Home Exercise Program

For Children with Hurler Syndrome

Your child may need long-term rehabilitation services, including physical therapy, occupational therapy, and speech and language pathology.

In this section, you will find:

- Range-of-motion exercises
- Tips for helping with speech and language
- Details about your child's therapy program
- Guidelines for therapy after you return home

Range of Motion Exercises for Upper Body

Passive range of motion exercises are done to preserve flexibility and mobility of the joints on which they are performed. It is important to perform these exercises to prevent deformities. All the exercises should be done several times a day. A good time to do them is after the baby's bath or at each diaper change. Your physical therapist will tell you how many times to do each one. These exercises should be done slowly and steadily. Never force a joint. Damage to the joint space can occur if too much force is applied. Joint range of motion is done on one joint at a time. Stabilize with one hand just above the joint and place your other hand below the joint to move the part through its full range of motion.

Shoulder

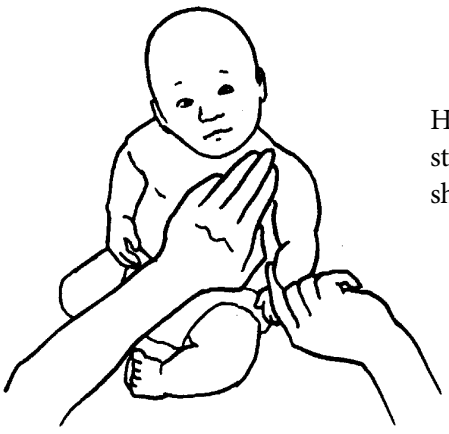
Shoulder flexion

Starting position: Place child lying on back.

Hand placement: Stabilize with one hand at the shoulder blade so that it doesn't come up. Hold wrist with the other hand (see Figure 1).

Motion: Start out with reaching for objects, then bend the arm up so the hand is over the head with the thumb leading. Keep the elbow straight (see Figure 2).

Only bend until you feel resistance, then stop and hold a few seconds.



Hand should stabilize the shoulder blade.

Figure 1

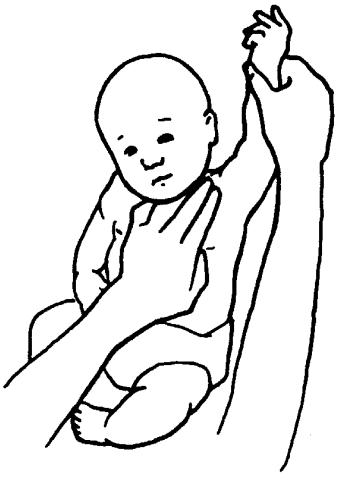


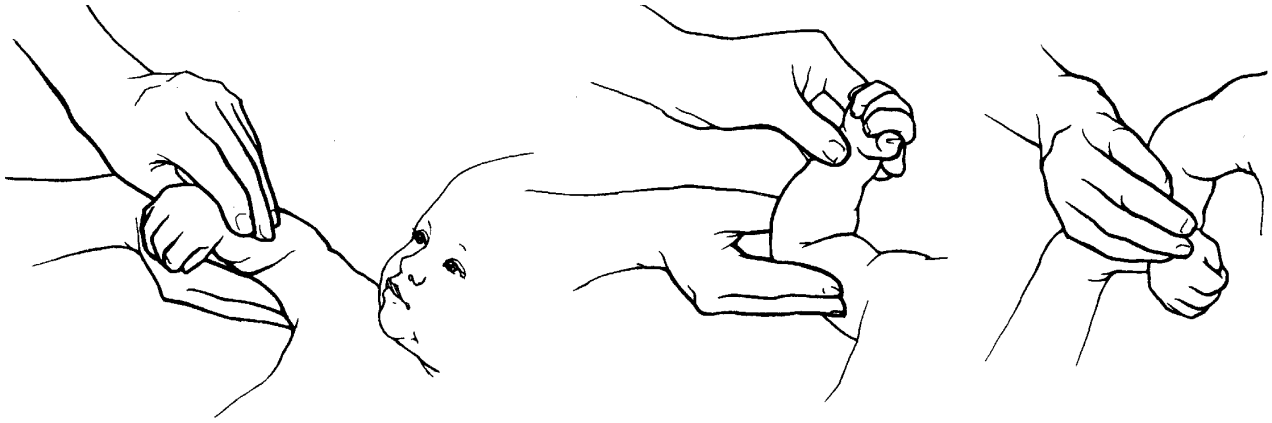
Figure 2

Shoulder rotation

Starting position: Lay child on back, elbow bent and arm straight out to the side.

Hand placement: Hold arm straight out to the side. Hold the forearm with the other hand (see Figure 1).

Movement: Roll the forearm up (see Figure 2), then roll the forearm down (see Figure 3).



Shoulder abduction

Starting position: Place child lying on back or in sitting position.

Head placement: Stabilize with one hand at the shoulder blade so it doesn't come up. Hold forearm with the other hand (see Figure 1).

Motion: Bend the arm sideways away from the body; bring the arm straight out to the side (see Figure 2).

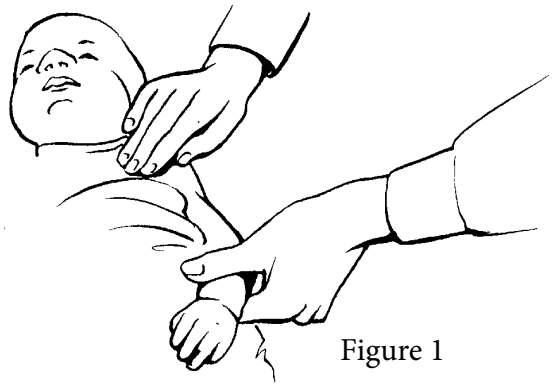


Figure 1

Place hand on shoulder blade to avoid the shoulder blade from popping off the rib cage.

