

Submission No. 466

(Inq into better support for carers)

A.O.C. 2/7/08

From: Jewels
Sent: Thursday, 26 June 2008 5:03 PM
To: Committee, FCHY (REPS)
Cc:
Subject: Submission to: Better Support for Carers Federal Inquiry

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. Therefore please accept this as my submission.

The Committee is seeking a better understanding of the situation for Carers in Australia. As a family carer of my daughter, of the age of 6 and has severe multiple disabilities and chronic health conditions is completely dependant on me for all her needs. I feel my role as a family carer and contribution of carers in society is not recognised. I would suggest that family carers in my situation, where I am a sole family carer and a mother of another child, needs to be given greater recognition in the community. This may be possible through educating the public, with the assistance of family carers to aid in this facilitation. The public need to know of the tireless work that occurs through our hard efforts. This is continual and will consume us for the rest of our life, and we as family carers need to feel supported in the community. I feel organisations such as Carers Australia require more funding to be able to facilitate community education programs and support to family carers.

Also the need for family carers to be provided with superannuation, holidays and other benefits that employees receive out in the community is vital in assisting family carers attain recognition and support in the community. Currently I survive off the carer payment and carer allowance, which puts me below the poverty line. It is difficult to live off this income and plan for the future needs of my family. As a family carer I have exceedingly greater expenses than others, with the costs of medical treatment, pharmaceuticals, equipment and basic needs such as electricity. I find it incredibly isolating, since I had to give up my part time employment when my daughter was about one year old, due to her deteriorating health. I found employers are not aware of the needs of family carers and therefore not supportive. I have endeavoured to continue studying at university however due to the unpredictable nature of my daughters health it has been difficult to complete because the universities are not very flexible. I have also endeavoured to attain part time work and this also has not been successful due to the lack of support to attain care workers who can look

27/06/2008

after my daughter whilst I work and or study. It is also astronomical in cost to employ care workers to relieve me whilst I attend to other matters. I would greatly appreciate more financial assistance to get back into the work force and attain study or training to do this.

I feel it is vital to increase the funds to family carers to access respite to pay care workers to assist in the everyday practical nature of looking after my daughter. It will become more difficult to bath and wash my daughter and I already have a bad back because I have had to lift her constantly from the bath to her chair and from the car to the wheelchair etc. At the moment it is a fight to attain funding from state and commonwealth departments to access respite, which takes energy away from my quality of life. There also needs to be a better system to credential care workers, as I need to do this whenever a new care worker commences working with my daughter. There seems to be a huge change over of staff in the care industry and these people are not supported enough it seems. I continually am faced with strangers coming into my home whom require training and education about my daughter. It maybe better to provide this funding for respite directly to family carers rather than to service providers who do not seem to manage these funds efficiently.

There is also a need for increase funding for equipment and health resources which I have to organise and fight for. This takes up incredible amounts of time and advocacy skills. As my daughter continues to grow her needs will continue until she's an adult and even then her needs will change from time to time. It would be a suggestion to provide this funding directly to family carers who can then manage these costs with the assistance of a therapy team etc. At the moment the system is not equitable with the funding going to service providers.

Key areas for me as a family carer for improved quality of life are

- * Access to high quality respite that is ongoing for my daughter, so that she can build relationships with the care provider.
- * Greater income to cover the cost of increase cost associated with her care with increases to the carer payment and carer allowance
- * Superannuation scheme for family carers
- * Holidays for family carers
- * Access to health treatments for family carers who need assistance with muscle aches and pains, and strain from the work they carry out every day.
- * Access to classes for family carers on the carer payment especially for example, swimming membership discounts etc.
- * Strategies in place to assist my daughter and I as she is gets older, one of my greatest fears is what happens to her if something happens to me. At this moment in time I do not know what exists to help us do this type of planning. Service providers do not assist with this at all. I know there will come a time when I will not be able to continue to provide the level of care my daughter requires, due to my own capacity to provide diminishing.
- * It is vital that family carers have a life and an identity besides providing care constantly for the rest of their lives.

