



Patient Education
intermountainhealthcare.org/pedsrehab

Managing Spasticity

Primary Children's Rehab Services


Intermountain[™]
Pediatric Rehabilitation



Managing Spasticity

The goal of Primary Children's Medical Center's Rehabilitation Department is to enhance the quality of life for children with disabilities. We aim to make the most of the child's potential—both during childhood and later, as an adult. Managing spasticity is one part of our comprehensive rehabilitation department.

Primary Children's Spasticity Care Team is specially trained to manage spasticity in children, adolescents, and young adults.

This handbook aims to give both parents and healthcare providers with a better understanding of spasticity and options for its management.

What's Inside:

WHAT IS SPASTICITY? 4

Things to consider for a spasticity management plan	4
Your child's care team	5
Spasticity management options	6

PHYSICAL AND OCCUPATIONAL THERAPY. 7

Positioning, bracing and splinting, serial casting, direct therapy.	7
---	---

BACLOFEN AND OTHER ORAL MEDICATIONS. 8

How does oral baclofen work?	8
What children might benefit from oral baclofen?	8
How is baclofen prescribed?	8
What are the possible side effects of baclofen?	9

BOTOX INTRAMUSCULAR INJECTIONS 10

What is Botox and how does it work?	10
What are the benefits of Botox injections?	10
How is Botox given?	10
What are the risks and possible side effects of Botox?	11
What happens after Botox injections?	11

PHENOL INTRAMUSCULAR INJECTIONS. 12

What is phenol and how does it work?	12
What are the benefits of phenol injections?	12
How is phenol given?	12
What are the risks and possible side effects of phenol?	13
What happens after phenol injections?	13

ORTHOPEDIC SURGERY 14

What is orthopedic surgery?	14
Which children can benefit from orthopedic surgery?	14
What are the risks and limitations of orthopedic surgery?	14
What happens after orthopedic surgery?	15

INTRATHECAL BACLOFEN PUMP. 16

What is intrathecal baclofen?	16
What are the benefits of intrathecal baclofen?	16
How is intrathecal baclofen given?	16
What are the risks and possible side effects of intrathecal baclofen?	17
How is the pump managed after surgery	17

SELECTIVE DORSAL RHIZOTOMY 18

What is selective dorsal rhizotomy and how does it work?	18
Which children might benefit from selective dorsal rhizotomy?	18
What are the risks of selective dorsal rhizotomy?	18
What happens after the surgery?	19

HOW TO CONTACT US. 19

Driving map	19
-----------------------	----

.....



Dystonia is a disorder of movement which causes abnormal stiff postures and repetitive movements.

Athetosis is slow writhing movements of the hands, feet, and other body parts.



What Is Spasticity?

Spasticity is a condition in which some muscles are continuously contracted (shortened and tightened)—causing stiff muscles, awkward movements, and exaggerated reflexes. Spasticity happens when a brain or spinal cord injury damages the nerve signals that tell a muscle to relax. Spasticity may occur with conditions such as cerebral palsy, traumatic brain injury, stroke, and spinal cord injury.

The degree of spasticity can vary from mild muscle stiffness to severe, painful, and uncontrollable muscle spasms. Spasticity can affect a child's comfort level and movement, often making it difficult to do activities such as sitting, eating, standing, dressing, and walking. Spasticity can also cause **contractures**, which are fixed, abnormal joint positions that may lead to deformity or the inability to move the related body part.

In addition to spasticity, children with brain or spinal cord injuries may also experience other neurologic (nerve-related) conditions, such as weakness and poor coordination. These other conditions may actually be more disabling than spasticity. Reducing the spasticity may be helpful in these situations, but does not “cure” the condition. In some cases, the spasticity can actually have benefits. For example, some spasticity in the legs may help a child stand.

Finally, it is important to note that there are several disorders, other than spasticity, that can cause stiff muscles. Two examples are: **dystonia**, which may lead to a fixed, abnormal posture; and **athetosis**, which may lead to uncontrolled movements. Management plans for these conditions will differ from management plans for spasticity.