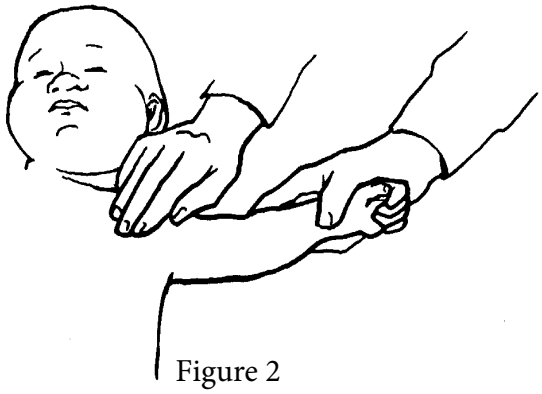


Figure 2

The exercises should be done only under the direction of a physical therapist.

Forearm supination and pronation

Starting position: Sitting with elbow bent, arm close to the body.

Hand placement: Stabilize the upper arm with one hand, hold the wrist with the other hand.

Movement: Roll the forearm and hand up (see Figure 1), then roll the forearm and hand down (see Figure 2).

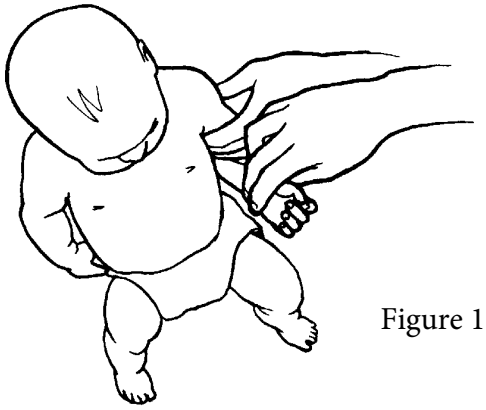


Figure 1

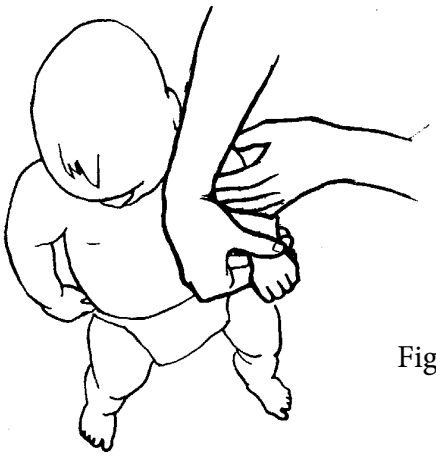


Figure 2

Wrist

Wrist flexion and extension

Starting position: Sitting.

Hand placement: Stabilize the forearm with one hand. Hold child's hand with your other hand (see Figure 1).

Movement: Bend the wrist forward and back (see Figures 2 and 3).

Figure 1

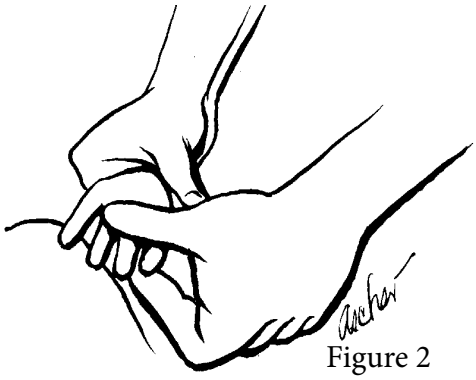


Figure 2

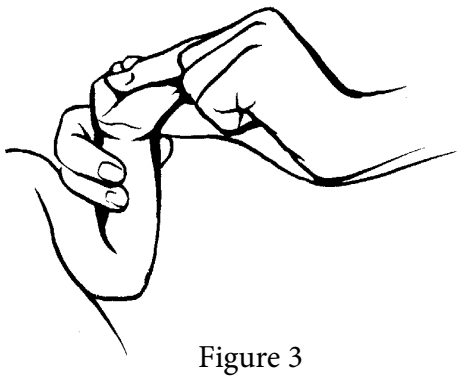


Figure 3

The exercises should be done only under the direction of a physical therapist.

Wrist abduction and adduction (radial and ulnar deviation)

Starting position: Sitting.

Hand placement: Stabilize the forearm with one hand. Hold the child's hand with your other hand (see Figure 1).

Movement: Bend the wrist from side to side (see Figures 2 and 3).

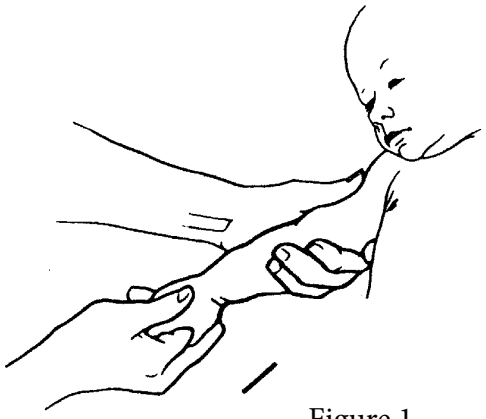


Figure 1

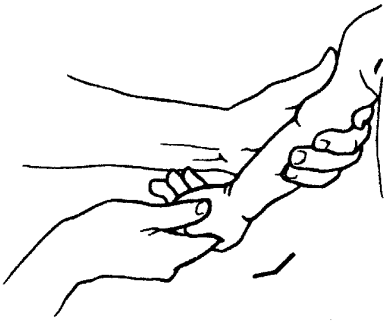


Figure 2

Figure 3

Fingers

Finger flexion and extension

Starting position: Optional.

Hand placement: Stabilize the forearm and wrist with one hand. Hold the child's fingers with your other hand.

Movement: Bend the fingers (see Figure 1), then straighten the fingers (see Figure 2).

