

PERTHES TOOLKIT



*Our Toolkit offers
specific guides for:*

- Physical Therapy
- Occupational Therapy
- Nutrition
- Psychological Support
- Navigating the School

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Occupational Therapy

ADAPTING TO LIFE WITH PERTHES

Occupational therapists (OT) and occupational therapy assistants (OTA) help people participate in the things they want to do and the tasks they need to do. Continuing everyday activities (referred to as occupations) is a comfort during the disease process as it allows a person to maintain independence and keep doing the things that make them feel like themselves. Anyone who has ever met a 4-9 year old can attest to the importance of independence in childhood! Accomplishing these acts of daily living for children and adolescents makes OT an important part of the treatment plan for Perthes.

Considerations

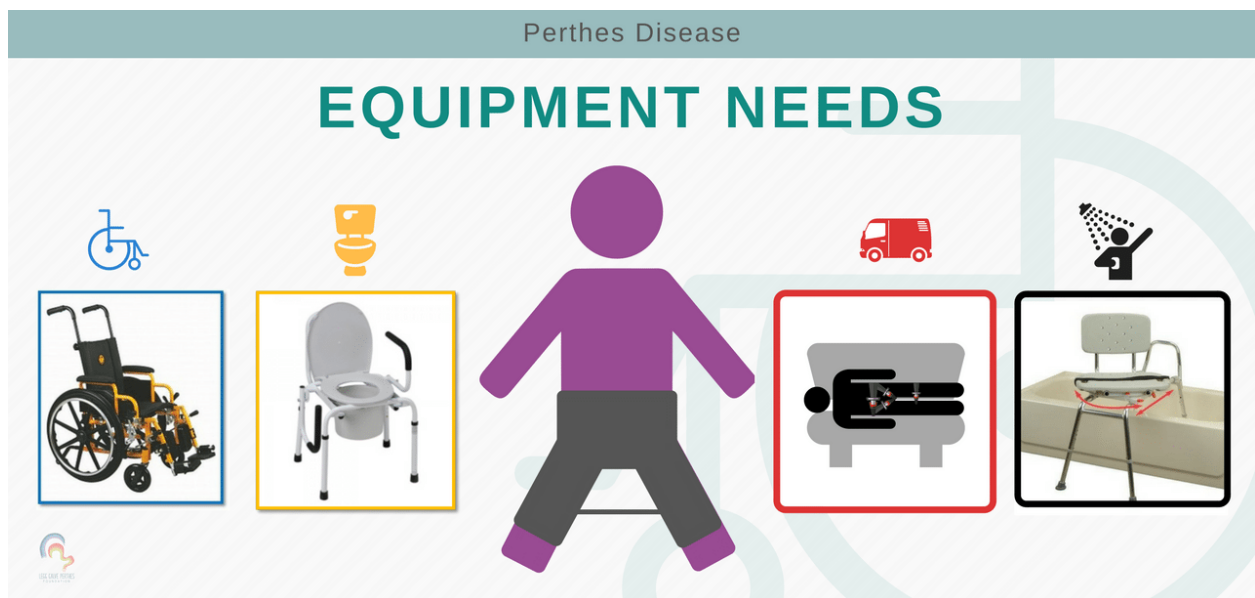
A diagnosis of Perthes disease can be overwhelming. As time progresses, needs may change based on treatment recommended by your pediatric orthopedic surgeon. Legg Calve Perthes Foundation recommends consulting with your medical-surgical team, including an occupational therapist for specific recommendations.

Throughout the disease process, take note of any activity that may need adaptation. This might include equipment needs such as

- Crutches
- Wheelchair
- Walker
- Showering/Bathing Equipment

There may also be environmental adaptations to consider at home and school. At home, think of the bathroom set-up. Can your child manage with sufficient space and support equipment? Does the home support independence with necessary equipment? Is there sufficient space for a wheelchair to maneuver; is your child's bedroom upstairs?

Similar questions will arise regarding school. How will your child get to and from school? Will the school support your child's medical needs?



Needs Based on Treatment

During early disease, weight bearing restrictions may be indicated without casting. Equipment needs in this phase may be a wheelchair, crutches, a walker, and adaptive equipment for showering or bathing such as a chair. Consider how these adaptations impact the school day to ensure your child is supported at school. Things to think about are access and ease of using the restroom, showering and locker room restrictions.

