

International Hydranencephaly Support Group

Providing support, information and encouragement to families of children with Hydranencephaly

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Hydranencephaly Frequently Asked Questions

General Information On Hydranencephaly:

1. What is the oldest person you know of with Hydranencephaly?

The oldest person that we know of is 24 years old.

2. What is the average life expectancy of a child with hydranencephaly?

According to the study conducted in 2002, and also the list of children we know of with Hydranencephaly, the average age of children living is 7.7 years, and the average age of death has been 4.7 years. These numbers really don't mean a lot. As with all averages many are older or younger than that age. I also believe that the average age of death is so low because it includes the children who died before or just after birth, and those who died because a Dr refused to treat the child, or those who were born too early due to a Dr insisting on an early delivery.

3. When will my child die?

Of course, that's impossible to say. Of the 53 children we know of who have died, 39% died before the age of 1. Our oldest child who has died was 17. We have 4 children/young adults who are now over the age of 20. Some of the children die suddenly with no warning. Most have either been ill, or have gradually had increasing health problems, or their bodies have just gotten tired. The most important part of being a parent of a child with Hydranencephaly is to cherish every single moment of your child's life. Take a ton of pictures and videos. You will never regret having too many pictures or videos and I can guarantee you that no matter how many you have, after your child dies you will wish there were more. Forget the dust in your house, sit and cuddle your child. Throughout Kayda's life, I never was able to plan ahead because I never knew how long she'd last. I didn't want to "jinx" things by planning too far ahead. But, about 4 months before she died I realized that she was dying and that I needed to let her do so. Because of that knowledge those last 4 months were so precious. I took a ton of pictures that still bring comfort. And, looking back at the pictures I'd taken over her life, I realized that she'd had a very happy full life. That made her death somewhat easier. Most families don't have that warning period. Just enjoy every minute you have with your child.

4. How will he die?

Again, that's impossible to say. Your Dr will likely tell you that it will be pneumonia that will take your child's life. For the 53 children we know of who have died, 28% died of respiratory problems, 9.4% of shunt or neurological related problems, 1.9% of GI shut down, 5 % of brainstem shut down, and 41.5% of unknown causes. A few of the children have died from acute respiratory illnesses. But, most children just keep developing more difficulties and gradually recover less quickly or completely from an illness. Some, like my daughter Kayda, just have their whole systems slow down and die. In Kayda she started having increased seizures, started sleeping a lot, got much colder, heart rate slowed dramatically, respirations decreased and food stopped moving through her system. We believe that her brain stem just shut down and wore out. Of course the end of life is different for each of the children.

5. One of the resident neurosurgeons said that "we were just delaying the inevitable by having the shunt put in, that respiratory failure would most likely be the cause

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of her death so we took CPR classes. Has anyone experienced any type of respiratory problems that required any cpr?

Yes, many of the parents I asked, know CPR and have an ambu bag or several on hand at all times and have had to use both. I never did for Kayda although she came close to needing it several times.

Another reason this is good to know is that some families have had trouble finding a Dr who is willing to resuscitate a child with Hydranencephaly. So, sometimes you are in a situation where no one else will do it. This doesn't happen often, but it was always my main fear with Kayda.

6. Every time my child becomes lethargic or vomits my Dr tells me that he/she is "shutting down" and is dying. How will I know if he/she is really shutting down or dying?

That's not easy to say. Please see also question 4. In most cases, the process of shutting down is fairly gradual and only recognized after it's been going on for a long time. That's what happened with my daughter. Generally a child who is "shutting down" will do so over a long period of time (weeks or months). If your child is ill, but was generally alert and aware and relatively healthy before that, he/she is likely not shutting down. In those cases it's always good to try treating your child with antibiotics, iv fluids, breathing treatments, etc just to see if he/she can recover from the illness. If the child doesn't respond to those treatments, then it may be time to stand back and not do aggressive further treatments. But, this rarely happens suddenly. Children with Hydranencephaly frequently have coma type incidences where for several hours or days, they are unresponsive, sleep all the time, and have a very low temperature and heart rate. Generally the children recover from this. Often these incidences occur before or after an illness. Kayda did this quite regularly during her life. And, when taken to hospital I was told she was shutting down. Well that never occurred and she always got better.

7. When my child was sick the last time, the Dr told me that if she needed to go on a ventilator she would never come off and that it would not be in her best interest. Have any of the children with Hydranencephaly gone on a ventilator when they were sick and come off of it?

Yes, quite a few of the children have done this. Helping the child with a ventilator gives him/her a bit of extra help and a chance to recover and declare if they can recover from this illness.

8. Are there any children with Hydranencephaly who are on ventilators? What is their quality of life?

Yes, again, there are a few children who have been on a ventilator or bipap for several years and in 2 of the cases at least, the children have never been as healthy or happy as they are now on the ventilator. Having the ventilator help with breathing gives the child more energy to interact with others. And, many of the children on ventilators aren't on them full time.

