



## Hydranencephaly Newsletter June 2008

This is our monthly newsletter about Hydranencephaly and the issues a child with Hydranencephaly might face. . Its purpose is to share information on the various aspects of Hydranencephaly as well as to show case our beautiful children. Much of the information presented in the newsletter will originate from the Hydranencephaly Mailing list or group, which is hosted by Yahoo groups.

### Topic of the month: Communication for a Child With Hydranencephaly Part 1

#### Learning to “Read” Your Child (Communication)

Contrary to what Drs are likely to tell you, your child with Hydranencephaly can communicate. But... not with the language most of us know. Someone explained it to me as sort of being like being dumped on an alien planet with this little being and then having to learn his/her language rather than teaching him/her yours. For children with Hydranencephaly communication is likely to be quite subtle especially at first. It will take observation and patience.

In this edition I'll include examples of children with Hydranencephaly communicating and some basic information how children learn to communicate and how we can help our children develop their ability to communicate. . Next month I'll give more detailed ideas of how to help your child learn to communicate.

#### How our children communicate:

On the following pages are examples families have given of how their child communicates. Most are taken from the book Caring For Your Child With Hydranencephaly which was completed in 2005. Therefore many of the

children mentioned in the examples are now much older. When available I have included an update on their development and communication.

I asked for examples from more of our families on the Hydranencephaly Mailing list of how their children communicate but got very few responses. Therefore, I'm leaving the invitation to share examples and stories open and invite more families to share. I will include any new examples I get in next months edition of the newsletter. Please email me your stories at: [angelbearmom@shaw.ca](mailto:angelbearmom@shaw.ca)

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**Noah, age 7:** Noah really just communicates to us through his expressions and eyes - pretty much like a baby would. We know what kind of mood he is in depending on his eyes (e.g. bright and alert, or tired and non responsive), and also his expressions he makes with his face. You can really tell just by looking at his face what kind of mood he is in. He can not communicate anything in particular (e.g. yes or no, or make choices), but mainly just his moods. For example if he is really well and happy he will give us a smile whenever he hears our voice.

**Ethan, age 2:** Ethan has always been very expressive He has always had a happy face to show joy and let us know usually with crying or "shutting down" that he did not like something. In the beginning they told us he was blind and deaf and I did some research which said to always give your baby clues to what you are doing. So I developed a few signs for him such as patting him on his hips before I would change his diaper and tapping his lips with the bottle nipple before starting to feed him. I figured even if he wasn't blind and deaf (he isn't) that any baby could use a little communication. It worked really well.

His vision therapist and I recently came up with a communication list of things he does and what they mean. She said it would help them at preschool and once we did it I thought it was an awesome idea:

**Smile or happy face** = Ethan is happy (obvious one)

**Cooing** = Ethan is content

**Kicking one leg, waving his arms in the air, or pushing off with both feet** = Ethan is excited

**Vocalizing** = Ethan is enjoying what he is doing and is stimulated

**Trying to put things to his mouth** = he needs some sort of oral stimulation such as a toy he can "chew on" or his binky

**shutting down** = he does not like what he is doing at all

**pulling away** = he doesn't want it or want to do it  
**being helpful** (such as pushing his arms into his clothing on his own) = He is just in a particularly good mood

**Stiffening up** = He is a little hesitant and unsure about what is going on

**Reaching for your hand** = he wants to hold hands and/or needs reassurance

**whimpering** = he is very displeased or in minor pain

**Crying** = something is very very wrong

**Elizabeth**, age 9, is on a ventilator, has a tracheostomy and can make no sounds with her voice. When she wants attention she moves in such a way that her ventilator alarms go off. As soon as you say "It's ok Elizabeth" or go over to her she stops.

She does this when her mom comes in from being out and hasn't said hello right away,

She has also figured out how to pull several parts of the tubing attached to her apart so that alarms go off and she gets the attention she wants.

When you stand near her, if you're someone she likes, she'll reach out her hand and rest it on your arm.

Update 2003: The part about her not making any sounds...well she can now "talk" around her trach...she has gained in many ways. She responds to smells like lotions, candles ect, She loves flavored lip gloss and she smiles a lot more.. She will set off her alarms if one of the other girls cries and stop when we go to the one who is crying. She moves her arm now to set off her pound puppy's barking.

Update 2008: Elizabeth is now 13 years old.

