

Friday 4 July 2008

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

Submission No. 826
(Inq into better support for carers)

AOL 16/7/08

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 bereaved carer. It is only because my son has passed away that I have the time to make a submission to this inquiry.

I would like to give you an insight into my life for eight years as a carer, and also to discuss some particular areas of concern:

- 1 support for working carers
- 2 support for carers of profoundly disabled children
- 3 paid support workers
- 4 treatment of children with disabilities by the Child Support Agency
- 5 the Australian Taxation Office rebate for medical items, and
- 6 border issues.

Background

My son Matthew was fine until he was two years old, when he suddenly lost the ability to crawl, and was diagnosed with a very rare degenerative disorder. He lost more and more abilities and developed several chronic illnesses (see Attachment A), and passed away from pneumonia in late 1996, at the age of ten.

See Attachments A-F for some indication of what was involved in his care on a day-to-day basis.

1 Working carers

I could not afford to stop working while caring for Matthew because the expenses relating to his care were so high. I dropped my hours at work to three seven-hour days, and took four weeks purchased leave each year as there was nowhere for Matthew to go during the school holidays.

My husband worked at two jobs throughout Matthew's life and we had little family support.

I was incredibly time-poor and stressed because of the many constant calls on my time, physical abilities and mental space. There was no chance to catch up on lost sleep during the day because I went to work. On my "days off" each week, Matthew and I did a round of medical and therapy visits, equipment fittings, or trips to Sydney (and much time was spent arranging for doctors and specialists to see us on those days rather than the ones I worked.)

Every day, there were issues to deal with such as taxis not turning up to take Matthew to school; paid support workers not available that day; respite arrangements to make for later in the week; medical, equipment or therapy appointments to coordinate and prepare for.

I had an account at the pharmacy, which I visited every week. Sometimes I needed a trolley to carry everything, or one of the staff would come out to the van with me. The pharmacy didn't usually allow accounts, but we were spending \$400 per month there (even after the Pharmaceutical Benefits Scheme discounts), and they could see I was very busy, so they acquiesced.

We had to build special units into cupboards all over the house to store all Matthew's medical needs.

Being a working carer has costs in both arenas. I missed out on the work front: I was getting less pay, putting away less superannuation, and because of my shorter hours and weeks in the year, I frequently missed important information, meetings and events, and did not have time for the social side of work nor corporate duties. Networking opportunities were minimal.

Because of these things and because I did not have the flexibility to work earlier or longer or different days, or come in on weekends, I missed out on travel and promotions.

I worked hard to quarantine my carer duties from my workplace, doing everything possible on my days off and in my lunch-hours. I probably spent less time on family arrangements such as school business and doctors' appointments at work than the full-time parents of able-bodied children. But it was stressful to achieve this.

At the same time, I missed out on carer activities run by carer support organisations, such as trips away, local meetings, social events, training and relaxation opportunities.

Due to the time it took to work and to care, I was not fully in either camp, and missed out in both.

My husband and I had no social life for eight years. We didn't have the time to keep in touch with friends, or time or money to go out, and are now working at rebuilding this area of our lives.

My husband was fantastic throughout all of this. Working long hours, he would work hard at home too, as soon as he walked in the door. But we barely had time to talk to each other. We were each other's shift change. If either of us didn't do our usual break-up of the work, the other one had to do

it. There were no options to put off the work, re-prioritise where our energy went, or take a break until we were revitalised. It's lucky that our marriage stayed together. The Australian Institute of Health and Welfare June 2008 Report into the Effect of Caring on Carers found that one in three marriages broke up after caring started.

1 What would help

- 1 Holiday and pupil-free day programs for children with disabilities
- 2 Respite even for when you are at work so that, for example, if your child comes home sick, you can still attend that important meeting
- 3 Flexible work practices (I am a Commonwealth public servant, and very grateful for the flexibility that was afforded me with working hours, days, and purchased leave)
- 4 Working from home. This is currently a prohibitively complex and expensive affair in the APS, and was never available to me.