At the moment it is a struggle:

- * to juggle finances because my low income and increasing costs such as petrol, electricity, food etc
- * participate in social life because of lack of respite and lack of understanding from the community
- * to participate in the work force or continued study because of the inflexible nature of the

work place and universities etc

In conclusion I have great need to worry about my future, because my focus is to get through each day and survive and I do not know what will happen to my youngest daughter as I grow old and my older daughter who does assist me, also needs my support. I would greatly appreciate for greater improvements in the above area, because I feel I make a genuine difference in the life of the Australian Community through my role as a family carer and I need to be recognised for this and supported.

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

Jewels

A day in Sienna's life **As At January 2007**

Our little Sienna is 4 years of age.

Sienna is unable to hold onto you, whilst lifting, so you need to hold on to her and provide her with support. Sienna cannot stand unsupported; she requires assistance to bring herself up to standing and then needs to be supported around the hips, and needs to be assisted to sit down again. She is unable to pull herself up from laying down position to sitting and needs assistance by you giving her a hand and then she will pull herself up.

When Sienna needs a nappy change, or needs to do go to the potty she may go over to the potty and hit it with her hand, as Sienna cannot speak clearly. When this happens, the assistance needed is to kneel down with Sienna and put one knee up, rest Sienna in a standing position over your knee and pull her pants and nappy down and then sit her back down on to the potty which is behind her. Sienna likes to play with some toys whilst on the potty and her favourite is the chewing caterpillar. Sienna may take up to 15 to 20 minutes on the potty. It is important to wait for a wee. When this happens congratulate her. Now have her nappy ready on the change table, I may have put an inserted pad inside it, if we are going out and there is no access to appropriate toilets. Then have a wipe handy and lift her up to standing position with her resting on your knee. Wipe her bottom and then lift her up onto the change table. Sienna will lift her bottom up, you need to ask her and then do up her nappy and then sit her up and then stand her up, then pull up her pants.

When giving Sienna a bath, Sienna needs assistance to get undressed. Her nappy and clothes need to be ready. Her hearing aids and glasses needs to come off. Her hearing aids need to be turned off. The cloth around her gastrostomy needs to be taken off. I wrap a towel around her and carry her to the bath and lift her into the water. Sit her on the non slip bath mat and there is a foam knee pad for you to kneel on whilst giving Sienna a bath. Sienna can sit in the bath, with your hand behind her. Sienna needs to have her mouth washed out and her teeth cleaned with a flannel which is wrapped around your finger and nuk toothbrush. When doing this you will need to support her by holding your hand behind her head and talking to her as she looks at you. Sienna does not like this. This is to get the asthma medication out of her mouth and to clean her teeth. Sienna needs assistance to get out of the bath. Have a towel open and tuck this under your chin and then lift her into it and then wrap it around her. Then carry her to the change table in her bedroom.

After drying Sienna, I put her nappy on and apply small amount of barrier cream around gastrostomy site and put a cloth around it. This is so the plastic from the button does not rub on her skin. When Sienna is fighting an infection off her gastrostomy site gets quite sore and needs to be cared for and monitored. I give her a lavender massage. As Sienna has dry skin and this helps with that and protecting her immune system and assist her sleep routine. When Sienna has a cold I apply a small amount of Vicks baby rub onto her chest and back of lungs. Then I dress her.

I do Sienna's hair by spraying a small amount of Johnson's no more tangles into the knotted parts and placing her in her posture chair, and giving her some fun toys to play with, this will distract her. Then gently combing out from the ends and holding the hair near the scalp. Sienna can get upset by doing this. I put her hair off her face up in a pig tail. I then place her glasses and hearing aids in both ears.

Sienna has Care Plans for Health Management, Asthma, Epilepsy, Sleeping, Continenence, Oral Eating and Drinking Care Plan. These are kept in a pink folder which accompanies Sienna wherever she goes. Sienna has feeding regime which is also in the pink folder. There is also Medication Plan's for her medication: Ventolin, Seretide, Oxygen, Seravit Paediatric, Paraffin, Lactulose, Epilim, Paracetamol liquid, signed by Doctor in her pink folder. Sienna also has a small A5 book with is called 'About Me: Sienna', which gives more information about Sienna's likes and dislikes etc.

