

The MHE / MO / HME Guide

Learning about your child's special needs and how you as a parent can help with your child's Education.

Authored by The MHE Research Foundation

The issues MHE / MO / HME parents face trying to help cover their child's educational needs and let the school, teachers and all staff know about the needs of their children can be over whelming. Children with special needs many times require what is called an Individualized Education Plan (IEP) as well as a letter from the parent. U.S. Department of Education *A Guide to the Individualized Education Program PDF guide book link is located on the MHE Research Foundation website*

The affects MHE / MO / HME can vary from child to child it is important to keep in mind not all the issues listed will necessarily happen to your child, but if they do you will have this information and other information located on our website to help guide you along the way. Children with MHE / MO / HME have challenges they will need to overcome in school they can have mobility issues, pain issues, sleep issues, fatigue issues, social issues and may miss a larger number of days from school than other children that do not suffer from MHE / MO / HME, all can affect your child's education. It also has been reported some children may also have learning issues, sensory issues there is research being conducted on these issues now.

You also need to remember that children with MHE / MO / HME are subject to the same educational issues as children that do not suffer from MHE / MO / HME. Sometimes learning disabilities can be over looked.

Before your child is enrolled or returns to school, write a letter directed to the school, teacher and all staff that will be in contact with your child explaining your child suffers from MHE / MO / HME and has disabilities as a result.

You can print some of the materials located on our website and given them to the school along with the letter you write to your child's school team. Remember that your child in not only dealing with one classroom teacher and school nurse in the lower grades, but other staff in the school as well. In the higher grades the challenges become even larger as children start to change classes and have a larger number of children to deal with throughout the day. So make sure that everyone is on the same page and knows your child's special needs can become more difficult.

When writing important letters to the school make sure you address your letter to all staff that will be dealing with your child.

The first paragraph could read your child is suffering from a condition called

Multiple Hereditary Exostoses or Multiple Osteochondroma. MHE / MO / HME is a genetic bone disorder in which multiple benign cartilage-capped bone tumors that outward from the long bones, growth plates or from the surface of flat bones throughout the body. These Exostoses / Osteochondromas can cause numerous problems, including: compression of peripheral nerves or blood vessels; irritation of tendons and muscles resulting in pain and loss of motion; skeletal deformity; short stature; limb length discrepancy; chronic pain and fatigue; mobility issues. Describe where and how MHE has affected your child and write please see the attached Clinical Information Guides . If you child already has an IEP make copies of this as well.

Close your letter by saying how you look forward to working with the school staff in the upcoming school year.

Signature

Your contact information

We also suggest that you can make this a tear of letter, this way all school staff that receive a copy of your the letter you are writing can mail or hand back that they have received and have read the information you have supplied the school. You can also attach a self addressed envelope with stamp.

Example

-----Tear of and return-----

Teacher or school staff name: _____

I have read the letter and information in enclosed sent by Your NAME concerning Your Child's Name.

Teacher or school staff signature: _____

Date: _____

You will need to write a letter to the school requesting an IEP for your child. Provide expectations and concerns regarding your child's school performance in a organized and concrete manner. Expect all language in the IEP to be clear, understandable. Ask what you can do to reinforce your child's school program and instruction at home, during holiday and summer breaks.

MHE / MO / HME School Needs Check List, this check list has been put into a PDF file linked on the MHE Research Foundation website.

(PDF form can be directly typed into and saved or filled out by hand, the check list contains the bullet information below with boxes you can simply check off.) This PDF file is also use full when given to the medical professionals who are caring for your child as well. This assists the medical professional to see some of the issues your child is facing.

School Needs Check List.

- Make sure to inform the school when surgery is planned and also if possible
- ▶ surgeries that you may know could be required in the future, like a fixator surgery the following year for example.
- ▶ Will your child need to be home schooled due to surgery?
It may take time for your child to get up and moving in the morning, so if
- ▶ your child is slow in the morning let the school know about this and the other issues below
- ▶ Your child may need to bath or shower to loosen up in the morning
- ▶ Your child may have a hard time getting fully dressed by him/herself putting on shoes and socks, clothing with buttons
- ▶ Does your child have pain at times throughout the day?
- ▶ Does your child need to take pain medication during school?
- ▶ Your child may use need to crutches, a walker, cane, or wheelchair all the time or from time to time
- ▶ Does your child have issues walking to school or the school bus stop?
- ▶ Does your child have issues getting on and off the school bus?
- ▶ Does your child need special transportation provided by the school?

Activities in School:

You can request in writing for an Occupational therapy (OT) evaluation for your child to be performed. Many of the issues below are addressed during Occupational therapy, where the school has an Occupational therapist work with your child during school hours. You can also request a Physical therapy (PT) as well. In many states, if the school cannot provide the service needed in the school itself the department of education will pay for these sessions with an OT or PT therapist that they have contracted with. You can also

- ▶ request Assistive technology evaluation and after this evaluation if your child need in the lower grades an AlphaSmart (small light weight key board to take notes and type small paragraphs the screen is very small on the AlphaSmart and only shows a few lines of text types) For older children laptops can be ordered. Learning to type software as well as word prediction and voice activated software can be ordered for laptops. These computers can be taken home with the child. If an AlphaSmart or Laptop is ordered make sure the classroom has a printer as well.

