

To who it may concern

We, Peter and Beverley Rubenach are full time carers (24/7) for our 24 year son Timothy (Tim) who suffer sever epilepsy and acquired brain injury (resulting in socialising and development difficulties).

Tim contracted meningitis, from an unknown bacterial/viral source when he was 5 months old. The severe epilepsy began at 11 months of age as a result of brain scarring from the meningitis. When Tim was 10 years old, he suffered an extreme bout of seizures and this caused him to 'forget' the limited ability he had acquired to read simple words and write the letters of the alphabet. Hence he cannot read and write at all and not motivated to again try to regain these skills. Also, at this point in time he developed aggressive and violent behaviour which is part of partial complex seizures.

At this point in time, Peter was a self employed builder/cabinet maker and Beverley had most of the responsibility for Tim's care but this problem from very frequent partial complex seizure became so compound that it was impossible for one person to cope with Tim alone. While Tim's older siblings were still living at home, it was somewhat manageable, but when they, one by one left home to pursue employment or higher education it became clear Peter was needed to give full time assistance for Tim's care. When Tim turned 16, Peter became eligible, along with Beverley, for a carer's pension and so it has been combined care ever since.

Tim lives in an almost constant seizure state having almost every known form of seizure. He has an average of 2 to 3 tonic clonic seizures a week. These seizures are very severe causing Tim to fall uncontrollably (unconscious 'dead weight') and he stops breathing. If someone is not right along side him to catch him at the onset of tonic clonic seizure he falls heavily and sustains injuries ranging from cuts, bruising etc to head injuries etc requiring medical attention. Even partial complex seizures can at times, be so severe Tim is unable to feed himself because of poor co-ordination.

Intellectually, Tim varies depending on the task he is performing. On 'good' days during his seizure cycle he can, under strict supervision, drive a small tractor, cut wood and mow the lawn. On 'bad' days he can only lie in bed and go for occasional walks.

Because Tim received acquired brain injury at such a young age Tim has no previous life experiences on which to draw or recall to help him socialise and 'live normally'. Everything he tries to learn or do is the with handicap of acquired brain industry.

Tim is basically still a small child in his interest but he is also very aware that is different. he talks about what he wants to do when he grows up. (The desires and dreams are there, but not the capability.) Tim loves to play 'goodies and badies' building lego, backyard cricket and soccer, and 'scaring' people. Even in public

and with complete strangers he will point his fingers like a gun and say 'Stick 'em up'. he gets right 'into people's faces' touching and pulling noses etc to strangers etc. which is intimidating. Tim frequently has difficulty communicating feeling and even his own needs. eg. he often doesn't 'feel ' cold even on a frosty winter morning or on a hot summer day he may want to wear 4 or 5 layers of clothing. He can rarely tell anyone if he has pain or feels ill as he thinks people can feel his pain/sickness. Therefore, as carers we need to constantly watch for subtle clues as well as being constantly aware of his seizure cycle. (His seizure cycle is from one tonic clonic seizure to the next tonic clonic seizures. As soon as an seizure has occurred the build up to the next one begins.) Weather conditions, especially thunder storms and cold southerly weather full of static electricity effect Tim's seizure cycle and behaviour. Moon phases also have dramatic effects especially full moon. Any form of sickness also influences his seizures cycle eg recently he was in a constant partial complex seizure state being only semi conscious in everything he did. This lasted for about 3 weeks until one day we saw him touch his right ear several times. We realised that maybe he had an ear infection. A visit to the doctor and some antibiotics released Tim from his constant, traumatic seizure state and his normal seizure cycle has resumed. Tim has both night time and day time seizures . Therefore, Peter has to sleep in the same bed as Tim for Tim needs oxygen and reflexology to assist his recovery during a tonic clonic seizure. For this reason (sleeping in bed with him) is why we do not take overnight respite help very often. On the rare occasions that we do family member and service carers need to either sleep in sleeping bags along side Tim or stay awake all night watching Tim for tonic clonic seizures. On these are 'sleep over' occasions we turn it into a fun time with Tim and carers sleeping on mattresses on the lounge room floor.

At present we receive 8 hours a fortnight respite. It is considered by care service providers as 16 hours of respite as they have to provide and pay 2 workers. But in real terms to us it is only 8 hours a fortnight. Even when we do have respite we have to be within calling out distance so we can come to administer oxygen if Tim has a tonic clonic seizures as they are not qualified to administer oxygen. We are still under stress during respite as we assist the service carers if Tim becomes aggressive or violent during a partial complex seizures. Also these carers are not trained to properly and safely catch Tim during tonic clonic seizures falls so they just have to let him fall. (This is NOT adequate care). if any of our sons or daughters are at home to assist service carers we can venture out of 'calling out' range.

