



Comfort, Caring and Elizabeth

Home Care for a Child
with a Neurological Illness

Marla Fine
Revised April 1996

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Dedicated to the memory of
Elizabeth Sabine Fine-Gagne
June 20, 1991 - September 29, 1995

*"The first time her laughter unfurled its wings in the wind,
we knew the world would never be the same."*



Comfort, Caring and Elizabeth: Home Care for a Child with a Neurological Illness
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Looking Back-Preface to the 1996 Revision

I began writing this document towards the end of 1993, when my daughter Elizabeth was nearing the age of two and a half. Just after her first birthday, Elizabeth was diagnosed with Tay-Sachs, a fatal neurodegenerative disease. The next year and a half was not only an emotional roller coaster filled with many lows and a surprising number of highs, it was also an intensive course in medicine, home care nursing, team management and public relations. Frustration was something I increasingly felt, particularly when it seemed that we hadn't been given helpful information soon enough.

That frustration, plus a background in methods and procedures and teaching, led me to write this document in the hope that other children would be able to avoid some of the problems we encountered or, if not, then there would be a variety of practical suggestions for dealing with them. That hope seems to have come to fruition in the two years that we have been distributing *Comfort, Caring and Elizabeth*. It is a great comfort to know that through me, Elizabeth is able to help many other children and their families.

Elizabeth died at the end of September of 1995, at the age of four years, three months and nine days. I record her age in such detail because I think one of the many things we learned from her was to focus more on each day as it happened and to make the time we did have with her as pleasant and as full as possible. Recently, I heard the survivor of a great tragedy speak of the magic of a boring evening at home and it struck a chord with me. I remembered all those times sitting with Elizabeth on my lap in the sun on the front porch or in our cosy chair in the living room, thinking there was just about nothing better in the world to do. And I know now that I was right, and that we need to value the simplest things, the small hand curled around a finger, the smell of freshly washed hair, a soft cheek, a yawn, a stretch.

I spend a lot of time talking about our life with Elizabeth to other parents in similar situations and to friends and family and other groups. I tell them about the difficulties, about the initial feeling of wanting it all to be over soon changing into deal making and goal setting (just let her make to the holidays or her birthday or a vacation), about wanting to escape especially when I was lacking sleep, about trying to fight something for which there is no cure. But I also tell them about the successes, that Elizabeth lived longer and more fully than anyone expected, that her fourth birthday bash was a terrific celebration that her passing was fairly peaceful and in a place she loved, that my sons and my husband and I have grown greatly in understanding and compassion through knowing Elizabeth. As a dear friend of mine wrote, "In her short life Elizabeth awakened more love, sympathy, joy and a heartfelt sense of the preciousness of existence than most of us can do in a long one. It is an enviable legacy."



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Introduction

Our daughter Elizabeth has Tay-Sachs disease. It seems odd how matter-of-factly I can now make that statement - at one time I couldn't even utter those words without falling into tears. But much has happened since that horrendous June day when Elizabeth, who had just passed her first birthday, was diagnosed as having Tay-Sachs, a fatal neurodegenerative illness. Time, while certainly not capable of healing this wound, nevertheless has allowed us to adjust and 'catch up' to our situation. It's not that the hurt has lessened; it's just that we have come to focus more on each day as it comes and on making the time we do have with Elizabeth as pleasant as possible. And that is what we hope this list of ideas will do for you - help you to make your child's life as comfortable and unstressful as possible.

That said, however, I want to warn you that reading through the following pages may well increase your anxiety initially as you wonder about what things you may encounter as time goes on. Bear in mind that each child, each illness and each family's experience is different. Just like other children, each of our kids has their own make-up and set of circumstances that will shape their life. We've had respiratory problems, but then this type of problem runs in my family - in fact our older 'normal' son has mild asthma. Another child we know of had difficulty sleeping at night, but so did her siblings. And a third child seemed to have a relatively peaceful time without major respiratory, sleeping or seizure problems. So rather than worrying about what might happen as you read through these pages, I hope you will feel more prepared to cope with your child's day to day life.

To make this document as useful as possible to as many people as possible, we compiled our list not just from our experiences with Elizabeth, but from our discussions with the other parents in the Canadian Association for Tay-Sachs and Allied Diseases (our support group), from books and from people in the medical community. We have given some background in each section on our experiences with Elizabeth in order to give a context to the ideas. **Please discuss the use of our ideas with the physicians and/or nurses that are helping you care for your child to ensure the appropriateness of the actions.** We hope our ideas and experiences will be of benefit to you.