Carers of children with profound disabilities

There wasn't much assistance available for us. The most useful thing would have been an Attendant Care Package, but they were only available for care recipients who were 16 or older. Across the years, we had a flimsy patchwork of bits of assistance from different agencies.

In-home care came from Home Care Services, Home and Community Care and the Homestart volunteer program. Between these agencies, there was little consistency in guidelines, staff attitude, training or skills. Each agency required its own range and brand of assessments, home visits, reviews, surveys, meetings, and copious, repetitive paperwork.

Staff would be trained by their agency in occupational health and safety issues, ethics and confidentiality, and their own rights, and how to do their paperwork. I would train them in how to look after Matthew. Because his needs were complex, I would spend at least three training sessions with them for any given period in Matthew's day. So if they were to spend 2 hours in the morning getting him ready for school, I would spend that two hours with them on at least three separate days, showing them what was needed.

This investment of my time had to be repeated with each new staff member (which was a frequent occurrence). The time I spent training staff was still counted as my respite time and came off my annual allowance. In no way could I leave Matthew with someone who did not know how to properly care for his needs as this would have been very dangerous for his health and wellbeing.

Having a night out alone with my husband was a major feat. We would need a paid support worker for Matthew who knew him and his needs well. The agencies insisted on a second person to look after our other two children. This made things very complicated. If we paid for a baby sitter, there would be two adults who didn't know each other, closeted together in the same space for a set period, looking after children separately. We would leave the house dismayed at the huge discrepancies between how Matthew and our two other children were being treated. They would be cared for separately, not as a family group. On one occasion, a baby sitter was cooing and fussing over our two able-bodied children as we left, while Matthew's wheelchair was

faced to look at the television while his support worker settled down to an evening of viewing.

When we came home that night, Matthew was still in his wheelchair, with a soiled nappy. My husband and I had both had back operations before Matthew was born, but easily managed to lift him individually, and had his bedroom set up with special high bed and change table to allow for easy transfers. His 197cm tall male support worker that night would not lift him on his own, and the baby sitter would not help the support worker to lift him from his wheelchair onto the change table to change him (a compliant undersize 9-year old), because her job was to look after the other two children.

Needless to say, we didn't go out very often.

I never had time (or money) to look after my own health. Since Matthew passed away, I have had a lot of really overdue work done on my teeth. I have also had two operations that each required a six-week period without lifting; each of these essential needs would have been impossible while he was alive.

A child with a degenerative disorder grows out of equipment like other children do, but then has a higher turnover again because their disabilities increase with time (see Matthew's equipment list at Attachment E). The Program of Aids for Disabled People (PADP) is meant to provide equipment. It is very poorly funded for the Queanbeyan area. Wheelchairs have a waiting list of several years. When Matthew had a gastrostomy operation because he could no longer eat safely without getting food into his lungs, the rules did not allow us to apply for a feeding pump until after he had had the operation. It was 12 months after the operation when the PADP finally provided Matthew with a feeding pump, an essential life-support machine.

Malkara Special School in Woden was always fantastic with Matthew. He was so well looked after there, so loved and had such a lot of fun. Without this dependable school, I would never have been able to continue working. This is one advantage of caring for a child, as opposed to an adult, with disabilities: that there is somewhere for them to go during the day.

2 What would help

- 1 More assistance with equipment for children with physical disabilities
- 2 Help with purchasing wheelchair vehicles
- 3 More respite options so that carers can take time out for their own health needs
- 4 Maintaining and sufficiently resourcing schools like Malkara
- 5 Respite for affected child and siblings through the one agency so that there is consistency of care and overlap of duties

3 Paid support workers

Home Care Services gave us limited hours per week of assistance. It wasn't enough, and there were a lot of red tape and rigid rules involved. However, I couldn't have managed without it.