If a Petrie or Spica cast is recommended, consider adaptations to the wheelchair itself such as an abduction board which supports your child's legs in the wheelchair. A walker may be useful. A Petrie cast brings some toileting challenges. A bedside commode with drop arms is helpful.

Adaptive clothing is also important. Pull on shorts, pants, etc. will need to be adapted or substituted for adaptive clothing. These items can be purchased, or you may adapt items yourself by cutting and sewing clothing to accommodate the base of the Petrie cast or bilateral Spica. To modify a clothing item, cut along the sides and install Velcro or snaps to the sides. This way the clothing can worn *around* the cast.

There are environmental considerations to think about with a cast also. Both Petrie and Spica casts hold the legs in abduction, or wide spread. Consider the rooms and places your child spends most of his or her time. Are the doorways wide enough? If your child will be attending school in a cast, consider the safety of your child getting to and from school. Will the family car accommodate the cast?

While a Spica cast requires many of the same accommodations as the Petrie cast, there are a few things to consider specifically. A reclining wheelchair is

helpful in addition to the abduction board. Safe transportation may require a bench seat; getting in and out of vehicles may be difficult.

Perthes Disease

ENVIRONMENTAL CONSIDERATIONS

Casts take getting used to!

- Stairs
- Restroom
- Bedroom
- Transportation
- Home
- School

Image credit: Texas Scottish Rite Hospital for Children, Perthes Parent's Conference, 2017.

Cost

Unfortunately, cost and insurance coverage is very individualistic. Contact your insurance company directly to understand your specific benefits. Some insurance companies require specific criteria to be met. The best way to ensure these are met is to communicate with your insurance company, and your medical-surgical team including an OT who can conduct a formal evaluation of your child's needs.

Adaptive equipment can also be purchased out of pocket. Shop around to ensure the price and the equipment specifics are right for your child. Abduction boards and adaptive clothing can be made, if you are handy! If your family vehicle won't accommodate a cast, renting a van is an option, or consider trading cars with friend who has a minivan, or contacting a church or other organization in your community with a van and work out a trade!

There are additional funding resources out there through grants, discounts, and other programs. We've included some information on established programs

below, however, it's important to note LCPF does not specifically endorse any one program or organization.

- Miracle Flights – free flights on Southwest Airlines
- Angel Flight – shorter distances on small aircraft (not ideal for casts)
- Ronald McDonald House – affordable lodging for medical appointments away from home
- First Hand Foundation – funds therapies, medicine, travel, car rental and more
- Habitat for Humanity – builds ramps

As you can see, creativity and community can be just what is necessary to make life with Perthes work. Consider adaptations you, the parent(s), will make too! Perhaps you have to drive your child to and from school while in a cast; you might need to adjust your work hours. Treatments and doctor visits will likely require time away from your career, especially if there is travel involved. Discuss flexible work hours and location (work from home) with your employer if possible. Additionally consider a *shared leave* program at work; if there's not one, talk with your employer and consider starting one! Use those reward points! Consider using rewards points from a credit card or loyalty program to help offset travel or other costs. Ask your friends about donating their reward points too.

Physical Therapy

PAIN MANAGEMENT, STRENGTH, RANGE OF MOTION

In the early stages recommendations will likely include activity restriction including restriction on weight bearing activities. It's important for the healing process to stay active. Adapting to hip-safe activities such as swimming as well as specific exercises recommended by the medical-surgical team, including a physical therapist, maintain strength, preserve range of motion, and have been linked to pain reduction and positive treatment outcomes.

An Interdisciplinary Approach

A physical therapist (PT) works with a multidisciplinary healthcare team to get your child the equipment he or she needs to stay active, learn to use that equipment, and strengthen muscles in the process.

A PT may be involved in ordering a wheelchair, walker, crutches, and other adaptive equipment. A PT may instruct your child in using this equipment; it takes some getting used to and even works new and different muscle groups. Working with the orthopedic surgeon, a physical therapist will recommend exercises to strengthen muscles and maintain or increase range of motion. These protocols, like Perthes, are specific and tailored to your child and take into consideration specifics of treatment such as "conservative management" or "post-op."

Weight Bearing Status

Due to the age at onset of Perthes disease, it can be a challenge to get an active child to understand he or she must “take it easy” especially during periods without pain. Furthermore, being told to give up a favorite hobby or sport can impact your child’s mood in a big way. Still, weight bearing restriction remains a cornerstone of conservative treatment, and it’s not as simple as your might think. Here’s the scoop on the many levels of weight bearing.