Finally, we are grateful to Dr. Joe Clarke at the Hospital for Sick Children in Toronto for his support and for reviewing this document.



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Dealing with Doctors and Other Medical People

Having a good 'medical support team' has been crucial to our ability to provide good care for Elizabeth at home. The various people we turn to for support (both medical and emotional) include Elizabeth's pediatrician, her genetics specialist, their nurses, her physiotherapist, her night nurses, the respiratory technician, the palliative care team and our pharmacist. Some of the things that have helped to keep our 'team' running well include:

- discussing and clarifying our goals in the care of our child (comfort, longevity, home care, hospital stays, respite care, resuscitation)
- clarifying the roles of the different medical people involved with our child so that we know who to call about different problems or questions
- making a list of questions and concerns to ensure we cover everything when we talk to the doctor
- discussing the possibility of house calls with the pediatrician before the need arises
- arranging for procedures (e.g., blood tests, oxygen saturation levels) to be done at home whenever possible
- finding out how to contact the doctor or whomever is on call during evenings and weekends
- writing up a care plan (daily & nightly routines, comfort measures, positioning, favourite toys, names of key people & how to reach them, etc.,)
- if we are unhappy or puzzled about the way our child or we are being treated, we discuss it directly with that person. It is important to remember that parents don't have to let themselves be pressured into making decisions before they are ready or have had time to consider all the options. It's okay to question the validity and usefulness of procedures.
- making a checklist like the following one for the nurses (& us) to refer to when Elizabeth is upset:
 - nostrils clear? use saline & bulb syringe to clear
 - rub feet gently
 - check feeding set/g-tube connection
 - adjust oxygen (increase, decrease, put on, take off)
 - adjust position
 - need to urinate (press gently on bladder)
 - release gas from g-tube (wait at least an hour after a feed)
 - check for a bowel movement
 - administer Tylenol, codeine or morphine (we've only used morphine on a couple of occasions)
- using the pharmacist as a source of information, as well a help to get medication quickly
- remembering that no one has all the answers --- we know that there is a certain amount of trial and error, guess work and luck involved in medicine so we try to be understanding and realistic. As one of our doctors reminds us, the doctors are still learning, too, as each child's needs differ



Nutrition/Oral Feeding

Elizabeth was breastfed until she was 10 months old, when we switched to bottle-feeding. She started eating 'solid' baby food from a spoon at about 4 months. Feeding her solids was often difficult, although we didn't know why at the time. While Elizabeth did learn to eat semi-solid food from a spoon, to feed herself cookies and to drink from a cup, she was a very picky eater who ate less than we thought she should. I still feel bad when I remember my lack of patience and anger with Elizabeth when she would purse her lips and make the face that meant "That's it, folks. I'm not letting another bit of food past these lips." She seems to have had more sense than we did, for at that point she was quite chubby and clearly not lacking calories.

Mealtimes became more pleasant & less tense after Elizabeth's diagnosis was confirmed and we understood why eating was becoming more difficult for her instead of easier. We found that mushy food was easier for her to swallow than thin, runny foods. (A Fisher Price food mill was really helpful for getting foods to the right texture.) She also came to like finger feeding rather than spoon feeding. Most importantly, we didn't push the quantity of solid food and we also left time and room for the treats (chocolate cake, cheese buns, peanut butter sandwiches) that Elizabeth really liked.

As time passed and Elizabeth's ability to eat solids continued to decrease, we began to supplement her milk with small amounts of Ensure with fibre™. She liked the vanilla flavour so much, that she eventually refused plain milk. We gave up on solids completely when Elizabeth was about 17 months old and struggling with the chicken pox. Things that may help include:

- grinding solids with a food mill
- using Ensure™, Ensure with fibre or Pediasure™ if a regular balanced diet isn't possible
- thickening liquids with Quick Thick™ or cornstarch to make them easier to swallow
- adding Polycose™ to regular, water or Gastrolyte™ feeds to maintain or boost calories
- using 'cleft palate' squeeze bottles if regular bottles get more difficult
- feeding pureed food in a Sassy bottle
- feeding smaller meals more frequently if prolonged oral feeding is tiring