It would take many hours to get Matthew and his daily requirements ready for school each morning. A worker would come for 1-1 ½ hours each morning on

the days I went to work. They would toilet, shower and dress him; clean his teeth; do his physiotherapy exercises and put him in his wheelchair, while I prepared his medicines and formula for the day, wrote in his school communication book; packed his clothes (he would need up to three sets per day to allow for toileting and feeding accidents); his puffer, feeding pump and communication equipment; plus the standard news items, library books, permission slips etc that any school child takes in their backpack.

Home Care also gave us three hours of domestic work each week. They would vacuum, clean the bathrooms, wash the floors, and do some washing and ironing. This was invaluable, and one of the easiest ways to provide help to a family with a person with complex needs, because there is less training involved than in caring for the affected person. While we were able to get this assistance in NSW; our counterparts in the ACT were not.

There is still some training involved with domestic work so that workers don't create hazards for the family. For example, when Matthew was smaller, I would carry him from the lounge room to his bedroom to put him on his bed, but sometimes I would find that whoever had vacuumed had put up the side rail on the bed to vacuum under it, and I couldn't lift him over it. This meant carrying him back to where we had come from, putting him down, putting down the rail and starting all over again. A child with no movement is much harder to carry than an able-bodied child of the same weight, and this was very hard on my back.

There were other downsides to this domestic assistance too. For instance, we had to be in the house while they cleaned. Sometimes when Matthew had a specialist appointment that we had to go to, I would arrange for my neighbour to come over and "babysit" the Home Care staff while they cleaned. Otherwise the house would not be cleaned that week.

Additionally, the turnover could be high. In one six-month period, we had more than 20 different workers come to clean our house. This constituted a huge invasion of our privacy, particularly as I would usually be getting Matthew ready for the day while they were there (they came in pairs). For example, sometimes "new" people would waltz right in while Matthew was being changed or bathed; those that came more regularly learnt to be more considerate.

Conversely, I saw Home Care workers weep in my house because they had cared for someone for years, then been removed without warning from their roster and had not been told that they had died. They had learnt via the grapevine that they had missed the funeral. The benefits of continuity work both ways.

Home and Community Care funded us for 4 hours on a Saturday. This would free me for household duties, shopping and administration, which was always overwhelming. It also meant that Matthew theoretically had someone who would play with him, take him for a walk, read to him etc, which my husband and I had limited time for. Matthew's mind was fine, but he couldn't move his body at all, so entertainment and stimulation were important and required assistance from a second party.

The turnover here was very high, and in the last few years of Matthew's life, quality of workers dropped considerably and good people, to spend our meagre funding on, were hard to find. For example, we had a university student who left Matthew unattended in the bath, and would regularly leave him in his on his shower chair without doing up the support straps. He also regularly didn't show up and was uncontactable when he was meant to be at our house on a Saturday. I discovered with time that he would get drunk (or something) on a Friday night and would be too hungover for work on Saturday. And wouldn't phone to cancel, nor take phone calls.

These workers were paid on a casual basis, and paid a low hourly rate. They weren't guaranteed a full week's work, and were often asked to work nights and weekends. That is when working carers are most likely to want a break. My husband and I were so tired all the time that the only night we could go out without falling asleep was Saturday night.

These workers, good and bad, were quick to move on if a fulltime job became available. Across the years, several good workers moved to the office to coordinate respite instead of provide it.

We had one worker from the **Homestart** volunteer program for disadvantaged families with pre-school children. She came faithfully, three hours per week, for years. When Matthew grew too old for the program, concerned about insurance she approached HACC and was taken on as a paid support worker and continued to work with Matthew, with increased hours. She was the one person who was with us all through the years, and she even visited and sat and read to Matthew in the Intensive Care Unit at Canberra Hospital in his dying hours.