**Jason**, who died at the age of 10 1/2 had a shunt malfunction at the age of 3 and since then cannot do anything but: When he doesn't want the OT or PT or school workers to touch him he goes into a seizure.

Even though Jason doesn't cry we still know when he is upset. His face gets red splotches everywhere until his entire face becomes beet red. That's how we found out about his two broken legs.

**Emily**, age 5: When she is put down for a little while, whether it's in her "chair" or on her blanket on the floor, when she's had enough, she whines loudly. She will continue to get louder and arch herself until she is picked up. As soon as she is picked up, she gives a great big smile.

Also, when she is extra hungry she will stick her tongue in and out. She will also tighten her lips and make a face if she doesn't like her food. Although there are few things she doesn't

like to eat. When she's full, she'll let the last mouthful completely slide out and down her face.

We get the biggest smiles from her every morning when we go into her room, open the shade, and she hears our voices. If she doesn't smile, it's a clear sign she is sick. She also does the "concentrating" thing with the therapists. The only thing different is she doesn't kick her legs and move her arms. If Emily is extra simulated to laugh, her right leg will bend up really fast. It's soooo cute.

Seeing Em wake in the morning is one of my biggest joys. Whenever I'm working from home, I always ask Kathy to let me know when Em is awake so I can go see her first thing.

2008: Emily died suddenly in December 2007 at the age of 8

**Daniel** age 8: also does this chewing thing when he has gas and needs venting. He also does this when he is fed (bolus) Its funny how some of our children are so similar.

When he has to poop he turns red and stiffens up his arms.

Daniel has a little wrinkle in his forehead for an itchy nose.

He will cry with pretty extreme pain. But he smiles most of the time.

The nurse the other day said that when she mentioned brushing his teeth he turned the other way so quick.

He is able to activate his with tape player with his head. I am positive he knows he is doing it.

Of course when we are not home for a while his heart rate goes high and won't settle until we are all back home.

**Update:** If I have been holding him on my lap for a while and then I put him down he has this really big frown on his face. He doesn't warm up to most people at first. But after 3 or so times he starts smiling. He does activate a switch toy with an obnoxious barking dog on it. He does it with his head on a pillow by turning it to the side. I actually use the side that he doesn't like to turn to so I know he knows.

2008: Daniel died in January 2005 at the age of 9.

**Megan**, age 7 does this also with the arching her back when she has had enough of something and shouts out. Also every night when she wants to go to bed she will push her head so hard on your arm and you say to her do you want to go to bed and she laughs and smiles so off we go and she really chuckles when you lay her in the bed and this she does every night.

2008: Megan is now 11 years old

**Heather**, age 3: Heather has excelled in the art of non-verbal communication. Even the un-initiated can understand, "You're not putting that in my mouth" when Heather wishes it to be known. She clamps her lips together, twists her mouth, and then turns her head away from you. When she is starting to get hungry she will groan a little. As she gets more hungry, she will put her hand up toward her mouth. If you've waited entirely too long to feed her, she will bite her hand and scream bloody murder until you put something else into her mouth (like food.) If Heather thinks you're not paying attention when you feed her, she will very likely reach out and try to grab your hand that is holding her bottle. She also likes to grab the spoon (or the hand that is holding it) and try to direct it toward her mouth.

She has a baby sister Elizabeth. On a number of occasions they have been fussing separately, but when I put them together, Heather reaches out and feels Elizabeth, and Elizabeth reaches back and feels Heather. They both get quiet at the same time.

One of Heather's best communication devices is the snuggle. You can ask anyone who has held her...her snuggle can make you feel like the most important person in the world.

2008: Heather died in 2007 at the age of 6

**Kayda**, who died at the age of 11 1/2: Her eyes were what were the most communicative. From looking at her eyes I could tell if she was recognizing something or listening to something. I think her eyes would stop flickering.

If she didn't like the story she was listening to or the TV show she was watching she would fuss

and yell. As soon as you put on what she wanted she would be quiet.

She knew what time her favorite show (Star Trek DS9) came on and would fuss if it wasn't turned on for her. It took me a while to clue into this. I'd look at my watch and say "Oh you want your show on". I'd turn it on, and she'd be quiet.

For several years she had 2 Big Macks (switches that talk when pushed) on her tray. She usually activated the switch on the left the most, but if she didn't like what it said (she especially didn't like it when her teacher put a message in French on it) she would reach her left hand over to the right to push the other switch.