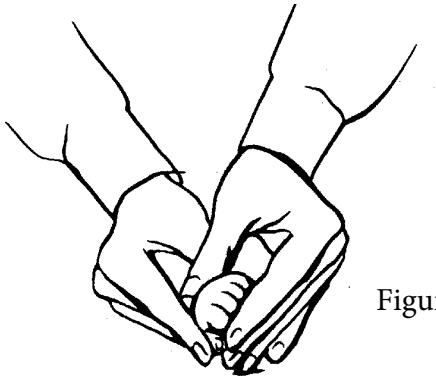


Figure 1

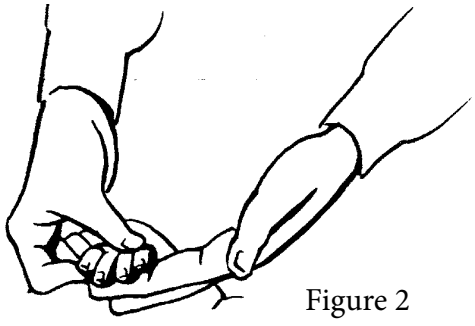


Figure 2

Finger abduction and adduction

Starting position: Hold the child's hand and wrist open and straight.

Hand placement: Hold the fingers straight (see Figure 1).

Movement: Spread the fingers apart gently, bring them back together (Figures 2, 3 and 4).

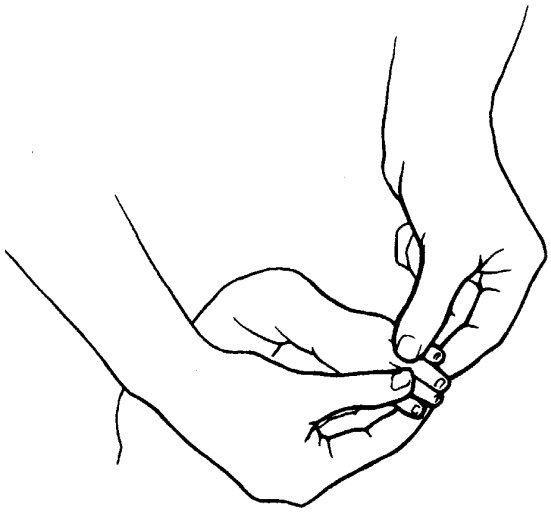
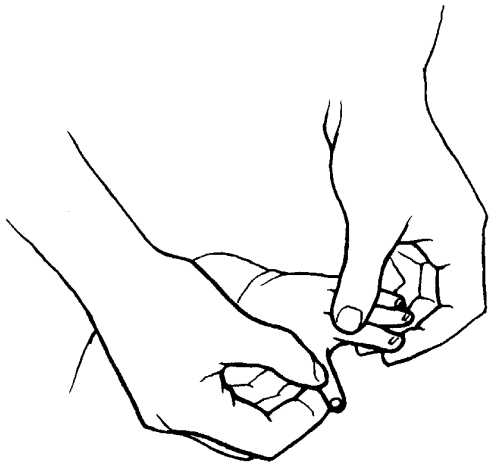


Figure 1



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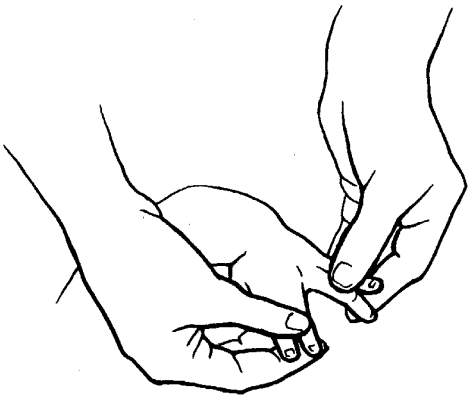


Figure 3

Figure 4

The exercises should be done only under the direction of a physical therapist.

MP flexion and IP extension (knuckle bent, fingers straight)

Starting position: Optional.

Hand placement: Stabilize the child's wrist with one hand. Hold the fingers with your other hand.

Motion: Bend the knuckle while keeping the fingers straight.

Thumb

Thumb opposition

Starting position: Hold the child's hand open with palm up.

Hand placement: Stabilize with one hand at the base of the little finger. Hold the end of the thumb with your other hand (see Figure 1).

Movement: Bend the thumb up and over toward the base of the little finger (see Figure 2).

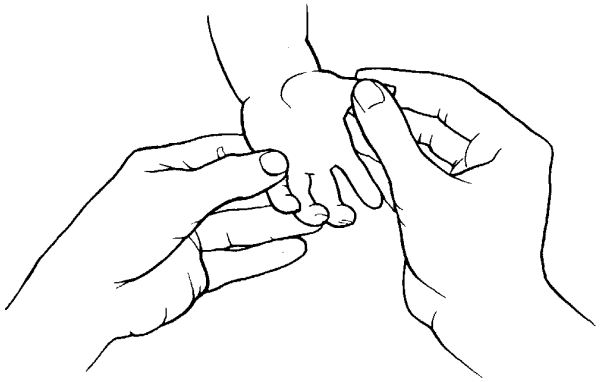


Figure 1

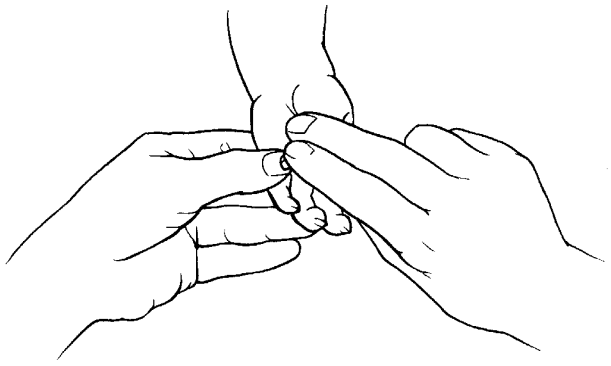


Figure 2

Thumb extension

Starting position: Hold hand open with palm up.

Hand placement: Stabilize with one hand in the palm of the child's hand. Hold the end of the thumb with your other hand (see Figure 1).

Movement: Straighten the thumb upward, away from the palm (see Figure 2).

