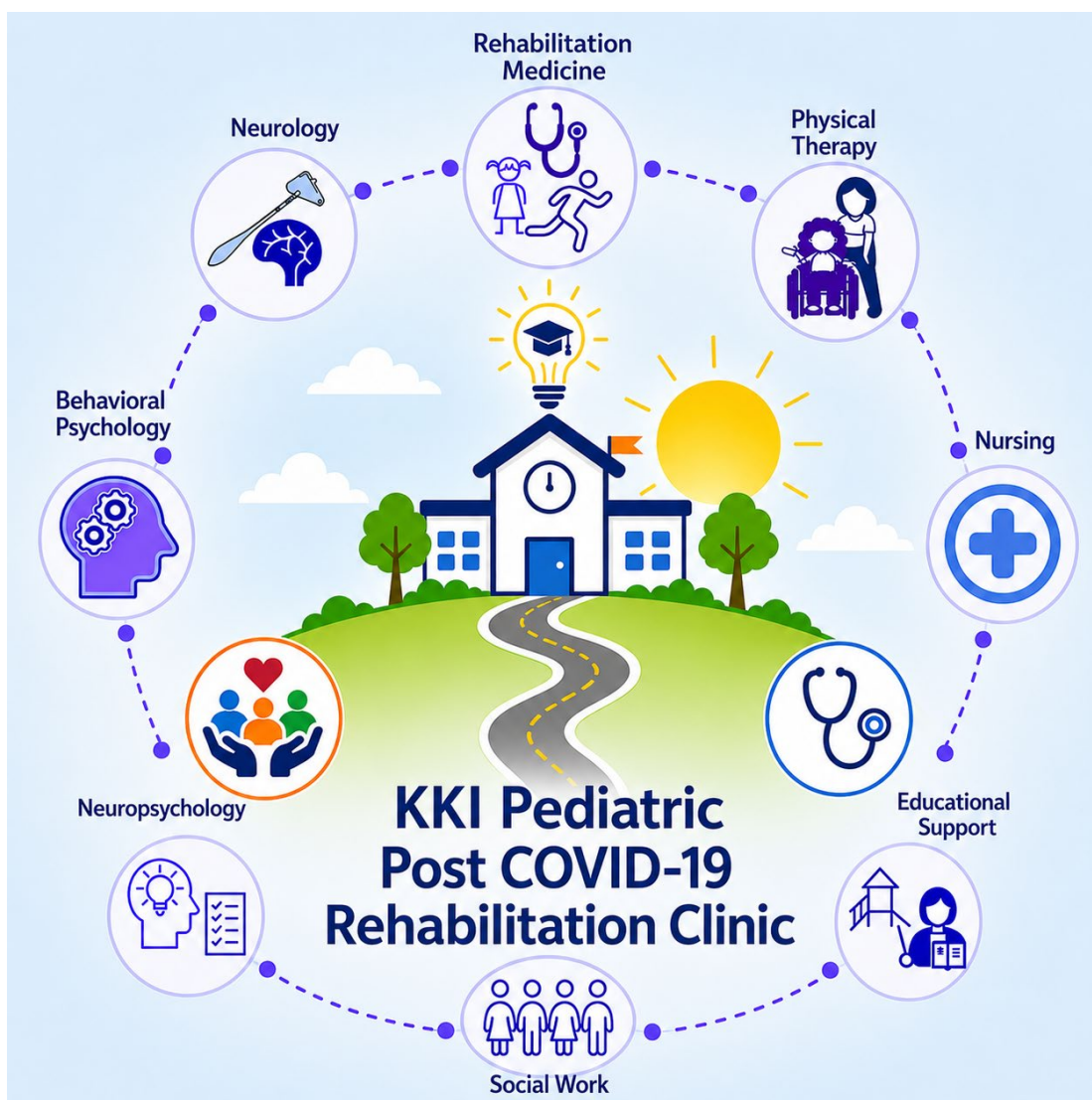


Parent Roadmap:

Supporting Children with Long COVID at School



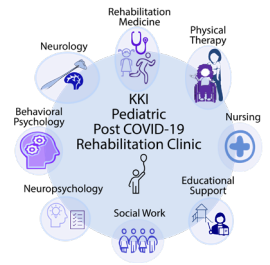


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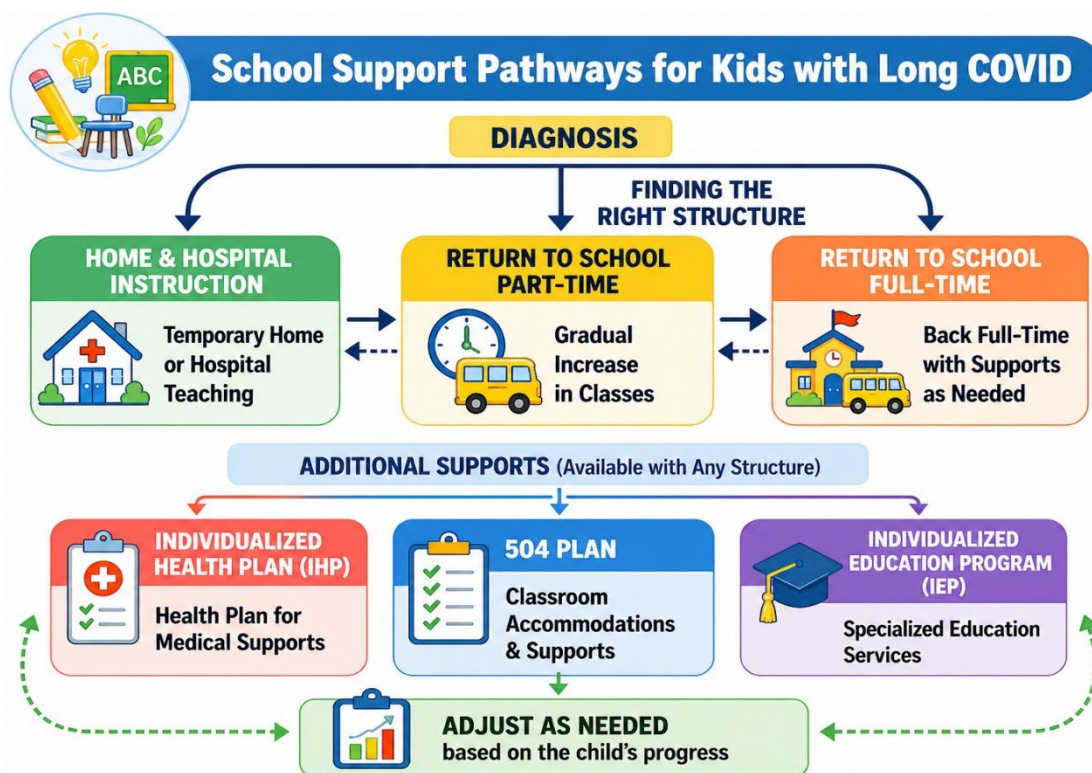
Parent Roadmap: Kids with Long COVID Still Need School

Beginning the Journey: Diagnosis

Your child has just been diagnosed with long COVID. You and your family are making lots of changes and learning a lot of new information. School might be the last thing on your mind. But school is important! It's not just about learning new subjects and doing homework. School gives children a chance to make friends and grow as people. This roadmap will help you ask the right questions. Write down information so you can look back at it later. **Our goal is to help your child return to school full-time, in person, when possible.**

Being flexible is really important for everyone! Schools are still learning about long COVID and how it affects students, just like you are. This means families, schools, and doctors need to stay in regular contact and share updates. Working together can help find the best plan that works for your child!