3 What would help

- 1 Better pay and conditions for paid support workers
- 2 Continuity of workers
- 3 Domestic help

4 Border issues

We live in Queanbeyan NSW, just over the border from Canberra. Queanbeyan is virtually a suburb of this city centre, but we were excluded from many of its resources for carers. For example:

- the Red Cross, operates a linen incontinence service in Canberra. For a small fee, it will deliver clean sheets, towels and incontinence mats for beds, wheelchairs etc to the person's home. The Red Cross would not allow us to access this service because we lived in New South Wales. It would not allow my husband's business in the ACT, nor my work location in the ACT, to be a pick up and drop off point.
- Canberra Hospital has a large pool of disability equipment available for loan to ACT residents. This is very handy because it is very helpful to trial equipment before buying it, as it often may prove unsuitable once trialled in the home environment. As residents of New South Wales, we were unable to borrow equipment from the Canberra Hospital.
- Advocacy ACT was unable to help us because we lived in NSW. We were forced to use Sydney-based Family Advocacy. This meant everything was done over the phone. There were no face-to-face

meetings; we did not meet our advocate; our advocate did not meet the people from the organisation we needed help with. It was a far less effective way to achieve an outcome.

- Carers ACT is a wonderful organisation for carers. It allowed us to be members and attend organised functions, activities and counselling. However, because of funding stipulations, it was unable to pay for respite for us while we attended any of these activities, which it can do for ACT carers.

Remember also (see page 5) that as NSW carers we could get house-cleaning when ACT carers could not.

4 What would help

- 1 Make funding "borders" more flexible

5 Child Support Agency

The Child Support Agency (CSA) probably caused us more heartache, and wasted more of our time, than any other agency (respite, medical, government or philanthropic) we had to deal with during Matthew's illness.

My husband paid child support for a child from a previous relationship throughout this period. The CSA allows families to apply for reduced payments if they can prove that a child under their care has additional costs. However, we were always made to feel like criminals and liars, had to regularly prepare lengthy documents requiring huge detail about our situation, and the reductions we were given did not relate in any identifiable way to what we had been able to prove our extra expenses were.

In order to demonstrate the complexity of Matthew's care, we provided personal and sensitive, irrefutable, medical reports as evidence. We asked that these not be provided to the other party, who was hostile to our situation. They were nevertheless sent to her. The only concession to our privacy was that our address (which she knows) was blocked out wherever it appeared. There was no possible reason that the other party needed to know any detail about Matthew's illness. This was a huge and unwarranted invasion of Matthew's privacy, and it constantly seemed that Matthew had fewer rights than the other child.

After the first ruling, which she contested in writing and which gave us only a \$30 per week reduction in payments, she would wait until all our papers had been sent to her. She would then not formally contest our application. This meant she was saved the time and trouble of listing the details of her (less complex) financial situation, and she would see our details but we would not see hers. She would be allowed a telephone interview instead, the content of which we were never allowed to know, so we had no way of contesting what she said. Then a ruling would be made, with the report taking into account things that must have been said on the telephone, for example "she has added expenses as she grows older".

We went through this process five times in eight years, when we were desperately time-poor. Once we were told we had to put in an application for review of assessment. When we did this (and it took ages to prepare), we

were told that we should have put in an objection instead, and that we had passed the deadline for an objection.

Each time our application for review of assessment was considered, our payments for the other child were reduced by less than \$2,000 per annum. We were able to demonstrate that Matthew's ongoing additional non-discretionary expenses alone were in excess of \$13,000 per annum (see Attachment F). This did not include the cost of major purchases such as wheelchairs and house modifications (see Attachment E).

The CSA calculations were based on my husband's income only, so the fact that I had had to reduce my working hours because of Matthew's illness was not considered. My husband only claimed half the costs related to Matthew's care in his applications to the CSA, as there were two of us working. However, the CSA included the Carer Allowance of less than \$50 per week as part of my husband's income in making its calculations, even though this money is not assessable for taxation purposes, and was paid to me as Matthew's primary carer, and not to my husband. Carer Allowance is also not intended to offset costs, but to compensate the carer for their time.