Things to consider for a spasticity management plan

At Primary Children's Medical Center, we consider many factors when recommending a plan to manage your child's spasticity. These factors include:

- Your child's ability to function in daily life
- The extent (and location) of the spasticity
- Your child's age and developmental level
- The condition causing the spasticity
- Other disorders of muscle tone and movement
- The strength of your child's muscles
- You and your child's preferences

One spasticity management plan may be best for a child at a young age, while another plan may be better for an older child. Some children may benefit from only one treatment option, while others may benefit from combining two or more. For example, if a child takes medicine to reduce spasticity, physical or occupational therapy may help the child learn how to function with less spasticity.

It is also essential to have a goal! Before recommending any management plan, the care team works with the family to develop personalized goals for each child. Goals may include:

- Improving hand use
- Improving walking skills
- Improving comfort, ease of care, and positioning
- Preventing muscle contractures and deformities

Your child's care team

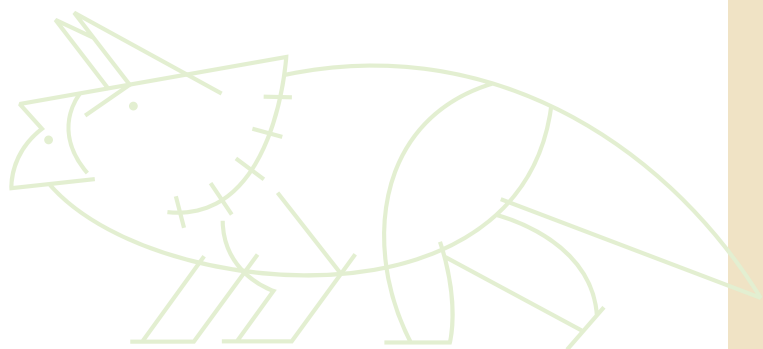
Medical professionals at Primary Children's Rehabilitation Department offer a complete evaluation to help you decide the best spasticity management plan for your child. Your child may be evaluated and treated by any or many of the following professionals: a physical therapist, an occupational therapist, a neurosurgeon, a rehabilitation physician, an orthopedic surgeon, and a nurse.

Each of these professionals has a unique and important role in working together to offer your child the best treatment. Above all, you, the child's family, are the most important part of the team. We recognize that parents or guardians are the experts when it comes to taking care of their child. We also coordinate our efforts with the child's primary care physician, local schools, and other community resources. Parents and guardians play an important role in communicating with all those involved in their child's care.

Spasticity is a condition in which some muscles are continuously contracted.

Feedback from **you** and **your child's therapists** is vital to your child's management.

.....



Notes

[illegible]

Physical and Occupational Therapy

Physical and occupational therapy may help reduce spasticity or may increase the effectiveness of other spasticity treatments. Together with other spasticity management tools, therapy helps children become more functional. Also, therapy may make your child more comfortable and make it easier for you to care for your child. Some therapy options are described below.

Positioning

Therapists can recommend positions and positioning devices to help lessen spasticity, prevent contractures, and encourage healthy bone growth. Some of these devices include corner chairs, standers, sidelyers, and wheelchairs.

Bracing and splinting

Therapists can make splints or braces that align and support joints. This support can help prevent contractures, lessen spasticity, and improve the quality of walking or hand use.

Serial casting

Therapists can place a series of plastic or fiberglass casts on either the upper or lower limb. Serial casting lessens joint contractures. It is often used in combination with intramuscular medicines, such as Botox and phenol.

Direct therapy

Therapists can provide children with stretching exercises to prevent contractures. They can also help improve your child's strength and motor skills, ability to do daily activities (feeding, dressing, hygiene), and mobility skills (crawling, transferring, walking).



.....

Recreation and active living
improve motor skills and
are vital to the **emotional**
well being of children
with disabilities.



Baclofen and Other Oral Medicines

Oral medicines are medicines taken by mouth. These are often used for children who have spasticity in many parts of their body. The most common medication prescribed to treat spasticity is baclofen (Lioresal®). Other oral medicines that may be used to treat spasticity include:

- Diazepam (Valium®)
- Clorazepate (Tranxene®)
- Dantrolen sodium (Dantrium®)
- Tizanidine (Zanaflex®)

How does oral baclofen work?

Baclofen closely resembles a natural substance in the body called GABA that calms nerve signals. Baclofen works in the spinal cord to control spasticity. However, when taken orally it has difficulty reaching the spinal cord. So the effect of baclofen and other oral medicines may be limited.

Which children may benefit from oral baclofen?