Long COVID symptoms can be hard to notice and may change over time. Symptoms might be different from day to day or week to week. Recovery is not always steady, so your child's school plan might need to change. You might move back and forth between different options in this roadmap, and that's okay.



Finding the Right Path Back to School: This diagram shows different ways children with long COVID can return to school, along with supports that can be added and adjusted as their needs change over time.

Health Care Related

Checklist of Things to Ask or Do

- Ask the treatment team what type of school plan they recommend for your child.
 - Should your child return to school full-time, or would part-time school or Home and Hospital Teaching (HHT) be better?
 - Should your child be referred to the school for school accommodations (e.g., Section 504 Plan) or an Individualized Health Plan (IHP)?
 - Does your healthcare team have any ideas about which accommodations would be helpful?
 - If your child had a pre-existing neurodevelopmental disability or learning concerns, should you ask about a new or updated IEP (Individualized Education Program)?
 - If your child is not yet school-aged, ask if they need **early intervention services** before starting preschool through your Local Infants and Toddlers Program (LITP).
- Ask whether your child should get **neuropsychological assessment**. If this is recommended, check with your insurance company to see if it is covered.
- Talk with the treatment team about any thinking or learning problems your child might have and how they might affect school. These problems could be new since their long COVID or pre-existing from before their infection.
- Ask the treatment team to pick one or more people who can be the main contact between the doctors and the school.
- Ask to sign a release of information to allow communication between the school and treatment team. You might need to sign one at your provider's office and the school.
- Keep a record of your child's medical visits, medications, and progress over time. This can help when sharing information with your care team and school. While schools are not required to implement medical recommendations, sharing medical paperwork may help the school team better understand your child's diagnosis and how it impacts learning.

School/Community Related

Checklist of Things to Ask or Do

- Tell your child's **primary care provider (PCP)** and the **school (nurse, counselor, and administrator)** that your child has been diagnosed with long COVID. Give them paperwork from the clinic.
- Talk with your child's school-based team about what information to share with classmates about the illness.
- Ask the school to pick one or more people who can be the main contact person to talk with you and the treatment team. Let this person know the best way to reach you/how you prefer to be contacted.
- Connect the main contact from the treatment team with the school contact, if possible. This could mean starting an email conversation together.
- Help your child stay in touch with friends so they don't feel alone while missing school. You could arrange video calls or in-person visits if appropriate.
- If your child attends a private school, talk to them directly about what supports or plans they offer to students, as this might be different than public schools.

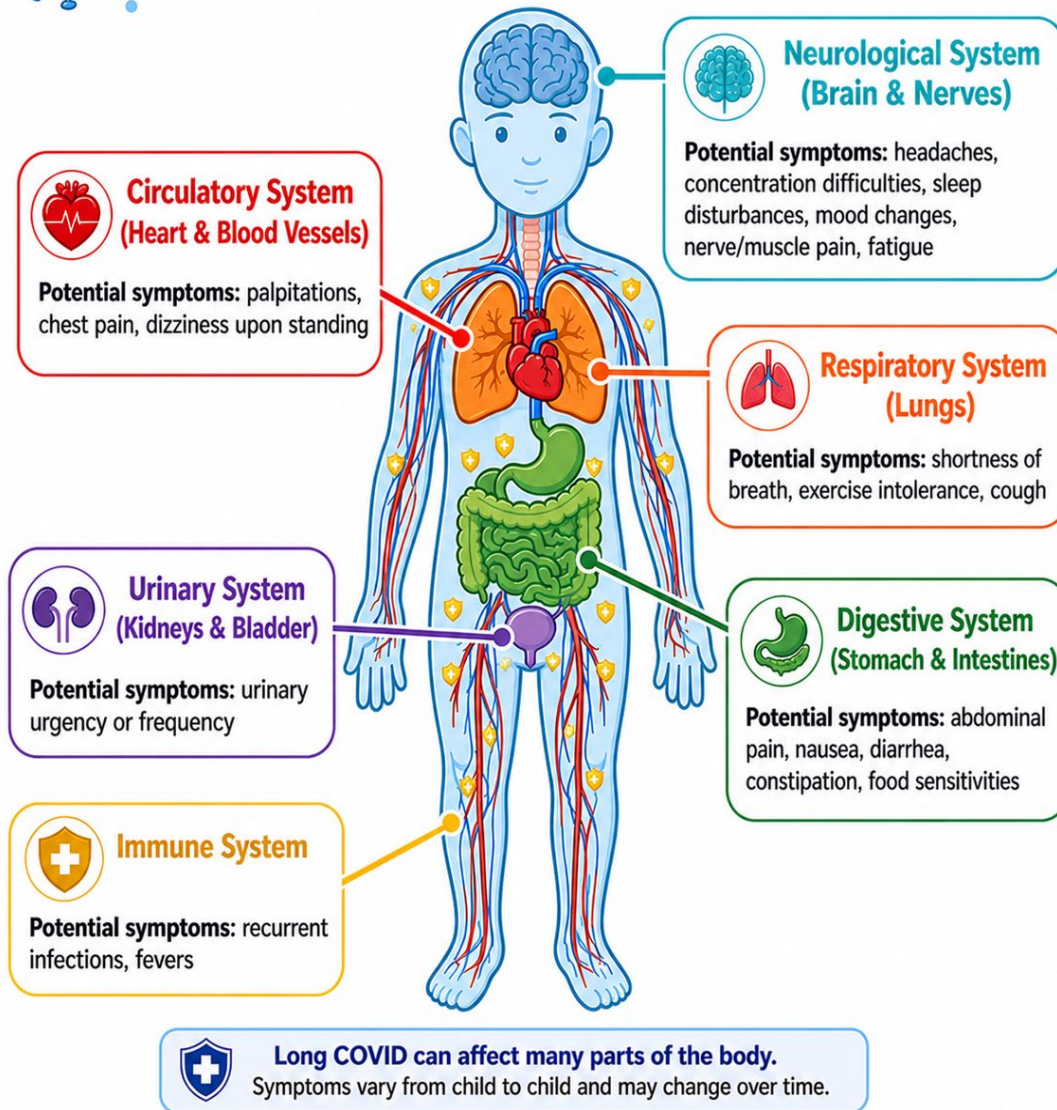
First Step: Things You Need to Know and Resources That Can Help

You will be learning a lot of new words about long COVID, brain fog, and treatments.

