

care/preschool and school settings. My daughter was fully included throughout her life. It's basically the same as for any child with special needs. Please contact me if you have more questions about this: angelbearmom@shaw.ca

23. Do you have a listerv for parents/caregivers of kids with Hydranencephaly?

Yes Go to the website:

<http://hydranencephaly.com> and click on the yahoo button that is on the side bar. That will take you to the mailing list subscription; all members have to be approved by either of the moderators so you will receive a letter asking you to explain your interest in the list. This is just so we know who is on the list. Or you can email me directly at angelbearmom@shaw.ca and I will subscribe you.

24. Why is it that everything the doctors tell me is so negative and what I read here is not?

Because there's a good chance that your Dr has never seen a child with Hydranencephaly in his own home environment. Please read Dr Shewmon's article. His theory is that if you treat your child as if they are a "vegetable" or will never do anything, then most likely they won't. However, if you treat your child as you would any other child, then they'll likely be very responsive and many can do surprising things given their diagnosis. We have one child who can walk and run, several who can talk, those who have favorite tv shows and toys, etc. For information on stimulating your child and possible toys please see chapter: Drs usually only see your child when he or she is ill or during an office visit of a few minutes duration. Because your child is in a strange environment there is a good chance that they won't be as responsive as they are at home. I'm afraid that many Drs believe what the text books say about out children.

A point from a mom: I think a good point to bring out for this question is that our kids don't just 'change' on their own - it takes a LOT of work - medical help - medication and changes in medication, therapy, equipment, stimulation

and then EVEN with all of this NONE of our kids are the same, BUT most if not all of them become happy children who do have a lot of good times.

25. I had a child one year ago born with Hydranencephaly. I am 16 years old now. I had my daughter when I was 15 and got pregnant when I was 14. I was just wondering how come other children can survive with this condition and mine did not?

That's such a difficult question to answer. The short answer is no, there's no way of knowing why one child lives and another doesn't. That doesn't help does it. One thing we've noticed is that it appears that the earlier the damage occurred in the pregnancy, the more severe the condition is and the less chance the child has of surviving. That's not a scientific fact and may not have any validity either. I've spent the last 3 years asking the same question as you. So many of the children have shown the same symptoms and signs as my Kayda did and they've recovered. Kayda started to deteriorate and it didn't let up. It does appear that the first year is definitely the hardest for children with Hydranencephaly. If they survive the one year mark they're likely to survive several years. There's just no way of knowing why some children live many years and others barely survive beyond birth.

These are only some of the questions on this topic contained in the full FAQ document we've developed. To read more of the questions and answers about Hydranencephaly please go to: <http://pub29.bravenet.com/faq/show.php?usernum=2462988606&cpv=1>

Or contact Barb at: angelbearmom@shaw.ca
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This pamphlets is one of a series of pamphlets about Hydranencephaly. Other pamphlets include:
When Your Child Has Hydranencephaly
Myths About Hydranencephaly
Hydranencephaly, The "Facts" According to Parents.
Frequently Asked Questions About Hydranencephaly
#s 1-7
They can all be obtained at the above address

**International
Hydranencephaly Support
Group**



**Children with
Hydranencephaly live
real lives**

**Frequently Asked Questions
about Hydranencephaly
2**

General Information About
Hydranencephaly (cont.) and The
Emotional Aspects of Caring for a
child with Hydranencephaly

(Questions 14-25)

<http://hydranencephaly.com>

General Information On Hydranencephaly
(cont. questions 1-13 are on FAQ Brochure 1)