G-Tube Feeding

Eventually bottle-feeding also grew more difficult. The feeds took longer, Elizabeth began to vomit more and our frustration was increasing. Then, Elizabeth was hospitalized with viral pneumonia. She had great difficulty sucking and feeding, and was put on intravenous feeds. One doctor raised the possibility of a gastrostomy, but it was suggested that we give Elizabeth time to recover and regain her ability to drink from a bottle. Unfortunately, she didn't have that time. When she came home she was sucking better, but continuing to vomit a lot. After about a week, she was back in hospital with bacterial pneumonia. A barium swallow showed that she was aspirating. We were faced with one of the more stressful decisions we have had to make - switching to gastrostomy tube feeding. While we had largely decided when Elizabeth was diagnosed that she eventually have a G-tube, it was happening sooner than we expected. And even though we felt that it was inevitable and that it would ultimately make her more comfortable and that bottle feeding was no fun at this point, it still seemed to be such a great step backward, such an admission of defeat. And it was. . . . but it was also what was going to keep Elizabeth most comfortable and well and here with us, so we went ahead with the gastrostomy.



In retrospect, the G-tube has allowed us to achieve our main goal: keeping Elizabeth comfortable and at home with us. Because she is well nourished, she is stronger, healthier and able to use her valuable energy for cuddling, exercising and going on outings rather than struggling to eat. It also makes giving medication quite easy. This is not, however, to say that g-tube feeding is the only choice; rather, it was our personal choice given Elizabeth's condition and our situation. We know of other families who have made different choices (nasal-gastric tube feeding, no tube feeding at all, or a combination) that were right for their children. It is an incredibly difficult decision, but it was helpful to talk to others who had already gone through it. Some of the other things we have done or are doing include:

- minimizing vomiting by
 - raising the head of the bed
 - keeping the child on an incline with head up
 - not moving the child for 30 minutes after feeding
 - clearing any mucus through doing chest physio before a feeding
- switching to G-tube feeding before the situation is critical
- reading booklets and websites on Gastrostomy Tube Feeding
- reducing the volume and/or lengthening the time taken to give each feed (for example, 200 mL over an hour instead of half an hour) if vomiting or spitting up is a problem. The kangaroo pump makes this easier to do. It can also be used to do a long, slow feed at night.
- releasing stomach gas by holding the opened G-tube face up for anywhere from a few seconds to a few minutes several times a day, especially after coughing or seizures. Getting out gas really seems to alleviate discomfort and vomiting.
- on outings, using 60 mL syringes to feed by G-tube. We do this at the park, the mall, Centre Island. You get some odd looks, but it beats staying at home all day.
- making sure that Elizabeth is fed at least the minimum amount of fluid set out by her doctor. In her case this is 80 mL per kilogram of body weight - for example, she weighs 15.5 kilograms so she needs at least 1250 mL of fluids a day. This can include Ensure, juice, Gastrolyte, Polycose & water, etc.

Bowel Movements

Constipation and hard, painful stools have always been a problem for Elizabeth. In addition to the discomfort, Elizabeth throws up when constipated. We have tried such things as:

- prunes (which she loved the taste of) and prune juice
- stool softeners such as Lansoyl (which she also loved) or Colace (which has a bitter taste)
- a fibre rich formula such as Ensure with fibre
- movement and exercise, especially the torso, hips and legs
- quite warm or quite cold liquids
- cranberry juice (it helps to bring water into the gut)
- stimulating the bowel by putting a plastic-covered, Vaseline tipped finger just slightly into Elizabeth's rectum. We buy plastic gloves from a medical supply store and use one of the glove fingers each time. We can feel some stool if Elizabeth needs to pass one. Her need to have a bowel movement is often signalled by flatulence, complaining/moaning, coughing or general agitation.



- giving plenty of fluids, especially in warm weather
- using a laxative tea as needed

Respiratory Care

Elizabeth's weak spot has always been her respiratory system, and she certainly had more problems in this area than many children we know. The main challenge on a daily basis is to help her deal with phlegm, particularly in her upper airways. Her breathing has always been noisy, even as a baby - we used to call it 'rusty pipes'. She often sounds worse than she is, so I got a stethoscope and listened to her chest daily. In time, I was able to sort through the noises to ensure that there was good air entry throughout her lungs and that she didn't seem to have pneumonia, which is the thing we worry about the most. So strongly did the doctors stress the dangers of bacterial pneumonia due to aspiration, that we felt that every time Elizabeth spit up or vomited, she would get pneumonia, but fortunately this hasn't been the case. We also worry that each cold or cough will lead to pneumonia, particularly with Elizabeth's immobility. Because of these concerns, we have taken a lot of preventative steps and have, by and large, been successful at keeping her comfortable and reasonably well in a quite unreasonable situation. Here are the things we have tried:

- chest physiotherapy (clapping, vibrating or percussing by hand or by massager, stretching, arm circling). We do this ourselves, but also have a physiotherapist come in 2-3 times a week through the Ontario government Home Care program. We bought a Wahl Massager for \$40 that both loosens phlegm and relaxes Elizabeth.
- frequent position shifts during the day and turning every 2-3 hours at night
- stroller rides (the bumping and jiggling help), making sure the head is adequately supported
- raising the head of the bed
- using a rolled up towel to position her on her side
- using mouth swabs (Toothettes) to clear away phlegm in the mouth rather than suctioning. They can also be used to stimulate the back of the throat, causing the child to cough and clear out phlegm.
- suctioning as needed, but not over-doing it
- using a nasal bulb syringe and a saline spray to clear a stuffy nose (instead of irritating her nose with the suction machine). Wash the bulb syringe thoroughly with soap and water after each use. Throw out the nasal spray after 30 days.
- feeding clear fluids (water & Polycose™, Gastrolyte™ or Pedialyte™ & Polycose™, juice & water) at night or as last meal before bed or for a couple of days when she has a cold or cough in order to loosen phlegm. We move back to "regular" feeds gradually to make sure that she is able to tolerate them.
- giving Ventolin inhalant masks to open the airways and help break up phlegm. Also adding an anti-inflammatory drug such as Pulmicort to sooth irritated airways. We increase or decrease the number of masks given according to Elizabeth's health.
- use an air purifier to minimize respiratory irritants (dust, bacteria, pollens).
- turning to G-tube feeding when oral feeding is becoming a struggle for the child. This decision is a very individual one - find more on this topic in the feeding section.



- using oxygen as needed. Signs of respiratory distress include:
 - purplish coloured lips and finger nails
 - sunken & darker skin around the eyes
 - rapid breathing rate (can be caused by other things too)
 - sucking in of the skin near the collar bone and the lower ribs,
 - laboured breathing
 - low oxygen saturation levels
- looking for alternative causes of coughing, e.g., conjunctivitis, bowel movements, G-tube irritation (check to ensure the balloon is properly inflated), too much or too little oxygen, allergies. It may sound nutty, but these things did cause Elizabeth to cough a lot; then when the problems were solved, she stopped coughing. It seems that coughing one of the major ways in which she expresses discomfort. We have also heard of other children who do the same kind of thing.

Infections (Coughs, Colds, Flu, etc.)

Right from the start, Elizabeth seemed to get every bug that was going around. She had her first ear infection at 2 weeks old, and has kept right on going since then through colds, coughs, croup, more ear infections, pneumonia (viral & bacterial) and even chicken pox. I guess it's due to a weak immune system, as well as the germs carried by parents who work in a hospital and a school and by her older and younger brothers. Ever vigilant to avoid what we can, we (rather obsessively) do the following things:

- get flu shots for the child and/or the family
- wash hands with antibacterial soap when entering the house or before dealing with Elizabeth. (This includes any visitors.)
- screen all visitors for colds or flu
- try to book doctor's appointments for first thing in the day, before there are too many other sick people in the office
- switch to clear fluids (juice, Gastrolyte, chicken soup) for a day at the beginning of colds or flu
- keep a supply of antibiotics (unmixed) on hand in case we want to start treatment at night or on the weekend. In consultation with our doctor, we have promptly started antibiotics at the first sign of a respiratory infection and are convinced that this has helped keep pneumonia at bay.
- use Ventolin inhalant treatments to break up phlegm in the lungs
- give yoghurt or acidophilus capsules to a child who is on antibiotics to avoid yeast infections and stomach upsets
- try vitamin C and other supplements. We're not sure how useful this one is, but it's worth a try. Everyone in our family is taking them.



Seizures

For about 6 or 7 months after Elizabeth was diagnosed, we did not have any real problems with seizures. They consisted mostly of what we called “checking out” - rolling her eyes and looking a bit blank for a few seconds. It was when Elizabeth was 19 months old and in the hospital with pneumonia that we started giving her anti-seizure medication . At that point, her seizures lasted about one to two minutes and consisted of facial ticks, limb twitching and irregular breathing. We were told that the seizure drugs would cause drowsiness; however, we noticed that with Elizabeth, they left her more alert overall since they reduced the seizures that made her tired.