Many children with long COVID have a group of symptoms that can make daily life hard. Physical symptoms like fatigue, headaches, and nausea can make school participation difficult. Some kids also have thinking problems, sometimes called "brain fog." This can include trouble paying attention, memory problems, and difficulty understanding or remembering information. The body **figure** on the next page shows how long COVID can affect different body systems in children and adolescents.



Understanding potential areas of impact from long COVID on a child's body



You might also need to learn some new words about school and learning.

What are neurocognitive skills or abilities?

Neurocognitive skills are the thinking and learning abilities we use every day. These are the mental skills we use to:

- Pay attention
- Understand information
- Remember what we learn
- Solve problems
- Answer questions or do activities

Why is this a concern for my child?

- Some children with long COVID report experiencing “**brain fog**.” This term describes neurocognitive symptoms that affect thinking and learning and are important for school participation.

What is a neuropsychological assessment?

- A neuropsychological assessment looks at how a medical condition or treatment affects thinking and behavior. A **neuropsychologist** is the doctor who does these types of tests with your child. See Helpful Resources Section for links on how to find a neuropsychologist in your area.
- You may also hear people call these tests *neuropsychological evaluations*, *neuropsychs*, or *neuropsych evals*.
- Testing usually includes tasks that assess:
 - Attention and executive function
 - Language
 - Motor skills (like balance or writing)
 - Reasoning (how someone thinks about things to come to a decision) and problem-solving
 - Memory

The assessment includes interviews and questionnaires to learn about the child's daily activities, how they are coping, and any changes over time. It includes tasks that are similar to school activities or “brain teasers.” If needed, the appointment can be split into more than one day. Remember to check with your insurance company about coverage.

What is the difference between neuropsychological assessment and educational testing?

Neuropsychological assessment focuses on understanding how the child’s medical condition(s) affects brain development and function, and how the child’s daily activities are affected (such as paying attention, learning, motor skills, or interacting with others). Neuropsychological assessment includes a broad evaluation of the child’s functioning, with a goal of understanding what might contribute to the child’s challenges and what interventions are needed.

Educational testing completed at school focuses on determining if your child has specific learning gaps that might make them eligible for special education services. This is determined by the school team of which you are a part. Sometimes, school testing includes academic and cognitive assessments, as well as behavioral ratings, to describe your child's school functioning. It is mainly focused on educational domains and gives a limited view of your child’s needs at school.

[See Pathway 3](#) for additional information on neuropsychological assessments and education testing.

Most kids with long COVID will not need educational testing. Ask your medical team for their opinion about which type of testing is right for your child.

Will having long COVID qualify my child for disability benefits from the Social Security Administration?

The Social Security Administration provides disability benefits to certain adults and children with qualifying disabilities and meet other criteria. A child is considered disabled if they have a long-lasting impairment that causes serious limitations in their daily life. When someone applies for disability benefits, the Social Security Administration reviews how their health conditions, including long COVID, affect them. Your child may also be eligible for additional support through programs in your state. More information is available in this Social Security Administration guide: <https://www.ssa.gov/disability/professionals/documents/EN-64-128.pdf>.

Based on your child's needs, your provider may recommend

1) Adjustments to the way your child attends school:

Pathway 1: Starting Home and Hospital Teaching

Pathway 2: Adjusted or Partial School

Pathway 3: Full-Time School

And/or

2) Supports your child might need:

Option A: Individualized Health Plan

Option B: Section 504 Plan

Option C: Individualized Education Program (IEP)

Helpful Resources

Understanding Pediatric Neuropsychology & Testing Services

- **American Academy of Clinical Neuropsychology – Pediatric Neuropsychology Overview**
<https://theaacn.org/pediatric-neuropsychology/>
- **Understood.org – Pediatric Neuropsychologists: What You Need to Know**
<https://www.understood.org/en/learning-attention-issues/treatments-approaches/working-with-clinicians/pediatric-neuropsychologists-what-you-need-to-know>
- **Neuropsychological Testing For Students & Adults (Ages 4+)**
<https://nchpsych.com/testing>



Parent Roadmap: Kids with Long COVID Still Need School

Supports Your Child May Need on the Journey:

Option A: Individualized Health Plan

Option B: Section 504 Plan

Option C: Individualized Education Program (IEP)

Any of these plans are confidential. Families can decide if post-secondary schools and training programs (e.g., college) get this information.

Talk with your child's medical team about your child's educational needs so they can include them in the medical documentation.

Option A: Individualized Health Plan

What is an Individualized Health Plan (IHP)?

- An Individualized Health Plan, or Health Plan, is created by the school nursing team. It identifies a health problem that affects your child's performance in school. The nurse shares the IHP with school staff who need to know about it, so they know what medical help your child might need during the day.
- Some examples related to long COVID might be:
 - If your child needs medication during the day, they might be allowed to take it in the nurse's office. They may also take breaks or use a quiet space to rest when needed.
 - If your child has special bathroom needs, they might use the bathroom in the nurse's office.
 - If your child needs extra salt or water, they might go to the nurse's station to get snacks.
- If your child does not need accommodations in class and only needs the nurse to monitor their symptoms, an Individualized Health Plan might be right for them.
- Your child might qualify for both an Individualized Health Plan and either a Section 504 Plan or an IEP, depending on their needs.
- You might need to get a letter from your healthcare providers that explains your child's medical needs. It's important for your provider to be clear about what medications, toileting, and lifestyle interventions your child needs at school.

Option B: Section 504 Plan

Long COVID and Disability Protections

- Long COVID can be considered a disability under federal laws like the **Americans with Disabilities Act (ADA)** and **Section 504 of the Rehabilitation Act of 1973**.
- If symptoms make it difficult to learn, focus, walk, or sleep, students might be able to get school accommodations. Schools can provide these supports through a **Section 504 Plan**, which lists the accommodations a student may need to learn and participate in their regular classes.

What is a Section 504 Plan?

