

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.

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
11870 285th st.
Maple Ridge, BC V2W 1L9 Canada

This pamphlet 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 # 7

Physical Needs & Development of a child with Hydranencephaly & Equipment

(Questions 72-80)

<http://hydranencephaly.com>

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: 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 Asym-

metrical Tonic Neck Reflex. This is a normal reflex in infants, which is retained by many children with severe neurological problems.

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 cross legged 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?

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