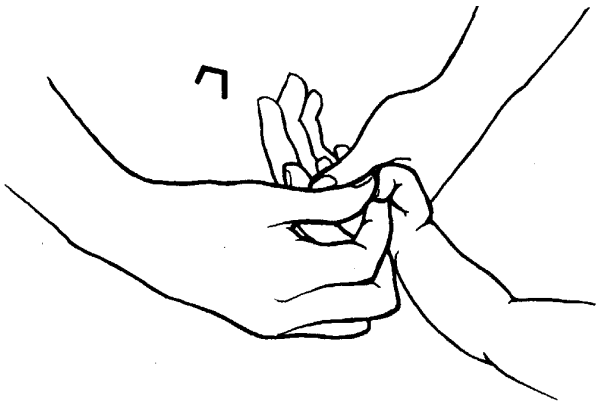


Figure 1

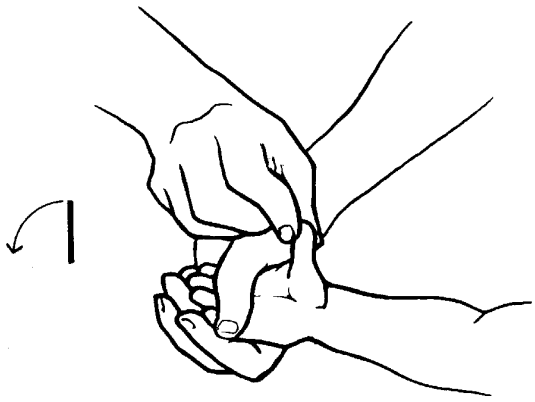


Figure 2

Thumb abduction-adduction

Starting position: Hold hand open with palm up.

Hand placement: Stabilize with one hand in the palm of the child's hand. Hold the end of the thumb with the other hand (see Figure 1).

Movement: Bend the thumb away from the side of the hand (see Figure 2).

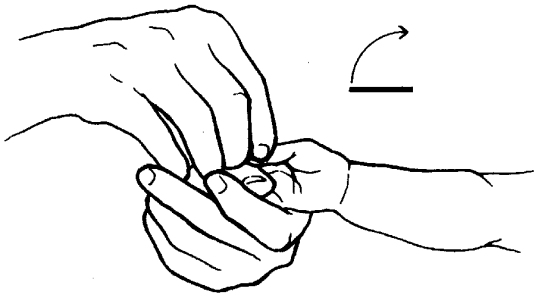


Figure 1

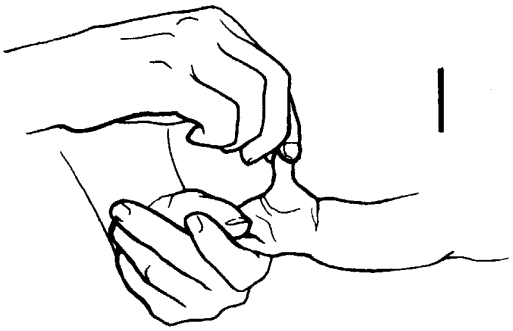


Figure 2

Range of Motion Exercises for Lower Body

Passive range of motion exercises are done to preserve flexibility and mobility of the joints on which they are performed. It is important to perform these exercises to prevent deformities. All the exercises should be done several times a day. A good time to do them is after the baby's bath or at each diaper change. Your physical therapist will tell you how many times to do each one. These exercises should be done slowly and steadily. Never force a joint. Damage to the joint space can occur if too much force is applied. Joint range of motion is done on one joint at a time. Stabilize with one hand just above the joint and place your other hand below the joint to move the part through its full range of motion.

Knee

Knee flexion and extension

Starting position: Place child on stomach.

Hand placement: Stabilize with one hand just above the knee. Hold lower leg with your other hand.

Motion: Bend knee as much as possible (see Figure 1). Then straighten knee as much as possible (see Figure 2).

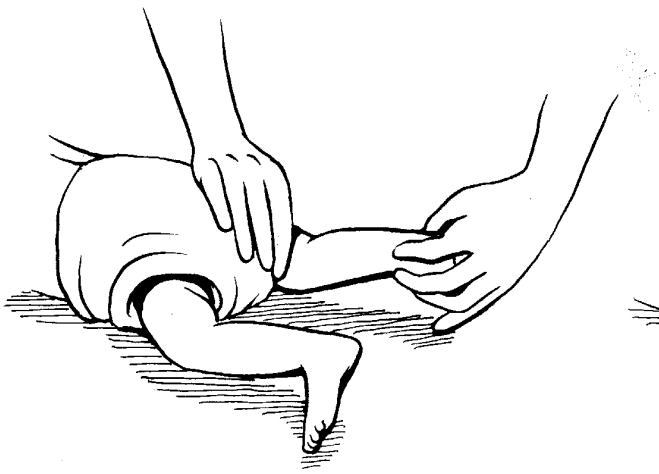


Figure 1

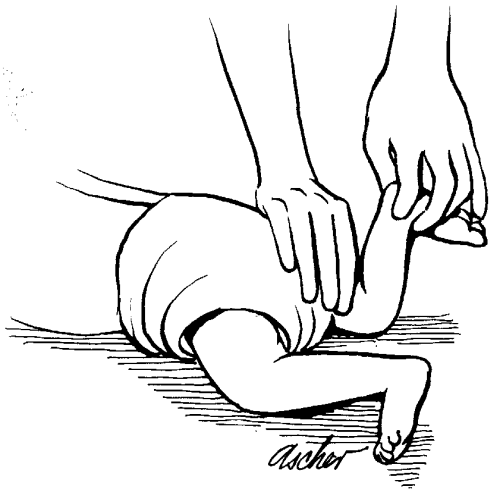


Figure 2

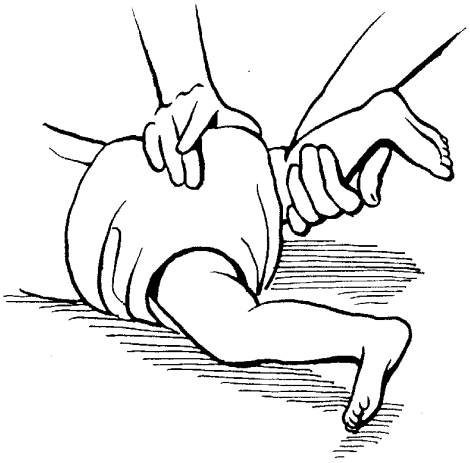
Hip

Hip extension

Starting position: Place child on stomach.