- Section 504 of the Rehabilitation Act of 1973 is a federal law that protects people with disabilities from being treated unfairly. A Section 504 Plan helps students with disabilities have the same opportunities as their classmates. It's a blueprint that includes specific accommodations or classroom supports a student needs. The plan doesn't change *what* the student learns, but *how* they learn it. Examples of support might include extra time on tests, scheduled breaks, or frequent access to the bathroom.
- Section 504 Plans are for students of all ages who have a physical or mental disability that affects major life activities. There is no specific list of conditions or disabilities that qualify.
- Section 504 Plans provide school-day accommodations. To qualify, your child's medical diagnosis must affect their access to learning. This means that your child has trouble learning in the regular classroom setup. Usually, the student is at grade level for academics and does not need specialized instruction/education.

What is the process of getting a Section 504 Plan?

- **Step 1:** Identify your child's diagnosis (e.g., long COVID). Ask your medical provider to write a letter that explains the diagnosis.
- **Step 2:** Ask in writing for a meeting with the Section 504 Plan team and request that the nurse, teacher, counselor, and administrator come to the meeting.
- **Step 3:** Explain how long COVID symptoms affect your child. Compare how your child is doing with other children of the same age. Some examples include:
 - Because of **frequent headaches**, your child doesn't sleep well and feels very tired in the morning. This makes it hard to get to school on time.
 - Because your child gets **dizzy when standing**, they also feel dizzy when walking between classes. This makes them late and sick at the start of class, so it's hard for them to understand the lesson.
 - Because of **brain fog**, your child has trouble taking notes and listening to the teacher at the same time. This means they miss important information.
- **Step 4:** Identify the major life activities that are affected by these symptoms and their frequency. Examples include:
 - Because of **headaches**, sleeping and focusing are affected once a week.
 - Because of **dizziness**, walking and focusing are affected many times a day.
 - Because of **brain fog**, reading, thinking, and concentrating are affected in most classes.
- **Specific Recommendations:**
 - Use this roadmap, the [body diagram](#), and the [supplemental table](#) of examples to connect your child's long COVID diagnosis to common symptoms that impact your child's functioning in school (e.g., migraines or ADHD).
 - Explain that long COVID is hard to notice and may change over time. Symptoms might be different day to day or week to week, and recovery is not always steady.
 - Long COVID symptoms and treatments (medications or therapies) can cause your child to miss school. This is part of the health condition.
- **Note:** Getting a Section 504 Plan can happen faster than getting an IEP, though there is no specific required timeline as there is for an IEP (see Option C).

What if my child is still struggling even with a Section 504 Plan?

- **Step 1:** Request a 504 meeting to review the Section 504 Plan and share your concerns with the team.
- **Step 2:** Work with the 504 team to decide if additional accommodations are needed on the Section 504 Plan and/or whether a referral should be made to the special education team (IEP referral).

Option C: Individualized Education Program (IEP)

What is an IEP?

- An IEP is a plan that gives your child special education support, services, and/or accommodations. In rare cases, some children with long COVID might need an IEP. If a child with an IEP gets long COVID, their IEP might need to be updated or changed.
- IEPs fall under a federal law called the Individuals with Disabilities Education Act (IDEA). This law makes sure all children with disabilities can get free and appropriate public education (FAPE), including special education if they need it. This law applies to public schools. Private schools (that do not receive public funding) do not have to provide special education. **But you should still check which resources are available if your child goes to a private school.**
- Most children with long COVID can learn without special education support, so they usually need a Section 504 Plan instead of an IEP. If a child does need an IEP (based on neuropsychological assessment and school performance), they might qualify under the Primary Disability of *Other Health Impairment*. Some children may also qualify for special education if they have a learning or intellectual disability found through testing. Other special education categories usually do not apply just because a student has long COVID.

What is the IEP process?

- The IEP team is a group of school staff (such as a school psychologist, special education teachers, regular education teachers, administrators, and a nurse). They follow a process to decide if a child meets the criteria for an educational disability and what types of school supports may be needed. The first step is to have a meeting to talk about your child's performance and health, and your concerns. More information about the IEP team: <https://www.understood.org/en/articles/whos-on-the-iep-team>
 - Think about bringing a friend, family member, or someone else to help you at the meeting.
- If you have a report from a neuropsychological assessment or paperwork from the long COVID treatment team, share it with the school team before the meeting. This helps them understand your child's medical history, strengths, and areas where they need help.
- At the meeting, you and the IEP team will talk about how your child is doing in school. You will also discuss if more testing is needed to see if your child qualifies for an *educational* disability category. If more testing is needed, the school may ask you to sign a form to allow them to evaluate your child's learning, thinking, speech, or movement skills.
- **Educational disabilities are different from medical diagnoses. Just having a medical diagnosis does not mean a student is eligible for an IEP.** Students must meet the rules in IDEA to qualify. You can learn about these rules and disabilities that qualify [here](#).
- Each school district has its own guidelines or processes for testing, determining disabilities, and creating the IEP. Check with your school district to find out the steps and timelines.

Educational Supports & Advocacy Resources

Note: Private schools may not use or have the same structure as these options. However, you can still use the information above to guide a conversation with the private school about available supports for your child.

Understanding School-Based Supports

- **Understood.org – Understanding Section 504 Plans**
<https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans>
- **Understood.org – What Is an IEP?**
<https://www.understood.org/en/school-learning/special-services/ieps/what-is-an-iep>
- **IEP Tip Sheet for Parents**
<https://www.ecac-parentcenter.org/wp-content/uploads/IEP-overview-parent.pdf>

Requesting School Evaluations

- **Project HEAL at Kennedy Krieger Institute – Sample Letter Requesting an Evaluation**
<https://www.kennedykrieger.org/sites/default/files/library/documents/community/maryland-center-for-developmental-disabilities-mcdd/project-heal/resources-for-parents/project-heal-sample-letter-requesting-evaluation-0.pdf>

Advocacy & Legal Support

- **Council of Parent Attorneys and Advocates (COPAA)**
<http://www.copaa.org/>
- **Project HEAL (Health, Education, Advocacy, and Law) – Kennedy Krieger Institute**
Project HEAL is Maryland’s only comprehensive medical-legal partnership, providing advocacy and legal support for Kennedy Krieger Institute patients with intellectual and developmental disabilities and their families, including help with special education and accessing services.
<https://www.kennedykrieger.org/community/initiatives/maryland-center-developmental-disabilities/project-heal/resources-parents>

Policy & Disability Guidance

- **Guidance on “Long COVID” as a Disability Under the ADA, Section 504, and Section 1557**
<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>



Parent Roadmap: Kids with Long COVID Still Need School

Pathway 1 on the Journey: Starting “Home and Hospital Teaching”

Even if your child didn't enjoy school before, they may now ask, “What about school?” This is a good sign! After all, school is about learning and spending time with friends. We want your child to get back to these important things as soon as possible.