- NWB – no weight on the leg which has the Perthes
- PWB – partial weight bearing
- TTWB – toe touch weight on side with Perthes – toes only on ground, uses assistive device to “unload” weight
- FFWB – foot flat weight on side with Perthes – places entire foot on ground, but uses assistive device to “unload” weight
- % of body weight (ie. 20% of 50# = 10# – practice on bathroom scales)
- WBAT – weight bearing as tolerated – weight on the leg which has the Perthes – with or without devices

Exercises may be categorized into levels, with specific goals and precautions for each. These exercises are some examples of what may be recommended by your medical-surgical team. It’s important to note Legg Calve Perthes Foundation offers this information as representative information only and recommends following the treatment guidelines set forth by your child’s specific team.

Level 1

Goals

- Contain hip by maintaining 25 degrees or more of hip ABD (abduction, or legs spread from midline).
- Protect from excessive hip joint forces
- Remodel contained femoral head with low load / high repetition exercise

Precautions

- NWB / TTWB / FFWB
- WBAT in brace or cast for transfers and supervised HEP (home exercise program)
- NO SLR (straight leg raise), HIP HYPEREXTENSION, ABD AGAINST GRAVITY

Mobility

- Crutches in home
- Wheelchair at school / long distances
- NWB / TTWB / FFWB
- WBAT in brace or Petrie cast for transfers and supervised HEP
- A-FRAME BRACE: 23 hours / day

Recreational

- Handcycling
- Pushing self in w/c – road racing in w/c
- Swimming (if 25+ degrees of hip ABD)
- UE weight-lifting
- Kayak, canoe, rowing
- Bowling from w/c
- Playing catch / disc golf from w/c
- Archery – seated
- Wii sports – seated
- Ping pong – seated

Remodeling; Supervised

- Stationary bike – no resistance, no pushing with affected LE (individual basis)
- Standing closed chain circumduction in brace or cast (hula hoop maneuver)
- *w/c – wheelchair*
- *UE – upper extremity – arm*
- *LE – upper extremity – leg*

Level 2

Goals

- Contain hip by maintaining 25+ degrees of hip ABD
- Protect hip from excessive forces
- Remodel contained femoral head with low load / high repetition exercises

Precautions

- NO STRAIGHT LEG RAISES
- NO HIP HYPEREXTENSION
- NO HIP ABD AGAINST GRAVITY

Mobility

- Crutches in home – weight bearing may change
- Wheelchair long distances / at school
- A – FRAME BRACE: 12 HOURS PER DAY

Recreational

- Handcycling
- Pushing self in w/c – road racing in w/c
- Swimming (if 25+ degrees of hip ABD)
- UE weight-lifting
- Kayak, canoe, rowing
- Bowling from w/c
- Playing catch / disc golf from w/c
- Archery – seated
- Wii sports – seated
- Ping pong – seated

Remodeling; Supervised

- Stationary bike – no resistance, no pushing with affected LE (individual basis)
- Standing closed chain circumduction in brace or cast (hula hoop maneuver)

Level 3

Goals

- Contain hip by maintaining 25+ degrees of hip ABD
- Protect hip from excessive forces
- Remodel contained femoral head with low load / high repetition exercise
- Early strengthening of hip ABD, EXT, and ER with a short lever arm
- *EXT – extension (move backward)*
- *ER – twists leg outward at the hip*

Precautions

- Partial WB – 50% body weight for supervised exercises with hip in ABD position
- WBAT for up to 10 feet on an individual basis (with AD)
- NO STRAIGHT LEG RAISES
- AD – assistive device (ie walker or crutches)

Mobility

- Crutches for PWB – 50% body weight or WBAT – if allowed for 10 feet
- Decrease wheelchair use
- Brace: (hours to wear)

Recreational

- Handcycling
- Pushing self in w/c – road racing in w/c
- Swimming (if 25+ degrees of hip ABD)
- UE weight-lifting
- Kayak, canoe, rowing
- Bowling from w/c
- Playing catch / disc golf from w/c
- Archery – seated
- Wii sports – seated
- Ping pong – seated

Remodeling; Supervised

- Stationary bike – no resistance, no pushing with affected LE (individual basis)
- Standing closed chain circumduction in brace or cast (hula hoop maneuver)

Level 4

Goals

- Advanced strengthening of hip ABD, EXT, ER
- Avoid hip / knee collapse with single leg loading

Precautions

- WBAT

Mobility

- Crutches PRN (*as needed*)
- Brace: (hours to wear)

Recreational

Once cleared by the doctor, can resume activities however you may want to consider low vs high impact activities and may consider avoiding contact sports such as football.