Routine for Sienna's Day dated 1st February 07 Version 2

Time	Activity
6 am	Turn off overnight pump if finished.
6.05 am	Prepare breakfast of 180ml of milk, warmed in home microwave 40 seconds, then with 20ml of seravit dissolved in some of the milk and then added together and shaken, along with $\frac{3}{4}$ tablespoon benefibre.
6.15 am	Disconnect pump tubing from Sienna's tube and prime milk mixture into empty bottle.
6.20 am	Set pump to 260ml per hour and then turn off.
6.25 am	Clean up milk bottle and other gear in the kitchen.
6.30 am	Attach pump tube to Sienna's and release block and start pump on 260ml p/hr.
7.10 am	Prepare Epilim, give 4ml of Epilim, push hold button on pump and disconnect and put connector valve on end of tube attached to Sienna and then syringe the Epilim via this and flush with 5ml of warm water and then connect to pump and recommence breakfast feed.
7.15 am	When breakfast is finished turn off, flush tubing with 20ml warm water.
7.30 am	Put aside some boiled water to cool for Sienna. Get Tallara her breakfast and pack her lunch for school.
7.45 am	Give Sienna 120ml warm boiled water via bolus feed slowly whilst still asleep.
8 am	Get Sienna up, if not already awake. Disconnect oxygen and tubing from button. Get her out of her grow bag. Carry her to the potty and stand her up against your knee and take her nappy off and sit her back down on her potty.
8.05 am	Give 2 puffs of Seretide via spacer and Ventolin if needed.
8.07 am	Check Sienna's bed and if wet, put wet bedding in washing machine and start cycle.
8.10 am	Get Sienna dressed, clean Sienna's glasses and put them on with her hearing aids. Make sure Tallara is dressed for school
8.20 am	Pack Sienna's bag, make sure Tallara is ready for school, put bags in car
8.25 am	Take Sienna off potty and put her nappy on. Comb her hair and put it up.
8.30 am	Put Sienna in car and take Tallara to school.
8.45 am	Get Sienna out of the car and take Tallara across to her class room.
9 am	Get Sienna into the car and go home.
9.20 am	Get Sienna out of the car and inside home.
9.30 am	Put Sienna in her standing frame and place her so she can watch Play School.
9.40 am	Get Sienna's juice ready with her medicine
9.55 am	Get Sienna out of Standing frame and put her in trip trap chair ready for morning juice.
10 am	Give Sienna her juice, total amount of fluid in bottle 185ml approx.(160ml with 15ml lactulose,5ml aloe vera juice, 5ml colloidal minerals and flush with 20ml water (room temp. boiled water). During this time sing songs and talk to Sienna.
10.20 am	Put Sienna from the trip trap chair to the potty
10.25 am	Wash out tubing, do the dishes, hang out the washing, vacume the carpet etc.
10.40 am	Take Sienna off the potty when she has done a wee, this maybe before this time. Put her nappy on.
11 am	Take Sienna for a walk with Toto, take Sienna's spectacles and hearing aids off and put her sunglasses on if it is sunny outside. Take care when walking, checking Sienna has still got her glasses and hearing aids on if they where on when you commenced walk. Sienna sometimes throws them off, because they get dirty, or the sun glares cause discomfort to her eyes, or the aids have increased feedback.
11.45 am	Get home and put Sienna on the floor to let her play with her musical toys.
11.50 am	Get Sienna's 200ml milk ready for lunch, add benefibre to this. Get a small taste of puree fruit. Get tubing for feed ready and damp cloth and spoon.
12 noon	Put Sienna in the trip trap chair and give her a taste of puree fruit on her lip. Then give her milk via button. During this time sing songs and talk to Sienna.
12.20 pm	Put Sienna on her potty.
12.25 pm	Wash out tubing etc and have lunch and make necessary phone calls re: Sienna's appointments etc.
12.35 pm	Check Sienna's potty, if done wee take her off potty and put her nappy on.
12.40 pm	Place Sienna on the floor with her kitchen utensils and I empty the potty and wash it.
12.45pm	Give Sienna asthma medication if needed via spacer
1.00pm	Do some exercises with Sienna: on the big ball and some stomach strengthening exercises and exercises for her lung.
1.30pm	Do some standing and walking exercises with Sienna.
1.50 pm	Put Sienna in trip trap chair and give her piano for play whilst sitting thereGive Sienna bolus feed of 100ml juice with aloe vera juice added plus 80ml warm water flush (cooled boiled water).
1.55. pm	Get Sienna's 200 ml milk ready.
2 pm	Give Sienna her milk, via bolus feeding and during this time sing and talk to her.