Hand placement: Place one hand on top of seat; place other hand under knee.

Motion: Lift leg straight up while holding seat down.



Hip flexion

Starting position: Place child on back, lying with leg straight.

Hand placement: Place one hand on upper leg; grasp sides of foot with other hand.

Motion: Bend knee toward chest (see Figure 1). Bring leg all the way down (see Figure 2).

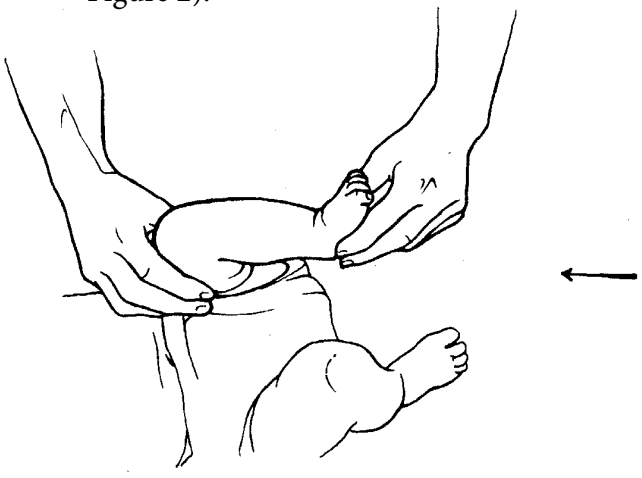


Figure 1

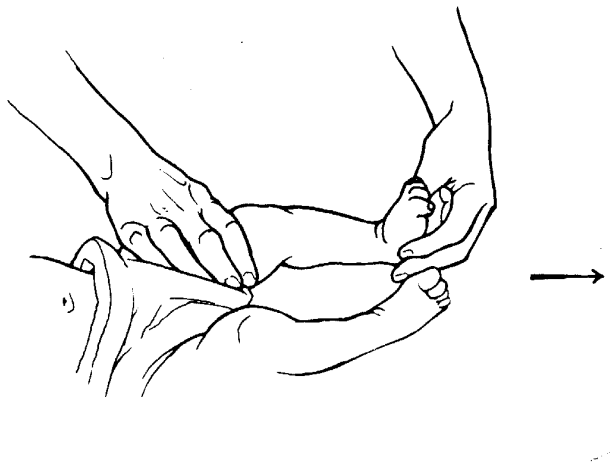


Figure 2

Hip abduction-adduction

Starting position: Place child on back, lying with other leg out to the side.

Hand placement: Stabilize with one hand on hip, the other hand on heel (see Figure 1).

Motion: Slide leg out to the side (see Figure 2) and then slide leg back in as far as possible (see Figure 3). Do not let knee roll outward or inward.

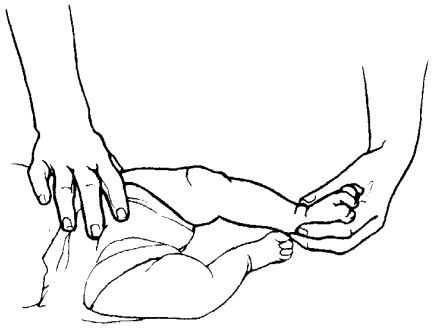


Figure 1

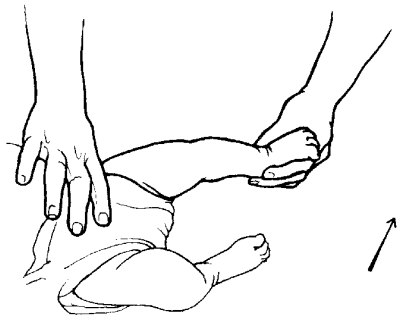


Figure 2

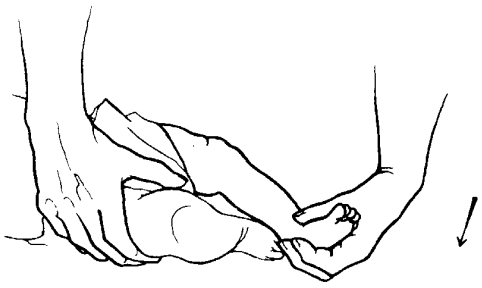


Figure 3

Hip rotation—Hip straight

Starting position: Lay child on back.

Hand placement: Place one hand on thigh, one hand on heel (see Figure 1).

Motion: Roll leg in (see Figure 2) and then out, using hand on thigh (see Figure 3).

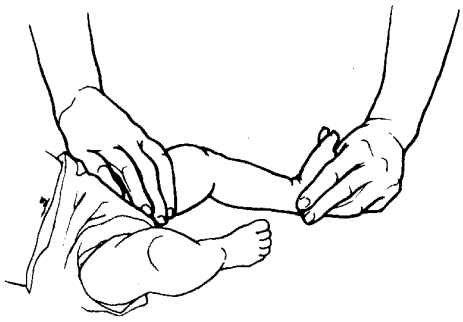
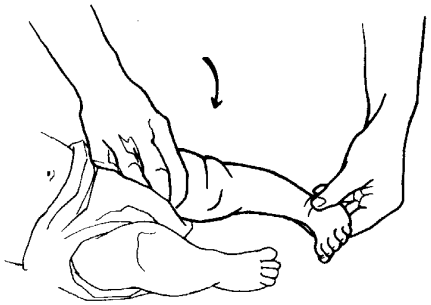


Figure 1



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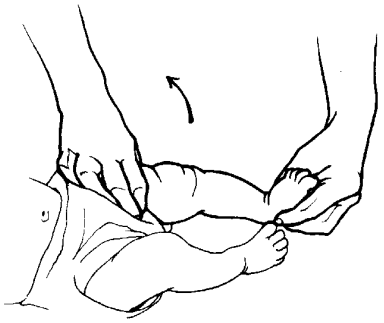


Figure 3

Hip rotation—Hip bent

Starting position: Place child lying on back.