Psychology and Perthes

MIND, BODY, HEALING

Most accept that disease is stressful, especially chronic disease. But stress can take a toll on the healing process. According to a meta analysis of 30 years of research, stress suppresses the immune system and chronic stress suppresses both humoral and cellular immunity (Segerstrom and Miller, 2004). Furthermore, there is a well documented link between a state of tension and a hyperactive reflex arc in skeletal muscle established by Dr. Edmund Jacobson in the late 1920s. For a child with Perthes, this can mean an increased risk of infection and treatment complications. Increased stress may also impact pain during Perthes as well as contracture due to increase, sustained muscle tonus. Why mention this? To illustrate that you can't isolate Perthes disease from the child affected by Perthes or the family impacted by Perthes. The best approach to health is patient centered care, caring for the whole patient – mind and body.

Stress

Stress is inevitable. Perthes disease brings its own stressors and these will likely change during the course of the disease. Certainly your child will feel physically stressed and may also experience anxiety over a change in routine, fear of treatment and disease progression, or even guilt (however misplaced) for being

diagnosed. This can change from day to day. It should be pointed out that children often display stress differently than adults and aren't likely to walk up and tell you that they are anxious because they aren't able to play football; children may need help labeling their emotions. It's also important to acknowledge that everyone in the family is dealing with Perthes. There may be guilt, jealousy, or frustration from a sibling due to the change in family routine. Parents often express extreme worry, fear of prognosis as well as financial burden, sadness, and guilt. Understanding the psychological impact of Perthes can help your whole family during the process.

Our response to stress is mitigated by both intrinsic and extrinsic factors. We can't change how we are genetically inclined to respond to stress. We can address coping mechanisms and include healthy habits such as staying active, even if those activities change during Perthes, as well as maintaining a support and social circle.

Grief, Loss, and Perthes

A feeling that commonly emerges when discussing Perthes, is grief. Grief is about loss, not only death. In the case of Perthes your family is grieving the loss of their sense of normalcy. Acclimating to a "new normal" can be traumatic. Some significant sources of grief are death, medical diagnosis and lifestyle alterations, divorce or dissolution of a relationship, social status changes, family crises/trauma, relocation. In processing loss there are several phases we go through. However, we don't progress through these phases in order, nor is there a timeline for how long each phase lasts. It's also common to experience these phases out of order, or to think the issue is reconciled, only to return to a state of loss.

- Loss – Any absence of, deprivation of, removal of person/place/thing that is a part of one's routine.
- Grief – What we feel or experience as a result of losing someone or something of value. (Reactive Process)
- Mourning – What we DO with what we feel or experience. The process of externalizing through activity. (Proactive Process)
- Resolution – Sharpening the focus on the issue at hand.
- Reconciliation/Integration – The process of coming to terms with the difference between what we thought we had and what we DO have and carrying the balance forward.

When a child experiences loss developmental tasks may be complicated. A child may find it more difficult to separate from family or may find difficulty with social development, self-esteem, and social/play experiences. A child may also experience a delay in developmental milestones. Dealing with Grief requires acknowledging that our experience is one of Grief and loss. Don't be afraid to talk about it in that context. Reflect emotions surrounding the diagnosis of Perthes and subsequent lifestyle changes. The stages of grief are different for everyone and they are not linear. You or your child can move in and out of the different stages in many ways and revisit stages, even after you feel like you've come to acceptance. You and your child may experience:

- Denial: numbness or inability to feel or cope.
- Anger: intense emotional reactions to EVERYTHING, may seem illogical or out of context.
- Bargaining: "It's not fair" "Why me?" What did I/we do to CAUSE this?
- Sadness: Can look like depression and may include loss of appetite, trouble sleeping, excessive fears, separation anxiety.
- Acceptance: It is what it is. And from here we learn to make accommodations, get creative and find the best support.



