

### 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 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 been 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.

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](mailto: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 # 1

General Information About  
Hydranencephaly

(Questions 1-13)

<http://hydranencephaly.com>

## 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 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?