We were very poor, and scrambling to meet the costs of Matthew's care. In 2000, the CSA made a ruling which still gave us a rebate of less than \$2000 per annum, but also had the effect of passing almost all after-tax salary increases my husband received onto the other child. This meant that Matthew never benefited from any salary increases.

Usually the salaries of my husband and his ex-partner were fairly similar. In one year, she had a very high income. Although the CSA was aware of this at the time through one of the telephone conversations we were not party to, we did not find out until after the year was over, when her tax return was lodged. (The CSA always sent each party a new assessment of payments whenever either lodged a tax return.) The CSA would not backdate lower payments for us, and cited the 25% minimum payment rule: the paying parent cannot pay less than 25% of what their payments would be if all things were equal. Even if the cost of the children in their care is exceptionally high and if the payee is earning far more than them.

In our CSA assessments, the other child is referred to as "the child in jeopardy". Yet Matthew was in far more "jeopardy" at any time. It was his medicines, therapies and equipment that were at risk because the CSA was very concerned about a healthy, able-bodied child who "needed" a private school and horse-riding, piano and ballet lessons.

5 What would help

- 1 Staff with experience in disabilities to assess applications
- 2 Established guidelines for children with disabilities
- 3 Personal and sensitive evidence documents screened by relevant staff but not forwarded to payee
- 4 Training in compassion, sensitivity and equity for all staff
- 5 Review of the 25% minimum payment rule

6 Australian Taxation Office

When a person is incontinent, tube-fed and has compromised respiratory and immune systems, there are additional expenses and hygiene requirements, which the Australian Taxation Office will not allow as part of the 20% tax offset on net medical expenses. Our house was like a little hospital. We always used copious amounts of the following items, and feel they should be considered as medical expenses:

- Napisan
- Milton's
- rubber gloves
- kitchen paper
- tissues
- nappies
- bibs
- baby bottles (essential for measuring, storing and transporting liquid feeds).

6 What would help

- 1 Allow the above items as medical expenses for people with physical disabilities.

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

Carolyn
BA (Hons), Dip Mgt
Board member, International Society
for Mucopolysaccharidosis and Related Diseases

Attachments:

- A Matthew at age 10
- B List of Matthew's hospitalisations throughout his life
- C Daily respiratory care plan for Matthew
- D List of medications and pharmacy items he needed
- E Major expenses related to Matthew's special needs
- F Sample of ongoing annual costs

MATTHEW AT AGE 10



Matthew's abilities continue to deteriorate due to his degenerative disorder. He cannot walk, talk or turn himself over in bed. He is tubefed via a Kangaroo Pump for 10 hours each night and has three bolus feeds during the day. His ability to eat solid food has gradually diminished, and in the past 12 months he has stopped eating orally altogether.

Matthew does not regulate his body temperature well. He also has:

- Quadriplegic Cerebral Palsy
- Oesophageal Reflux
- Epilepsy
- Asthma
- Osteoporosis
- Dislocated hips.

He wakes frequently throughout the night due to the pain of osteoporosis, dislocated hips and reflux. He has seizures at least four times every 24 hours (including during the night), and absences at least 12 times during that period.

Throughout his life, he has had regular:

- Physiotherapy visits plus daily physiotherapy regime
- Dietitian visits
- Osteopathy visits
- Occupational therapy visits
- Hydrotherapy and
- Speech therapy.

He doesn't laugh or smile much anymore.