9. Are there any kids that you know of that were misdiagnosed with hydranencephaly?

Yes, children's diagnoses often change. The most common other diagnoses are: Lissencephaly, Porencephaly, Lobar Holoprosencephaly, and Schizencephaly. Some children end up with numerous diagnoses throughout their lives. For most of the other

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diagnoses, the over all prognosis and care doesn't really change. Some like, Porencephaly are a milder version of Hydranencephaly. Schizencephaly also is a less severe condition. There are also children who are originally diagnosed with Hydranencephaly who are later found to just have severe hydrocephalus. For more information on the different conditions see: <http://www.neurologychannel.com/cephalicdisorders/types.shtml>

10. Are there conditions that are similar?

Yes, see previous question. We are also seeing children whose brains were damaged shortly after birth who have the same sort of challenges as a child with Hydranencephaly. Their brain scans appear to be the same of those of children with Hydranencephaly. We include them in our group and statistics even though their official diagnoses is not Hydranencephaly. For more information on similar conditions see:

<http://www.neurologychannel.com/cephalicdisorders/types.shtml>

11. Can my child have hydranencephaly and not be diagnosed with it?

Yes, definitely. Diagnoses of conditions such as Hydranencephaly isn't an exact science. Often if you show a child's CT or MRI scans to different Doctors, you will get a different diagnoses.

12. Can brain tissue grow back? Or can parts of the brain my child has be trained to do things that it normally does not do?

Unfortunately brain tissue does not grow back at all. But that does not mean that the status and abilities of a child with even extensive brain damage are fixed and unalterable. For one thing, it may be that even parts of the brain that are there do not work properly because they are not getting the input they would ordinarily get from the parts that are missing. But these parts may eventually adjust to that absence and start functioning. Then there are various forms of learning and so-called plasticity at every level of the nervous system, including the brain stem. Needless to say, in all these instances, stimulation, the opportunity for exercise, and loving care are what allow the potential functional capacity of the child's neural equipment to emerge. (Dr Bjorn Merker)

13. Can Hydranencephaly be diagnosed prenatally by ultrasound?

Yes. It's becoming more and more common to have a diagnosis before the child is born. Unfortunately, a down side of this, is that Drs then promote that the parent terminate the pregnancy. Often the medical professionals put a lot of pressure on the family and paint a very dismal picture of the child's life.

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

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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.

17. My wife and I have been through some very hard things in our lives and even though my child is only 2 months this with out a doubt is the hardest thing we've encountered to date. Has going through this caused a strain on any of you alls marriage?

Yes, it definitely has an effect on all aspects of family life. In my case, even though my child was a foster, child, my marriage didn't survive the stress of this sort of care. It probably would have ended any ways at some point as it was in deep trouble almost from day one, but caring for Kayda did add to the stress and to the resentment that my husband felt about the amount of time that was focused on Kayda. A big stress relief for families is respite care, either in your home for a few hours at a time, or overnight with a trusted caregiver. Taking the time to be a couple, and also to be a family if you have other children, is very important.

Another point of view from April, mom to Chris who went to Dance with The Angels on Feb. 1 2003 at the age of 14: "Although I never married, I had 2 long term relationships in my life. My first long term relationship was with Paul. After I broke up with Paul, he continued to visit with Chris often and take him for his walks in the park. He even kept Chris for overnight visits when he was able. My current boy friend loved Chris to the fullest. Still does. Never was Chris a factor in our relationship strains. Them 2 knew how to suction and feed Chris better than most family members. The bond they had was unbreakable. I don't know if this answer was exactly what you were looking for. Marriages break up all the time and to blame a child

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with disabilities is just an excuse. There is probably underlying problems to begin with. I get very upset when people blame the child for their failed marriages. I was once told by a "friend" "It must be hard for you to get a boyfriend because of your child." Can you tell it hit a nerve?

From Kimbra, mom to Dillion age 1: I would say having Dillion has put some strain on my marriage at times when things have been very difficult but over all I think having Dillion has brought me and my husband together.

From Lisa, mom to Noah age 20 months: Every week we try to spend just a little bit of time ALONE. We are lucky to have good friends who babysit every week who we have 'trained' to care for Noah. We don't go far, or for long and take our phone with us, but just that small amount of time is great to be together without the boys. It is sometimes easy to forget that we were a couple before we were parents.

Also - I find that when we both share the responsibility of caring for Noah it is a lot easier. I am home full time so obviously I spend more time with Noah, but I am trying to get Aaron to take on more responsibility rather than just feeding and giving meds, such as doing more physio with him, coming to appointments when he can etc. I find that if we both know what is going on with Noah it takes the pressure of me doing everything and it is easier then to spend time as a couple.

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://cshcnleaders.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?

