

A Child Like Herbie

A BOOK FOR PARENTS ABOUT
BRACHIAL PLEXUS INJURIES /
ERB'S PALSY

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Illustrations: Heidi Sharpe, Steve Chadburn





Plexuskinder e.V. is an association of people with a brachial plexus injury, their families and professionals.

We want to help these people learn as much as possible about it and we want to help them to cope.

In our Plexusfibel (booklet for parents and professionals) and on our homepage www.plexuskinder.de you can learn more about brachial plexus injuries.

We enjoy being with many children and their families at our meetings.

This Herbie book belongs to _____

A Child Like Herbie

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A Child Like Herbie was written by Mirjam Mahler,
the mother of a son with a brachial plexus injury.

Erb's Palsy Group has allowed Plexuskinder e.V. to use the Herbie illustrations.

A Child Like Herbie

Hello, my name is Herbie and I have a special left arm.

The arm has an injury called **brachial plexus injury** (or Erb's Palsy).

In this booklet I explain how children like me, their families and the people around them can cope in the best possible way.

In my other Herbie booklets I talk about my affected arm, my surgery and my exercises. *

You can find lots more information on www.plexuskinder.de

* The German versions of the booklets "Herbie & His Special Arm", "Herbie Has An Operation", "Herbie and His Exercises" can be ordered on www.plexuskinder.de, the English versions are available through www.erbspalsygroup.org.uk



Mom and Dad are experts

Luckily brachial plexus injuries are rare. Most doctors will only meet very few children with this injury throughout their careers.

My parents have learned a lot about brachial plexus injuries and their treatment, for example on www.plexuskinder.de and in the Plexusfibel (a booklet for parents, doctors and therapists that can be ordered at www.plexuskinder.de).

Shortly after I was born we went to see a specialist for brachial plexus injuries. He examined me and he also performed my surgery when I was a bit older.

Many of these injuries are treatable, but they have to be treated promptly and sometimes surgery is necessary. You cannot just wait it out.



All people are different

I want to be just like other children. This is sometimes difficult for my parents, because they realize that a child with a brachial plexus injury is not as skillful and some things are just not possible at all. Nevertheless I don't want to be protected and wrapped in cotton wool.

I have to have my own experiences and find out how to handle my daily life.

Often my parents and the people around me are surprised by all the things I can achieve.

I like getting praise and recognition!

But being proud of yourself is the best feeling!



I want to do this! I want to achieve this!

Everybody is not so good at doing certain things. Sometimes you can ask for help, but sometimes you have to try hard, learn from others how to do it in the best way and try and practice. When something is important to me, I make an effort and practice until I get it right.

Everyday activities like tying shoelaces, cutting bread or getting dressed can be difficult for children like me. We want to find our own way of doing things. We don't want others to take over and do things for us all the time.

Ask us what we want to be able to do and support us in getting there. Together with our physical- and occupational therapists we can think how we can practice and train to succeed in things that are important to us.



What is your challenge?

Everybody has to face challenges. Dad is out of breath when he runs fast. He wants to take part in a city run and is training hard.

Grandma wants to knit a nice sweater for me and goes to a knitting class. The other day she made a mistake and had to start over again.

As a family we think about the challenges we each want to face together and encourage and cheer for each other to help us achieve our goals.

By this summer I want to be able to

By my next birthday I want to

By the next holiday I want to learn how to

I like to think about quotes that motivate me and hang them up in my room.

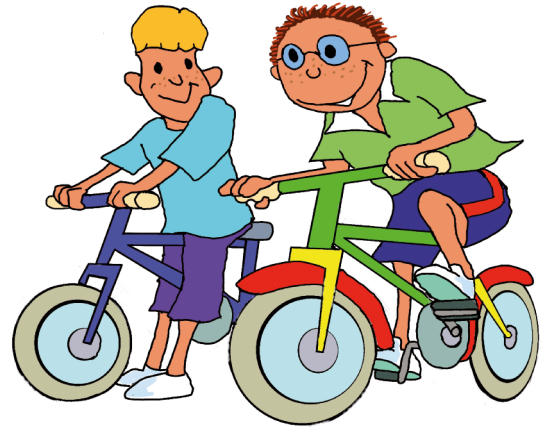


Practice and train

The exercises for my arm and for my body are fun and train strength and skilfulness. My therapist develops new exercises for me all the time. My siblings and my friends help with my exercises and join in. My parents make videos, take photos and write things down to see how I improve and also to check if the exercises are working.

