

ROB'S HEALTH PLAN UPDATE 9-1-2005

General information: Cerebral palsy is a term used to describe a group of chronic conditions affecting body movements and muscle coordination. It is caused by damage to one or more areas of the brain before or during childbirth. "Cerebral" refers to brain and "palsy" to muscle strength and coordination. Cerebral palsy (CP) itself is not progressive. Secondary conditions can develop which change over time. Rob understands spoken language, he responds to yes/no questions with a smile for yes and pursed lips for no. He also uses an augmentative communications device called a Dynamyte, which he activates with a head switch, to communicate. Verbal communication is limited and you must allow time for him to process the question and answer. Rob is a happy guy with a terrific sense of humor and he thrives when in the presence of peers and adults. He occasionally can get over stimulated in large crowds and loud noise. His smile invites everyone to be his friend and he is well received and like by everyone.

Medical/Health concerns:

1. Severe Cerebral Palsy
2. Seizures
 - a) Tonic Clonic (Grand Mal) last documented was 2003
 - b) Partial complex (psychomotor or temporal lobe) last documented 5/05
3. Nutrition, hydration, swallowing and choking
4. Asthma
5. Headaches
6. Muscular-skeletal concerns
 - a) Scoliosis and positioning
 - b) Poor muscle tone putting joints at risk during transfers
 - c) limited ability to weight bear
7. Skin concerns
 - a) incontinent of urine and stool
 - b) pressure from sitting in wheel chair
8. Asthma
9. Headaches
10. Low vision

CEREBRAL PALSY

Spasticity is an ongoing issue for Rob and he does receive medication at home and at school for this. **Medication at school:** Baclofen 2mg 1 tablet crushed in water via the g-tube. This is given at the same time as his seizure medications.

Side effects could include drowsiness, dizziness, weakness, fatigue, nausea and vomiting. We need to be cautious with all mobility to protect extremities.

Awareness of Rob's place in space is important. Moving through doorways and through the crowded hall requires our close attention.

Safety is always a concern and keeping restraints in place and never leaving Rob unattended is critical.

More information is available in Rob's EEN file

Physical therapists and Occupational therapists work with Rob.

SEIZURES

Medications at school:

1. Keppra (Levetiracetam) 250 mg **crushed** and given via the g-tube at 1:30 to 2:00PM and flushed with at least 2-3 syringes full of water.
Side effects could include: tiredness, weakness, dizziness, nervousness and/or headache. Rob receives this medication three times each day...two doses at home morning and night...if our time varies mother needs to be notified.
2. Valproic Acid (Depakote) **four** 125mg capsules **do not crush empty** Capsules into liquid and give via the g-tube at 1:30-2:00PM and flushed with at least 2-3 syringes full of water. Side effects could include: nausea, vomiting, drowsiness, tremor, dizziness, hair loss/thinning, weight gain and thrombocytopenia. Blood levels are needed periodically to monitor the therapeutic level.
3. Diastat (Diazepam rectal gel) 10mg
Only given by the school nurse or under the nurse direction prior to administering for a tonic clonic (grand mal) Seizure.
Seizure must last longer than 3-5 minutes. This medication is given rectally and is provided in a one time does syringe.
If the seizure does not respond to the Diastat and continues longer than 5 minutes call 911 and he will be sent via ambulance to the UW hospital emergency room.
Side effects could include tiredness, headache and rash.

Rob has history of seizures, last fall he had increased seizure activity and was evaluated and medications were changed. Rob's cerebral palsy, spasticity, low vision and limited communication make it very important that we observe and evaluate his seizures. It is important that we record our observations on his seizure log and communicate activity with his staff and his parents. The next page is the protocol to follow.

SEIZURE PROTOCOL FOR ROB

1. Recognize a seizure.
 - a. Rob will not respond to you or to any yes or no questions.
 - b. Rob will not respond to a potty/swear word or phrase. These words always get smile type of reaction.
 - c. Rob will not respond to questions about his mother. For example "I wonder what your mother or Mrs. Cooney is doing today." These words also will get Rob to smile.
2. Call for assistance
Kathy Brockman School nurse 575-9541 or 608 214-3797
Ann Juzwik School nurse (back-up) 845-4115 or 219-4883
Anne Iverson School nurse (back-up) 845-4715 or 4815 or 219-4884
Paul Riehle SEA if he is not with Rob (he is available by walkie talkie)

3. Move Rob to the sensory room and transfer to the mat table or find a quiet place for him to lie down (could be the nurses' office). Place him on his side and move his chin to as neutral position to maximize his breathing. Keep everyone calm and quiet... Phone numbers are also listed on the back of Rob's phone.
4. Select a lead person until the nurse arrives...Paul, Krista, Michelle or Cathy.
5. Time the seizure and be prepared to describe and record in the seizure log.
6. ****If this is a tonic clonic (grand mal) school nurse will give the diastat or direct someone who is trained to do so.
7. Whenever possible the school nurse will call Janice Cooney at 848-1640 or Pager #550-0113, give your phone number and she will call you right back.
8. 911 will be called if the Diastat is given and grand mal seizure continues Rob will be transported to the UW Hospital.
9. It is important to remain calm and maintain a quiet relaxing environment. Rob may need to rest after having a seizure; he can remain at school and return to activities when able.