While one of our daughters was at home she would sometime take Tim and his service carers on outings. (She could give Tim oxygen if required and know how to cope with Tim's behaviour during partial complex seizures). Now she is not living at home so these outings, which Tim enjoyed greatly, have cease because service carers are insufficiently trained to deal with Tim's epilepsy and acquired brain injury. Also male carers are required if Tim did go on outings as he as to be accompanied to the toilet as tonic clonic seizures frequently occur in the toilet.

We have only had 1, 24 hour 'holiday' since becoming full time carers. On that occasion our daughter who lives 40 metres away gave us her home for the night

and she helped the service carers care for Tim in our home. Even then we checked that Tim was OK several times.

Tim has to have in home care as being away from home, even for a few hours, greatly stresses him. Even if we occasionally visit our sons and daughters, Tim is soon saying ' I want to go home now' . He loves his brothers and sisters but home is where he feels safe and secure.

In 2001 we rented a house in Launceston so Tim could attend St Georges school in the hope he could be motivated and relearn his limited reading and writing skills. On family member would stay in the classroom with Tim but he hated it. He was so stressed he would have a tonic clonic seizure almost every evening and he withdrew into himself. We withdrew Tim from St Georges after a few months and returned home full time. Tim still fears going to Launceston until we reassure him he will not be going to school.

Tim need 2 full time carers 24 hours a day 7 days a week because: he is in almost constant seizure state and therefore need care appropriate to each type of seizure.

- tonic clonic:

to catch him and put him a safe place; to administer, bag and give him oxygen; to do reflexology; to see he does not jerk off bed/couch etc or injure himself during a seizure. (Tim has 2 to 3 bouts of severe jerking during each tonic clonic seizures); to wipe his mouth of saliva etc; to see he is not choking on food (seizure sometimes occur while he is eating); to help him walk when he recovers as he is very unco-ordinated and bashes into doors etc.; to give him fluids as soon as he can safely drink and to take him to the toilet.

- absent seizures:

to see he is safe for the duration of this type of seizure and help him resume whatever he was doing before the seizures eg he could be turning on the hot water tap to wash his hand when an absent seizures occurs and he could not remove his hands or turn it off or he could be crossing a street and suddenly stop unable to move.

- partial complex and other seizures:

to give support and care according to the severity. Eg, he may need someone to hold a cup while he drinks if his co-ordination is bad; to 'defuse' him if he is aggressive or violent (different techniques are need at different times so carers have to learn to 'read the sign's to keep close vigil to act instantly if the partial complex seizures changes to a tonic clonic seizure * 'read' signs and understanding seizures types is vital .

- General care:

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- to see Tim dresses appropriately according to weather and occasions. He may want to wear gum boots and raincoat on a hot summer day; to know how to divert Tim from inappropriate clothing without too much trauma.
 - to go with him to the toilet and encourage him to use proper hygiene etc.
 - to stay with him during bath time as well as prepare his bath etc (Tim will NOT have a shower)
 - to see he has sufficient and appropriate fluid intake
 - to see he has proper and sufficient food. Tim likes to sometimes prepare his own toast, etc but mostly his food has to be prepared for him.
 - to encourage him to do activities when he is having a 'good' day and provide reassurance and comfort on 'bad' days.
 - to operate DVD player etc and supervise watching time etc.

* Tim cannot be left alone because of: seizures; wandering off to do his 'own thing'; he is not able to make appropriate decisions; unpredictable actions etc.

* Two people are needed for Tim's care to enable one person to watch him while the other goes to the toilet, prepares food, washes, does house cleaning. etc.

Areas of concern

- We recently found that emergency respite care is not readily available. Beverley was sick with a migraine and at about 7am phoned requesting respite. (Tim was showing all the signs of soon having a tonic clonic seizures, so Peter would need assistance). Beverley needed bed rest for a least 12 hours thus 12 hours of respite were requested. The request for respite could not be provided until midday and only 5 hours were available.

* What happens if we both get ill or if it is a serious illness?

- Some days Tim will walk almost the entire day (and sometimes most of the night) he is unable to stop as he is having a seizure of one type or another. This is extremely exhausting and we need extra help on these occasions.
- We want to have reassurance that Tim can remain here in our family home as long as it is at all possible.

