

## INFORMATION/EDUCATION PAGE

### Improving Life After Childhood Stroke: Helping Your Child Get the Most Out of Their Home Activity Program to Improve Upper Extremity Function

#### Childhood stroke and the home activity program

We use our brains for everything (walking, eating, speaking, thinking, and using our hands). When a stroke happens, sometimes it affects the area of the brain responsible for using the upper extremity (your hand and arm). Sometimes this difficulty persists and can have a lasting effect on family routines and the child's daily living activities including self-care, school, work, play, and leisure activities.<sup>1</sup>

We know the best way to improve movement and function after stroke includes lots of practice in the specific areas that are difficult. By focusing in on the areas that are a challenge for the child, therapists hope to help the child “re-wire” their brain with the goal to regain as much function as possible, even if the movement “looks” different than it did before.

Science tells us that both younger and older children can benefit from therapy and home programs to help improve hand skills.

Your child may be referred to occupational therapy to help with function in the upper extremity. If your child sees other therapists for other needs (physical therapy and speech-language pathology), those therapists can also help carry over upper extremity goals in their sessions.

An important part of your child's recovery is learning how to do things outside of therapy sessions. Children need to practice A LOT to learn (or relearn) skills. They also need to practice these skills in their own environments (home, school,

etc). Therapists will design a home activity program (HAP) tailored for your child's specific needs.<sup>2,3</sup> Therapists and caregivers can work together to help your child get the most out of their HAP.

#### Key ingredients for a good HAP

- DO work closely with your therapists on determining what your child's goals are for therapy—this is what sets the stage for making a good HAP!
  - Goals should be important to your child and you, measurable, and specific—this will help with both motivation and feeling the progress later!
  - If you are not sure about goals, ask your therapists for ideas. There are many questionnaires that can help you figure out how satisfied you and your child are with various skills, and how important they are to you and your child.
- DO be honest with your therapists about your schedule and responsibilities at home.
  - Research suggests that children require at least 30–40 hours of practice to build new hand skills.<sup>4–6</sup> This includes practice with the therapist and with the caregiver.
  - Therapists understand that families are busy and will help you balance recommendations and your schedule. Please refer to the Information/Education Page on selecting

therapies for frequency of occupational therapy recommendations.<sup>6</sup>

- There are many ways to schedule the HAP. If your child needs 30 minutes of practice per day to reach those minimum hours of practice, talk with your therapist about how to do this. Sometimes, your child can practice at meal times, in the grocery store, or even in the car when it is safe to do so. Some children and caregivers find it helpful to get all the practice done in one sitting, whereas others prefer to practice 5-10 minutes a few times per day.
- DO talk with your therapist about how the HAP is going. They will make sure it is the “just right” amount of challenge—not too easy, not too hard.
- DO ask questions about when your child’s HAP can be progressed to the next level.
- DO talk to your therapists about tips and tricks to keep your child motivated.
  - Therapists can help create a sticker/reward chart that celebrates your child doing their HAP. For example, your child might earn a sticker on their chart for each task completed, and 5 stickers earned could equal a motivating prize (such as a small toy or extra play/screen time).
- DO take pictures or make a list of what you already have at home that your child likes to play with. Ask if these can be added into the HAP.
- DO ask your therapists for ideas on community activities that will help support your child’s goals (swimming, martial arts, rock climbing, yoga, sports, and music class).

### Special considerations for hemiplegia

- Similar to how kids are bombarded in the media with messages about how they are “supposed” to look and act, people may accidentally say things that set up a negative self-perception of the child’s more affected side. YOU can help your child by focusing on the positives of what your child is doing with their affected side.
- YOU CAN encourage your child to use their more affected side. Use positive words and phrases,

such as “I like seeing you steady your homework with your left hand!” or “Can we try using two hands for that?”.

- AVOID referring to your child’s body as a “good side” and “bad side.” These phrases can have unintended consequences.
- AVOID striving for “normal” in the more affected side. This can potentially set up feelings of inadequacy, failure, and burn-out.
- YOU CAN embrace your child’s more affected side as it is—right now—and work on realistic and measurable goals that are important and meaningful to them. That may include working toward having the more affected side serve as a stabilizer, an assisting hand, or more. Talk with your therapists about the overall goal and plan for treatment.
- Research shows that repetition and practice in a variety of activities and places are important—ask your therapists for ideas.<sup>4-14</sup>
- It is ok—and even a good idea—to take breaks from formal therapy. Talk with your therapists about what HAP activities should be done routinely when your therapy is completed.

### Choose a format that is right for you

Your child’s HAP can be given to you in a variety of ways. Ask your child’s therapists what formats they offer. A few examples may include:

- Videos/Pictures of your child doing the activities/exercises—this can help you and your child complete the activities correctly.
- Written or print-out version—hanging the HAP in an open space can help remind you to practice.
- Mobile application—some applications may allow you to keep track of exercises or set reminders to practice.
- A version to view on a smart device or computer so you can use the HAP easily when you need it.

### Things to remember

- Safety first! Trust your instincts. If something seems unsafe or causes pain, do not do it and contact your child’s therapists.

- Keep the HAP fun and try not to make it feel like work.
- Evaluate the outcomes with your therapists.

## Resources

- Therapy choices for children with difficulties using 1 hand after a brain injury.<sup>6</sup>
  - This Information/Education Page has more information about the minimum number of hours of practice needed for different types of therapy.
  - [https://iapediatricstroke.org/wp-content/uploads/2024/03/TherapyChoicesForChildrenWithDifficultiesUsing1Hand\\_2023.pdf](https://iapediatricstroke.org/wp-content/uploads/2024/03/TherapyChoicesForChildrenWithDifficultiesUsing1Hand_2023.pdf).
- CPToys: [www.cptoys.org](http://www.cptoys.org). Matches toys with therapy goals. Sets up home programs and provides education forums for parents.
- HEP2Go is an example of an online home exercise application that therapists can use to provide instructions and pictures of some exercises.

## Authorship

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## Disclaimer

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