Nutrition, feeding, hydration, swallowing and choking

Only trained staff can feed Rob. Staff who feed Rob will be trained, observed and supervised by the school nurse.

1. Rob has gastric esophageal reflux, contents of his stomach can at times come up into the esophagus and cause discomfort in his chest and stomach. If he is given too much fluid and placed in prone or supine position too soon after eating this can cause reflux. He should be kept up for at least 30-45 minutes after eating. Medication: Metaclopramide (raglan) 4cc's is given via the g-tube 30 minutes prior to lunch. Side effects could include: restlessness, anxiety, drowsiness, and seizures.
2. Hydration during the school day...Rob should have between about six ounces of fluids in the morning and in the afternoon...lunch should include about 6-8 ounces.
3. Nuk brushing prior to eating and oral hygiene after eating is required.
4. Feeding procedure:
 - a) **Anyone feeding Rob must be trained by the nurse before oral feeding and g-tube feeding. Rob gets apprehensive if someone new feeds him.**
 - b) **He can eat noodles, potatoes, quiche, ice cream, casseroles using a coated metal spoon (NO PLASTIC) he bites them.**
 - c) **Ask yes and no questions about what he wants.**
 - d) **Place small amounts of these soft foods into the side of his cheek...give him time to swallow.**
 - e) **Oral feeding should take about 20 to 30 minutes. Then process the rest of his food in the blender, add 6-8 oz of liquid (whole milk and/or the nutritional supplement provided)**
 - f) **Attach the tubing that has the clamp closed to the g-tube.**
 - g) **Attach the syringe that you have pulled apart to the tubing**
 - h) **Fill the syringe with the blended food (pieces of meat like beef can still get stuck in the tubing even after blending)**

- i) **Open the clamp and push the feeding in slowly using the syringe plunger.**
- j) **Flush the tubing with at least two full syringes to clear all the food from the g-tube.**
- k) **Clamp the tubing and put the cap on the g-tube.**

TROUBLE SHOOTING THE G-TUBE:

1. Extra supplies are in the back pack and in the nurses' office.
2. If the g-tube comes out do not panic! The school nurse will reinsert and notify mother if he needs a new one.
3. Contact the nurse as soon as possible.
4. School nurse can reinflate the cuff of the g-tube or will tape it in place until parents arrange for a new one.

Choking, swallowing and reflux

CP and spasticity can inhibit swallowing and Rob is at risk for choking. Only those staff that have been trained may feed Rob.

1. Rob gets very panicky and dusky in color if choking
2. You **must** remain calm. Reassure him with a quiet voice and encourage coughing.
3. Unstrap him and lean him forward. Get him out of his chair if necessary.
4. If he does not cough and continues to look dusky use the Heimlich maneuver.
5. Call the school nurse immediately 575-9541 or 608 214-3797.

Asthma

Rob is allergic to dust mites and has seasonal allergies. He takes medication at home for his asthma and allergies. At school he has an albuterol inhaler. His asthma can be viral induced, meaning you are more likely to symptoms if he has a cold. The asthma symptoms you will see are coughing and wheezing. His loud breathing is not usually asthma it can be that he needs to take a deep breath. If you have concerns call the school nurse. He can get the inhaler to help him clear a cough if he seems to be struggling. Encouraging him to cough helps. Placing him on his stomach over the large pillow with his hands over his head also helps. His increasing scoliosis does make it harder for Rob to take deep breathes.

Headaches

Rob can be given Tylenol for his headaches, as noted above his medication could cause headaches, also stress and dehydration. Crush the medication, mixing with water and give via the g-tube, flushing with at least 50-100 cc's of water. Rob sometimes demonstrates pain by tensing his body, flushing and saying no to a number of questions. Be persistent and ask the yes and no questions. Have his

temperature checked by the school nurse if he feels warm and continues to be uncomfortable.

Musculo-Skeletal concerns

Rob has scoliosis that has progressed. He has no weight bearing so muscle development is limited joints and bones are fragile and movement with the exception of his spasticity is provided by staff.

It is very important because of Rob's low vision and limited ability to communicate that staff explain what you are planning to do. Prior to transferring Rob you must have been trained by PT or OT staff. The school nurse is also available to train and supervise.

1. Two person transfers are required
2. Two people are also required when using the Arjo lift
3. Positioning in the stander, wheel chair and on the mat table should always be done to maintain good alignment without pressure
4. Rob also has AFO's and splints that need to be properly used as directed by the therapy staff.
5. Rob's safety must be considered at all times so focus on the activities that you and Rob are doing.

Skin concerns

Rob has no bowel or bladder control and he wears pull-ups that need to be checked and changed through out the day. It is important to clean the area with wipes and if a rash or redness occurs report to his parents. Using Desitin if rashes occur.

If areas of pressure are observed we need to have this evaluated for equipment fit or other causes and we need to notify parents.

Signature and date of approving parent

Signature and date of approving physician