Your Child’s Therapy

For Children with Hurler Syndrome_UMMCH

The information in this section will help you understand the role of rehabilitation in your child’s development.

About occupational therapy

Occupational therapy can help children who have:

- Problems with fine motor skills (using a pencil or scissors, stacking blocks, sorting shapes)
- Problems with daily activities (dressing or feeding oneself, playing)
- Orthopedic concerns that affect development (such as carpal tunnel syndrome or limited range of motion)
- Vision and perception problems

Your therapist can also provide equipment, answer questions and address other concerns you may have as your child grows.

Children with Hurler syndrome have limited joint movement in the neck, spine, hips, shoulders, wrists and fingers. All of this can affect their fine motor skills. For example, your child may have problems bending their fingers. This may not greatly impair the child’s ability to pinch, but it can limit the strength of their grasp. Your therapist will work with the child to maintain finger flexibility and improve strength.

Your child may also have limited shoulder motion, making it hard for the child to reach. In an effort to reach higher or farther, children with Hurler syndrome often compensate for this problem through trunk movements. In fact, this can decrease the child’s reaching ability. An occupational therapist can offer new positions to help improve reaching and other skills.

Children may need wrist splints if they begin to show signs of carpal tunnel syndrome. Your therapist can create these splints or help you order them.

Occupational therapy offers home exercise programs—see the precautions on the next page. If your child has attention or cognition (thinking) problems, your therapist will provide guidelines for school workers and other adults who care for your child.

Speech and gross motor skills tend to be more delayed than fine motor skills. For this reason, your child may also need physical therapy to improve gross motor skills (crawling, sitting up, climbing, walking). A speech therapist can help with language skills.
About physical therapy

Physical therapy can help children who have:

- Problems with gross motor skills (sitting, rolling, squatting, climbing)
- Mobility problems (crawling, walking, running)
- Orthopedic concerns that affect motor development (such as problems in the spine or legs)

Your therapist can help you obtain equipment, answer questions and address other concerns you may have as your child grows.

For children with Hurler syndrome, limited joint movement can affect gross motor skills. For example, a child may not be able to straighten or rotate some joints, which makes it hard for the child to change positions. If the spine does not straighten and the child cannot reach overhead with their arms, the child will not be able to crawl. Perhaps the child can sit alone to play, but they cannot move from lying down into a sitting position without help. Maybe the child can walk but needs help to stand up from the floor.

Because these children have problems changing position, they often have developmental delays by the time they are 1 or 2 years old. You may see gaps in your child’s ability to crawl, climb, squat, run, and propel on a riding toy or tricycle.

To improve your child’s gross motor skills, your physical therapist may:

- Teach movement patterns to help the child compensate for their joint problems
- Arrange for foot and ankle orthotics (to increase joint stability for standing and walking)
- Provide a home exercise program
- Offer guidelines for school workers and other adults who care for your child (to help with safety, mobility or behavior problems)

Mobility concerns

Children who cannot walk long distances may need a wheelchair or adapted stroller (made for older children who have balance problems). Other children may need a cane or walker to help them balance. Your physical therapist can help you choose and order equipment as needed.

Some children need surgery to correct problems in the spine, hips or knees. A therapist can help with mobility concerns right after surgery (moving in bed, being transferred to a wheelchair, etc.). When the child has healed, the therapist can help improve balance, walking and transfer skills (moving from a bed to a chair, for example).

Precautions

Children with Hurler syndrome often have heart and lung problems. These may affect activity level. If you are concerned about your child’s endurance or activity level, please call your doctor.

Avoid vigorous joint stretching. Children with Hurler syndrome have abnormal joints—they rarely have true muscle and joint tightness. You can maintain joint flexibility through:

- Gentle range-of-motion exercises
- Active play that includes bending, squatting, reaching and climbing

Children with Hurler syndrome have spinal problems in the neck and upper back. Avoid activities that might put stress on these areas.
About speech and language therapy

Speech and language therapy can help children who have:

- Delayed speech and language skills
- Delayed cognition (thinking) skills
- Hearing problems
- Trouble swallowing
- Feeding problems

Children with Hurler syndrome take longer to develop speech and language skills. Sometimes parents overlook this because their child’s physical problems are so severe.

It is important to treat speech and language problems as soon as possible. From birth to age 3, your child is in a sensitive time of brain development. Progress depends on what kind of stimulation the brain gets, and how much. To help the brain develop, therapy should be intensive during this time. Stimulation will have less of an effect as the child grows older.

You will work with your speech and language therapist(s) to improve your child’s skills.

Language skills

Children with Hurler syndrome have more trouble expressing themselves than understanding what is said to them, even when they have hearing loss.

If your child does not speak, your therapist will work on the imitation of sounds and oral movements (teaching your child how to move the tongue, lips and jaws). They will also teach other ways to communicate, such as through gestures or American Sign Language.

If the child has problems understanding what is said to them, the therapist will work on these skills as well.

Hearing

Many children with Hurler syndrome also have hearing problems. While poor hearing is not the sole cause of language delays, it does play a role. Your speech and language therapist will urge you to have your child’s hearing checked regularly.

If the child has hearing loss, it should be treated right away. Treatment may include PE (pressure equalization) tubes or hearing aids.

Blood and bone marrow transplant

If your child has a blood or marrow transplant, it will prevent or slow the further decline of their mental development. It will not reverse delays that have already occurred. Children often have a slightly lower level of mental function after the transplant, but they keep learning new skills and their hearing often improves.

The parents’ role

Intense speech and language therapy can make a big difference in your child’s development, both before and after transplant. Children who practice their therapy activities each day do better overall than children who only go to therapy sessions or do nothing at all.

Your child may make great progress with a speech and language therapist. But your help is essential. While the therapist will guide the learning process, you must carry out the daily program. You are the best source of language stimulation for your child. For tips on helping your child, see the section in this binder called Home Exercise Program.