Tools to Move Through Stress, Loss, and Grief

The ability to express yourself through art, play, and talk are essential. Daily practice of Mindfulness can help teach children how to quiet a worried or anxious mind. Empathy is a powerful tool to support your child through the Perthes process and help him or her gain a greater emotional intelligence. Empathy is the psychological identification with the feelings, thoughts, or attitudes of another. This differs from sympathy because sympathy essentially feels *sorry* for someone. Pity does not build strength. Empathy is particularly important for children diagnosed with Perthes because it validates them and their process. It is common for a child with Perthes to feel constantly invalidated or misunderstood due to the disease itself; Perthes is an *invisible* disease. Children diagnosed with Perthes don't "look sick," adaptive equipment may be used predominantly at home or for demanding outings. Unfortunately, this can put a child with Perthes in the position of having to defend his or her medical needs to others. Fortunately, it's not hard to show empathy. This can be accomplished through a process called reflection, where you essentially mirror a person's feelings, thus validating them. Reflection of Feeling:

- Conveys understanding
- Gains insight into child's emotional responses

- Validates child's emotional experience
- Teaches a child an emotional vocabulary
- Focuses on the need expressed, not the behavior
- Decreases the need for escalation
- Increases connection
- Reduces anxiety in parent and child

When reflecting emotions in a child, you will likely need to help them *name* the emotion. For example, a young child may be stomping in the kitchen, slamming cabinets. When asked a general question such as “what’s wrong,” the child is likely to respond with something to the effect of “there’s nothing to eat; I hate all of the food here; it’s gross.” That’s probably not the answer that the parent wanted. In order to help the child build emotional intelligence and begin to name his own emotions, help him label them. That parent could try something like, “you’re stomping and slamming; you seem *frustrated*. Are you *frustrated* that there are no cookies?”



Mindfulness

Mindfulness is simply noticing the moment with all of your senses. It's being fully engaged in the present. It's watching, observing and considering your thoughts/mental processes without judgement. Mindfulness allows people to examine long standing patterns of thinking that have become habits and it encourages development of new neural pathways. Mindfulness can help reduce rumination on the past or constantly rehearsing the future. It's best to practice mindfulness daily and it can be formal or informal practice where you simply integrate bits of mindfulness into your daily life, particularly when you are feeling stressed or anxious. At first it can seem awkward or difficult but soon it will be second nature! Mindfulness is particularly helpful in a chronic disease state like Perthes since each day is a bit different. Certainly there are plenty of emotional ups and downs and mindfulness can help your child to relax and remain present. Mindfulness can also help your child focus on subtle changes in his or her physical state such as increase or decrease of pain or an activity becoming more or less difficult. There will be good days and bad days both physically and emotionally. One informal and easy to begin mindfulness is to focus on the breath and consider how your body feels as you inhale and exhale. Imagining a square is helpful to illustrate the continual pattern of breath.



Resilience

Resilience is all about being able to overcome the unexpected. The goal of resilience is to *thrive*. When we tackle obstacles, we find hidden reserves of courage and resilience we did not know we had. And it is only when we are faced with loss or failure do we realize that these resources were always there within us. Resilience can't be bought or taught – it must be developed! There is a common misconception that people who are resilient experience no negative emotions or thoughts and display optimism in all situations. The reality is that resiliency is demonstrated within individuals who can effectively manage setbacks by using their internal resources and coping mechanisms. In other words, people who demonstrate resilience are people who balance both positive and negative emotionality; they possess a full range of emotions. Resilience in Perthes:

Use empathy, not pity, to connect with your child. The #1 key to resilience is a strong bond with a role model – your relationship is so powerful!

Use reflection with their feelings and help them feel understood. This will help them develop emotional regulation and fight anxiety, fear and sadness.

Acknowledge, deal with and process grief so you can move to the Acceptance phase even if other phases are still present. Through Acceptance, you can access your problem solving skills to advocate for sustainable resilience and create opportunities for your child to enjoy childhood!

Diet and Nutrition

HEALTHY BODY. HEALTHY BONES

Nutrition is important to the growth and success of all children. There are certain nutritional guidelines that can be helpful during the course of Perthes disease. A balanced diet is essential for bone health, additionally there are specific supplements recommended for bone health and development. A cornerstone of Perthes treatment is weight bearing restriction which changes the activity level for many children, causing weight gain. There are proven strategies to overcome this and they're easy! We'll address these common concerns

- Bone health
- Obesity in Perthes
- Strategies for healthy eating
- Ellyn Satter's "Division of Responsibility"
- Diet and ADHD

Peak Bone Mass is defined as the amount of bony tissue present at the end of the skeletal maturation and it can be an important predictor of osteoporosis and fracture risk in adulthood. During childhood bone is deposited at a more rapid rate than it is resorbed causing the bone to grow in both size and density until skeletal maturity. Bone mass is determined genetics, hormones, and extrinsic factors such as diet, weight, lifestyle, and medications. What a child does to promote healthy bones during childhood can impact adult bones! We can't change our genes, so let's focus on extrinsic factors. And we'll start with Vitamins and Minerals.

