

# Growing Up with a Brachial Plexus Palsy

A guide for older children and their parents



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This booklet is written for you to read and use as you grow and experience changes in the use and function of your arm.

### **Note to Parents**

This booklet was also written for you to use as your child grows and gains independence. **Note to Parents** sections will be placed throughout this booklet with tips and information for you.

## **What is the brachial plexus?**

The brachial plexus (it sounds like “brake ee oh pleks us”) is a set of nerves from your spinal cord to your arm. They control the muscles in your arm. Nerves are soft tube-like structures in the body. They help carry signals to and from your brain to help the muscles in your arm move.

## **What is brachial plexus palsy?**

Brachial plexus palsy happens when there is damage to the brachial plexus nerves. This may have happened when you were being born or from an injury you had to your neck and shoulder when you were older. The damage to the nerve(s) can cause your muscles in your arm and or hand to be weak or unable to move the way your other arm moves. It can also make your arm or parts of your arm have no feeling. How well you can move your arm depends on the type of damage to the nerves. It also depends on the treatment you have had and continue to receive.

## **How might my arm change as I get older?**

As you grow, your affected arm might start to feel and move differently. It is common for older kids to say they notice changes in how their arm moves. Over time, the weakness of muscles on one part of your arm can cause tightness of a joint in another part of your arm. As your joints become tighter, you may get something called contractures (pronounced “con track tur”).

A contracture is when the joint can no longer move the way that it did before, and is almost stuck in a position. This can change the way that your affected arm moves and works. Contractures often happen when you grow quickly. They can also happen if you forget your daily stretching.

## **Working with your therapist**

Your occupational therapists (called “OT”) or physical therapist (called “PT”) can help teach you stretches, ways to strengthen your movements and how to adapt your environment. They can give you activities you can do at home on your own to help you build body strength, balance, flexibility and coordination for daily tasks. Other activities may be done during therapy. You can set your own goals, and work towards independence with their help. Work with your OT or PT to follow the activities in this booklet.

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## Check in with your OT or PT when:

- You are in a growth spurt
- You are having concerns or changes in your movements
- You are having concerns or changes in your activities

## What can I do to help keep my arm working as well as possible?

Here are things that you can do to help minimize changes in your arm.

- **Stretch every day:** It is very important to stretch every day. Make it as routine as brushing your teeth. If your muscles are tight, your OT or PT will give you stretches to help. When your muscles stay stretched, you are less likely to get a contracture.
- **Notice your posture:** Whole body balance and posture can affect your coordination and how you use your body in everyday activities. An OT or PT can help you learn and feel how to move your body in a balanced way.
- **Wear a splint:** There are many kinds of splints that may help you stabilize or stretch your body. They may help to decrease contractures and increase active muscle use of your body. Not all kids need splints, but they can help in some cases. Common types of splints used are elbow extension splints and wrist splints.
- **Use special tape.** A tape called Kinesiotape might be helpful to stretch muscles or to help position your joints in alignment.

### Note to Parents

Stretching can often become difficult during the toddler years. Play-based stretching and activity is a great way to get your child to start to participate in their own growth and independence. Try these tips for stretching:

- Make stretching fun. Play music your child likes.
- Sing songs and move your child through arm motions with focus on the specific stretches that will help your child's affected arm. Your therapist can give you examples and help create a program to encourage stretching and whole-body awareness and use.
- Use a reward system for when your child completes their daily stretches. A reward system usually works best for children age 3 and older.

## How can I do more for myself as I get older?

Up to now, people may have been helping you with things like getting dressed, cutting your food, and brushing your hair and teeth. This may have helped you when you were younger, but you may be ready to do many of these things on your own. Here are some ideas to help you do more on your own.

It is very important to take time to practice. Ask your parents to let you practice. Try and work hard to learn how to do activities on your own. You might be surprised how much you can figure out if you just **try!** A therapist can give you more ideas, but here are some to start with.

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## Dressing

Getting dressed by yourself is a goal to have as you get older. Try these tips for putting on (donning) your shirt:

- Put on (don) shirts by placing your affected arm into your shirt first.
- Take off shirts (doff) by taking out your affected arm first. First in and first out.
- If you need to, use your teeth to help pull clothing on and off.
- Choose clothing with Velcro, elastic and snaps instead of buttons and zippers.

## Personal Care

Sometimes it can be hard to shower, wash your hair, brush your teeth and fix your hair all by yourself. Items like toothbrushes and hair brushes can be adapted so that you can do these things alone, or with a little help. Talk to your therapist to learn more about this.

## Eating and making meals

You may find it hard to cut your food, carry your plate or tray, and help with cooking, etc. There are a lot of ways to help keep your food stable for cutting and cooking. Dycem is a nonstick plastic product that you can put on your table or counter to help prevent items from tipping over. You can use it to help hold plates and bowls while you make a meal or snack. Ask your OT or PT about this idea and others.

### Note to Parents

Dressing, grooming and eating are great ways to let your child practice using their affected arm. It adds active stretching and strengthening to normal daily activities. Ask your therapist or pediatrician for general developmental milestones of these activities, to be sure you are asking your child to help when they are developmentally ready.