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You can contact local nursing agencies. Call all of them. Ask how they are staffed. Staffing is important because of "sudden call-off's." 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 daycare/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 \(chapter 3, page \)](#). 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?

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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.

Cause of Hydranencephaly

26. What causes Hydranencephaly?

It appears that hydranencephaly is caused by an interruption of the flow of blood to the baby's brain. This can happen at any stage of gestation, usually after the first trimester, right up till just before birth. In our experience it appears that the earlier the damage happens, the more severe the condition is and the shorter the life expectancy. And, the later the injury happens the milder the damage-this is just a theory based on talking with various families.

The most common cause given to families is that the baby had a stroke in utero (38%). Other common causes are: death of twin in utero(5%), stroke in mother, drug use (11%), infection in mother(7.4%). In most of the children we know of, the cause is unknown (44%).

For more information on the cause of Hydranencephaly see:

<http://hydranencephaly.com/causeofhydran.htm>

27. My child was diagnosed with Hydranencephaly. He is a twin. How come it just happened to him?

I don't know. The only explanation I can think of is that at some point in his development the supply of blood to his brain was cut off. It only takes a fraction of a second of interruption of blood flow for the damage to occur. Hydranencephaly is frequently seen when one twin has died in utero. There is also the condition called "twin to twin transfusion" where one twin gets all the nutrition and the other gets none. Perhaps this is what happened. Of the cases we know of, over 50% have no clear cause for the condition.

28. Is Hydranencephaly hereditary? Will it happen again if I have another baby?

In most cases no. The only condition that we know of that can cause Hydranencephaly is Neonatal Alloimmune Thrombocytopenia (NAIT) This is a rare condition that causes the mother's body to attacks the fetus- my (her) platelet type does not match the fetus which causes my (her) body to create antibodies against his platelets causing low platelets in the fetus. Anytime you have low platelets there is a chance of intracranial hemorrhage. Therefore damage to the brain tissue that loses the blood supply, that brain tissues dies, dissolves and is filled with cerebral fluid. When the damage is small = porencephaly when damage is huge = hydranencephaly. For more information on NAIT see

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<http://www.itxm.org/TMU1996/tmu1-96.htm> page 33, Part 2

We have found a slightly increased incidence in families of children with Hydranencephaly of other neurological conditions. Out of 23 families that participated in a poll, 30% had another family member with a neurological condition. Two of the families had had a previous child with anencephaly. Most (8) had another unspecified condition. I don't know if this means anything in the long run. It will be interesting to see results over the next few years. No family has had 2 children born to them with Hydranencephaly. This of course is except for those families who have adopted multiple children with Hydranencephaly.

29. Can smoking, addiction to analgesics, asthma in pregnancy cause hydranencephaly?

At this point there seems to be no one cause of hydranencephaly. For a little more information check out: I did find one study which looked at the relationship between maternal smoking and hydranencephaly. Their conclusion was that there was no relationship. The most likely cause of hydranencephaly is an interruption of the blood supply to the baby's brain. Anything could cause this. The most common reasons given parents seem to be: stroke in the baby, death of twin in utero, drug use, etc. Most cases, though seem to have an unknown cause.

30. Does anyone know of any person or persons who may be conducting any research on why hydranencephaly occurs?

Not at this time. Dr Bjorn Merker, who helps us with understanding some of the more technical aspects of Hydranencephaly, is hoping to do a thorough search on this at some time in the not too distant future.

Vision, Hearing, Mood of Children With Hydranencephaly

31. Why doesn't he smile or laugh very often. Or play with toys?

Children with conditions such as Hydranencephaly often have limited energy and awareness. For my daughter, her first 5 years were spent mostly just working on breathing. Once her breathing improved, she started taking an interest in her surroundings and playing with toys. Yet with any illness or surgery, she would stop playing and being so responsive. She had to use her energy dealing with the pain or illness. Also if your child is having seizures, or difficulty eating, they're just not going to have the energy to notice their surroundings. Some children never do smile or play with toys, but most do respond to familiar people, surroundings, and toys. And, according to most of the families on the mailing list, their children soon become very good at running the household and being the Queen or King.

32. Why does he scream all the time?? Why is he so unsettled? Is he going to be like this his whole life?????

The first year is the hardest for your child. In our most recent study, out of 81 children, 58% of the children were fussy or irritable as infants and most became happy or quiet after their first birthday. If your child is fussy, things to check out are reflux (food not staying down, chapter:), seizures which can be painful (chapter:), pain from a physical cause, low temperature, etc. There are many things that can cause a child to be irritable. Some medications have that effect. It's really a matter of trial and error. My daughter went through a period of 3 months of screaming when she started her menstrual period, We never did figure out why she was

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screaming but it stopped when I started giving her a mild sedative each day when she'd get fussy. Sometimes that's what is needed.