- ▶ Does your child have issues with stairs in school?
- ▶ Does your child need to use the elevator at school?
- ▶ Does your child need help to use the bathroom by him/herself due to buttons on clothing at school?
- ▶ Does your child need help to carry a lunch tray?
- ▶ Does your child need help opening a milk carton?
- ▶ Could your child be embarrassed to speak up concerning problems your child is having in school with the teacher or school nurse?
- ▶ Does your child get tired at school and want to rest? and is there a location to rest?

- ▶ Does your child tend to get fatigued during the school day?
- ▶ Does your child have a hard time raising my hand in class because of his/her MHE?
- ▶ Does your child need a second set of books (one to stay at school and one for home)?
- ▶ Has your child's Orthopaedic physician given you guide lines on the amount of weight your child backpack can weigh?
- ▶ Does your need a set of notes of class work due to writing issues?
- ▶ Does your child need to get up and walk around in the classroom because of stiffness or pain?
- ▶ Does your child need extended time for exams/tests?
- ▶ Does your child need a scribe, answer recorded in any manner written into his/her IEP
- ▶ Would it help your child to take exams/testing at a different location, so they could get up if they needed to move because they are stiff?
- ▶ Would you like a Para - Professional to be assigned to your child or class room if needed?

PE/Gym:

- ▶ Does your child have trouble sitting cross-legged/Indian style, running, jumping, hopping, skipping, bending, pulling, hanging, pushing, kicking, throwing, tumbling?
- ▶ Can your child play soccer, basketball, volleyball or contact sports?
- ▶ Has your Orthopaedic physician given any restrictions to participate regular gym activities?
- ▶ Could your child have issues with getting undressed for gym in front of other kids because of my scars or the appearance of their bone or exostoses/osteochondromas.

After School hours:

- ▶ Does your child need to take a nap or rest period after school?
- ▶ Does your child need amount of homework modified to insure that your child completes homework given?
- ▶ Be sure to keep records of the number of days missed from school and why and also the number of days your child maybe need to come home early.

Other warning flags to watch out for and bring up to the teacher and during your IEP meeting.

Attention:

- ▶ Fails to pay close attention to details or makes careless mistakes in schoolwork, work, or other activities
- ▶ Has difficulty sustaining attention in work tasks or play activities
- ▶ Does not follow through on instructions and/or fails to finish schoolwork, chores
- ▶ Has difficulty organizing tasks and activities
- ▶ Avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort such as homework and organizing work tasks
- ▶ Loses things consistently that are necessary for tasks/activities (i.e., toys, school

assignments, pencils, books, or tools)

- ▶ Is easily distracted by outside influences
- ▶ Is forgetful in daily/routine activities

Other

- ▶ Confuses left and right
- ▶ has a poor sense of direction; slow to learn the way around a new place; easily lost, confused or has fear in unfamiliar surroundings
- ▶ Is slow to learn new games and master puzzles
- ▶ Performs inconsistently on tasks from one day to the next
- ▶ Has difficulty generalizing (applying) skills from one situation to another

Comprehension:

- ▶ Not interested in listening to stories, audio tapes, songs and a variety of listening activities
- ▶ Experiences difficulty distinguishing between similar sounds
- ▶ Experiences difficulty following directions, especially when it's more than one at a time
- ▶ Doesn't enjoy participating in class discussions and rarely raises his/her hand to respond
- ▶ Slow to follow oral discussion and take notes

Oral Language:

- ▶ Weak articulation skills
- ▶ Difficulty with oral language uses lots of interjections and hesitations (umm, uh, well...)
- ▶ Weak verbal expression
- ▶ Grammar skills are quite weak
- ▶ Forgets a lot of words and can't often remember what he/she was going to say
- ▶ Weak vocabulary

Reading:

- ▶ Confuses words and letters
- ▶ Has difficulty recognizing and remembering sight words
- ▶ Confuses similar-looking words (i.e., beard/bread)
- ▶ Demonstrates poor memory for printed words
- ▶ Often loses place when reading, requires finger tracking
- ▶ Difficulty when silent reading, needs to mouth words or whisper when reading
- ▶ Doesn't enjoy reading
- ▶ Reluctant Reader
- ▶ Reading is slow and deliberate
- ▶ Lots of word substitutions, omissions and invented words
- ▶ Cannot skim or scan for pertinent information

- ▶ Has poor retention of new vocabulary
- ▶ Cannot re-tell parts of the story, prediction skills are weak

Written Work:

- ▶ Rarely enjoys writing and responds negatively to written activities
- ▶ Written work is rarely legible, writing is messy and incomplete, with many cross outs and erasures
- ▶ Experiences difficulty when copying instructions from the board, orally or chart paper
- ▶ Rarely completes written assignments
- ▶ Written work is poorly organized and difficult to follow
- ▶ Punctuation and grammar is weak and often missing
- ▶ Lots of word substitutions, omissions and invented words
- ▶ Written ideas lack cohesion and sequence
- ▶ Ideas are poorly written and expressed
- ▶ Written work is often difficult to understand
- ▶ Spelling is weak, Spells poorly and inconsistently (i.e., the same word appears differently other places in the same document)
- ▶ Letters and/or words are often reversed
- ▶ Demonstrates delays in learning to copy and write
- ▶ Uses uneven spacing between letters and words, and has trouble staying 'on the line'
- ▶ Copies inaccurately (i.e., confuses similar-looking letters and numbers)
- ▶ See Occupational therapy (OT) evaluation and Assistive technology evaluation information above

Mathematics:

- ▶ Has trouble learning multiplication tables and rules
- ▶ Rarely sequences numbers, equations and formulas appropriately
- ▶ Has trouble telling time
- ▶ Has trouble conceptualizing the passage of time
- ▶ Poorly aligns numbers resulting in computation errors
- ▶ Has difficulty with learning and memorizing basic addition and subtraction facts
- ▶ Difficulty mastering number knowledge(i.e. Recognition of quantities without counting)
- ▶ Has difficulty with comparisons (i.e., less than, greater than)
- ▶ Has difficulty estimating quantity (i.e., quantity, value)
- ▶ Unable to perform 'mental math'
- ▶ Has trouble interpreting graphs and charts
- ▶ Computations are usually inaccurate
- ▶ Many careless errors, often chooses the wrong operation
- ▶ Difficulty understanding mathematical concepts
- ▶ Rarely uses mathematical terms appropriately both orally and in written work
- ▶ Does not remember the math facts (although today, many children aren't committing the math facts to memory)
- ▶ Cannot do mathematical word problems

Motor Skills:

- ▶ Is often clumsy and accident prone
- ▶ Has limited success with games and activities that demand eye-hand coordination
- ▶ Has weak co-ordination
- ▶ Awkward gait
- ▶ Weak fine motor skills (evidenced in art, written work, copying, writing on the chalkboard etc.)
- ▶ Holds pencils, pens, crayons, scissors inappropriately - too hard, due to exostoses/osteochondroma
- ▶ Also trouble with buttons, hooks, snaps, zippers and trouble learning to tie shoes
- ▶ Exhibits weak large motor co-ordination during gym and recess (falls or trips frequently)
- ▶ Experiences difficulty using small objects or items that demand precision (i.e., Legos, puzzle pieces, tweezers, scissors)

Social Skills:

- ▶ Has a difficult time establishing friends or has friends that are younger
- ▶ Rarely accepted by peers (kids could be being teased)
- ▶ Has difficulty 'joining in' and maintaining positive social status in a peer group
- ▶ Argues with peers
- ▶ Doesn't accept responsibility well
- ▶ Has trouble knowing how to share/express feelings
- ▶ Has trouble 'getting to the point' (i.e., gets bogged down in details in conversation)
- ▶ Avoids peer contact and is often ridiculed or involved in ridiculing
- ▶ Demands instant gratification, seeks a great deal of attention
- ▶ Doesn't like to follow rules or routines or does not like when routines are broken
- ▶ Prone to tantrums
- ▶ With drawn
- ▶ Takes issues with large numbers of people, example lunch room or play ground
- ▶ Has a hard time picking up facial expressions, bodily gestures, tone of voice, etc...example your child think a person is upset with them and they are not or takes common experiences that most people take in stride out of context.
- ▶ Has trouble setting realistic social goals

Behavior Skills:

- ▶ Often is hyperactive
- ▶ Rarely completes tasks in the allotted time
- ▶ Often acts out in the classroom and doesn't follow routines and rules
- ▶ Can be extremely moody and acts impulsively
- ▶ Very disorganized or over organized

- ▶ Inattentive and distractible
- ▶ Rarely thinks before acting
- ▶ Does not get along well with peers
- ▶ Decision making skills are weak and is often late or absent
- ▶ Easily Frustrated
- ▶ Anxiety

Other Sensory issues:

- ▶ Touch/Texture, feeling of certain clothing on skin, clothes feel scratchy or itchy, children could not tolerate the roughness
Food texture, Easily gags due to texture or tastes. A "picky" eater or crunchy texture may be loved, while any other texture is rejected or groups: sweet, sour, bitter or salty. Sometimes a child may only eat foods from one of these categories
- ▶ Loud noise examples music, movies, play ground, lunch room, parades, parties, fireworks

Evaluation requests

- ▶ IEP evaluation
- ▶ Learning disability evaluation
- ▶ Occupational therapy (OT) evaluation
- ▶ Physical therapy (PT) evaluation
- ▶ Assistive technology evaluation