From our conversations with doctors & other parents, it seems that the nature of seizures, their control and the effects of anti-convulsant drugs differ from one child to another. The drugs and dosages used will vary. Some parents choose to use very little in the way of anticonvulsants while others move in the opposite direction. Again, it depends on the child, the parents and the doctor.

We have had to increase Elizabeth’s dosages and add drugs as her illness has progressed and seizures became more of a problem. Our main guide with seizure control has been to adjust her medications when the seizures seem to be causing her a lot of discomfort or unease. The medication itself can be a little hard on the stomach so we usually give it to her after she has had about 50-75 mL of her feeding. Doing it this way also seems to slow down the absorption rate a little. It also seems to us that seizures sometimes increase temporarily due to stress (illness, constipation, lack of sleep). Once we deal with the root cause, the seizures go down. Other ideas include:

- discussing the benefits and possible side effects of different anti-convulsant drugs with the doctor
- recording the times, duration and types of seizures if you are unsure about changes in the seizure pattern
- adjust anti-convulsant drug dosages as necessary and in consultation with the doctor
- give anti-convulsant drugs at sleep or nap time if possible
- use Lorazepam (a short term anti-seizure drug) to stop prolonged seizures

Positioning/Seating

Elizabeth was never able to sit or stand completely on her own. She has grown increasingly more ‘floppy’ and unable to support or move her body. The challenge here is not just to provide comfort, but to do it in such a way as not to break the bank (\$\$\$\$). These ways include:

- a bean bag chair. Absolutely fantastic -- they can be rearranged to suit a variety of positions and they don’t look ‘institutional’. If the chair starts to lose its size, more styrofoam ‘beans’ can be bought to fill it up. It helps to put a soft blanket or quilt on the chair. The only difficulty we’ve had with the chair is trying to keep other kids and adults from taking it over - they like it as much as Elizabeth.
- a Tumble form seat with a rolled up towel just under the neck to support the head and keep the airways open
- removing the front bar (the one over the legs) of the stroller to make it easier to put toddler size children in it



- using a double stroller with the front seat flattened for the child to lie in.
- layers of eggshell foam in the bed to create a raised pillow for the head and to avoid bedsores
- raising the head of the bed/crib
- putting a rolled up towel behind one shoulder/back to lie Elizabeth on a side incline. Then shift sides through the night. This position helps her to cough out phlegm and mucus. A face towel or cloth under Elizabeth's mouth keeps the sheets dry.
- using an inflatable bath pillow with suction cups to anchor it in a shallow bath to support Elizabeth's head (much cheaper than an expensive bath chair). A hand held shower spray can also be used.

Irritability/Poor sleeping

Elizabeth was a very irritable infant. She cried and wanted to be held a great deal. While she slept well at night, she rarely napped for more than 45 minutes at a time. When she was about 6 months old, she was down to 15 minute naps, from which she would awake screaming and almost inconsolable. Given that our son Jesse is two years older and also needed his share of attention, life was pretty stressful. In retrospect, we know that some of Elizabeth's irritability was due to gas pains and hard stools, but some was simply a symptom of Tay-Sachs disease which at that time had yet to be diagnosed.

After diagnosis, we were told that nitrazepam, an anti-seizure drug, helped to alleviate irritability when given in low doses. We were, however, unsure as to when we should start using it and the guidance we were given was rather unclear. Elizabeth was 18 months when we did start giving it to her and the result was a very definite improvement. It was as if the connections in her brain had been cleared. We were back where we were a few months before and Elizabeth was brighter, happier and more responsive than she had been for some time. Our great regret is that we hadn't tried it earlier, so you might think about:

- investigate suggested drugs. They can always be stopped if they don't work well.
- maintain regular sleeping and eating routines. If we find our child awake in the middle of the night, we let her go back to sleep rather than encourage her to stay awake. After all, we need our sleep in order to give her good care the next day. We also try not to let her sleep excessively during the day.
- chloral hydrate can also help the child to sleep
- rubbing the feet. Poor circulation means the feet get quite cold. Rubbing them really calms Elizabeth down. I also wonder whether she gets cramps or 'pins & needles' from having her feet & legs still for long periods of time.