Vitamins and Minerals

Vitamin D is a powerhouse for your bones. Sufficient vitamin D intake enhances Calcium absorption by 30-40%, Phosphorus absorption by 70-80%, and improves musculoskeletal function. Vitamin D combats soft, thin, brittle bones. You can find vitamin D in foods such as liver, eggs, butter, margarine, fatty fish, and vitamin D fortified milk or other fortified products. However we only get about 10% of the vitamin D needed from food. Your body produces vitamin D when it's exposed to the UVB rays of sunlight! There are also supplements such as D2-Ergocalciferol and D3-Cholecalciferol. D3 is the most effective. According to the National Institutes of Health, 600 IU/day is the recommended intake of vitamin D.

Calcium is important during growth phase. Calcium and Phosphorus comprise 80% of the mineral content of bone. During periods of calcium supplementation, bone mineral density in cortical bone increases, but stops when supplementation ends. We know that calcium supplementation supports whole body bone mineral density and increased calcium intake reduces bone turnover. However extra calcium will not improve bone mass. The recommended daily dose of calcium for a child 1-3 years of age is 700 mg/day; 4-8 years of age 1000 mg/day; 9-18 years of age 1300 mg/day.

Phosphorus is integral to bone development. 85% of the body's phosphorus is bound to the skeleton. However, excess phosphorus can increase bone resorption. Phosphorus can be found in fish, meat, poultry, eggs, dairy, legumes, nuts, grains, cereal, and even soda. But before you add soda to your child's "healthy diet" it's important to note that in addition to the added calories and sugar, soda (diet or regular) has been linked to an increased risk of hip fractures in adults!

Vitamin K is involved in bone formation and reduces urinary calcium excretion. Vitamin K is synthesized by intestinal bacteria and found in food sources such as dark leafy vegetables and fermented dairy/soy products, fish, meat, liver, and

eggs. Many other vitamins and minerals aid in bone formation too: Magnesium, Fluoride, Zinc, Iron, Copper, Manganese, Silicon, Boron, Vitamin D, Vitamin B12.

A common concern when dealing with Perthes is obesity. Often treatment for Perthes disease alters a child's activity level, creating a more sedentary lifestyle. When activity is modified, dietary habits should also be modified.

Obesity in Perthes

In a 2016 study, Neal et al. report of 148 Perthes patients 16% were categorized as overweight, 32% were obese, statistically presented in a later stage of disease process. These patients were also found less likely to receive surgical intervention and noted to have a lower household income and an increased use of government-funded health insurance. What's more striking is increased weight correlates with an increased of higher preoperative morbidity and complications, poor wound healing, higher risk of infection, and delayed bone healing among other medical complications. Obesity is also linked to higher incidence of bilateral Perthes disease. The solution is to look at food choices in a healthier way by employing Satter's Division of Responsibility. This model is a balance of caregiver decisions and child decisions and encourages a dialogue about nutrition rather than an approach of consequences and rewards (clean your plate or no dessert). To simplify Satter's model, a caregiver may choose what, when, and where a child eats, leaving the child to decide whether he or she eats and how much. Weight itself should not be stipulated, instead it should be approached as a process of learning "eating competence." It is a process-it takes awhile to initiate structure and let go of control, as well for children to show eating capability and become relaxed and comfortable around eating. Some tips include

- Have structured, sit down meals
- Have sit-down snacks at specific times between meals
- Let the child eat what and how much they want from what the parents make available
- Don't let the child have food or drink (except water) between meal/snack times

- Portion sizes; limits on food
- Limiting amounts and types of food, increasing fruit, vegetables, and fiber