Health Care Related

Checklist of Things to Ask or Do

- The school system sets up Home and Hospital Teaching. Home and Hospital Teaching might also be called home-bound instruction, home teaching, interim instructional services, chronic health impaired program (CHIP), or medical support teaching. Ask your treatment team if they recommend Home and Hospital Teaching based on your child's current level of functioning. If Home and Hospital Teaching is recommended:
 - Ask who from the treatment team will sign the paperwork.
 - Contact your school's guidance counselor or administration team for the specific paperwork and process.
 - Ask your team if they recommend *in-person vs. virtual* Home and Hospital Teaching because of your child's symptoms. Note: if *in-person* teaching is requested, it may take longer for the school to set up.
- Are there any health/medical concerns that should be discussed with the home and hospital teacher?
 - If your child already has an IEP, you will want to meet with the IEP team to discuss Home and Hospital Teaching. The home and hospital teacher (and school) will need to follow the IEP and Section 504 Plan adjustments.
- Stay in contact with your child's primary care provider (PCP), especially if you live out of state, to help manage prescriptions and medical needs for school participation.
- Work with your school system to choose a specific time and place at home for completing schoolwork.

REMEMBER: Ask your treatment team and school to communicate. They should get into the habit of sharing information with you and with each other (with your permission).

School/Community Related

Checklist of Things to Ask or Do

- Contact your school's guidance counselor or administration team for the specific paperwork and process for Home and Hospital Teaching.
- Check with your school district about the minimum classes or credit requirements needed to move on to the next grade level.
- Set up a communication link so the home and hospital teacher knows if your child's health changes and how it might affect their schedule.
- Figure out the best schedule and place for teaching. Think about what time of day your child usually feels the best and which room/environment will be most comfortable and not distracting.
- Talk to the home and hospital teacher about your child's school history and experiences. Share things like their least and favorite subjects, what they miss about school, and any school problems before diagnosis.
- Clearly explain your treatment team's recommendations to the home and hospital teacher. Remember, your child might be very tired, so keep goals simple and easy at first. For example, allow your child to rest before their teaching session begins.
- Help your child stay connected with friends and community activities when possible.

First Pathway: Things You Need to Know and Resources That Can Help

You have learned many new words and procedures about long COVID and treatment. Now you're learning new words and procedures about school and learning to help your child.

What is Home and Hospital Teaching?

- Home and Hospital Teaching is a temporary service for students who cannot attend their regular school due to physical illness and/or extended hospitalization. The goal is to help them return to school.
- Teaching is usually done one-on-one in the home or hospital room, led by certified teachers.
- There is no cost to the family for Home and Hospital Teaching for students in public schools. If your child attends private school, ask the school and your local district about available home and hospital services.

How does my child get access to Home and Hospital Teaching?

- Usually, the treatment team recommends services when appropriate and can help with the necessary paperwork.
- Contact your school or district for the specific paperwork and process to set up Home and Hospital Teaching. Check your school's website for information.
- Home and Hospital Teaching may be offered in-person or virtually. Be patient and work with your school until they can find a teacher. It might be quicker to set up virtual instruction.

- Home and Hospital recertification is required in all districts (how often varies). You must maintain contact with your treatment team to continue getting approval.

And remember...

- If you have not yet scheduled a neuropsychological assessment for your child, it is a good idea to do this. Ask your healthcare team for help. The test results are an important tool to help understand which accommodations might be necessary.

Maryland Home and Hospital Teaching Program Information

<https://marylandpublicschools.org/about/pages/dfs/sssp/homehospital/index.aspx>



Parent Roadmap: Kids with Long COVID Still Need School

Pathway 2 on the Journey: Return to School Part-Time

Even though your child still has many symptoms and/or is getting treatment for long COVID, some days they might feel better and be able to do their usual activities. This is probably a good time for your child to return to school part-time. Keep in mind their schedule of clinical visits and therapies.

Health Care Related

Checklist of Things to Ask or Do

- Is my child ready to return to school part-time?
- Start talking about how long COVID might affect your child's thinking and learning. Consider getting a neuropsychological assessment if one hasn't been done yet.
- Are there any school activities you think my child should avoid? (Examples: participation in gym class, contact sports, field trips)
- Add appointments and school attendance priorities to a calendar to create a schedule. Keep in mind that some children with long COVID will experience crashes or post-exertional malaise. Start with short periods each day to **maintain a regular routine**, even if your child has crashes. This follows the pacing approach used for long COVID ([see Energy Bucket Diagram](#)). Then slowly add more time, as your child can handle it, to build strength. In many cases, an every-other-day schedule may not work well. It can lead to over-exertion and a crash pattern of long COVID.
- Find someone on your healthcare team who can talk with school staff and answer questions.

School/Community Related

Checklist of Things to Ask or Do

- Can my child attend school part-time and continue Home and Hospital Teaching at the same time?
- Set up a plan with the school on how to contact you in case of emergencies. Include a backup person to call.
- Talk with the school team (the nurse, teacher, and administrator) about your child's health. Talk about ([see Body Figure](#)):
 - Symptoms might change throughout the day, week, or month.
 - In the long COVID phase, your child is not contagious with SARS-CoV-2. You might ask your treatment team to explain this to the school if needed.
 - What is your child's normal energy level? Will they need to have rest breaks during the day?

- What time of day does your child feel best? Work with your school team to identify when the core classes are scheduled.
- How is your child's appetite? Share any food or drink limits (or if your child needs to drink more fluids).
- Share concerns about your child's bathroom needs, including how often they might need to use the bathroom. Ask if your child can have a special hall pass or elevator pass if needed.

School/Community Related: A Few More Things to Ask or Do

Checklist of Things to Ask, Do, or Think About (continued):

- Talk with your child about coming back to school and seeing friends. Suggested topics include:
 - What information does your child want to share with classmates? How can you help your child stay connected with friends?
 - Discuss any concerns you or your child may have about bullying. Ask the school team to develop a plan to watch your child more closely. File an incident report if needed.
- Work with your school to create a return-to-school plan and update it often. For example, at first, your child may just want to come to school and see friends. Over time, schoolwork will become more important.
 - The goal is to get your child back to school. Sometimes, participating in social activities at school can be very helpful. Talk with the school about which activities are most important for your child to attend for short periods while still continuing Home and Hospital Teaching.
- Be flexible and ready for a few bumps along the way.
- Ask for a Section 504 Plan to help with your child's needs at school, including physical and academic support. ([See supports options](#))
- Going back to school after a COVID-19 illness, especially with long COVID symptoms, can be challenging. Consider reaching out to a counselor, psychologist, or social worker for support with stress and feelings about having a chronic illness and disability.
- If you haven't already, ask to sign a release of information to allow communication between the school and treatment teams.

Second Pathway: Things You Need to Know and Resources That Can Help

You learned a lot of new words about long COVID. Here are new words about school procedures you may need:

What does a part-time school plan look like for a child with long COVID?