Should he be removed from his home he would fret and we believe become very ill and severely stressed. Unless he was continually sedated we believe he would run away and try to return to his family home.

- Ideally Tim would be permitted to remain in his family home with responsible service carers when we no longer can provide care.

We DO NOT want our sons and daughters to have the responsibility of caring for Tim as they have their own lives to live. (They already know from 23 years of experience how difficult and different life is having a disabled sibling.)

We are also concerned that at present most institutions demand additional income over the person's disability pension to maintain care. Family should NOT be expected to provide extra finance.

Family should NOT feel pressured to leave assets/property to a disabled family member — Government should take the responsibility of providing care.

We have both worked very hard for 35 years of our marriage to have our property in tact and debt free to give our 6 children a title of their own as their rightful inheritance. We do not want any of this forfeited in anyway so Tim can be provided for. Government MUST take their responsibility and care for the disabled. We have well and truly responsibility contributed by provided care for Tim to date on the meagre, grossly inadequate carers pensions.

* Pension should be increased according to the care that has to be provided.

Why to service carers receive approx \$20 per hour while we as carers receive approx. \$1 or less per hour?

We have saved the Government many hundreds of thousands of dollars, thus far, in our caring for Tim at home (and not institutionalised him)

We need help and we need it now so we can continue to give Tim the love and care he deserves.

Beverly Rubenach

Peter Rubenach



Australian Government
Productivity Commission

Inquiry into Disability Care and Support

Easy English
version

17 May 2010

A better way of helping people
with a disability



The Australian Government wants to help people who are living with a disability.



To do this, we need your ideas on how we can make things better.



Please answer the questions on the following pages.

If you don't have enough room on these pages, you can write your answers on the back of the page or on another piece of paper.

We have written the questions in a way that is easy to read.



Some of the words are written in **blue**. We tell you what these words mean.

Are you using any **services** to help with your disability? There are a lot of different services available to help people with housing, activities, transport, work or doing things at home.

Family Based Care

TABIS (Tasmanian Acquired Brain Injury Service)

Would you like more help to find a job? Or do you already have a job?

Cannot work because of severe epilepsy and acquired brain injury and so I need 24/7 care and supervision in all I do

Would you like more help to take part in activities, such as sports, being with other people or doing new things?

On days that I am feeling OK (note having real bad seizures etc)

I would like to learn mechanics and play golf and go fishing

I cannot read or write or follow instructions very well I have a very short attention span

Are there other kinds of help that you need?

On goods days I would like to learn to read. I could read a little bit until I was 10 year old

I want to learn music and drive a care. I can only do these things on goods days (which isn't very often)

I also want to learn to dance and mime

If you could change any service right now, what would you do?

Have an individual support package so that I and my parents (who are my carers) could choose the people who give respite and to choose how many hours a week of this extra care I want



Do you have some ideas about what your life will be like when you get older? What sort of services do you think you will need then?

I want to be able to live here in may family's home as long as I live.

I want people I like and trust caring for me

Do you think that things could be fairer? If so, what would you change?

I think carers like my parents should get much more money. I think my service carers need more money and more money for disabled people I should be able to live here until I die with people caring for me



Would you like more **choices** about the services you use? Having choices means that you can pick what you want.

YES

If so, what other choices do you want?

Individual support package so that when my parents cannot look after me full time (24/7) carers can care for me here at home.

Individual package now so my parents can have more rest so they don't burn out.

Flexibility and individual recognition in all things

Please tell us any other ideas you have about how we can make disability services better.

Educated service cares better so they are trained to understand my acquired brain injury and epilepsy and how to catch me when I fall at the onset of a tonic clonic seizure.

To make sure service providers don't try to 'put us in a box' thinking I must act and behave in certain ways. I can't very often act 'normal' . I am a unique individual and my injury/disability is unique. Every person is different so we have to each be treated as individuals

Service providers need to know they are there to SERVE people like me and not set rules and treat us a 'normal' people I have a disability if I didn't have I would not need their service

Educate people in the community and elsewhere on what to expect and how to response to people with acquired brain injury

How to send us your ideas



You can write to us.



You can send us your answers in the mail.

Our address is:

**Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601**



You can send us your answers by email.

Our email address is:

disability-support@pc.gov.au



You can phone us if you want to ask us any questions.

Call us on:

02 6240 3221



Please give us your answers by 30 June 2010.

June

We would like to put your ideas on our website for others to read. Do you want us to put your ideas on our website?

Please tick yes or no.

Yes

No

Thank you for your ideas!

This paper benefited from the interpretation services of the Information Access Group (Victoria).