## School

School can be a great place to use your arm and body doing things you enjoy with your friends. At school you may notice how your arm moves differently than other kid's arms. Find a friend or grownup who you feel safe talking to when you need help with problem solving or just want to talk about the challenges you may face with brachial plexus palsy.

Here are some ideas to try at school. Talk with your OT or PT for more ideas.

### Classroom activities

If you have weakness in your hand, you might need more time to finish class work. Ask for extra time for cutting, art, typing and note taking. You can learn how to type on a keyboard with one hand. You can use an adapted keyboard or a regular keyboard. If you find your paper keeps slipping, use Dycem and a clipboard to keep your papers in order.

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## Gym class, recess and playing outside

Changes can be made to almost all sports gear, like bike handlebars, baseball gloves and jump ropes to adapt them to your needs. You might need to teach your gym teacher and friends about things you need help with, extra time for, or just more practice with. This can help them understand why some activities can be hard for you.

## Lunch and snack time

It can be frustrating to struggle when you need to open your lunch or carry your lunch tray. It might be hard to open plastic food bags, bottles and food storage containers. At times like this, ask for help. Talk to your parents about packing your lunch into things that you can open. You can also try wedging items in your elbow or thighs to open them. Your therapist can help you learn and practice methods that work for you.

## Music

Most musical instruments can be adapted so that you can play them with one hand. Ask your therapist for further help finding or making adaptations.

### Note to Parents

Be honest with your teachers and care providers about how to help your child become independent and successful in these environments. Your child's teacher may not know anything about brachial plexus palsies. This may cause them to treat your child like they have a delay that they do not have. A letter is a great way to share information.

A 504 plan is an option in the public schools that allows for your child to get help and or adaptations during their school day. For example, you can request for your child to have extra time during tests, create time to learn one-handed typing, have two sets of books (one at school and one at home), get help in the lunchroom, or adapt gym class to their needs. Talk with your child's healthcare provider or school about how to set up a 504 plan.

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## Sports, recreation and hobbies



Being active in community and school events and sports can keep you moving and strengthen your arm. Let your coach and teachers know how to best support your skills. Let them know if you need anything adapted for you to participate. Hobbies are a great way to use your affected arm without worrying whether you might not win. Try swimming, Tae Kwan Do, dance, yoga, or any activity that works on balance, uses both your arms, and is fun!

### Note to Parents

Community-based activities are a great way to work on stretching and active use of your child's arm while they are with friends and other kids their age. You can talk to the teacher or coach to let them know your child is working hard and may be learning the same way as other kids, but might not move exactly the same.

## Friends

Many of your friends have already learned about your affected arm. As you go to new schools or try new activities, there may be kids who don't know your story. Work with your family to come up with the story you want to share with those kids. Think about how much you feel OK sharing with them. Some people may make comments about your arm. Most comments about difference come from not understanding, rather than not accepting.

Some kids have found it best to have a quick answer to share with people who ask about their affected arm. That way, you feel good about your response and that might be enough to stop the questions.

Find people who you feel safe sharing with about how it feels to have an arm that doesn't work as well as your other arm. Parents and loved ones, friends, teachers and counselors, and your therapist can listen and talk with you.

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### Note to Parents

This is an age when your child is listening closely to what and how you explain the story of their affected arm. Being honest and creating a short answer to tell people will help your child gain confidence in their story. You may also benefit from finding people who you can trust and discuss your feelings with, being sensitive of where your child is when you have more in-depth conversations.

### Beyond therapy

Sometimes therapy and changing your environment is not enough to keep you doing the activities you want to do. If you still can't do many of the things that you want to, there may be other options or there may be options to have surgery. Surgery may help with how your arm moves or how it is positioned. Your brachial plexus team will talk with you and your family about options.

Here are a few common ways to manage your arm beyond therapy:

- **Tendon transfers:** This is when surgeons move one tendon of a muscle that is working well, to take over the job of a muscle that isn't working well.
- **Osteotomy:** This surgery involves turning the bones in your arm to help with positioning of your wrist and hand. This may be a choice if a tendon transfer is not possible.
- **Botox and casting:** This can be done when joints are contracted to provide a long stretch to a relaxed muscle.

### Living with brachial plexus palsy

Your brachial plexus palsy will always be with you. With practice and with the natural course of your life, what you are able to do will change with time. It is most important to stay active with what you love! Keep stretching and using your whole body, and be sure to listen, ask questions and be honest about how you are feeling.



### Note to Parents

Contact your brachial plexus healthcare providers for more information on support groups and therapy groups for children and teens.

Resource- Emily Ho, Occupational Therapist at The Hospital for Sick Children in Toronto, Canada

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### To Learn More

- Brachial Plexus Clinic  
206-987-4680
- Occupational & Physical Therapy  
206-987-2113
- Your child's healthcare provider
- [seattlechildrens.org](http://seattlechildrens.org)

### Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.



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1-866-583-1527 (Family Interpreting Line)

[www.seattlechildrens.org](http://www.seattlechildrens.org)

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Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.

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