- At first, it may be helpful to attend for short periods every day to maintain a regular routine.
- Pick the class or time for in-person attendance with your healthcare team. In our experience, trying to start at the beginning of the school day has better success. Think about choosing important academic subjects or classes that your child enjoys.
- Slowly add more time (e.g., every couple of weeks, add one class or one hour). It's important to add more time to build up strength and help with the recovery process. The body needs small challenges to build up endurance.

- In some cases, schools will require occasional Home and Hospital Teaching for students who cannot attend regularly or for a full day. This can be helpful if your child has extreme crashes or flares but can sometimes attend school.
- Talk about what to do with your healthcare team if your child has crashes or if their symptoms become worse during this slow return.
- At times, because of flares or crashes, your child may not be able to participate in activities they used to do. Think about other ways they can stay involved in the activities they enjoy. For example, they might help manage a sports team when they can't play or help direct a play instead of acting.
- Return to the most recent successful plan if symptoms worsen, and if the healthcare team wants to reduce school time.

You might need to add scheduled breaks during school based on symptoms. The key to part-time school is pacing and preventing post-exertional malaise or feeling worse after doing too much (if your child experiences this). We want to **avoid “crashes”** and maintain consistent schedules with rest breaks as needed. This helps build activity tolerance slowly over time ([see the Energy Bucket Concept Diagram in the Appendix](#)).



Parent Roadmap: Kids with Long COVID Still Need School

Pathway 3 on the Journey: Returning to School Full Time

Most children and adolescents with long COVID can return to school full-time, as usual. There may be some things to consider as you plan for this return. You may need to stay closely involved in your child's schooling. You want to make sure your child gets the additional school supports they have a legal right to.

Health Care Related

Checklist of Things to Ask or Do

- What will my child's ongoing care look like? What kind of medical visits will there be, and how many?
- Should we monitor long-term thinking and learning changes after my child's diagnosis?
- Should my child have a(nother) neuropsychological assessment*? How does my child access this service?
- Key Differences: Neuropsychological assessment vs. Educational Testing**
 - Who Does It & What It Covers:** A **neuropsychological assessment** is a special test done by a neuropsychologist. It provides a deeper look at how the brain works, including memory, attention, thinking skills, feelings, and behavior. It often includes academic testing, too. School systems can also conduct **educational evaluations** as part of the special education process. These assessments evaluate how a student is doing in school, including their grades, classroom performance, behavior, psychological functioning (cognitive, social, and emotional), participation, and access to learning. Families can also choose to get private evaluations if they prefer.
 - Diagnosis & Treatment Guidance:** Neuropsychological assessment can identify *medical diagnoses* (such as ADHD, anxiety, or autism) and help guide therapy and treatment. It gives recommendations for home and school settings. Educational testing is designed to determine whether a student has an *educational disability* and provides information to the IEP team to help decide if a student qualifies for school-based services.
 - Purpose & Recommendations:** Neuropsychological assessments help explain *why* a child may be struggling and give detailed recommendations, including possible accommodations. Educational evaluations explain how difficulties affect school functioning and what specific learning supports are needed. Both are important, and what works best for your child might depend on access to testing services.
 - Talk to your healthcare team about how your child is doing in school at each follow-up visit. Even if the main reason for the visit is to discuss long COVID symptoms, your healthcare team will want to know how school is going. Also, talk about these issues during visits with your child's regular pediatrician.

*[The First Step: Diagnosis page](#) has information about this term.

School/Community Related

Checklist of Things to Ask or Do

- Ask for a Section 504 Plan to help with your child's needs at school, including physical and academic support.
- If your child has had a neuropsychological assessment, talk to the neuropsychologist about how to use the results to help your child at school. Share the testing report with your child's school team.
- Get to know the people on your child's school team. Many families say that finding someone at school who has experience with long COVID or wants to learn about it helps things go more smoothly.
- Going back to school after a COVID-19 illness, especially with long COVID symptoms, can be challenging. Think about reaching out to community resources such as a counselor, psychologist, or social worker to help with stress and feelings about having a chronic illness and disability.
- At the end of *every* school year, ask how your child's teacher/school administrator plans to transition and communicate your child's supports to the next grade. This is especially important during the transition to middle school and high school. Reach out to upcoming teachers so they know about your child's needs.

Encourage your child to participate in social and extracurricular activities.

Third Pathway: Things You Need to Know and Resources That Can Help

Pacing Reminder

Remember the concept of pacing for both cognitive and physical activities at school and home. See the [Energy Bucket Concept Diagram in the Appendix](#) for more information.

Finding Support Providers

Ask the treatment team, the child's pediatrician, or even the school counselor or psychologist for providers they recommend. The resources below can also help families find mental health supports:

- **Psychology Today (Finding Local Mental Health Providers)**
This resource is helpful in finding local therapy services and can be filtered by specialty and insurance status. Learn more: <https://www.psychologytoday.com/>
→ Specialties such as "Child," "Chronic Illness," and "Chronic Pain" may be particularly relevant, in addition to mental health conditions.
- **Headway (Finding Pediatric Mental Health Providers)**
This online tool helps families find licensed therapists and psychiatrists who accept their insurance. Learn more: https://care.headway.co/lp/get-care?page_variant=children

Additional Resources

- **Centers for Disease Control and Prevention (CDC) Long COVID Resources for Families & Caregivers**
Learn more: <https://www.cdc.gov/long-covid/resources/index.html>



Parent Roadmap: Kids with Long COVID Still Need School

Beyond: The Journey Continues

Long COVID can change a lot. It's possible that you and your child might discover new learning differences. This can happen more often in higher grades, like high school or college. School assignments might become harder. Social situations can become more complicated. These changes can bring new problems. But there are lots of things that you, your healthcare team, your school, and your child can do to make things better.

Health Care Related

Checklist of Things to Ask or Do

- Make a list of questions or concerns before each visit with the clinical team. Include questions about your child's school performance and any health concerns. Also, make notes of progress and changes in functioning in the weeks leading up to the appointment. Write down any triggers that make symptoms worse and what helps manage them.
- Should my child have a(nother) neuropsychological assessment*? How do I access this service? Many colleges or universities require these assessments to be completed within a year of admission.
- Get documentation of any changes or new recommendations from the medical team that the school may need to update attendance or support plans.
- If your child is a teenager (age 14 and over), ask for guidance to help them learn to take care of their own healthcare needs. Have a conversation with your teenager about allowing them to lead discussions during medical appointments. In some hospitals, children move from pediatric clinics to adult care clinics when they turn 18. Healthcare processes change when youth turn 18. This includes how treatment decisions are made, who shares information, and how parents are involved. Ask about transition planning (This means planning for the move from one type of care to another).
- Ask the healthcare team for a referral to a counselor or psychologist if needed. As time goes on after your long COVID diagnosis, children sometimes do not want to tell their parents about their worries. But you might notice your child is struggling to adjust. Chronic illnesses are hard, and sometimes children need help adjusting.