33. Although she's only 2 months old it seems at times that she's hurting she'll cry non-stop up to an hour straight. Drs. say its just the irritable stage of her condition.... its just something we will have to get use to...did any of you experience this?

Yes, definitely. Please see previous question. A large number of the children are very irritable and fussy during their first year of life.

34. Do children with Hydranencephaly ever sleep through the night without drugs?

Yes, some never have problems with sleeping (44%). 53% of the children do have trouble and are on a variety of medications. It's different with each child of course. For information on medications to help children sleep see:

35. How can he/she smile/live, recognize me, etc with no brain?

There is no easy answer to this question but possibilities are: a. the brain stem does more than anyone previously believed and b. the "plasticity" of the developing child's brain. That means that the parts of a child's brain that remain, no matter how small, can learn to do things other than that usually done by that part of the brain. New pathways can be made. And, in Hydranencephaly, it is usually only the "higher" portions of the brain that are missing, <http://hydranencephaly.com/abouthydran.htm> (See chapter 4 for more information).

The other important factors are love and stimulation. In order for new pathways to be made in the brain the child has to be stimulated and encouraged to do all that they can.

36. My doctor told me that my son should not be hearing or seeing. But he took and hearing test and passed. But they will not give him an eye test, why not?

In our experience and according to the statistics we've gathered almost all (except maybe 1 out of over 100 children) the children can hear. Often the Doctors don't want to do further tests because they think that the diagnosis of hydranencephaly means the end of the road for the child, there's no hope and no point doing any further tests. Keep stimulating your child as much as possible-I used to say that I treated my daughter as if she could see and as if she couldn't-her room was decorated brightly, I always told her what color things were, she was put so she could see the tv, etc but at the same time, she had lots of things to touch, toys that made noises and I told her what she was seeing or touching. Eventually she clearly saw.

In Hydranencephaly, most of the children have cortical visual impairment. This means that their eyes are normal, however, their brain isn't able to tell them what they're seeing. Vision is possible for children with cvi, however it tends to come and go.

For more information on sensory stimulation please see:

<http://hydranencephaly.com/sensorystimulation.htm>

For more information on Cortical Visual Impairment see: <http://hydranencephaly.com/cvi.htm>

37. Right now we feel that she can hear us but we are unaware about her vision and by the way the ophthalmologist acts we think she's unsure too. She just says it's too early to tell. Did anyone else have this happen to them?

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Yes. It's really hard to tell how much vision a child with hydranencephaly has at any time. There are some tests that can be used, but over all the best way to know how much vision your child has, is just through observation. And, as mentioned in the previous question, vision is changeable in Cortical Visual Impairment.

Hydrocephalus

38. My grand daughter (4 months old) "may" have water surrounding the brain. Is that the meaning of Hydranencephaly?

Probably not. "Water on the brain" usually refers to hydrocephalus and can be treated by a shunt. Hydranencephaly is a very severe condition where due to an interruption in the flow of blood to an unborn babies brain, the brain tissue dies and the skull fills with fluid and leave only a brain stem. Many of the children with hydranencephaly also have the symptoms of hydrocephalus and are helped with shunts. Sometimes a child diagnosed with hydranencephaly is found to just have severe hydrocephalus after the shunt it in place. For more information on Hydrocephalus see: <http://hydranencephaly.com/hydrocephalus.htm>

39. What is the connection with hydrocephalus?

The condition of hydrocephalus (an accumulation of fluid in the skull) is often present in a child with hydranencephaly and is one of the first noticeable problems. However, in a child with Hydranencephaly there is little or no higher brain tissue remaining and the skull is entirely full of fluid. In a child with just hydrocephalus the brain is more or less intact and has enlarged ventricles. A good recovery is possible with shunting. In hydranencephaly there is much less brain tissue. However, some children thought to have hydranencephaly, have after having a shunt placed are found to just have hydrocephalus. For more information see: <http://hydranencephaly.com/hydrocephalus.htm>

40. Besides the obvious setting eyes, vomiting and so on.. How do you know for sure he doesn't have pressure?

I think the eyes, nausea/vomiting, seizure activity (if they have it), level of consciousness, regression, excessive sleepiness and firmness of the fontanel are the only things I can think of. When the pressure is bad you can tell, there are definite changes in personality and demeanor. I am sure someone will say, but so and so had high pressure and never acted or appeared different. I can see that happening too!!! (Karin, mom to Cookie, Drew, Lawson & Adrian)

For more information on recognizing shunt malfunctions see:

<http://hydranencephaly.com/shunts.htm>

41. My child has never needed a shunt. Does he/she still have Hydranencephaly?

From Dr Bjorn Merker: I am no expert on the ventricular system, and know almost nothing about how it is affected specifically in hydranencephaly, but there is one general principle which makes the hydranencephaly situation rather easy to understand. The principle is that cerebrospinal fluid, the fluid that bathes the brain, is produced in the ventricles by a flimsy tissue called choroid plexus, and that all the fluid that is produced has to drain "downwards" to get to the fourth ventricle, and from there out into the outer fluid-filled space surrounding the brain. So any obstruction at any place along this successive drainage path will cause pressure to build up ABOVE that place. There are the lateral ventricles (inside the hemispheres, one in each), the third ventricle (inside the tweenbrain), and the fourth ventricle

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(in the hindbrain), and there are narrow passages between each of these which can be obstructed. The lateral ventricles produce more CSF than the others, and so a slow flow from them downwards along the chain is taking place all the time. Applying this to hydranencephaly, the choroid plexus continues to produce fluid after the hemispheres are resorbed in hydranencephaly, and if the passage to the third ventricle (tweenbrain) and fourth ventricle (hindbrain) is open, there is no problem. That child will not need a shunt. But you can imagine that it easily happens, during the massive damage to the hemispheres in hydranencephaly, that the passage to, say, the third ventricle, or between the third and the fourth, gets blocked, and so pressure will build up, and sooner or later such a child will need a shunt.

42. Can my child get hydrocephalus at a later date if he does not have it now?

Yes, although that isn't too common. An obstruction and thus a buildup of Cerebral Spinal Fluid can happen at any time. Please see previous question for more information on Hydrocephalus.

Health Care Needs

43. Do any of your children have problems with their sodium level?

Yes, this is one symptom of Diabetes Insipidus, which is fairly common (16%). Some children never have the diagnosis of Diabetes Insipidus but still have trouble with controlling their sodium levels. My daughter would get a high sodium level when she was very ill. That was always one way I could tell if she was really sick. If the sodium level is very high and there is uncontrolled urine output the child would take a medication called DDAVP. In other children, just giving extra fluids is enough to control the sodium level. For more information see: <http://hydranencephaly.com/diabetesinsipidus.htm>

44. Do any of your children take steroid replacements? Dr. M. said she would also need steroid supplements/medication in case of an infection.

I'm not sure about this one. Many of the children take steroidal medication to prevent asthma attacks but I haven't heard of steroids being used automatically during illnesses.

45. Are there any issues regarding vaccinations that I need to be aware of? I know that the "P" part of DTP should not be given to seizure prone children.

Not that I know of in general. Some children do have reactions to vaccinations but likely would if they didn't have Hydranencephaly. There is still some discussion on whether children prone to seizures can safely be given a "dead" version of the Pertussis vaccine (called DtaP) rather than the more commonly given live version. My daughter's Doctor felt that it was too risky so she never got the Pertussis vaccination. I just informed her school that if any child was found to have it, I needed to be contacted so that I could keep her home.

46. Are there any shots that my child can get to keep him/her healthy?

Yes, In children under the age of 2, it is recommended that they get the vaccination for RSV (Rhinal Syncytial Virus) (see page:). Over the age of 2 the child should have a Pneumovax shot which protects children from 23 different strains of Streptococcus pneumoniae. (see page:), and an annual flu shot is recommended for all children and their families and caregivers.

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47. My Doctor wants my child to take antibiotics on a long-term basis in order to prevent illnesses. Is this necessary or helpful?

There are some conditions that do respond best to a long-term low dose of antibiotics. However in most cases this is not recommended. When you use a particular antibiotic on a long term basis the body builds up a resistance to it, and then the child would need a stronger antibiotic to treat future infections. This is why people are now afraid of “superbugs”. They are caused by over use of antibiotics. For more information please see: <http://www.cps.ca/english/statements/ID/id99-05.htm> (This is a fairly technical article but does make some good points).

48. Are your children in the hospital for the most part of the year? Brianna's doctor also said that if we wanted to go through with all of this, she most likely would spend most of her time in the hospital.

No. Many children spend very little time in the hospital. Often when the children are younger, they will spend more time in hospital as their parent's comfort level for dealing with illnesses is lower. As the child gets older and the parent is more confident, often children will be kept at home even when quite well. Some children are in hospital a fair amount but this is certainly not the case for most of the children. Some of the reasons a child will be in hospital for are shunt complications, feeding difficulties/dehydration, and respiratory illnesses.

49. My child is 8 months and still doesn't have any teeth. Is this common?

Yes. Many of the children don't get their first teeth until much older than usual and some get them right on time. One of the reasons the teeth may not come in until later is if the child does not eat orally; there's nothing to put pressure on their gums to push the teeth through. Another factor can be the medications that your child is on. Seizure medications like Dilantin and Phenobarb cause the gums to thicken and that can hide the teeth.