Even when she first came to live with us and was mostly unresponsive, when ever we'd come home after being out with her she would get a big smile on her face and relax right away.

One time we took her on holidays with us, and every time we took her outside she'd start to fuss. Once we took her back inside and had her lying on the couch listening to stories as she did at home, she would relax.

When she was very sick, or had come near dying, she would make this high-pitched whine unless I was with her. I usually had to hold her. She would start to cry if I even moved and she thought I was going to put her down.

She hated having her hair brushed when she wasn't feeling well. It was the only time just about that she would ever cry.

During her last couple of years she would only sleep if she had her husky dog under her left arm and her bunny under her right. If either was missing or not in the "right" arm she would not sleep. I tested this many times, always with the same result.

She would only sleep listening to a story not music. Again, we tested it numerous times.

If you put on a book that had more than one tape she would stay awake to listen to the whole book.

If she didn't want a particular toy or stuffed animal you'd given her she'd push or toss it onto the floor.

**Leo, age 12**, Leo smiles a lot so I know he's happy sometimes makes happy noises, he also make mad noises and cries when unhappy.

As you can see from these examples our children are very good at communicating. It is us who need to learn to understand what they're trying to "say". Sometimes, when I'd finally catch on to what Kayda wanted I'd feel so dumb. I'm sure she wondered how on earth she'd gotten stuck with such a dense mom.

### Early Communication

<http://www.novita.org.au/Content.aspx?p=60>

We all know how exciting it is to see a baby's first attempts at communication! A child's early communication is very important in determining what follows. This page provides practical information about how children with physical disability can be helped with their early communication.

Babies all start out not actually meaning to communicate but adults 'read' their actions as meaning something. For example, a child cries and the parent says they are hungry, but in the beginning a child would cry even if an adult is not there. This type of communication is called unintentional (unplanned, accidental). Children learn to become intentional (deliberate) communicators after people react to their actions as if they had meaning. They realize that their actions have an affect on others, that is, they learn the meaning of their actions from others.

Some children do not make the 'step' to deliberate communication automatically.

Speech pathologists can help develop the child's skills by teaching parents and other important people in the child's life to:

See how the child is communicating at the moment;

- Work out which actions they could learn to do on purpose, for example, to make a noise, to touch their mouth;
- Respond to this action every time it is done as if it does mean a certain thing,

for example, touching mouth means they want to eat;

- Say what the child's action means every time it happens, for example, "You touched your mouth. That means 'want food'. I'll get some food.", and to
- Come up with activities so the child can 'practice' the new skill.

### **Communication and children with physical disabilities**

- Children with physical disabilities are often not able to respond to their parents in the way that other young babies do. For example, a baby may not be able to kick his legs to show delight or turn his head to look at something;
- Parents and other adults may not realize that the baby is trying to communicate something. If they do not realize it they will not react by saying things like, "You're happy. Happy baby. You like it";
- Children with physical disabilities often cannot go and get the things that they want or even point to them. This makes a way of saying or communicating what they want really important. If children have too long in their life when they are not able to say what they do and don't want they can become very passive (inactive, not wanting to do anything). Early intervention is therefore important;
- A number of children with physical disabilities also have vision or hearing impairments. Early intervention can be provided to show parents and others ways to interact with the child which help to develop their skills;
- If children cannot get other people to understand them they can become very frustrated. They may start to do things like scream, hit, kick and bite others or themselves. Speech pathologists can work with families and other therapists to work out the reasons for the behaviours and then to work out another way for the child to communicate what they want. The new way of communicating must be as easy for the child to do and get as quick a reaction as the biting, kicking, and so on;

- Much early learning involves actually moving about and doing and feeling and touching and tasting things. Crawling in and out of boxes, for example, helps to learn concepts about in, on, under, big, small, dark, hiding, and so on. Children with physical disability may need help to do this.

### **What can be done to encourage early communication?**

The earliest things children usually learn to communicate are related to making choices. This happens when they:

- 'Ask' for things;
- Try to get an adult's attention, or
- Refuse things.
- These things allow the child to have power over their world. They are often worked on first because they are easier to teach and are motivating to the child. Speech pathologists can provide suggestions about how to teach the child to do these things.

### **Specific communication skills**

The following information describes children's early communication skills and how parents can encourage children to develop them. It is brief and general. The Hanen Parent Program\* is a training course for parents that goes into these ideas in much more detail and helps parents to relate them to their own child. To view, print or download the Hanen brochure, go to the Download section of this site.