Oral baclofen is used to treat spasticity that affects many parts of a child's body. It is usually more effective in children with a spinal cord injury than those with a brain injury. Many times, baclofen does not have a large effect on spasticity. However, it can make walking a little easier, help prevent contractures, and improve hand use, ease of care, and your child's comfort.

How is baclofen prescribed?

Baclofen is usually started at a low dose and increased gradually while the care team monitors your child for lowered spasticity, improved function, and possible side effects. Your child's doctor may prescribe the medicine on a trial basis, to see how it works. If your child has side effects or if the spasticity or overall function does not improve, the medicine can be easily lowered and stopped. If your child suddenly stops taking baclofen, he or she may experience baclofen withdrawal



.....

Dystonia requires medications other than the ones described in this booklet.

symptoms. These symptoms include muscle spasms and even seizures. Therefore, it is very important that the medicine's dosage is lowered slowly if you, your child, or your child's care team decide to stop using it.

What are possible side effects of baclofen?

Baclofen does not have any permanent long-term side effects. Some short time side effects include:

- **DROWSINESS:** This happens mostly at high doses and when first starting or increasing the medicine.
- **REDUCTION OF SOME BENEFIT OF SPASTICITY:** For example, reduced spasticity may make it hard for some children to hold themselves upright.
- **UPSET STOMACH:** This is a less common side effects and usually occurs at higher doses.
- **MUSCLE WEAKNESS:** This is a less common side effects and usually occurs at higher doses.



If oral medications cause side effects and do not help, they can be stopped.



Botox® Intramuscular Injections

What is Botox and how does it work?

Botox is a form of botulinum toxin type A. It is a protein that is injected through a needle directly into muscles (an intramuscular medicine). Botox blocks the message sent from the nerve to the muscle telling it to contract. When this message is blocked, muscle spasticity is lessened. Botox usually takes effect within one to two weeks and lasts about three to six months.

What are the benefits of Botox injections?

Botox is used to treat spasticity in a specific part of the body, providing many benefits such as improving your child's motor functions and increasing comfort. However, every child reacts to Botox differently. And, since the effects of Botox injections are temporary, benefits will be greatest when Botox is combined with other treatments such as splinting, casting, stretching, positioning, or strengthening.

How is Botox given?

Usually, Botox is injected into several different muscles. These injections feel much like immunizations, but they don't cause muscle aches. Many kids say they feel a sting or a pinch when the Botox is given. You can do several things to help your child be more comfortable during Botox injections. See the box below.



To help your child be more comfortable during Botox injections, you can:

- Place EMLA cream on the site to numb the skin.
- Give a medicine by mouth to relax your child before the injections, especially if Botox must be used in many muscles or if your child is very nervous.
- Use child life specialists at Primary Children's Medical Center to help your child relax and teach you techniques to distract your child and help her through the procedure.
- Stay with your child during the procedure to help offer comfort and support.

What are the risks and possible side effects of Botox?

Botox has been shown to be safe. Using Botox repeatedly has not been shown to cause long-term or permanent effects. Short-term side effects may include bleeding or bruising in the area of the Botox placement, and rarely, a rash in the area or flu-like symptoms that last a day or two. Botox may also causes weakness in the muscles where it was injected.

What happens after Botox injections?

Your child may continue normal activities as soon as the procedure is over. As stated before, since the effect of the Botox is temporary, it is very important to combine this treatment with others like casting, splinting, or other therapies. You should arrange this with your therapist before the procedure. Your child should return for a follow-up appointment four to six weeks after the procedure. At this time, the care team can measure the results of the Botox and make additional treatment plans as necessary.



Phenol Intramuscular Injections

What is phenol and how does it work?

Phenol is a chemical that has been used for many years to treat spasticity. It blocks the message sent from a nerve to a muscle telling the muscle to contract. When this message is blocked, muscle spasticity is reduced. Phenol needs to be injected at points where the nerves enter the muscle. These points are called **motor points**. Phenol takes effect immediately and lasts about 6 months.

What are the benefits of phenol injections?

Like Botox injections, phenol injections are used to treat spasticity in a specific part of the body, providing many benefits such as improving your child's motor functions and increasing comfort. However, every child reacts to phenol differently. And, since the effects of phenol injections are temporary, benefits will be greatest when phenol is combined with other treatments such as splinting, casting, stretching, positioning, or strengthening.

How is phenol given?