50. My child keeps having trouble with constipation. Is this common?

Yes it is. In our latest study 66% of children have problems with constipation. Part of the cause is that because the child has high tone (tightness) in their muscles, they also have tightness in their smooth muscles and digestive system as well. The other main cause is that the child doesn't move or stand so it's just hard for the food to move through their body. For more information see: <http://hsc.virginia.edu/cmc/tutorials/constipation/>

51. My child has been having bowel movements but was still uncomfortable. When I took him to the hospital an xray showed that he was still constipated. Does this happen often?

Again, yes. Sometimes children do what is called “stooling” where stool gets stuck and new stool goes around it. It is hard to tell if this is what is happening. Your child's Dr will be able to help you with this.

Seizures

52. My Doctor told me that as my child doesn't have a cortex he couldn't have seizures. But, he really looks like he's having seizures. Is this true?

Not really. Most of the seizures originate in the cortex, and as our children don't have much or any cortical tissue, yes, they aren't having cortical seizures. But, our children usually have

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seizures that originate in the brain stem. Very little research has been done into brain stem seizures.

53. My child had an EEG, and no seizures were seen, but she had what the Doctor has already told me were seizures. Who is right?

EEGs are set up to monitor cortical activity; so don't pick up seizures that originate in the brain stem. My daughter had numerous seizures that everyone knew were seizures, and numerous EEGs throughout her life but never once had any seizure activity show up on the EEG.

54. Do all kids with hydranencephaly have seizures?

No. According to our latest study, 75% of the children were reported to have had seizures. Some children start to have seizures from day 1 and have them throughout their lives. Others have different types of seizures and may go for long periods of time without any and then start up with a new type.

55. Why do they have seizures?

Seizures are common in anyone with neurological damage.

56. Do the seizures get worse as they get older?

Not necessarily. Some times they even disappear, as the child gets older. My daughter had what was thought to be seizures as a young child and then had none at all for several years, and then as she got older she started having different ones and they increased in number. One factor is that in girls, seizures often do increase once they start puberty.

57. What do I do if a seizure happens?

Basically make sure that he or she is safe; that there is nothing he's going to bump his/her head on, that he/she is able to breathe. For more information on how to deal with seizures please see <http://www.northeastrehab.com/Articles/seizurefaq.htm>

58. How will I know if he is having a seizure or not?

There is no easy way as there are so many different types of seizures. And, there has been little research or information on brain stem seizures so the seizures our children have may be totally different from what is seen in a person having seizures that originate in the cortex.

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59. Do seizures hurt my child?

Not usually. Sometimes children do seem uncomfortable while having a seizure. You just need to keep an eye on them and protect them from injury. If the child stops breathing during a seizure then you need to be ready with whatever emergency remedies that are necessary.

60. Can the seizures kill my child?

No, not usually. The danger would be if the child stopped breathing during the seizure and wasn't resuscitated. But uncontrollable constant seizures (status epilepticus) can be life threatening and require emergency treatment. For more information on Status Epilepticus see: <http://epilepsyontario.org/faqs/seizures/status.html>

61. The doctor said my child would have seizures. What should I look for?

Again, it's hard to say. Please see: <http://hydranencephaly.com/epilepsy.htm> for a chart of the common seizure types. Children with Hydranencephaly can also have different sorts of seizures. There are ones where it looks like the child has been startled, some children have seizures that are laughing spells, and some children have coma incidences where they are unresponsive for a long period of time and if an EEG is done during these episodes, it is found that the child is in "status" seizures.

62. Should I call the pediatrician or neurologist if my child is having seizures?

If you're concerned, yes. If it's a first seizure or is a different type than is usual for your child. It's a good idea to work out a seizure protocol for your child with his/her Dr. This will help guide you as to the appropriate steps to take. [*sample seizure plan](#)

63. Should I call an ambulance if my child is having seizures?

Only if your child is having trouble with breathing or if the seizure lasts beyond the time limit specified in your child's seizure plan.

64. Are all forms of seizure activity detrimental? (e.g. like what others were referring to - laughing or staring seizures).

No. Most of the children have frequent mild seizures. The seizures are only detrimental if they last a long time or if they interfere with the child's breathing. Even then, they may not be a problem in your child. Your child's neurologist and/or pediatrician can help you know when a particular seizure or type of seizure needs treatment or changes in medication. For more information on making an assessment as to if this seizure needs different treatment please see: <http://www.northeastrehab.com/Articles/seizurefaq.htm>

65. Is medication necessary for all types of seizures?

No. As seizure medications, like all medications have side effects it's often weighing the risk of the side effects versus the risk of the seizures. My child had horrible reactions to most anticonvulsants and eventually we just gave up and tolerated the seizures. Because children with hydranencephaly have brain stem seizures, it's often hard to bring them under control with the usual medications.