\*Some information on the Hanen program will be presented in next month's newsletter.

### **Attention and concentration**

#### **Description:**

The child is able to look at an object or activity and concentrate on it - he listens to sounds and turns towards them.

#### **Idea:**

Share attention - follow the child

#### **Examples:**

- The child is looking in a particular direction - look where he is looking, touch it and talk about it in very simple words, let him touch it, show how you can make the toy work and help him to do it;
- Hold brightly coloured toys near him and encourage him to look at and follow the toy;
- Encourage the child to look at things for a little while by doing interesting things with it.

**Eye contact****Description:**

The child looks at other people and objects with interest and learns that getting a person's eye-contact (getting the other person to look at you) is a way of getting their attention.

**Idea:**

Try to get the child to look at you during communication and encourage her when she does so.

**Imitation****Description:**

The child copies actions, for example, clapping hands, coughing.

**Idea:**

Babies love imitation games. If he is doing an action, copy it and play games around it.

**Examples:**

- If a child reaches for his toes, touch his toes too and play 'This little piggy' - also copy any sounds that he makes with his mouth to encourage him to have another turn;
- Other things to imitate are coughs, laughing, clapping, and kissing.

**Turn taking****Description:**

The child takes turns by waiting, listening, looking and doing

**Example:**

Rolling a ball back and forth, waving 'bye bye'.

**Ideas:**

- When playing games always allow enough time for the child to have a turn - children with disabilities often take longer to respond, so leave even more time than usual;
- Play games that will encourage turn-taking, even if you need to help him to have his turn.

**Example:**

- Rolling a ball, putting objects in a container, building with blocks;
- Using turn-taking sound games can help to encourage communication. When the child makes a sound, copy it and encourage him to have another turn.

**Object permanence****Description:**

The child learns that something still exists even if it can't be seen.

**Examples:**

- He will look for a dropped item;
- The child begins to remember things and relate to events other than 'here-and-now' events.

**Ideas:**

- Play hiding games with objects and people.

**Examples:**

- Hide a toy under a scarf and gradually show it;
- Play peek-a-boo games with your hands or a scarf – cover your face for a moment then reveal it and say "boo" - help the child to remove the scarf from your face, or her own, to play the game.

**Cause-effect****Description:**

The child understands that if he does something there will be a result.

**Example:**

Understands that pushing a button on a toy will make a noise. This develops to apply to people as well as objects. The child learns that they can use another person to get what they want, for example, "If I cry, someone will pick me up".

**Ideas:**

- Help the child to play with toys and show her what happens when she does something - act excited about what she has done;
- If a child finds playing with toys a difficult task the occupational therapist can provide information about how to modify the toys.

**Anticipation****Description:**

The child learns about events and knows when they are going to happen.

**Example:**

Looks excited when they see food.

**Ideas:**

- Show the child what you are about to do and talk about what is coming next - young children learn a lot from their routines (things that happen over and over);
- Help the child to learn about routines by doing things the same way each time.

**Examples:**

- If he is always near the bathroom when the water is running - he will learn that this sound means bath time;
- If you always show him the car keys before going for a drive - he will learn that when he sees the keys this means you are about to go in the car.

It is important to look for your child's signs that they know what is going to happen and talk about it.

**Example:**

Child looks excited when they hear the microwave beep, knowing that food is coming, talk about this by saying "Yes, lunch is coming".

Objects or pictures can be used to show what is going to happen.

**Example:**

Show the child a towel before putting them in the bath and tell them it is "bath time".

A speech pathologist can help to get a set of objects or pictures that show what is going to happen.

**Active communication****Description:**

The child makes choices, indicates what they want and shows likes and dislikes.

**Ideas:**

Let the child know that you understand what he is trying to 'say' when he uses gestures, pointing, body language and so on - say what he wants.

**Example:**

"Book. You're looking at the book. I'll get the book for you."

**Other ideas to encourage good communication development**

- Children learn by repetition and they enjoy it - repeat games and activities over and over and notice how the child gradually learns more about communication;
- Children learn by watching and imitating - to teach a child how to do something, you need to show them examples.

This means:

Doing it yourself while the child is watching, or

- Gradually giving the child less help, so they can learn to do it themselves - refer to modeling A.A.C. use;
- Consistency is one of the most important ways to encourage children's communication development. Once you have decided to

encourage a skill using a particular idea, be consistent. That is, keep doing it the same way and encourage other people to do it the same way too.

