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours Sincerely,

24/06/2008

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary,

I ~~wish~~ to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

My name is [redacted] I am 14 years old and I am a young carer. The person I care for is my brother Daniel, he is 8 years old and has autism. He needs me to look after him so I can keep him safe inside and outside. I try to teach him things other kids pick up easily like tennis and soccer. I give him extra time on the playstation and often miss out on my turns to make him happy.

The things I do in my caring role are to help my mum so she's not so stressed trying to look after my brother. I remind Daniel to go to the toilet so he doesn't wet himself all the time. I make his lunches for school and often his breakfast too. I clean up after him and remind him to get his clothes on when mum is in the shower.

I miss out on social things because I sometimes babysit for mum so she gets a break and time away from Daniel. I don't miss out on too much now I'm

older but when I was younger mum wasn't able to come and watch my soccer matches as Daniel ran on the pitch and was hard to control.

I worry about my future because I want to see my brother grow up to be normal and live a normal life. I want him to have a wife/girlfriend so he can be happy and so that when mum dies I won't have to look after him by myself.

The things that stress me most about being a young carer are that my brother acts weird around other kids and I feel embarrassed.

The things that would help me are more support to look after my brother, babysitters or other carers for him. For people to understand disabilities better and not judge us then I wouldn't feel bad in public.

I think the government can better help young carers by helping my brother more to get things that would help him and make our life easier. I think we deserved more help to get him to talk and toilet and do normal stuff, mum did it all on her own without any help or services and that meant that I didn't get much time with mum as she was always looking after Daniel.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely,

Aged 14

Sent: Friday, 27 June 2008 3:06 PM
To: policygrp@carersnsw.asn.au
Subject: Young Carer Parilamentary Inquiry

Friday 27th June 2008

Committee Secretary

Standing Committee on Family, Community, Housing and Youth

PO Box 6021

House of Representatives

Parliament Hose

Canberra ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am twenty-four years old but I am not like others my age because I am a Young Carer. Ten years ago when my Mum had to return to full-time work I took over the responsibilities at home including looking after my younger sister and two younger brothers - my youngest brother has Down Syndrome.

As my brother has gotten older, my care towards him has changed. Over the years he has needed constant supervision. Every day I get him ready for school and with his homework and speech therapy, getting his meals, I used to bath and put him to bed, helping him with anything he needs help with, looking after him when he is sick. Disciplining and dealing with his behavioural problems. Often feeling more like a parent

27/06/2008

than a sister. I have cared for my brother while also taking on the responsibilities at home like cooking dinner every night, the washing up and the washing, and cleaning etc. I have had to grow up quickly and feel that I have missed out on having a childhood.

I feel that I am the only thing keeping my family together. Without me doing what I do, it would effect my parent's relationship and my family would be in pieces.

Every day when I went to school I was reminded how different I was to my friends. They had no responsibilities or worries and could just be teenagers. The most important thing to them were their friends and having fun. For me, my brother always has to be considered and I always put his needs before mine. To go out with my friends, someone else needs to be able to look after him. With both my parents working full time, no one else to care for him and respite being too expensive meant that I often was not able to go out with my friends. They had free time to chat on the Internet, often the conversation continue at school leaving me out. While I found it hard to find time to do my homework in between all that needed to be done at home. Not having my homework done or finished got me in trouble at school, the teacher of favourite subject wanted me out of her class because of my poor return of work.

Going to school was important to me not just because it was the only place I could be like others my age but because getting an education was (and still is) the most important thing to me after my brother. For me to go to school, care for my brother had to be arranged. I also missed school to look after him when he was sick or suspended. I found both school and home stressful and it was hard to juggle both. So for all these reasons I left school. (I left school and returned two years later wanting to complete my education only to leave again).

In leaving school I also left my friends. Caring for my brother is all I do - it's my life. He needs me to be there for him and so does my family.

Because my brother/family have always come first I have missed out on a lot. I love my brother and would do anything for him. But now as he is needing me less and less (though he will always need support), I am worried about my future. Soon I am going to have to put my needs first and am terrified that when I do it will cause my family to fall apart, because they are so dependent on me. Also I feel that I don't have the social skills that I need and I don't have any qualifications/references to get a job. I have no support or friends and worry about how I will cope in the world. (I have been completely isolated since I left school, not have any contact with anyone outside my family). I have no idea how I am going to put my needs first because it means turning my back on my brother

(and family).

I would like to see the Government continue to support Young Carers so they have a chance of being a kid/teenager and the opportunity to finish school and pursue their dreams. And to help ease the financial pressure on families caring for someone. I would like to see a greater awareness and understanding of Young Carers and what we do.

Thank you for taking the my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of Young Carers.

Yours sincerely

Get the name you always wanted with the [new y7mail email address](#).

Attention: Policy Team

27th June 2008

Committee Secretary on Family, Community, Housing and Youth

P.O Box 6021

House of Representatives

Parliament House

CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives standing committee on Family, Community, Housing and Youth's enquiry into better support for carers.