Things to avoid include fast food, rigidly controlling foods, second guessing “are you sure you want *that?*” and using food as a consequence-reward mechanism. Some ways to combat that instead are discussions with your child to educate him or her on nutrition thus offering guidance rather than restrictions. Help your child learn to recognize what his or her body really needs. If the message or tactic encourages you to eat less, to avoid foods you like, or to lose weight, it is controlling and therefore negative. Consider normal growth, normal calorie variation-consistent growth is only reliable sign that child eats the right amount, evaluate structure

Children who get the message that they are too fat feel flawed in every way, not smart, not physically capable, not worthy. They tend to diet, gain weight, and weigh more than they would otherwise. – Ellyn Satter

- Provide structure to family life
- Eat meals together as a family
- Be active 30-60 minutes every day
- Set limits on screen time
- Encourage and model healthy choices
- Division of Responsibility



Many questions arise regarding nutrition and ADHD. Studies offer conflicting information regarding the restriction of sugar, additives, salicylates, and other dietary components. This may be in part due to compliance with the diet, differing parental reports, and confounding variables such as impulsiveness and emotional distress potentially leading to self medicating with food.

Nutrition in ADHD

Despite conflicting reports regarding sugar and other additives, experts do not recommend giving caffeine to children, especially if they are taking prescription medication for ADHD. One area of study showing promising results is regarding Omega-3 and Omega-6 fatty acid, zinc, and iron supplementation. There has been a small, but beneficial link in one study. Moving from a “Western Diet” high in saturated fat and refined sugar, toward a “Mediterranean Diet rich in fruits, vegetables, fish, and whole grains is also a healthy choice that may provide added benefits.

- “Western Diet”
- High in saturated fat, refined sugar, processed food, caffeine
- Low in protein, fruits/vegetables, fatty fish
- Skip meals, eat fast foods

- Mediterranean diet
- Rich in fish, vegetables, fruit, legumes, whole grains

Navigating the School

PLANNING, EDUCATION, ACCOMMODATION

There are plenty of restrictions that come along with a diagnosis of Perthes. Some are obvious, such as limiting weight bearing. Others may only come to light through trial and error, for example, does your child need a little extra time in the restroom at school now that he or she is in a cast? You may need a specialized plan. While every school system is different, here are some tips to get started.

504 Plan

What is a 504 plan? Section 504 is a federal statute (anti-discrimination law), which protects the rights of individuals with disabilities to equal opportunity in programs and activities which receive federal funds. A 504 plan can include accommodations, modifications and special services that are similar to those in an individual education plan. It's important to be proactive when forming and modifying your child's 504 plan.

A person is eligible for a Section 504 evaluation if they:

- Have a physical or mental impairment that substantially limits a major life activity
- Have a record of such impairment or
- Are regarded as having such an impairment

To begin the process there must be a referral made by the parent, teacher, administrator, etc. At this point the school may attempt to address any concerns and make accommodations. If this is not resolved, consent forms for formal process are sent home for parental signature and, pending parental consent, the campus begins the 504 evaluation. Some other items that may be collected with consent for evaluation include a parent input form, proof of doctor's medical diagnosis, teacher input form, release of confidential information form.



Individualized Health Plan

Individualized Health Plan addresses a medical or physical disability. This may be necessary if your child has medication in the school's clinic or if he or she has physical restrictions. If a child has a condition for which an IHP is recommended, it may be recommended that he or she have a 504 plan in place.

Important Distinctions

Neither a 504 plan nor an IHP is "special education." Each 504 plan or IHP is evaluated on a case by case basis. 504 committees do not want to discriminate by over accommodation or under accommodation. Teacher, nurse, and parent input is vital and necessary to determine appropriate accommodations. No two plans should be identical due to differences in student needs.

Many parents are concerned that such a plan will cause discrimination against their child. These plans are meant to "level the playing field" not provide an advantage to your child. These plans are also confidential. To ensure fairness, evaluation should be data-driven and directly related to, in this case, Perthes disease.

Things to Consider

If your child is doing well with informal accommodations, that's wonderful! There is potential, however, for informal accommodations to fall through. This may happen due to switching or substitute teachers, miscommunication, or simply forgetfulness. We are all human after all.

Some things that can be included in a plan could be increased time to use the restroom due to casts, access to accessible restrooms (the only restroom that may accommodate a wheelchair could be far from your child's classroom).

Additionally participation may need to be modified for certain activities or the activity itself may be modified to include participation via adaptive equipment. When you take the time to educate the school and your child's teachers on Perthes disease, accommodations can be made without causing undue stress and feelings of isolation for your child.

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THANK YOU
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