The best training for children like me in everyday life are are activities we do together as a family like swimming, crafts or bike rides. Use your imagination to help us use the affected arm as much as possible.

Help us find a sport that is fun for us and that we can do regularly. We can train with other children and take part in competitions with a special classification that judges our achievements fairly.



Role models

We need you as our role models.

Children with a brachial plexus injury go to therapy and practice sports every week. You remind us to do our exercises at home and guide us through them. You drive us to therapy and to the doctor, wait in the waiting area, make appointments and get our prescriptions for therapy.

I work hard, because I know how important exercise is for a healthy body. When we work together on being healthy and fit, it's much more fun. Food and nutrition also play an important role.

You encourage us to try everything despite our limitations. It's important to us that you also work on yourselves and don't give up when things get difficult.

Many people with a disability are successful athletes and in almost all sports there are athletes with a disability. The best ones take part in world championships, the Paralympics and some even the Olympic games.

Find out about athletes with a disability in your favorite sport.

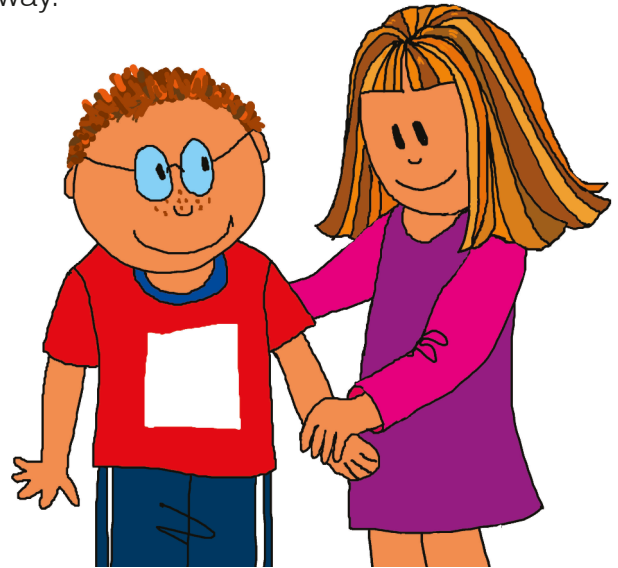


Family

Parents of a child with a brachial plexus injury sometimes forget that there is a happy, healthy child attached to the affected arm. We can do so many things and we need you to give us courage and to cheer us on to find our own way.

Our siblings and friends can help us with our exercises and join in. Many of these exercises are fun and train strength, endurance and agility.

Because of the brachial plexus injury, therapies and operations I'm often the center of attention. My siblings don't always enjoy that. It's good for me just to be Herbie and to be treated in the same way as the other children.

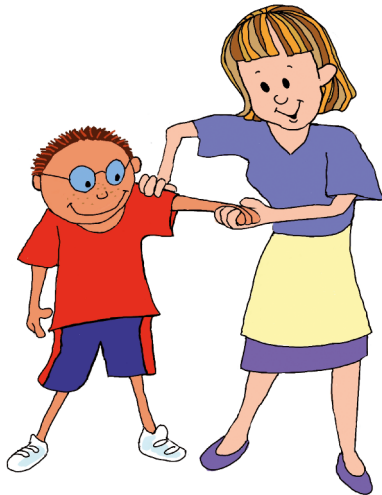


Parents are not just parents

Sometimes parents need a break from being parents. A life with many worries, therapies and operations is often difficult for families with a child with a brachial plexus injury.

I think it's great, that my parents take time for their hobbies. Mom likes to ride her racing bike and Dad says that running clears his head. They also like to go dancing together.

When we go hiking or kayaking the whole family comes along.



It's often difficult for parents to be a parent and a therapist at the same time. My therapists often take time to explain and show my parents everything we are working on.

My parents take turns doing my daily exercises at home with me and try to go to doctors appointments together and to alternate on therapy appointments. If one of them can't make it my aunt or my grandma comes along.

The people around us

Every time I try something new, a new sport or a new leisure activity or when I change groups in pre-school or school my parents give the coach or teacher information about the brachial plexus injury. We like to hand over the Herbie books for this purpose. You can read all about the injury in them. I can say what it is that I can't do so well or do differently from other children.

When we are open and honest about the reasons why I do things differently or can't do things at all we usually find a solution together.

Children with a brachial plexus injury don't want special treatment, but we want to be treated fairly.



At school

My doctor can write a letter explaining what a child like me needs to be able to learn just like the other children.

This is called „detriment compensation“ and is different for every student. Some children need more time for a test because they can't write fast. Others need to have a second set of school books so that they can leave one at home and their backpack is not too heavy.