I am a young carer. The people I care for are my parents.

The things I do in my caring role are many. I need to look after my parents. I get them up from bed. On the weekend I get their breakfast. I get their medication ready for them every morning, more so with my mum and this is hard sometimes because she does not like to take it. I help them get into bed of a night. If my dad is not well enough to take me to the supermarket I need to ride my bike. Even if he does drive me I still go into the shop alone to buy the food. If the cleaners do not do the washing I have to do it. Dad will turn the machine on for me.

I face the following problems:

When mum makes up excuses for not taking her medication I need to keep asking her to take it by giving her the glass of water. It is very difficult to put them to bed because my mum gets a bit angry because she just wants to stay on the lounge. My parents suffer from post traumatic stress syndrome and they get very tired and keep sleeping but my mum has a worse case than my dad. I have to clean up after cooking but my mum and dad turn on the machine because they think it is dangerous for me to use.

I miss out on social things because:

I know my parents can't drive me anywhere. I also do not have any friends where I live because my school friends live 30 minutes by car. I did have a friend but she moved away. I cannot use public transport because that is very limited, costs too much and I can't leave my parents.

I have difficulty attending school at times because I don't want leave my parents, I get worried. Also I have days where I just don't want to get out of bed and care for my parents. I feel sad about this and guilty.

I worry about my future because what are they going to do when I am gone. I want to be in the Mounted Police Force (I saw them on the news when I was little and saw how they protect people and that is what I want to do) and I know they will never see me because my dad does not like Sydney and they will not have the strength to do it anyway.

The things that stress me most about being a young carer are:

My parents think that when I get older I will not want to do this any more.

Mentally I don't think I can do this anymore. I get stressed when mum has to go into hospital because dad gets stressed and we have to travel to the hospital to see mum.

I get stressed because if they both go to hospital I have no where to go. Who will look after me?

Things that would help me are:

To have someone to do the shopping and pack away the groceries for me.

To have a nurse come to my house and help me to put my parents to bed.

It would be nice to be able to go to church youth group once a week if some one could come and sit with my parents.

I think the government can better help young carer by listening to us and to give us more credit for what we do. They recognise cares as adults but I am young and it is so very hard.

Thank you for taking my views into consideration as a part of the committee's enquiry. I look forward to hearing about the outcomes that will improve the lives of young cares.

Yours Sincerely

Example of letter to Inquiry

{Insert date, your address and contact phone number here}

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my.....

Mum

I feel that my role as a young carer is...

to look after mum, support her, protect

The things I do in my caring role are...

clean the house every morning before school & weekends

I face the following problems...

try to get my HSC work

I miss out on social things because...

I can't have people over because of mum or mother
reason worry about home

I have difficulty attending school/work because....

I worry about my future because... Sometimes find it hard to study or do work

worry that doing so much will stress me out & effect my HSC

The things that stress me most about being a young carer are... how much work I expected

to do plus my social life school & dancing

Things that would help me are....

my friends, family & some group leaders

I think the government can better help young carers by....

providing more financial assist or support network for carers

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Jobs such clean yard, clean the whole house looking
after my brother by his school in which I get stressed

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

(Sign your name here)

[Type or clearly print your name here]



RECEIVED

30 JUN 2008

Dear secretary,

Greetings.

My role as young carer is normally easy but sometimes hard.

Some of the things I do are: get my dads pills, feed my dog every night. I taste and smell for my dad and read small writing I also get drinks for him and do other things around the house.

My dad will be having a hip operation soon and will need my help a lot more. After he recovers I will have more time to do a lot more things, that I want.

I enjoy going on young career outing's and camps but I wish there were more.

My dad pays for my music lessons once a week and I have just started tennis lessons.

My dad cannot afford any more at the moment. I want to start dancing and drama lessons.

I have free time after school, during the week for these things. I am also keen to start another sport for the weekends.

I would like it if young carers could assist me with more things. Thankyou.



RECEIVED
30 JUN 2008

Example of letter to inquiry

(Insert date, your address and contact phone number)

Committee Secretary
Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a young carer. The person/s I care for is/are my.....*Man and she has catatonic*

I feel that my role as a young carer is... *to take care of people.*

The things I do in my caring role are... *watching kids and helping nan.*

I face the following problems... *the kids hurting me*

~~I miss out on social things because...~~

~~I have difficulty attending school/work because...~~

~~I worry about my future because...~~

The things that stress me most about being a young carer are.... *the kids.*

Things that would help me are.... *some advise of taking care of kids.*

I think the government can better help young carers by.... *giving us some more rewards.*

(Remember it will be helpful for people to understand if you can write down examples of your own experiences).

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to hearing about the outcomes that will improve the lives of young carers.

Yours sincerely

(Sign your name here) *[Signature]*
[Type or clearly print your name here]