Time	Activity
2.20 pm	Take Sienna out of her trip trap chair and put her on her potty. Wash out tubing. Bring washing in from outside.
2.30 pm	Take Sienna off her Potty if she has done a wee and put her nappy on. Put Sienna in her Pony Walker.
2.40 pm	Empty potty and wash it.
2.45 pm	Take Sienna outside on the ramp and let her work her way down the ramp in her pony walker. Do this several times.
2.50 pm	Bring Sienna inside and take her out of her pony walker and place her on the floor, sitting up and let her play with blocks and drum.
2.55 pm	Put bags in car, and get ready to collect Tallara from school.
3 pm	Put Sienna in car and go collect Tallara from school.
3.15 pm	Take Sienna out of car and get Tallara from class room.
3.25 pm	Put Sienna in the car and Tallara's bag and go home.
3.40 pm	At home take Sienna out of the car and get the girls inside and put Sienna in her standing frame and set her up so she can watch 'Play School'.
3.50 pm	Give snack to Tallara and get her set up to do her homework. Get Sienna 200ml milk ready with 25 ml paraffin.
4.00pm	Take Sienna out of standing frame and put her in the trip trap chair and give her milk via bolus feeding, slowly. During this time sing, talk to her and help Tallara with her homework.
4.20 pm	Take Sienna out of trip trap chair and put on her potty.
4.25 pm	Wash tubing and start getting dinner ready.
4.30 pm	Take Sienna off potty when she has done wee and put her nappy on. Put her in the posture chair with some activities. Give Sienna asthma medication.
4.40pm	Cook dinner and tidy up table and assist Tallara with activity.
4.55 pm	Get 120 ml of water ready for Sienna and take her out of posture chair and put her in the trip trap chair give her the water. Get Tallara to set the table.
5.10 pm	Take Sienna out of trip trap chair and put her on the potty. Clear up the activity she was doing.
5.20 pm	Take Sienna off the potty when she has done a wee etc and put her nappy on. Place her on the floor sitting up and give her switch toys to play with.
5.30 pm	Wash out potty and get put dinner on the table, check Tallara has done her homework.
5.40 pm	Sit with Sienna on the floor and sing songs with signing and action movements. Read her a story and let Tallara ready us a story.
5.50 pm	Get Sienna 200 ml milk prepared and 4ml epilim medicine. Put Sienna in trip trap chair. Put dinner on the table for Tallara.
6 pm	Give Sienna bolus feed of milk and towards the end of feed add 4ml Epilim and flush with 20ml water. Tallara eats her dinner at the same time and we all talk about the day.
6,20 pm	Take Sienna out of trip trap chair and put her on potty.
6.25 pm	Wash tubing out and eat dinner.
6,35 pm	Put on bath for the girls.
6.40 pm	Get Sienna undressed for bath and if Sienna has done a wee or bowel movement then take her to the bath and give the girls a bath.
6,55 pm	Take Sienna out of the bath and give her a massage, dress her gastrostomy site and get her dressed into her pyjamas.
7.10 pm	Put Sienna on the floor to play with her switch toys.
7.15 pm	Wash potty and empty bath. Put girl's dirty clothes in the wash and then clear the table and do the dishes from dinner.
7.45 pm	Sit down with the girls and read stories, check Tallara's homework, get Tallara to clean her teeth.
8pm	Give Sienna bolus feed of 160 ml of milk and flush with 25 ml water, leave tube connected to button and put green connector in the end of it and this acts as a stopper and close the clamp so that no air gets into the tube. Wrap the tubing up and tuck under her singlet or pyjama top.
8.20pm	Take Sienna out of trip trap chair and stand her up in front of potty and take her nappy off and sit her down on the potty.
8.25pm	Set up kangaroo pump for overnight water and juice, set 350ml liquid on 35ml per hour
8.30pm	Get Sienna night time nappy and put insert pad inside and then if she has done a wee take her off the potty, taking care not to pull the tubing attached to her button and then put her nappy on. Carry her to her bed and follow the bedtime sleep routine plan.
8.40 pm	Get Tallara into bed, wash out potty and clean up.