Because phenol injections can be uncomfortable, your child may be given medicine to help him or her sleep during the procedure. If you choose to have your child sedated, the Same Day Surgery department will contact you the afternoon before the procedure, so you can know what foods and liquids your child can have before the procedure.

Your doctor gives the phenol in the Rapid Treatment Unit. First, they stimulate the skin over the muscle with a surface stimulator. The surface stimulator looks like a small rectangular box. It uses mild electricity to stimulate the muscle. The doctor marks points on your child's skin that produce a good muscle response. These points are called motor points. Each muscle may have several motor points.



Next, doctors use a needle stimulator to find the exact point to place the phenol. They then inject the phenol. After the procedure, your child may be drowsy, and the care team spends time monitoring your child before you go home.

What are the risks and possible side effects of phenol?

Phenol has been shown to be safe. Side effects may include bleeding, bruising, or minor discomfort in the area where the phenol is placed. Occasionally, a small muscle knot will form. Rarely, a small sensory nerve may be disturbed. If this happens, the discomfort may last for a longer period of time.

What happens after phenol injections?

After your child receives the phenol injections, she should do only gentle stretching for about one to two weeks. Also, if your child is able to walk, she should limit walking to short distances for a week or two after the procedure.

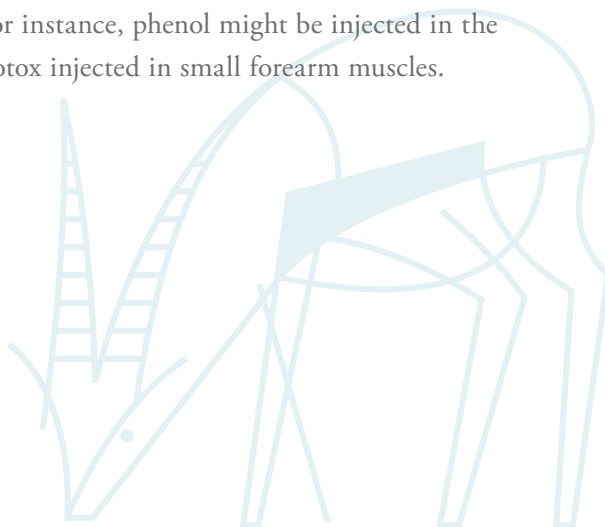
To relieve discomfort, you may give your child ibuprofen (Advil®, Motrin®, etc.) and acetaminophen (Tylenol®) on an alternating basis for 24 hours after the procedure.

As mentioned earlier, phenol is much more effective when used in combination with other treatments. You should arrange other treatments with the care team before the procedure. Your child should return for a routine follow-up appointment in four to six weeks. At this time, the care team can measure the results of the phenol and make additional treatment plans as necessary.

Often children receive both Botox and phenol injections at the same appointment. Phenol is usually most effective in larger muscles while Botox is preferred in smaller muscles. For instance, phenol might be injected in the large hamstring muscles and Botox injected in small forearm muscles.

.....

Phenol is usually most effective in **larger muscles** while Botox is preferred in **smaller muscles**.



Orthopedic Surgery

What is orthopedic surgery?

Orthopedic surgery is sometimes used to treat deformities of the spine, legs, and arms. The goal of the surgery is to get the best possible motor function for daily activities (sitting, standing, and walking) and to improve ease of care and comfort. There are two types of orthopedic surgery, soft tissue procedures, and bony procedures.

- **Soft tissue procedures** lengthen or transfer (move) tendons in order to lessen contractures and balance the pull of muscles. This lengthening or transfer improves function, comfort, and ease of care. When soft tissue surgery is done early, together with physical therapy and bracing, bone surgery may not be needed. However, when a child's limbs are not the same length or bone deformities remain, then bony procedures may be needed.
- **Bony procedures** include controlling limb growth using staples or screws around the joint, stabilizing unstable joints, and fixing bones to straighten or correct deformities. Children with spasticity resulting in **scoliosis** (abnormal curving of the spine) may need to have their spines straightened with metal rods.

Orthopedic surgery may be used in combination with other spasticity treatments like oral or intrathecal baclofen, Botox, or selective dorsal rhizotomy, described elsewhere in this handbook.

Which children may benefit from orthopedic surgery?

Children with spasticity who have worsening contractures or deformities may benefit from orthopedic surgery.

What are the risks and limitations of orthopedic surgery?