Hand placement: Place one hand on thigh, one hand on heel (see Figure 1).

Motion: First roll knee inward (see Figure 2) and then outward (see Figure 3).

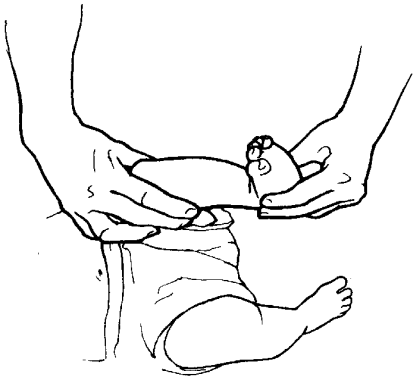
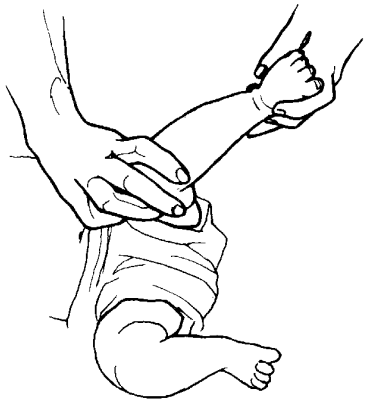


Figure 1



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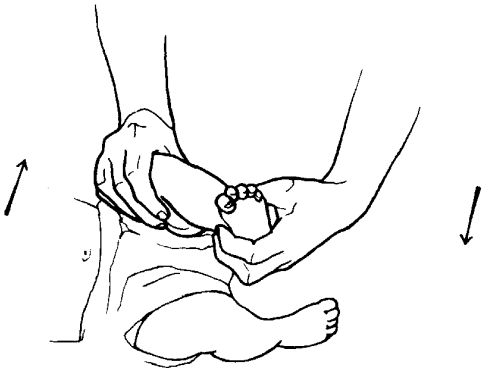


Figure 3

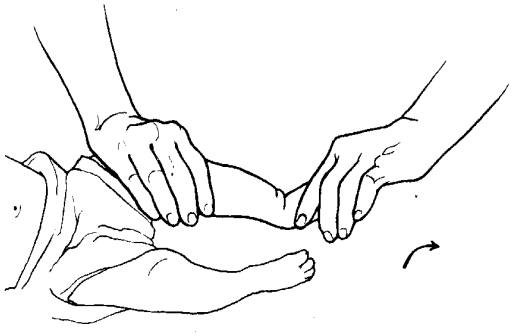
Ankle and foot

Ankle plantar flexion

Starting position: Lay child on back.

Hand placement: Stabilize with one hand on leg; grasp foot with other hand.

Motion: Bend ankle down as much as possible.

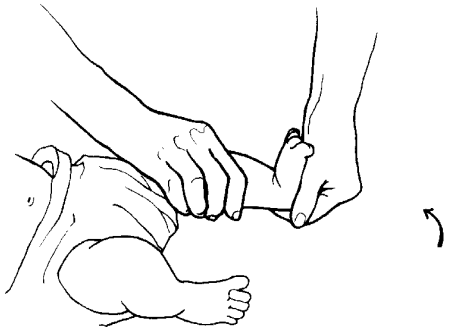


Ankle dorsiflexion

Starting position: Lay child on back.

Hand placement: Stabilize with one hand on leg; grasp heel with other hand.

Motion: Pull heel down and bend ankle as much as possible.



Ankle inversion and eversion

Starting position: Lay child on back.

Hand placement: Stabilize with one hand on leg; grasp outside of foot (see Figure 1).

Motion: Turn foot in (see Figure 2) and then turn foot out (see Figure 3).

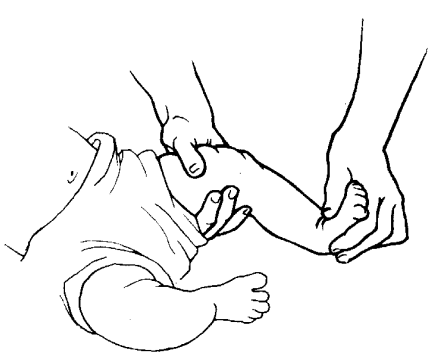
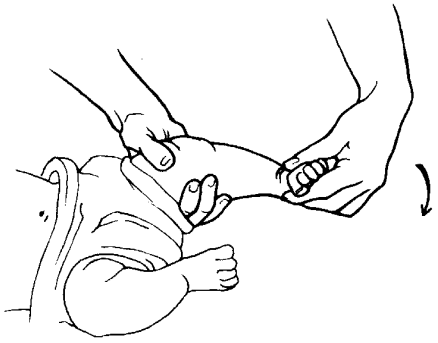


Figure 1



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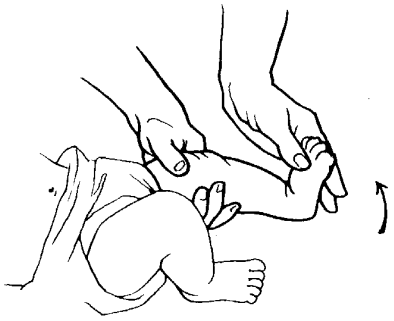


Figure 3

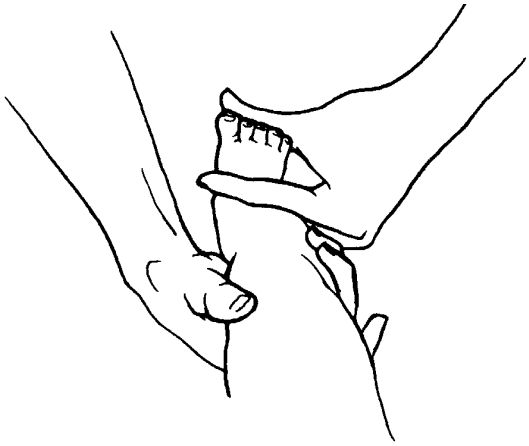
Toes

Toes

Starting position: Place child lying on back.