Written by Sienna's Mum: Jewels 01/02/07.

Additional Expenses for Sienna

as at July 2007

Disabilities	Items	Cost	Month	Year
Unable to eat or drink requires nutrition via gastrostomy	Feeding tube 3 per year	21.00 each		63.00
	Cleaning Brush for tube 2 per year	16.00 each		32.00
	Pump hire	15.00 per mth	15.00	180.00
	Bottles to transport milk/juice (8 per yr)	8.00 each		64.00
	Bottle seal (8 per yr)	3.16 for 2		12.64
	Bottle Brush 1 per year	8.00 each		8.00
	Cloth protector around site script	4.70	4.70	56.40
	Special tape to hold cloth in place 2 per yr	4.70	4.70	9.40
Unable to eat or drink requires extra nutrition for growth.	1.2 litre soya milk a day	2.00 each	60.83	729.96
	200ml per day juice (high fibre)	3.00 for 2 litre	6.50	78.00
	50ml prune juice per day	5.79 for 1 litre	6.00	72.00
Unable to walk or stand requires continence products for toileting	Nappies needs 7 a day	36.80 for 72	55.20	662.40
	Disposable Change mat 1 day	3.99 for 4	30.34	364.08
	Booster pads (eg Tena) 1 night	5.40 for 8	20.53	246.36
	Wipes for nappy changes	4.13 each	8.26	99.12
	Utility Pad for sleeping and stroller 2 per yr	13.00 each		26.00
Hearing Impairment	Batteries for aids and toys that make sounds	80.20 for 3 months		320.00
	Hearing Aids			26.25
Hypotonic Muscles	Massage oil for muscles daily	8.95 for 125ml	8.95	107.40
	Special seat for trolley and chairs	55.00 each		55.00
	Physio 1 per month	13.40 gap		160.00
Sleeping Disorder	Mattress Protector	23.80 each		23.80
	Gro bag for sleeping 2 per year	75.95 each		151.90
	Foam Underlay	45.04 each		45.04
Myopia (short sightedness)	Spectacles Jan 06	103.95		103.95
	Lenses Nov 06	208.80		208.80
Memberships	Novita Children's Services			10.00
	Toy Library memberships (Unley & Prospect)			50.00
	Association for children with Disability			5.00
Transport	To attend appointments to specialists and treatment for Petrol	38.62 per mth	38.62	463.44
Medications for Chronic Health Management				
Asthma	Seretide prescription	4.70	4.70	56.40
	Ventilin prescription 10 per year	4.70		28.20
	Spacer/Mask 1 per year	15.96		15.96
Constipation	Benefibre 168g per month	12.76 each	12.76	153.12
	Lactulose prescription	4.70	4.70	56.40
	Paraffin prescription	4.70	4.70	56.40
Nutrition	Saravit prescription	4.70	4.70	56.40
	Lifestream minerals 100ml per mth	36.00 for 500 ml	7.20	86.00
Epilepsy	Epilum prescription	4.70	4.70	56.40
Reflux	Aloe Vera 200ml per mth	12.76 for 500 ml	6.38	63.80
Central Sleep Apnea	Oxygen nasal specs 4 per year	4.70 script		18.80
Middle Ear Infections	Ear, Nose and Throat Specialist (5 visits per year)	15.00 gap per visit		75.00
	Antibiotics Ciproxin ear drops 5 per year	28.95		144.75
Medical Tests	Blood tests (hormonal growth)	50.00 gap fee		50.00
Respiratory Disease	Olive leaf elixir 100ml	22.20 each		22.20
	Antibiotic prescriptions 8 per year	4.70		45.60
Carnitine Deficiency	Carnitine enzyme medicine prescription WCH	4.70		56.40
Totals				5475.77