Attachment B

Matthew's hospitalisations throughout his life

1	Grommets insertion and adenoidectomy	Mar 1998
2	MRI scan of brain	May 1998
3	One week of diagnostic tests at Prince of Wales Hospital, Sydney including nerve conduction studies, skin biopsies, blood tests, eye clinic	May 1998
4	Viral asthma	May 1999
5	Videotelemetry for seizures	Jun 1999
6	Ph probe study, Connective Tissue Dysplasia Clinic, Westmead Children's Hospital Sydney	Aug 1999
7	Hip x-rays	Nov 1999
8	Videofluoroscopy study including barium swallow	Jul 2000
9	EEG	De 2000
10	Gastrointestinal specialist, Sydney	Feb 2001
11	Dental Extraction and restoration, spinal x-rays, blood tests, Westmead Children's Hospital Sydney	Apr 2001
12	Bilateral pneumonia	Oct 2001
13	Seizures	Nov 2001
14	Bloodstream infection	Dec 2001
15	Seizures with vomiting and cyanosis	Feb 2002
16	Videofluoroscopy study including barium swallow	Apr 2002
17	Congenital Heart Clinic, Westmead Children's Hospital Sydney	Jun 2002
18	Gastrostomy and fundoplication	Jul 2002
19	Grommets	Jan 2003
20	Videotelemetry for seizures	Jun 2003
21	Pneumonia	Jul 2003
22	Pneumonia	Sep 2003
23	Dental Extraction	Nov 2003
24	Grommets	Feb 2004
25	Grommets	Oct 2004
26	Cardiology review including EEG, respiratory review, bone density scan, sleep study, psychological medicine review, metabolic review, dental review, neurology review, Westmead	Octo 2004
27	Videotelemetry for seizures	Jan 2005
28	Paediatric gastroenterologist, Sydney	Feb 2005
29	Grommets and botox injections to legs, Westmead	Apr 2005
30	Dental Extraction	Jun 2005
31	Colon evacuation	Jul 2005
32	Botox injections to legs, paediatric gastroenterology review, dermatology review, bone density scans, x-rays, urine and blood tests, Westmead	Sep 2005
33	Upper GI endoscopy	Nov 2005
34	Pamidronate infusion for osteoporosis	Jan 2006
35	Pamidronate infusion for osteoporosis	Feb 2006
36	Pamidronate infusion for osteoporosis	Mar 2006
37	Botox injections to legs, Connective Tissue Dysplasia Clinic, Genetic Metabolic Disease Clinic, Westmead	Apr 2006
38	Grommets	May 2006
39	Pamidronate infusion for osteoporosis	Jun 2006
40	Pamidronate infusion for osteoporosis	Jul 2006
41	Double pneumonia	Aug 2006

Attachment C

DAILY RESPIRATORY CARE PLAN FOR MATTHEW

Item	How administered	When
Zyrtec	3.5ml through button	At beginning of overnight pump feed
Narium Nasal Spray or saline	2 squirts or 0.5 ml in each nostril	On rising
Chest Percussion	2 minutes on front of chest, and 2 minutes on each side/back	Every morning. Also at bedtime when Matthew is phlegmy
Seretide asthma preventer	Two puffs, using spacer	In morning, then rinse mouth or clean teeth
Biotene Oral Balance Gel	1/4" on tongue and around mouth	After cleaning teeth in morning
Narium Nasal Spray or saline	2 squirts or 0.5 ml in each nostril	At morning bolus feed
Ventolin	2 x 2 puffs, one minute apart	When going out into cold air or when coughing, maximum of once per hour
Narium Nasal Spray or saline	2 squirts or 0.5 ml in each nostril	At afternoon bolus feed
Oral Balance Gel	1/4" on tongue and around mouth	At afternoon bolus feed
Narium Nasal Spray or saline	2 squirts or 0.5 ml in each nostril	At bedtime
Zyrtec	3.5ml through button	At end of overnight feed
Nasonex	One squirt in each nostril	At bedtime (at least five minutes after Narium)
Seretide asthma preventer	Two puffs, using spacer	At bedtime, then rinse mouth or clean teeth
Oral Balance Gel	1/4" on tongue and around mouth	After cleaning teeth at night and once during night
Amcal Junior Cough & Cold Elixir	5 ml through button	At bedtime
Vaporiser and Amcal Inhalant Fluid		Overnight, when air is dry