As with any surgery, there is a risk of infection and bleeding. Your child receives general anesthesia medicine so he or she can sleep during the surgery, and there are potential risks with the anesthesia. Talk with your doctor about these risks. In addition, there is a risk that the tendons or bones will not heal properly or the hardware (staples, screws, or rods) may fail.



Limitations of orthopedic surgery include the fact that it does not directly treat spasticity, but instead is aimed at the effects of spasticity. Also, there is a chance that more deformities may happen as your child grows.

What happens after orthopedic surgery?

What happens after orthopedic surgery depends on which type of surgery is performed. For example, after tendons are lengthened in the ankles, your child may be allowed to walk in walking casts shortly afterward. However, if your child has more extensive surgery, he may stay in the hospital for a few days and be unable to move for up to six weeks. Often, the hardware (staples, screws, or rods) are removed once the bone is healed.



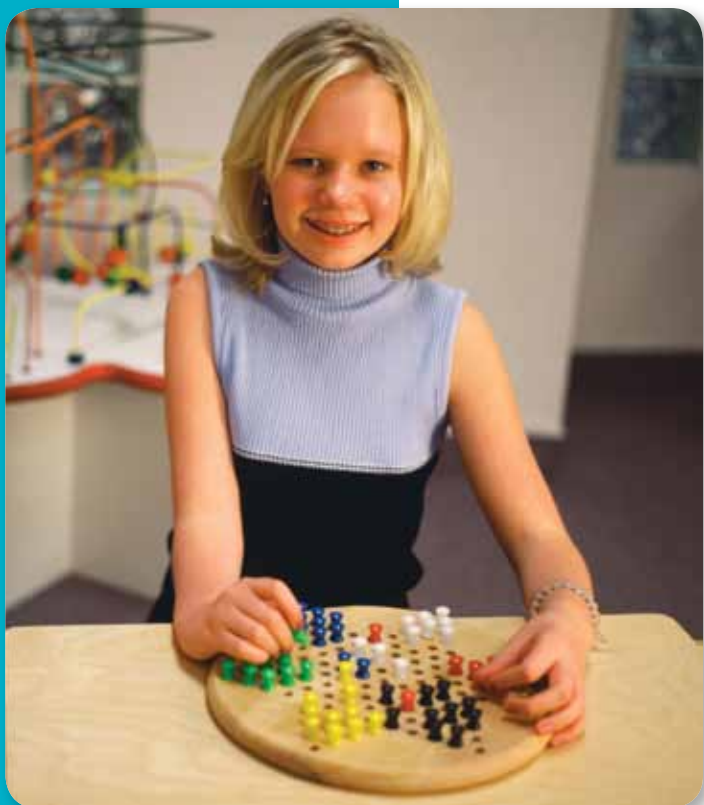
Intrathecal Baclofen Pump

What is intrathecal baclofen?

Baclofen is a medicine that is used to lessen spasticity. It can be given by mouth (as described on page 8), or through a pump and catheter that goes into the area around the spinal cord, called the **intrathecal space**. A pump placed in the abdomen continually sends the baclofen medicine into this space. Because baclofen works mostly in the spinal cord, it can have a substantial effect on spasticity. The pump is programmed to deliver a specific dose of medicine to your child. An external computer adjusts the rate of the pump based on your child's needs.

What are the benefits of intrathecal baclofen?

Intrathecal baclofen often drastically reduces spasticity. Therefore, it may have major benefits in children with severe spasticity in many parts of their body. These benefits include lessening pain, improving the ease of caring for the child, and preventing a deformity. The greatest effect of intrathecal baclofen is usually in the legs. Intrathecal baclofen may lead to improved walking skills, hand function, and speech. The pump rate can be adjusted to decrease spasticity yet keep some underlying strength in your child's muscles.



How is intrathecal baclofen given?

To help decide whether a child would benefit from an intrathecal baclofen pump, a test dose is given during a one-day trial. This is done with a small needle that is placed into the spinal column in the lower back. Your child must stay very still for this procedure — child life specialists at Primary Children's can help your child relax. A cream may be used to numb the area where the needle is placed. This area may also be numbed with a medicine called Xylocaine®. It may sting briefly when injected underneath the skin. During the one-day trial, your child is monitored at Primary Children's for changes in spasticity and function.