Please accept this as our story:

'Jewels and Sienna's Story'

Sienna was born in winter 2002, after a difficult birth. I held her in my arms and was amazed that she made it through the difficult labor all in one piece. However the Obstetric Registrar that was on duty at the time, decided to put her on antibiotics, because I was very unwell with a virus. So they took her some place I did not know where. After some time I decided to try and find her, because I wanted to breastfeed her, hold her close to me and talk to her. I eventually found her and insisted that they bring her up to my room. After day two she was struggling to feed and turned purple quite a few times during the day, and then that night the nurse on duty rushed her out of the room, without telling me where she was going. She came back and told me after several hours of waiting. The nurse informed me that Sienna had been taken to a special neonatal unit, as she had cleared her airways and helped her to breathe again and now some tests were being done. After a few hours I had to go find her and give her a breastfeed. When I found her the Doctor and Nurse on duty told me they were isolating her because there was something not quite right about her, she looked different and they wanted to test her chromosomes. I told them I did not care what she looked like, I loved her and I just wanted to feed her and hold her. So I did, and she seemed much warmer after that. I had to leave her in the unit and go. I did this over several days and as I had been insisting they bring her up to my room, they decided to move her to a room with other babies with feeding issues. After a week had gone by the neonatologist visited and told me all the tests were normal, she had all normal chromosomes. We were able to go home, however he informed me she had a dysmorphic appearance and that meant that she would most likely have developmental delay. Then as he checked her for discharge, he found she had dysplasia of the hips. Sienna then needed to have a splint on her hips which did not allow her to move her legs or hips for 3 months. This was an extremely difficult time for Sienna because she found it difficult to sleep and move around with this splint on. I was not allowed to bath her to comfort her. I would hold her lots and sing to her. The hospital did not support me to breastfeed, however I knew it was the best for her. It would take a long time to feed her, then at about 5 weeks of age, I noticed she did not look at me or focus her eyes on me or anything really. I followed this up with the ophthalmologist at the hospital, which took considerable amount of time and then finally this person did not know what was wrong; she said we just had to wait and see. I insisted there was something that perhaps would be done, and then they suggested a Brain Stem test. This resulted in a finding of cortical vision loss. When we saw the Ophthalmologist next, we were told Sienna was blind. Of course I did not believe them, I knew Sienna did see some things and so I learnt to help Sienna. I knew that she loved looking at moving objects and toys that made noises etc. So we spent lots of time trying to improve her vision. Sienna did not enjoy going to the hospital, because the Doctors would not talk to her, like she was there, and so she quickly learnt to switch off from their comments.

I noticed for some time that Sienna would get upset at loud noises and her little face would be expressionless at times. I asked the hospital doctors about this, and they did not believe me. So I found a path through my GP and I insisted on getting a referral to the Hearing Assessment centre with Child and Youth Health. After this appointment it was confirmed that Sienna had severe bilateral hearing loss. We were told grommets would help to improve her hearing loss. So then it was a journey to find an Ear, nose and throat Surgeon who would operate. We had a couple of referrals and when they meet Sienna they just said it would not help her and were quite arrogant about their position. Then we went back to our GP and asked him to phone around for us, we would not leave the room until he did, he found a Senior ENT surgeon, who would see us, he was fantastic and talked to Sienna and Sienna laughed as talked to her. I was able to see that he had a lot of compassion and Sienna liked him. He did the operation and it did improve her hearing to a Moderate permanent bilateral hearing loss. By the time Sienna turned