Hand placement: Stabilize with one hand on lower leg; stabilize ankle with the other hand.

Motion: Bend the toes upward. *Do not touch the ball of the foot.*

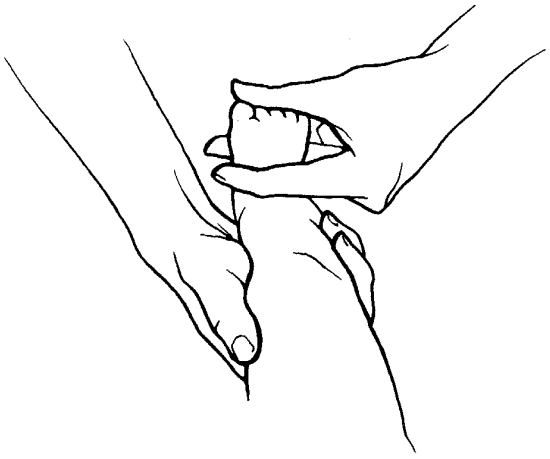


Toe flexion

Starting position: Place child lying on back.

Hand placement: Stabilize with one hand on lower leg; stabilize ankle with the other hand.

Motion: Bend the toes down.



Speech and Language Pathology

How can I get the best services for my child?

Be proactive. Contact your school district and/or your local hospital or clinic to request a speech and language therapy evaluation. You will need a referral from your physician to get therapy services at your local hospital or clinic.

For children under age 3, school districts offer early intervention programs. These programs should provide therapy at least three times a week, including services for speech, language and oral motor skills.

It is always best for school and medical services to work together. When a child receives speech therapy from more than one provider, the therapists can supplement each other's services and support the parents' efforts. You can help them work together by:

- Signing an information release form for each therapist
- Making sure that each therapist has contact information for the other therapists
- Asking the therapists to share information about your home treatment program

If you cannot arrange for speech and language therapy through your school or local hospital, ask your doctor or psychologist for help. Or, contact University of Minnesota Medical Center.

How can I help my child improve speech and language skills?

Set goals as you work with your child. These may include increasing the number of words your child can say or understand, using more signs and gestures, and teaching more play skills that involve language.

Some ideas for building language skills:

- If your child cannot yet speak: blow bubbles, blow raspberries and play other oral games that require mouth movements (see handout for other activities).
- Use language all of the time. Do not use baby talk, but keep your sentences short and your words simple. Speak to your child when you are doing any activity, whether it needs language or not. For example, when dressing your child, name body parts and pieces of clothing. Use simple sentences to describe actions: "Your foot goes in this shoe."
- Help your child point and make other gestures. Guide the child's hand if you need to.
- Do not anticipate your child's needs or desires. Try to get your child to express their own preferences and wants. Wait patiently if it seems that the child is trying to signal a choice. Praise them for making an effort.
- If the child cannot say a certain word, say it for the child. For example, when helping the child point, you can say, "Oh, you want the blue car."

- If your child has mastered gestures or pointing, urge your child to vocalize. Let the child try to speak before your respond.
- Keep talking, even if your child doesn't respond. If you think the child is having problems understanding, you can speak in simple terms, but do not stop talking to the child.
- Imitate the sounds your child makes. Play imitation games. Give positive encouragement. Get excited about your child's vocalizations.
- If your child has developed speech and language skills, ask the child questions. If your child does not respond, answer your own questions, but keep asking them. Urge your child to ask questions, too.
- Read to your child every day. Be sure to read stories that are at the right age level.

How do I know if my child has speech problems?

The following chart shows normal speech skills for children up to 4 years old. It measures intelligibility, or how well a listener can understand what a child says.

For example, the average 2-year-old can be understood 65% of the time. They speak at least 50 words and are starting to combine words to make short phrases.

Your child's intelligibility should be close to the levels listed here. If it is lower, your child may have speech problems.

Child's age	**Intelligibility** *(percent of words a stranger would understand)*
1	25%
2	65%
3	80%
4	90 to 100%

From Arizona Articulation Proficiency Scale, *third revision, by Janet B. Fudala (Los Angeles: Western Psychological Services, 2000).*

The chart on the next page lists sounds heard in 90% of children ages 2 through 7. If your child does not use all the sounds listed in their age group, the child may have problems with speech.

Child's age	**Sounds and where they appear in words** *(beginning or end)*
2	h (beginning) b (beginning) p (beginning) n (beginning) m (beginning and end) most vowels
3	b (end) p (end) n (end) k (beginning and end) g (beginning and end) d (beginning and end) t (beginning) f (beginning and end)
4	t (end) y (beginning)
5	ng sh (beginning and end) v (beginning and end) l (beginning) ch (beginning)
6	l (end) r (beginning and end) s (beginning and end) z (beginning and end)
7	ch (end) th (beginning and end)

From Arizona Articulation Proficiency Scale, *third revision, by Janet B. Fudala (Los Angeles: Western Psychological Services, 2000).*

Difficult sounds—such as l, r, sh, ch, y, ng, th, s and z—may take several years to fully develop. Many children do not develop these sounds until ages 7 or 8.