An alternative to medications is the Ketogenic Diet. This is a special diet, which can eliminate or reduce seizures. For more information on the Ketogenic Diet see:

<http://www.stanford.edu/group/ketodiet/>

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Feeding a Child With Hydranencephaly

66. What is a Pyloroplasty? Can it help a child with chronic diarrhea? Is it done at the same time as a feeding tube?

What it does is create a larger opening at the pylorus, which is at the bottom of the stomach and leads into the intestines. I don't know that it would help a child with chronic diarrhea. It helps most if the child is proven to have delayed emptying of the stomach. That has to be diagnosed by a stomach-emptying scan. It's often done at the same time as the Nissen Fundoplication.

For more information see:

<http://health.discovery.com/diseasesandcond/encyclopedia/900.html>

67. What is the difference between vomiting and reflux?

Technically the term "gastroesophageal reflux" means that stomach contents move the wrong direction. . . i.e. backwashing up the esophagus instead of moving down toward the intestines. If reflux is strong enough we see the refluxed contents as vomit. Reflux that does not result in vomiting is still reflux but is harder to identify because it is "silent". Lots of times people think that the reflux has gone away because the child is no longer vomiting. Not necessarily true! If we see vomiting as part of an acute condition like the flu, we don't call it reflux. It sounds as though ____'s stomach is just getting extra full with the larger volume of food he's able to take with the tube feedings. He may also be experiencing slow emptying of the stomach into the intestines so that more of an earlier feeding remains in his stomach as you are giving him another meal. Giving him more frequent smaller feedings should reduce or eliminate the intensity of the reflux because there is less in his tummy to be refluxed upward into the esophagus.

Also, none of the medications we give kids for reflux actually prevent reflux. They simply reduce the amount of acid that is mixed with the stomach contents or they move the food through the stomach faster. The reflux itself is caused because the valve at the lower end of the esophagus isn't closing tightly enough to prevent stomach contents from moving upward.

Suzanne Morris

New Visions

www.new-vis.com

68. My doctor told me that my child would soon lose the ability to suck and swallow and will need a feeding tube. Is this true?

Not always. In our most recent study of 81 children with Hydranencephaly, 39% eat orally, 39% by tube only, and 16% eat both orally and by tube.

Many of the children never get feeding tubes at all. Or if they have them don't use them except in times of illness.

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69. Right now she eats great by mouth sometimes it takes her a little longer than other times. Can anyone tell me anything I may need to know when it comes to feedings; is it possible that she may stop feeding by mouth one day?

Yes, it is possible. There are several factors in whether a child can continue to eat orally. One is, if the child is aspirating, (food going into the airway instead of the esophagus), and another is if the child is getting tired eating orally. It takes a lot of energy to eat and swallow safely so sometimes it is better for the child to have some nutrition via tube (NG or G). It's really different for each child. See previous question about numbers of children who eat orally and who have tubes.

70. My child has a feeding tube, does this mean that she/he will always have to be tube fed?

Not necessarily. The main thing to know is why your child needed the tube. Is it because they were aspirating when fed orally or just because of failure to gain weight and get in enough nutrition. If the child is aspirating then you would need to know for sure that, that is no longer happening. When my daughter was 3 she had a swallowing study done and everything either went into her lungs or up into her nose. When she was about 6, she was swallowing her saliva well and coughing. So, quietly I started feeding her small amounts. She did fine and when she finally had her swallowing study several months later (the feeding team refused to do the test until after I'd started feeding her orally), much to the surprise of all professionals there, she did not aspirate-she had the same radiologist who had done the previous one. She ate orally with no problems for over 3 years. She finally got tired and it was just too difficult for her to eat orally. I kept being reminded of the risk of feeding her orally and finally gave into the fears of others.

Please see the paper on Transitioning to Oral feeding by Suzanne Morris <http://www.new-vis.com/fym/papers/p-feed15.htm> for more information on the signs and symptoms that a child might be ready to eat orally.

If your child is not found to be aspirating or at extreme risk to aspirate (only a swallowing study can show this) then he/she can likely eat for pleasure and eat as much as they want orally.

71. What is Polycose? My Dr said that my child needs to take it.

Polycose is basically a calorie booster and it's used if a child isn't gaining weight from food or tube feeding formula. For more information on Polycose see:

http://rpdcon40.ross.com/mn/Ross+MN+Nutritional+Products.nsf/web_Ross.com_XML/F96F8514BF440D4085256466006A4E4F?OpenDocument

Physical Abilities, Development, Needs

72. Do you think that how much my child develops physically has a lot to do with how good his Therapist is?

Again, not necessarily. You will find that how your child develops has a lot to do with you. You will do most of your child's therapy on a daily basis. As your child's parent and chief caregiver you are also their "case manager" It will be up to you to coordinate all the various people who are in the life of a child with Hydranencephaly.

Here is the experience of one of our families:

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Noah has physio therapy, but not very much with the therapist. Mostly she has given us a home program to do to keep his range of movement - just lots of stretching, trying to relax him etc. The best thing for Noah has just been lots of love, stimulation and good medical treatment (which we are still working on at times!). Our physio says she is amazed by Noah all the time as he has such a personality and character also. Our kids always end up surprising the 'professionals'.

