



Tips for Staying Active and Preventing Fatigue

Note: These tips may or may not be appropriate for your situation. Feel free to take away any of these ideas that may assist your child with general mobility, at school and in the community.

At School

Individual Education Plan (IEP):

An IEP is a legal document that is filed in the student's records, developed together by the school and parents to ensure accommodations are met. See PHA Canada's School Resource Package for further information on student education plans (visit www.phacanada.ca/school-package). You can also ask to meet with your Principal to discuss and review the IEP.

Classroom and Locker Placement in Middle/High School:

Meet with your school's guidance staff to ensure your child's locker and classrooms are centrally located (such as near entry/exits, main office, library, gym, bathrooms, music room, etc.), so that they do not have to travel great distances to get to class and their locker throughout the day. If there are no elevators in the building, insist classrooms remain on the ground floor to avoid stair climbing, which may contribute to shortness of breath and/or fatigue. Also, avoid having your child travel outside to portable classrooms, which can often be a great distance from the main school building.

Classroom Seating:

Ensure proper seating and desk height to optimize energy conservation. Smaller students may need to sit closer to the front and should be able to see the board from their desk location in the room. Desk placement may need to be adjusted to accommodate oxygen or other medical equipment (i.e. being closer to an electrical outlet).

Classroom Rest Station:

Request a space in the classroom where your PH'er can rest comfortably throughout the day if needed.

Textbooks:

Ask for a second copy of your child's textbooks that you can keep at home so they do not have to carry them to and from school each day.

Recess:

Arrange for your child to remain indoor during days that are hot/humid or extremely cold. Students may need relief in an air-conditioned room on hot/humid days.

- Suggestions for indoor school activities for hot/humid days and cold days: library helpers, art club, guitar/music club, book clubs, and lunch monitors.



Music Class:

Some children may not tolerate playing woodwind or brass instruments. Instruments like drums, piano, or xylophone may be a good substitution.

Gym Class:

Connect with the classroom teacher and/or school team to ensure the needs of the student are met. Schedule a meeting with Physical Education (P.E.) teachers and coaches to negotiate accommodations.

- Activities can be altered and roles for games can be modified to be inclusive and focus on strengths as well as energy conservation.
- Walk and Talk Test—Ensure kids and teachers know the signs of distress. If the student can walk and talk they are not in distress. Teachers and students need to make a change to the activity if there are signs of trouble.
- Listen to your child. They will tell you if they need a break.
- Avoid activities that involve possible sudden impact to the chest (such as dodge ball, baseball, etc.)
- Avoid sudden lifting of heavy weights (such as weight lifting, pushing a heavy object, etc.)

In the Community

Accessible Parking Permit:

Permits are government issued by your province/territory and allow you to park closer to entrances and exits at various venues. Your doctor can help you with the required documentation.

Community Activities/Outings:

- Consider community classes and lessons that are not focused on physical exertion, such as pottery, art, music, book clubs, and crafts.
- Consider roles within athletic teams to ensure continued involvement and to conserve energy (such as team manager, score keeper, equipment manager, etc.).
- When experiencing hot/humid days, try to plan your activities in the early morning or evening when it is not as hot outside. Schedule frequent drink breaks. Look for cool and shady places to stop and rest along the way.
- Plan trips ahead of time and pace yourself. For example, if you are planning on going to the zoo in the afternoon, avoid having a busy morning to reduce fatigue.
- Use the elevator or escalator when available.
- Assist your PH'er (according to what is age appropriate for your child) with daily tasks like getting dressed and ready to leave the house for your outing.
- Assist your child with tools to pace themselves throughout the day. Let them know it is okay to sit down and take a break when needed. As your child gets older, they will become better able to advocate for themselves and plan their day with consideration for their energy levels.
- Help your child plan their day so they can save as much energy as possible.
- Changing terrain can be something to consider when planning a community outing. Upward slopes and inclines can be difficult. Plan routes accordingly and take breaks along the way.



Weather:

- When it is cold outside, keep your child's oxygen tubing close to their body to keep it from freezing up or cracking. You may want to run tubing through the inside of winter gear.
- Windy weather can make breathing difficult so try to avoid prolonged exposure to wind.
- Cold weather can make it difficult to breathe for many with PH. Try using a scarf or neck warmer that can be pulled over the face to warm up air before it hits the lungs, making it more difficult to breathe.

Appropriate Clothing and Footwear:

- Layering clothing makes it easier to keep core temperature optimal and to avoid using extra energy to stay warm or cool down. Layers allow kids to have more control over their body temperature. They can take layers off or add them back on when needed. Consider hats and hoods to protect against wind and cool temperatures.
- Consider clothing that is comfortable and easy to wear. Try to stay away from clothes that can be difficult to put on and take off. Fabrics should breathe and move with the child.
- Consider comfortable shoes and boots with treads. Slip on shoes and boots may be better than those with too many laces to tie.

General Mobility

Wagon:

Consider using a wagon to cover distances once your child is older and out of a stroller. This may apply to pre-school or school aged children depending on the size of the child.

Electric Car:

This allows young children to have independence, as well as a way to keep up with older siblings and neighbourhood kids.

Scooter:

As the child gets older, a scooter allows kids to keep up with their peers in the schoolyard, on school trips, and out in the community.

Oxygen Tank Carrier/Cart:

For those patients on oxygen, a cart on wheels allows kids/teens to pull it along. It provides more independence without them having to carry the tank. Contact your local oxygen provider to get one for your child.

Oxygen Backpack:

This could be useful for patients who have the strength to carry their oxygen tank on their back. Contact your oxygen provider for details.