Oral Alerting Activities

Oral alerting activities help "wake up" your child's face and mouth before a meal, so the child can be a more active and efficient participant in the eating process. These simple activities include touching, wiping, and tapping techniques used on your child's face and mouth.

Why oral alerting activities?

At any meal, the goal is to take in a well-balanced diet to maintain proper growth and health. But some children have muscle tone or attention difficulties which make them less aware of their mouths and less able to pay attention to the meal. Therefore, it can be difficult from them to take in a balanced diet. Oral alerting activities can help your child eat better and eat a greater variety of food, leading to better nutrition.

Because alerting helps children use their mouths more efficiently, over time their oral skills are strengthened. These skills are critical not only for eating but also for clear speech and making distinct facial expressions.

When are these techniques used?

Oral alerting activities are used just before meals to wake up the face and mouth, and during meals to help keep the mouth active. They are designed for children with floppy muscle tone or those who have trouble focusing their attention on the oral skills of eating.

Discuss these techniques with your child's feeding specialist or occupational, speech, or physical therapist to determine if this approach is appropriate for your child and, if so, which techniques would work best.

How are they done?

These techniques must be modified for each individual child. Be sure your child is in a comfortable, supported position prior to the meal. Keep the head upright and not tipped back when doing these techniques.

Before alerting the mouth, pay attention to the rest of your child's body. Give a brisk body rub, a tickle on the trunk, a rapid game of "patty cake," or a bounce on your lap or a ball to help wake up the whole body. By activating the body muscles, you help the mouth become more organized as well.

Your child's occupational or physical therapist will help you develop a body alerting program that works best for your child. Here are some general oral alerting suggestions.

Washcloth wake-up

Wipe your child's face briskly with a cool to cold washcloth. Wipe cheeks up, down, and diagonally. Wipe chin up and down. Be random and uneven in your touch until the end of the rub. Then wipe cheeks and upper and lower lips toward a closed mouth position in preparation for food presentation.

This technique is effective if done prior to a meal and then intermittently throughout the meal as more "wake-up" is needed.

Washcloth wake-up

Finger tapping on the face

Tap your child's face with your fingers. Tap lips and cheeks in a playful fashion as you would play a piano with one finger at a time, tapping in a sequence.

Hands-together tapping

Hold the heels of your hands together at your child's chin, and tap or clap your child's cheeks and jaw joint with your fingers held together. (The purpose of holding the heels of your hands together is to keep your hands close to your child's face and to prevent tapping too hard.) This tapping wakes up the face and the jaw area.

Hands-together tapping

Lip tapping

Hold your fingers together, and tap or clap the fingers on your child's lips in a playful fashion. This is especially effective if your child opens and closes the mouth while you are doing it.

Lip tapping

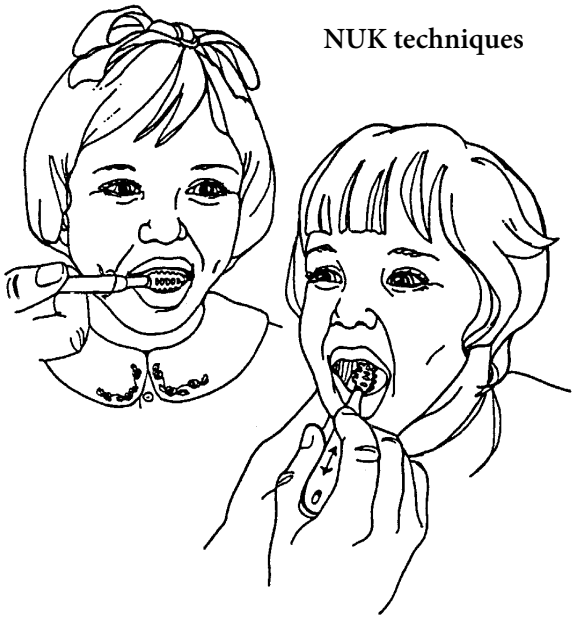
Infa-Dent finger toothbrush/gum massager

The Infa-Dent finger toothbrush/gum massager is a soft plastic baby toothbrush that fits over your finger. It has a nubby part on the fingertip end that is used to clean baby teeth and massage gums. This can be used to stroke your baby's cheeks, tongue and gums to "wake up" the mouth before a feeding.

NUK massage

Use a toothbrush or NUK massage brush to apply "wake-up" pressure on the tongue. The brush should remain in contact with the tongue and be pressed firmly up and down—not too hard so that it hurts, but not so soft and slow that it has no "wake-up" value. To increase the alerting value of this activity, try dipping the brush in ice-cold water before doing this. Other "wake-up" tastes, if you child enjoys them, might be lemon water, lemonade, or pickle juice.

NUK techniques



To alert the cheeks, place the NUK massage brush on the inside of the cheeks and roll upward.

Press the NUK massage brush on the center and front of the child's tongue several times. On the way out of the mouth, stroke the brush along the palate (roof of the mouth) behind the top teeth, moving toward the mouth opening.

Roll the NUK massage brush gently and teasingly on the sides of the tongue, to tickle it to move toward the side of the mouth. Roll it away from the tongue on each side (clockwise on the right and counterclockwise on the left).

All of these NUK techniques should be done carefully and should be demonstrated by your child's therapist. Be careful not to jab your child's teeth, gums, or tongue or accidentally gag your child with the brush.

To prevent accidental choking, never leave the child unattended with the NUK.

Children tend to enjoy these activities more if they have some control. Before putting the NUK in the mouth, place it gently on your child's lips and wait for the child to open up. If your child resists the NUK, don't force it but consult with your therapist for more ideas.

Vibration

When moving your hands on your child's face or using the NUK brush, vibrate your hands a little to add a different type of alerting sensation.

A hand-held vibrator used on the face is very alerting for some children. Sometimes they want to play by holding it themselves. Other times, they respond best if you hold it. You can gradually get a child used to the vibration by touching the child's face with the back of your hand while the vibrator is vibrating in your hand. This way the vibration is not as strong because it is coming through your hand.