* [The Beginning the Journey: Diagnosis page](#) has information about this term.

School/Community Related

Checklist of Things to Ask or Do

- Check in with your child about how they are adjusting to their new normal. Be willing to discuss any social challenges that come with long COVID.
- Remember to let your child's teacher(s) know when s/he will need to miss school for follow-up medical visits. Make a plan for how missed work and assignments will be communicated. Clarify when missed work is due.
- At the end of **every** school year, ask how your child's teacher/school administrator plans to transition and communicate your child's supports to the next grade. This is especially important during the transition to middle school and high school. Reach out to upcoming teachers to make sure they know about your child's needs.
- Meet regularly with your child's teacher(s) to monitor their progress. Ask about their performance and if they are working on grade level. If they are not working on grade level, ask about any remediation or other possible changes to their plan.
- Ask about any needed accommodations for standardized testing (such as state-wide testing, SAT, or ACT). Ask whether your child will need any new assessments to obtain accommodations on such testing, if needed.
- If your child is thinking about college, ask the high school counselor about schools with strong disability support programs, if needed. Your child, rather than you, will need to take the lead to request any accommodations in college.

The Journey Continues: Things You Need to Know and Resources That Can Help

On this journey, you have learned so much about how to help your child. As your child gets older, it is important to teach them how to help themselves. When they are young adults, this will help them be independent in college and deal with any potential long-term health conditions. You can start by helping your child talk with adults about what they need to succeed in school.

Legal Resources:

- As noted earlier, your child might need additional supports in school, which could be provided through a Section 504 Plan or an IEP. See the [Support Options](#) section for further information on these services. These are relevant through high school. The Americans with Disabilities Act (ADA) still protects students' access to learning beyond high school. This means that teens and young adults entering college, community college, or other vocational training programs may also be able to get needed supports or accommodations after leaving high school.
- You can always ask to be connected with a parent advocate, find an educational attorney, or check if your state has a legal agency that supports youth with developmental disabilities. The state Division of Rehabilitative Services or Developmental Disabilities Agency may also be helpful.

Legal & Transition Resources



- **Wrightslaw – How to Use Wrightslaw (Video Overview)**
<https://www.youtube.com/watch?v=PzXzIqMOX3k>
- **Council of Parent Attorneys and Advocates (COPAA)**
<http://www.copaa.org/>
- **Got Transition – Guidance for Transition from Pediatric to Adult Healthcare**
<http://www.gottransition.org/>
<https://www.gottransition.org/youth-and-young-adults/>

The Journey Continues

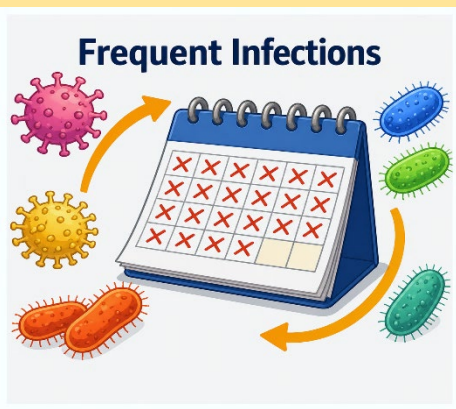
As you and your child continue on this journey, stay in touch with the school and healthcare teams. Help them stay in touch with each other.

Supplemental Table: Examples of Common Symptoms, Functional Impacts, and Possible Section 504 Plan Accommodations

**Note: Not all accommodations will apply to every student.*

Symptom	Functional Impact	Accommodations to consider
<p>Frequent headaches/ migraines</p> 	<ul style="list-style-type: none"> • Reduced ability to pay attention or complete detailed thinking tasks • Trouble with reading/computer-based work or tasks requiring long periods of visual concentration • Decreased productivity due to unpredictable headaches and the need to rest • Increased sensitivity to noise/light/busy environments 	<ul style="list-style-type: none"> • Adjusted school schedule • Separate quiet/dark room for rest break and/or exams • Opportunity to pick class times • Ability to choose where to sit in class • Copy of teacher’s notes • Use of noise-canceling headphones during independent work • Allow sunglasses, hats, or reduced screen brightness
<p>Orthostatic intolerance</p> 	<ul style="list-style-type: none"> • Reduced tolerance for standing, walking, or engaging in tasks that require upright posture • Increased risk of dizziness, near-syncope, or syncope during transitions from sitting/lying to standing • Limited ability to perform activities that require standing for long periods 	<ul style="list-style-type: none"> • Allow movement breaks, stretching, or position changes • Help carrying backpack or heavy objects • Extended time between classes • Copy of teacher’s notes • Pass to nurse’s/guidance office • Frequent breaks/positional changes to manage symptoms • “Buddy walk” help between classes • Access to water/salty snacks • Elevator key/pass if stairs are required • Ability to transition early/late between classes to avoid crowded hallways • Altered dress code to accommodate symptoms

Frequent infections



- Frequent absences due to recurrent illness
- Reduced stamina/longer recovery times, limiting participation in everyday activities
- Greater risk of getting infections in crowded places (limits ability to join group activities that require close interactions)
- Decreased physical conditioning

- Virtual access to instruction during extended illness periods
- Work sent home/extended deadlines
- Copy of teacher/classmate notes
- Identify school point person to coordinate missed work and communication
- Limit group work that requires close interaction
- Pass to nurse's office
- Reduced physical education (PE) demands

Gastrointestinal symptoms (e.g., nausea, diarrhea, or constipation)



- Difficulty maintaining adequate nutrition/hydration, affecting overall endurance
- Reduced ability to participate in activities away from bathroom access – due to urgency, discomfort, or fear of symptom onset
- Impaired focus/performance due to gastrointestinal distress
- Limitations in physical activity when symptoms are triggered by exertion or movement

- Copy of teacher/classmate notes
- Pass to nurse's office
- Unlimited, immediate bathroom access
- Frequent or flexible breaks
- Access to snacks/water/medication
- Adjusted school schedule and/or no penalty for being late
- Teacher assistance prioritizing essential assignments during high symptom periods
- Reduced or modified PE demands

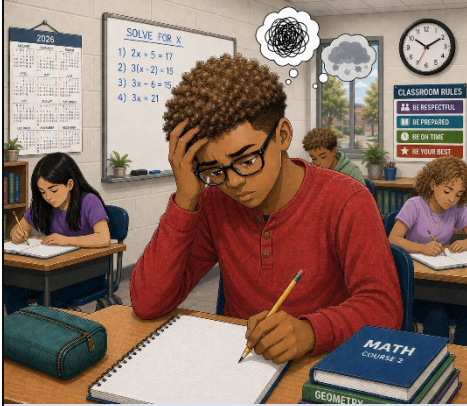
Shortness of breath/Exercise intolerance