14. What is the progression of this condition? What can we expect to see?

That's a tough question to answer. No 2 children with Hydranencephaly are alike. The most common problems you see in the first few months are: hydrocephalus needing a shunt, seizures of various types and difficulty controlling his/her temperature. Some children have other difficulties as well such as feeding problems, breathing difficulties or diabetes Insipidus. Others have none of these problems and appear to be quite normal and healthy. As the children grow more problems may show up; muscle tightness will likely occur which can be helped by physical therapy, vision, & eating problems may also show up. There is no set pattern to this condition. The first year seems to be the hardest for our kids. Those that survive the first year often live many years. My daughter lived until she was 11 1/2. We have 4 members who are over the age of 20. For more information on the various conditions/problems that children with Hydranencephaly may have please see: <http://hydranencephaly.com/researchresults.htm>

15. Does he feel pain?

Yes, in my experience children with Hydranencephaly feel pain like any other child. They also have the same emotions as any other child. Some children are less responsive than others, but yes they do experience pain. Parents will come to know how to tell if their child is in pain. If your child is on a monitor often you'll see his/her heart rate go up when in pain. Kayda cried only when in extreme pain, and even then, only if I wasn't holding her.

Emotional Aspects of Caring For A Child With Hydranencephaly

16. How do I explain my child's needs and condition to family members who have never met him?

With my daughter I found that it was best if I

just let people meet her and then answer any questions they had. If I told them all about her needs and her condition ahead of time it scared them off. Once people had met her and seen how beautiful and responsive she was, and given them one of her giant smiles, they were more ready to find out more about her. I suggest that you treat and talk about your child as the child he is, forget the diagnosis as a major thing. He's still a beautiful little child. If family members want to know more about Hydranencephaly, there is the Brochure which is available online at http://hydranencephaly.com/fact_sheet.htm) It's at the bottom of the page. On this page is also the "Fact Sheet" which can be printed out and given to interested people. I would suggest using the brochure first as the Fact sheet is more technical.

18. I feel guilty for feeling this way but, I am always on the edge about my daughters condition meaning... it's been said that she will be taken from me one day so if I'm at work, at the gym, or anywhere and I get a call I automatically think it could be THAT DREADED CALL where before I never thought that, has anyone else gone through this?

Yes, I think all of us have gone through these sorts of feelings. I remember that when Kayda first came to live with me, I felt I couldn't make any plans more than a day ahead of time in case I "jinxed" Kayda and something would happen. Every time she saw a Dr they would remind me that she had no life expectancy and that I should expect her to die any day. It's a hard way to live. I eventually relaxed to a certain extent but was always on edge. I never knew when I got her up in the morning or put her to bed at night, if she would end up doing something and end up in the hospital. And that happened regularly. I made sure I was reachable at all times when I was away from her by cell phone or pager. It's a difficult way to live but know that you're not alone in having these feelings and concerns.

19. How can I afford to take care of my child?

There are many services available to help families with the expense of caring for a child with so many health care issues. Your hospital or early intervention program should have a social worker that can help you with what services are available for your child. There are special waivers available to help with medical costs not covered by other programs. In some areas children with severe disabilities automatically get Medicaid and in others they don't. If a social worker isn't able to help you, contact your local Association for Retarded Citizens, Cerebral Palsy Association, etc. They will know whom to contact. For information on services in your area see: <http://cshnleaders.ichp.edu/TitleVDirectory/directory.htm> There are many other places to go to find information on funding in your area but this is a good starting place.

20. I have a job -- who will take care of my child while I work?

You can contact local nursing agencies. Call all of them. Ask how they are staffed. Staffing is important because of "sudden call-offs." There are also a variety of daycare options. What is available varies considerably from area to area. Having a social worker who has a lot of contacts is helpful. Their local Association for Retarded citizens is a good start.

21. If this is too much for me to handle, what options do I have for my child?

There are respite programs available, which can provide short term care. Guardianship is also an option. I believe that in guardianship you maintain legal custody of your child but he/she lives in another family. There is also adoption and foster care. And, for many families it is extended family members who care for the child-either full time or part time.

22. Can anyone share experiences about success including very young children with hydranencephaly in typical day care settings?

The families on the mailing list will be the biggest help in answering this question. Many of the children have been included in typical day-