- Every person in the family needs to know what the other people in the family are teaching the child. That way, they can all do the same thing and be consistent with the child;
- Routines (things that happen over and over) are a crucial part of a child's development - routines help the child to predict what is about to happen. For example, the child may learn that the evening routine is tea-time, bath-time, a story then bed-time;
- Young children begin by understanding single, important words - do not use long sentences to talk about things with young children - use single words and short phrases;
- Provide opportunities for the child to communicate (a speech pathologist can suggest ways to do this);
- Include music and singing into the child's day - some singing games for babies and young children include:
  - Everybody do this;
  - This is the way we....;
  - Old MacDonald;
  - Twinkle Twinkle;
  - Hello songs;
  - This little Piggy;
  - 3 Little Ducks, and
  - Pat-a-cake.

**What can a speech pathologist do to help?**

- Speech Pathologists look carefully at each child's communication skills. They give advice about how parents can encourage development of particular communication skills. This can be done by demonstration during a therapy session whilst talking to parents and giving them ideas about what they could try with their child and providing written information.
- Early intervention is very important for babies and young children. A speech pathologist may provide regular therapy sessions, mainly to work with parents and help them to interact with their child to encourage communication. This usually occurs in the home during the early years.
- A speech pathologist may suggest introducing signing to help the child to develop communication. Augmentative and Alternative Communication (A.A.C.) may be suggested.
- C.C.A. speech pathologists are able to provide training and education for families and other people who work with children who have

disabilities. This may relate to a particular area of communication, or it may be a training course that is held regularly by C.C.A..

The speech pathologist may recommend that parents and other significant adults attend a Hanen Workshop.

Next Month: more information on the Hanen program

### Story of the Month

Heather, mom to Addison age 1 ½ related the following story of an encounter she had recently:

While standing in line at the grocery store the other day, I had a rather snooty lady ask me what was wrong with my daughter, she didn't seem "normal" for her age? After telling her a little bit about Addison she proceeded to ask me why I chose to let her live. I told her that I didn't choose anything, It wasn't up to me. If she was meant to be here ( for however long she is) then she was meant to be here. She then went on to explain to me how much she probably suffers and has no connection to the world more or less the people around her. She didn't know how I could put an innocent child through so much. All this while her kids were in her basket whining; her throwing whatever she could in to get them to stop. By this time I was through the check out. I told her to have a good evening and walked away, but before leaving I turned said to her " I notice you have a pretty badly bruised finger tip and black fingernail... like it was squished in a door or something...looks dead and must have no connection to this world, would you like me to cut off your hand... I wouldn't want your finger to suffer!" " Just because my child has a disability, wasn't a reason for me to terminate her life!" " If you would get your head out of your A\*\* long enough you might see there is more to life than meets the eye, you must be the pushover type, cuz us strong ones were blessed with children like my daughter who need us, not some whiney brats who at the age of 5 look like they are still attached to mommahs teets"

### June Birthdays

Kaylee: 6/6/03  
Gavin: 6/12/99  
Alacea: 6/13/05  
Jori: 6/18/02  
Sky: 6/24/99  
Johanna: 6/25/01  
Kwan: 6/25/00  
Noah: 6/26/01

### June "Sadaversaries"

(birthdays and anniversary dates for children who have died)

Robbie F.: 1/25/92-6/2/06  
Jana: 6/3/03-8/8/03  
Madison Lee: 11/22/01-6/5/04  
Kael: 6/6/04-4/29/05  
Neveah: 6/8/06-8/28/06  
Teal: 6/12/98-11/14/98  
Madison F.: 6/13/01-6/20/01  
Matthew C: 6/14/99-4/9/04  
Carlos: 10/28/93-6/16/02  
Riley: ?-6/20/05  
Jonathan B.: 6/23/95-4/27/07  
Kayda: 2/12/88-6/23/00  
Dameon: 6/24/02-12/30/03



Help raise awareness of Hydranencephaly by purchasing a magnetic car ribbon.

Please go to:  
<http://www.hydranencephaly.com/awarenessribbons.htm> for information on how to order yours.

Do you have a story of how you've responded to someone saying negative things about your child. If so, please send it to me at:

[angelbearmom@shaw.ca](mailto:angelbearmom@shaw.ca)

**Next month:** More information on ways you can help your child learn how to communicate