I need more time for bathroom breaks and to get dressed for sports class and I have a non-slip mat and a larger desk to prevent my papers from falling off.

It's important that our teachers know exactly what we need to work and learn well. The expectations have to be adapted to what we are able to achieve and have to be adjusted continuously. If necessary, we have to be offered help and support.

In sports class we should only be graded on things that we can do. A handstand is not possible for me, but I can do a one-handed cartwheel.



Why?

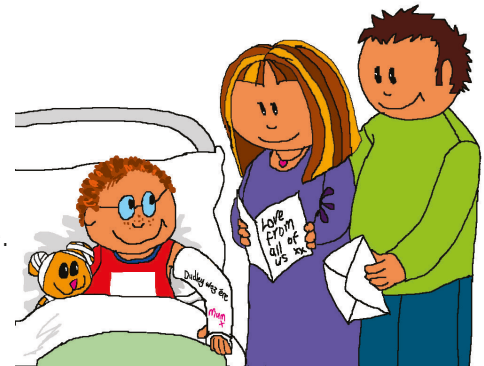
My start in life was not as my parents had expected. My birth was difficult and my brachial plexus injury sometimes makes them sad and angry. They are often worried about me.

My parents have asked for help from a professional to cope with it better and they have learned a lot about my birth and my injury. I think that this is a good thing. Don't wait to get in contact with a professional.

When our parents are doing well and can accept us and our injury we are also doing well. I went to therapy with a doctor who helped me understand and accept my brachial plexus injury and its consequences. I have learned a lot about myself and have much more self-confidence. The brachial plexus injury is a part of me.

Parents often find it difficult to accept that we are different. They fear that this may define us. There is a lot of support for us that we can and should use. I have many friends with a disability. There are many programs for people like this, from sports to assistance in school, university and in the work place.

For children with a brachial plexus injury and their parents it's important to know why this injury happened. A legal expert should be consulted to decide if legal action is advisable.



Contact and exchange

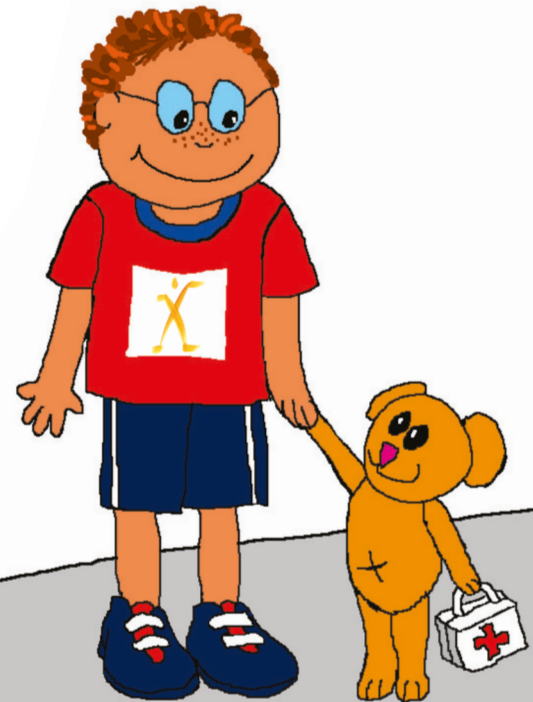
Families with a child with a brachial plexus injury enjoy exchanging information, stories and advice with other families. They have had similar experiences and can share how to cope. We go to the annual meetings and family days and meet other families who live near us on a regular basis. Many friendships have developed through these meetings.

For children and parents it's very interesting to meet adults with a brachial plexus injury. They can tell them how they manage their life with this injury.



Suggestions and advice:

- get information on the brachial plexus injury and its treatment
- contact other affected families
- use all available assistance
- get help to cope
- be our role models
- be physically active, eat healthy
- follow you hobbies
- let us be children
- let us make mistakes
- let us try things
- let us have fun together
- don't be just parents
- love us



A Child Like Herbie

Herbie speaks to parents of a child with a brachial plexus injury from the point of an affected child. He gives advice and recommendations about life with a child with a brachial plexus injury in the family.

Other Herbie books for small and big people who want to know more about brachial plexus injuries are:

- **Herbie & His Special Arm**
- **Herbie Has An Operation**
- **Herbie and His Exercises**

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the English versions are available through www.erbspalsygroup.org.uk

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Plexuskinder e.V. offers information, advice and support for people and families affected by a brachial plexus injury.



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