11 months of age, she had hearing aids to hear. The operation for inserting the grommets was done quite a few times because Sienna's body wanted to expel the grommets. So it was good that the Surgeon was so helpful. We had to do these operations at a private hospital because there was an 18 month waiting list at the public hospital and they did not see Sienna as a priority. There were many challenges for Sienna and I and of course her big sister, who cared immensely about her little sister. One of the biggest challenges was when Sienna got very ill with pneumonia and the nurses insisted on me not breastfeeding because it was too much work for Sienna. They put a nasogastric tube into Sienna. This was not good and Sienna got most upset and stopped eating completely. Then at about 9 months of age she had been admitted to hospital with more cases of pneumonia the doctors informed me that Sienna needed to have a gastrostomy so that she would be able to continue to grow, as her weight was decreasing and she was not growing now for some time. The doctors also informed me they suspected Sienna was aspirating. Due to this consideration and as Sienna did not like the nasogastric tube in and it was becoming more difficult to breastfeed her. At about 12 months of age Sienna had a gastrostomy in. Sienna began to grow and got well and about 20 months of age she refused to breastfeed. I continued to bottle-feed her, however not long after this she got pneumonia again and then stopped eating completely, so all her nutrition was via her gastrostomy. At this stage the pediatrician made a referral to palliative care for Sienna. However I knew that Sienna had a very determined spirit and we found they limited Sienna accessing therapy etc. I was told by the pediatrician that Sienna would not be able to walk, talk, eat or drink etc again, however he did not know why, except to say it is due to some type of neurological disorder. Sienna had previously had a CT scan of her brain and it showed atrophy of corpus callosum (it had wasted away).

There were so many more challenges now, as Sienna had been referred to IDSC Early Intervention Team, however we did not receive very much assistance from them. So I had to appeal to the Minister for Disability to change services to Novita Children's Services. This was quite a process. Novita eventually accepted her as a client when she was about 2 1/2 years old. It was difficult to get assistance from the Commonwealth Government before then because Sienna did not have a clear diagnosis, so that required appealing to Centrelink during that time as well. It was not until Sienna was referred to the Palliative Care service of the hospital that I was able to receive the Carer Payment.

Sienna really enjoyed going to child care in the morning, and now with the gastrostomy she was not able to be given her nutrition, until the staff were credentialed. So I had to give up my part time job and care for Sienna, this was when Sienna was about 13 months of age. I wrote many letters to the Government for them to assist in credentialing. Then the funding came through and so the staff at child care, were able to give Sienna her nutrition.

As Sienna was not able to speak so that others understood her, I developed a picture card system, this was textured, and so when Sienna wanted to do something she was able to look to the picture she wanted and then would be able to do this. This was very effective; however many other people would not use this method of communication, such as Doctors, Nurses and child care staff. So I taught Sienna some basic signs which she learnt quite quickly. However the other people, such as doctors and child care staff, would often not see the signs because they were too busy and they did not give Sienna time to respond. Sienna always likes people to talk to her and many people would stop when they did not get immediate response. Sienna would nod her head up and down to say 'yes, please keep talking to me'. So I became one of Sienna's main forms of communication, we would sing, talk, read stories etc. We found this to be most helpful, especially when having to visit the pediatric emergency department, the staff would not listen to us and they would do unnecessary tests and Sienna would get extremely distressed, so I would sing her songs to comfort her and then the staff would see how Sienna listened to me and responded and then they realized Sienna did understand.

When Sienna was two years old, she wanted to go up with her peers to toddlers, we were told this was not possible, because Sienna was a baby and needed to stay in the baby section.

Sienna wanted to go up to the next level with her friends and play with new toys and learn other things now. So I persisted in many ways, as she would catch many viruses from being in the baby room. So I insisted her health would be better for her to move up to the kindy by the age of three. So when Sienna turned three, they transitioned her up. This was very interesting because the staff had not seen a little girl like Sienna. I explained many things to help them to understand Sienna. Now Sienna was moving around the room on her bottom and using her hearing and vision to get around the room. It took a few months for Sienna to get used to the kindy because it was quite noisy and this would often scare her and the other children would not understand that they needed to come up close and talk to her so she would know they were there. Now as Sienna is 5, I have been asking the Department of Education to transition her to the local primary school, where her sister has been attending for the past 5 years. This is proving to be difficult; they will not transition her until term 4. The Department of Education has recommended that Sienna goes to a special school for children with complex needs. However after Sienna visited these environments, she told me through using signs and picture cards she wanted to go to school with her friends that she knows from her kindy. Sienna has been walking with support and enjoys walking alongside her friends and hearing them talk and sing around her.