- Decreased capacity for physical tasks (walking, stairs, moderate to high exertion activities)
- Need to work at a slower pace, take frequent breaks
- Need to avoid physically demanding environments
- Limitations on mobility over longer distances
- Difficulty participating in exercise-based activities

- Extended time between classes
- Elevator access
- Rolling backpack or preferred locker access
- Frequent rest breaks
- Reduced physical activity requirements; exemption from hard activities in PE class
- Preferred scheduling to reduce walking demands

Brain fog



- Difficulty with planning, organization, problem solving
- Slowed information processing, making complex or time-sensitive tasks more challenging
- Trouble remembering things, task sequencing, or multi-tasking
- Reduced accuracy/increased error rate during academic activities
- Difficulty with executive functioning, including task-initiation, prioritization, and task-completion

- Ability to choose where to sit in class
- Extended test time/shortened assignments
- Chunking assignments
- Copy of teacher's notes/outlines or another student's notes
- Advanced warning before being called on in class
- Written instructions, visual supports for instructions
- Frequent comprehension checks
- Teacher assistance prioritizing essential work
- Separate testing location for exams

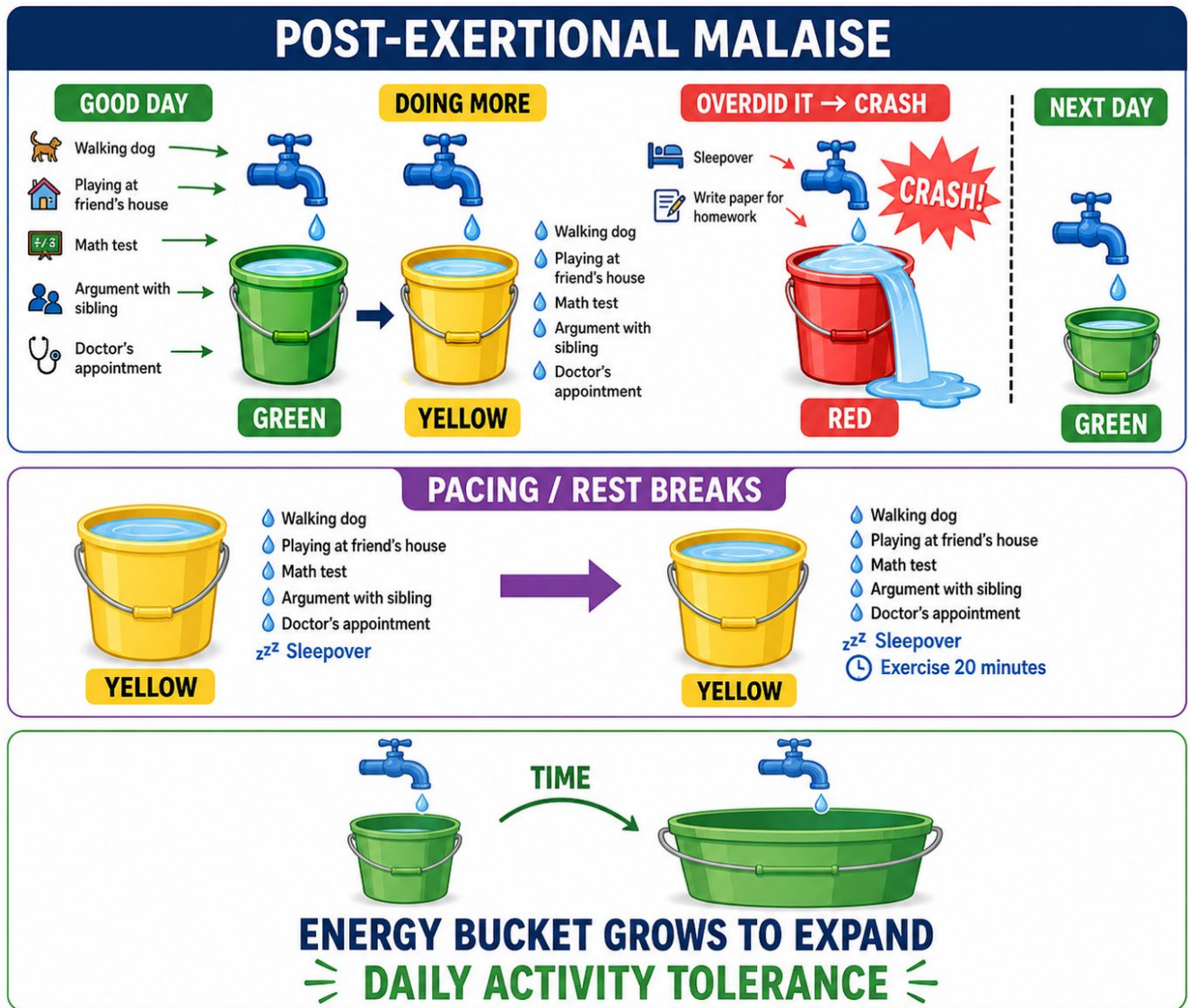
Fatigue/ Post-exertional malaise



- Limited endurance or fluctuating energy levels (both physical and cognitive activities)
- Difficulty maintaining consistent school attendance or productivity
- Reduced participation in school and academic activities
- Less participation or involvement in class

- Frequent rest breaks in or out of class
- Extended time between classes
- Adjusted school schedule to allow for pacing
- Extended time for tests/shortened assignments/assessments as determined by the teacher
- Copy of teacher's or another student's notes/outlines
- Elevator access
- Reduced physical activity requirements; exemption from hard activities in PE class
- Teacher assistance prioritizing essential work
- Support with make-up work after absences

Appendix: Energy Bucket Concept Diagram



This diagram shows how energy works like a **bucket** for children with Long COVID:

- **First Row:** The **green bucket** represents your daily energy. Each activity (like schoolwork, walking, or social time) uses some of that energy. The **yellow bucket** represents when your bucket fills up. The water is at the top of the bucket – you have no more room to do more activities.
 - If you try to do **more activities once you are at your bucket's limit**, the bucket can **overflow** (shown by the **red bucket** and “**crash**”). This is called post-exertional malaise (PEM), and it can make symptoms worse.
 - After a crash, the **next day's bucket is smaller**, meaning you have even less energy to use.
- **Second Row:** Through pacing and rest breaks, your yellow bucket (the maximum amount of activities you can do in a day) increases over time. Note how, as the bucket grows, we can add activities (green text; “Sleepover” and “Exercise 20 minutes”).
- **Third Row:** Over time, with careful pacing and gradual increases in activity, the **bucket can grow bigger**, allowing you to safely do more each day.