Skin

One of the important ways to keep a child comfortable is to keep their skin healthy. Although we've managed to avoid them, pressure sores can be a problem with largely immobile children. One of the basic ways we have managed to avoid skin problems is by making sure our child is well nourished and given enough fluids. Other ways are:

- frequent position changes, including at night
- lying the child on a lambskin (or an imitation if the child has a wool allergy)
- leaving diaper area exposed to the air to help cure diaper rashes
- keeping the skin dry and clean
- baby oil to loosen and remove seborrhea, cradle cap and dry skin

Hiccups

Everybody's heard of some cure for hiccups. For a healthy person, our surefire method is to hold your arms straight up (thereby stretching the diaphragm) and have someone feed you a glass of water. With this in mind, we tried a variation which works quite well for Elizabeth:

- after the 1st or 2nd hiccup, lift both arms above the head for 10 seconds or so (or until the interval between hiccups has safely passed)

Complementary Therapies

Just after Elizabeth turned 3, I read a book by Tom Harpur called *The Uncommon Touch*. It looks at the roots of spiritual healing and then focuses on the modern day technique of Therapeutic Touch, which is used by over 30,000 nurses in North America. Therapeutic Touch stems from the ancient practice of the laying-on of hands. It is a 'consciously directed process of energy exchange during which the practitioner uses the hands as a focus for facilitating healing'. It was developed by a nurse, Dolores Krieger, and is used in many hospitals. It basically involves centering or focusing oneself and then moving one's hands in graceful, sweeping motions a few inches from a person's body in order to scan the person's energy flow and restore order and balance to the diseased system. Therapeutic Touch seems to promote a person's natural healing ability, quickly elicit a relaxation response and reduce anxiety.

Now, I am a non-religious, not particularly spiritual person who jokingly refers to the five minutes that I spend twice a day doing therapeutic touch on Elizabeth as hocus-pocus. But it does seem to help. Since I started doing Therapeutic Touch, our use of pain medication (Tylenol, codeine) has gone down. Elizabeth is more relaxed and better able to fight off infections. I don't know if it would work for everyone, but as well as being helpful, it's really pleasant time for Elizabeth and me.

More information can be obtained in Ontario from The Therapeutic Touch Network, phone (905)454-2688.

Another family we know used acupuncture and chinese herb treatments with their child who did quite well. Like us, they also used Western medicine such as anti-biotics, chloral-hydrate and



oxygen. They call it the best of the East and the best of the West, highlighting that different approaches to medicine and health can work very together.

Outings/Trips

Given our natures and the fact that we have two other children, we have taken Elizabeth on quite a few day trips and vacations. Early on, it didn't pose much of a problem, but it has since grown more complicated. Some things that have made things go more smoothly are:

- renting or borrowing a mini-van so that Elizabeth can lie on her side while travelling
- trying to travel during nap times
- using a double stroller with the seats flattened
- taking a portable suction machine along
- giving a clear feed if vomiting is a problem
- preparing a checklist of the items you need to bring
- arranging for a nurse or friend to accompany you on vacation

Odds & Ends

In no particular order, here is some helpful information:

- make use of support groups. Talking to other parents in similar situations has been invaluable for us in many ways. Check with your doctor, hospital or Easter Seals organization for contacts.
- the Canadian government disability tax credit can be claimed on your income tax form by the parent with the higher income
- Ontario government programs include:
 - Special Services at Home (Community & Social Services) which covers up to 10 hours per week for someone to provide parental relief
 - Home Care program which arranges & co-ordinates such things as nursing, physiotherapy, homemakers, oxygen, blood tests at home
 - Assistive Devices Program which pays for 75% of the cost of a variety of medical supplies and equipment
 - Handicapped Benefits
 - Private health insurance coverage may cover the cost of having a nurse in your home and other medical needs
- Easter Seals has a fantastic information package & newsletter
- Local community groups/charitable foundations such as the Lions' Club, Rotary may be able to help with the financial burdens.



Contacting Us

If you would like more information, you can write to:

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Canadian Association for Tay-Sachs & Allied Diseases, Inc (CATSAD) is a non-profit charitable organization. It was founded in 1988 by a small group of people who shared a common tragedy. They were parents or supportive family members and friends of children who had rare, fatal genetic diseases.

CATSAD was created to: establish and maintain a parent peer group to provide emotional support and practical guidance to parents of children with one of over forty diseases such as Tay-Sachs, Niemann-Pick, Krabbe or Canavan; provide information, guidance, services and resources to members and to the public; develop, coordinate and implement educational, medical and research programs concerning the prevention of these diseases.

CATSAD is affiliated with National Tay-Sachs and Allied Diseases, a non-profit, voluntary health organization in the United States that supports international programs to help eliminate Tay-Sachs and the allied diseases.



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