In the past years, Sienna has been diagnosed with severe asthma (at 2 years of age, managed with medication), central sleep apnea (at 3 1/2 years of age, after waiting a year on the sleep study waiting list, managed with oxygen when asleep, we were told Sienna most likely had this from birth), reflux (diagnosed at 4 years of age, however when they did the test at the hospital they probe was inserted into her lung instead of her stomach and Sienna got pneumonia, this is managed with medication), chronic constipation (diagnosed at 3 after been admitted to hospital with pneumonia and during the night coughed so much she had a bowel prolapse, because the doctors didn't believe Sienna had a history of constipated, this has been managed through surgery and medication), carnitine deficiency metabolic disorder (diagnosed at 4 1/2 years of age, after a blood test showed she had 1% carnitine in her body, this managed with medication), myopia (diagnosed at 3 years of age and now wears glasses to help bring objects into view), foveal hypoplasia (diagnosed at 1 year of age, after looking at her eyes under anesthesia), optic nerve hypoplasia (diagnosed at 2 years of age after looking into her eyes under anesthesia), epilepsy (diagnosed at 3 years of age and is managed with medication), moderate bilateral hearing loss (has bilateral hearing aids), hypotonia, autism spectrum disorder (diagnosed at 3 1/2 years of age by Autism SA), (bronchomalacia, tracheomalacia, chronic lower lung collapse (managed with respiratory physio everyday); scoliosis of the spine. Sienna has been admitted to hospital over 33 times in the last 4 years. We have had assistance from the therapists at Novita and have appreciated all of this. This has been in the form of a therapy visit once a fortnight, eg Physio twice a term, Speech Therapist twice a term and Occupational Therapist twice a term. We have also been able to access hydrotherapy group and the Novita Toy and Resource centre, which have assisted my daughter learn and develop.

Sienna loves music and is motivated by others around her and enjoys story time. After the last Negotiated Education Plan meeting with Department of Education, we have a feeling it is going to be difficult to attend the local primary school, because the principal does not have an awareness of children with disabilities. The Principal did not come up and say 'Hello' to Sienna; it was though she was not there. He wanted to know what a gastrostomy is, and the nurse at the NEP had to explain this to him. However I am going to persist that she is given the opportunity to be a child and attend the local school. I will have to work with them to assist their understanding of Sienna, as she will love going there and sitting beside the other children and learning from them. I had to write to the Minister for Education to get a space for disabled car park permit, as there were none and the Principal told me it would draw attention to people with disabilities and he did not want to do that.

Sienna also loves to go out to the local park; however there will eventually be no equipment she can play on, because as she gets bigger the swings will not support her enough. So I have written to the local council for them to make improvements to the Council parks, however this will

be a hard task, because we have been told, there are not very many disabled children who use the parks. I explain to them that when the parks have disability access, and families are informed of this, more families who have a child with a disability will access the parks. There is also a need for more car parking facilities for those with disabilities. Sienna takes considerable amount of time to get out of the car and most car parking space is very limited. The doctor at the hospital signed off on a disabled car parking permit, however most time when we park in a disabled car parking space, people ask us if we have a disabled car parking permit. It is especially difficult to access the hospital because there are only two disabled car parking spaces outside the hospital and when it is cold and wet it is difficult to find a car park to get Sienna out of the car safely. There are also long waiting lists for equipment, as we have had to write many times to the Government to access equipment such as a standing frame, which helped her to learn to stand. After waiting about 18 months Sienna now has a wheelchair for mobility and a walking frame to assist her develop her walking skills. These pieces of equipment were accessed through advocating on my behalf with various charities, agencies and other sponsors who have been helpful. Now Sienna is at school this year and can get around at school and also has a communication device, so that the other children and teachers can communicate more effectively with her.

Last year Sienna received a diagnosis of hypotonic cerebral palsy. Sienna is loving school and is at our local mainstream public school, with her big sister. Sienna only attends until 12 noon. There has been so many meetings to achieve this outcome, it has been hard work, but worth every drop of perspiration.

There is so much more to our Story, however it would require a book to be written to capture, this above is a small glimpse. Stay tuned for a book about Sienna's journey.

Jewels
Sienna's Mum