In my case with my daughter I eventually realized that I was able to do most of her therapy on my own. In our area there is no physiotherapy available to children over the age of 7. I relied heavily on information I got from several people I knew online and used their suggestions. You will know best what works and what doesn't for you child.

You also need to provide the stimulation and toys that your child will respond to the most. Again a therapist will help you with these.

For more information on sensory stimulation and toys please see:

<http://hydranencephaly.com/sensorystimulation.htm>

73. My child is always turning his head to one side. It's adding to the curve in his back. Is there a reason for this?

Yes, what is happening is called the Asymmetrical Tonic Neck Reflex. This is a normal reflex in infants, which is retained by many children with severe neurological problems. Please see the chapter on Physical conditions for more information, page [fix link](#)

74. Do any of your hydran kids bear weight on their arms or push up while on their stomachs? If so, have they gotten on all fours and rocked?

Our PT uses an exercise bolster and also the ball for Brennan. She told us we could pick up a foam bolster at an upholstery shop which is what we ended up doing and then taping a plastic trash bag over it and used a king size pillow case to cover it. He does pretty well lifting his head for a while when placed on his chest over it but we have to help him with tucking his elbows under and to the side of him and then we'd let him do it himself for a little bit. Also his PT does work with him stretching his leg out toward his opposite hand and trying to make him grasp his foot. We have not seen him on all fours & rocking (that would be great if he could do that). (Renee, mom to Brennan, age 1)

Heather can bear some weight on her arms. She also can bear weight in her legs. The hard thing is to get them positioned so they feel secure. For Heather we've used a boppy on the floor and had her chest over the back of it. If you put something she finds interesting directly in front of her, you can even work on head control at the same time. We've also had her sit in a crosslegged position (Indian style) and put a pillow on her lap. Then we rest her arms on the pillow and she can use this position to push up with her arms. You can either do this in your lap or against a couch. Today I sat on the couch, put her crossed legged on the floor between my legs and set her up with her arms on a pillow in her lap. If I rub the area at the top of Heathers back at the base of her neck, it helps her to raise her head. I guess it stimulates the muscles needed for lifting the head. Trunk support is key too. With good trunk support, it will be easier for her to lift her head. (Karen, mom to Heather, age 2)

75. Have any children with Hydranencephaly ever been able to walk at all or sit up on their own? Are they able to use a wheelchair?

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Yes, we have one child who walks, runs and climbs. And yes, his diagnosis is definitely Hydranencephaly.

However, most of the children are quite involved physically. A few are able to use gait trainers (walkers). Some can roll. Some can sit for short periods of time unassisted. Some can use their hands to manipulate or pick up items.

76. As Hydranencephaly has global physical effects do you or anyone you may have come across have children with extremely high levels of spasticity and therefore have the need to deal with associated complications such as spinal scoliosis, or anyone who has had a Intrathecal Baclofen pump?

Yes, many of the children do have extreme spasticity. All of the children have some. Several of them have the baclofen pump, and others use oral baclofen. Quite a few have had botox injections in various parts of their bodies to relieve spasticity and contractures. For more information on treatments for spasticity please see: <http://hydranencephaly.com/cerebral.htm>

Equipment Questions

77. Can anyone recommend a rear facing car seat? _____ is now sixteen months old and has outgrown her infant car seat but still has limited neck control. I have found several car seats that have extension footrest bars, but I am unsure whether they are used for rear facing.

We got Nikki (4 1/2 years) a Britax Special Traveler car seat last year and we love it! It is made for special children with little to no head control and will grow with her until she is 60 inches and 110 pounds! It was about \$300.00 but your insurance, including medicaid may help you to get it, ours did. We have since went and got another one for the trip to/from school!

Here's the link for the Britax Traveler

<http://www.britaxusa.com/products.cfm?id=230EE52A-3FE7-4A7F-AD224AF3982398CB>

(Britax Traveler plus)

Here is a link for some other car seats: <http://www.adaptivemall.com/safetycarseats1.html>

Please check out chapter..... for more information on equipment your child might need.

78. How can I know what equipment my child needs?

Your early intervention worker or therapist will help you choose equipment. They'll know what your child needs when and how to go about getting funding to cover the costs.

79. How will I pay for this equipment?

In most areas around the world, there is funding for equipment. But, what is paid for and what isn't varies greatly from one area to another. Your social worker and therapists will be able to help find what coverage is available in your area.

80. What age do children usually get their first wheelchair?

This varies from child to child. Often once a child is too big for an infant carrier they will get a special seat for use in a stroller. Sometimes people go straight to an adapted stroller like a Kid Kart or Convaid. Some children go straight to wheelchairs. For more information on this sort of equipment please see:

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