If the family, patient, therapists, and doctor agree that the intrathecal baclofen test dose worked well, a refillable baclofen pump may be placed to deliver the medicine. The programmable pump is placed during surgery. It is about the size of a hockey puck. The pump is placed under the skin of the belly above the waistline. A catheter is connected to the pump and travels under the skin to the intrathecal space in the back. The usual hospital stay for placing a pump is three to four days.

What are the risks and possible side effects of intrathecal baclofen?

In any surgery, there is a risk of infection and bleeding. The tubing may break or kink. Surgery would be needed to repair this problem. If the pump is not refilled when it needs to be, your child may experience symptoms of baclofen withdrawal including high levels of spasticity, agitation, itching, and in severe cases, seizures. Occasionally, in patients who are unable to walk and who have scoliosis, the lessened control over the upper torso may lead to worsening of scoliosis.

How is the pump managed after surgery?

At follow-up appointments, a doctor or nurse reviews how the pump is working. The pump is programmed with a computer that acts like a remote control. The rate at which the medicine is released can be increased or decreased according to your child's needs. Usually, the rate is gradually increased for several months after surgery to reach the best level.

The baclofen pump needs to be refilled every two to four months. Prior to coming to the clinic for refilling, the parent places EMLA cream to numb the skin. At the clinic, the spasticity physician or nurse inserts a needle through the skin into the pump to refill it.

The pump battery lasts for six to seven years, depending on the dosage. Before the battery runs out, the pump must be surgically replaced. Additional orthopedic surgery to treat contractures may be recommended after the pump is placed.



Intrathecal baclofen pump
with catheter

.....

The usual hospital stay for
placing a pump is **three to
four** days.



Selective Dorsal Rhizotomy

What is selective dorsal rhizotomy and how does it work?

Selective dorsal rhizotomy is a type of surgery used to lessen spasticity. The surgeon operates on the nerve roots leading to sensory nerves in the legs. Your child receives general anesthesia for the surgery, which means your child is given a medicine that helps him sleep. First, the surgeon makes an opening in the lower back to see the nerve root in the spinal column. Next, the nerve roots are divided into their smaller rootlets. Each of these rootlets is stimulated with a small amount of electricity. When a muscle responds abnormally to the stimulation, this rootlet may be surgically cut. Usually, less than half the total number of rootlets is cut.

Which children may benefit from selective dorsal rhizotomy?

Rhizotomy can significantly decrease spasticity. However, doing so may reveal underlying muscle weakness. Thus, it is important for a child to have relatively good strength in the legs to benefit from this procedure. Children with spastic diplegic cerebral palsy usually benefit the most. It is also best if a child has a low number of fixed contractures, a high level of motivation, and spasticity, rather than other types of abnormal muscle tone like dystonia or athetosis.



What are the risks of selective dorsal rhizotomy?

As with any surgical procedure, rhizotomy does have some risks. There is a small risk of infection and bleeding. Your child receives general anesthesia during the surgery, and there are potential risks with the anesthesia. Talk with your doctor about these.

Your child may experience some areas of numbness in the legs. This usually goes away, but small areas of numbness may last. As mentioned above, reducing the spasticity may reveal some weakness. Selective dorsal rhizotomy decreases only spasticity and not contractures. Additional orthopedic surgery may be needed after the dorsal rhizotomy surgery.

What happens after the surgery?

For the first two days after rhizotomy surgery, your child must remain flat in the hospital bed. Your child receives pain relievers. After the surgery, intensive inpatient therapy is recommended to help your child re-learn how to control his or her legs without the spasticity. Primary Children's case managers will arrange this prior to the rhizotomy surgery.



How to contact us

We want to help you find the best spasticity management plan for your child. Call 801.662.4949 for more information.

.....

Driving map to

Primary Children's Medical Center

100 North Mario Capecchi Drive

Salt Lake City, Utah 84113

www.primarychildrens.org



To find these and other resources, go to:
intermountainhealthcare.org/pedsrehab



IntermountainSM
Pediatric Rehabilitation

© 2002 – 2010 INTERMOUNTAIN HEALTHCARE, Primary Children's Medical Center.
All rights reserved.

The content presented here is for your information only. It is not a substitute for professional medical advice, and it should not be used to diagnose or treat a health problem or disease. Please consult your healthcare provider if you have any questions or concerns. More health information is available at intermountainhealthcare.org.

Patient and Provider Publications 801.442.2963 IHCEDPES003 – 11/10