MEDICATIONS AND PHARMACY ITEMS**Prescription Medications**

Epilim
Lamictal
Acimax
Amcal Junior Cough & Cold Elixir
Seretide puffer
Ventolin puffer
Nasonex
Zantac
Panamax
Elecare Formula
Elocon Lotion

Other Pharmacy Items

Nappies (part-funded by PADP [Program of Aids for Disabled People])
Maxipads
Zyrtec
Saline (for nose)
Vaporiser cleaning tablets
Vaporiser inhalant fluid
OralBalance (dry mouth) Gel
OralBalance (dry mouth) Toothpaste
Lansinoh (cracked lip) Ointment
Infacol
Buscopan
Nurofen
Daktozin (nappy rash) Cream
Voltaren Gel
Syringes: 5, 10 and 60 ml
Earplugs (for hairwashes and hydrotherapy)

Natural Medicines

SuperMaritime Prime
Slippery elm
Psyllium Husks
SerinOtyde Powder
Ambrotose
C Plus powder
L-Glutamine
Tasty B
CoEnzyme Q10, 60 ST
Polybac 8
Shark Liver Oil 570 mg
Natural E
SB Floractiv
Lipoec 100 mg
Pyridoxal
Picmins
Herbal Lungs
Zinc Drink
Herbs (Licorice, St Mary's Thistle, Echinacea, Gingko, Bittersweet)

Attachment E

**MAJOR EXPENSES RELATING TO MATTHEW'S SPECIAL NEEDS
(does not include items provided by government schemes e.g feeding pump)**

Major Purchases

Date	Item	Cost	Comments
1998	Hospital cot	\$2,000	
	Rehabilitation stroller	\$4,000	
1999	Walker	\$1200	
	Standing frame	\$420	
	Airconditioning to house	\$10,000	as Matthew's body had poor temperature regulation
2001	McLaren Buggy	\$1000	
	Large car seat	\$1200	
	Toilet support	\$1200	
2002	Wedge	\$240	
	Wheelchair paths in backyard	\$1600	
	Wheelchair	\$1800	
	Sheepskins	\$600	help protect skin in bed and on other equipment
2003	Large change table	\$500	
	Communication equipment	\$600	
	House extensions – purpose-built bathroom and family room to accommodate use of equipment	\$100,000	Increased mortgage payments by \$2,000 pa, and extended term of loan to age 71 years
	Hospital bed (secondhand)	\$200	
	Van with hoist	\$28,000	
	Tinting for van windows	\$330	
	Tilt-in-Space Wheelchair	\$12,000	
2004	Commode chair	\$2400	
2005	Hoist/Lifter (indoors)	\$3600	
	Gel chair/tilt bed on wheels	\$2600	
	IV drip pole and base	\$230	
	Bedrail	\$46	
	Baby monitor	\$100	
	Modifications to bedroom fittings to accommodate use of hoist by Home Care staff	\$850	power points, smaller wardrobes, magnetic doorstops
	Wheelchair modifications (pressure care foam)	\$310	
	Repairs to airconditioning in van	\$2,300	
TOTAL		\$179,326	

Sample of ongoing annual costs

Item	Cost per annum
Medical Gaps	\$785
Natural Medicines	\$5800
Pharmacy Items	\$1700
smaller rehabilitation items	\$500
Respite	\$700
Hygiene Items (rubber gloves, Milton's, Napisan, kitchen paper, tissues)	\$1500
Incontinence items	\$1200
Medical trips to Sydney	\$900
Memberships: <ul style="list-style-type: none"> • International Mannosidosis and Related Diseases Society • Mucopolysaccharidosis and Related Diseases Society • Gastrostomy Information Support Service • Paraquad • Queanbeyan Children's Special Needs Group • Spastic Centre • Friends of the Brain Injured • Carers ACT 	\$80
Total	\$13165 per annum