



**Liesl (right) and her daughter, Adeline (second from left)**  
LIVING WITH HPP, PICTURED WITH THEIR FAMILY

# Could it be hypophosphatasia (HPP)?

**Reflecting on symptoms  
to take action**

The information captured in this tool can help support clearer conversations with a doctor about symptoms affecting you or a loved one. This tool is not meant to diagnose HPP or any other condition.

It is designed to help organize symptoms, experiences, and observations so they can be communicated clearly during a visit.

**Remember, you are the expert on  
how your symptoms feel.**

# HPP is complex, but your *doctor visits don't have to be*

Many patients share that their most productive doctor visits happen when they're well-prepared for the appointment, use the appointment time efficiently, and leave with a clear plan.

- **Bring your key medical records**
- **List and track your symptoms**
- **Determine your top priority for your visit**
- **Share a list of your care team contacts**
- **Prepare a brief health history**

**[Click here](#) or scan for more information on how to have the best doctor's visit possible.**

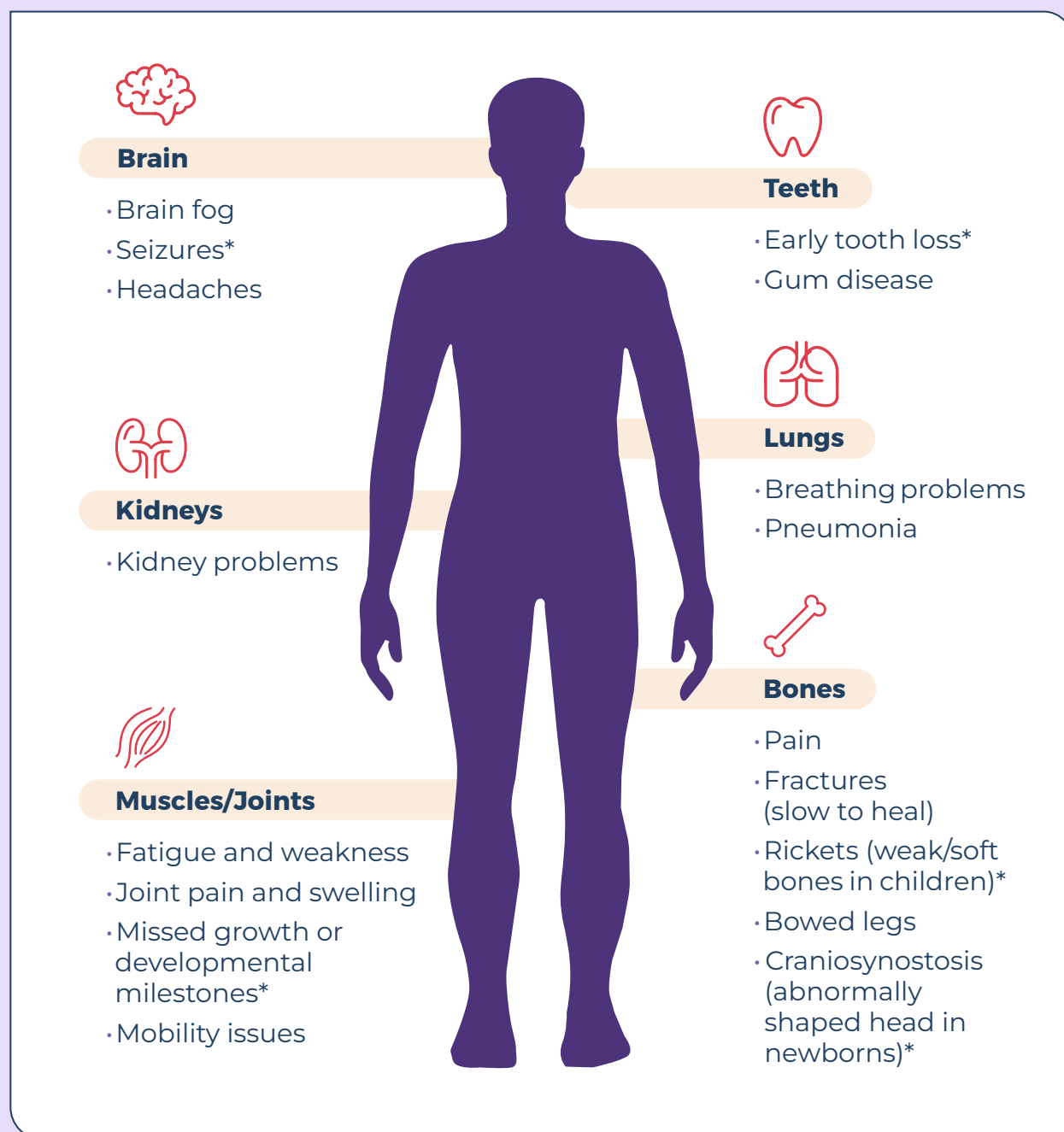


<https://qr.short.az/r/salsnj6u3rwuau7>

# Understanding *HPP* symptoms

HPP happens when the body has low levels of working alkaline phosphatase (ALP), an important enzyme. It is an inherited, lifelong condition that **can affect many parts of the body and may get worse over time.**

This visual highlights the most common HPP signs and symptoms. It's important to remember that **HPP can affect different people in different ways**, including pain, headaches, fatigue, muscle weakness, and more frequently broken bones.



\*Symptoms commonly seen in infants and young children.

# Health history overview

Because HPP symptoms can impact everyone differently, it's important to reflect on details across your health history.

This overview highlights what's most important to discuss with your doctor. Check the boxes below if anything sounds familiar.

## What you have experienced

HPP symptoms may show up in the body in ways that you can see or feel. Think back from childhood to now and check anything that describes your experience.

|                                                                                                                                                                                                                                                                                                                           |                          |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| <p><b>Have you had repeated dental problems, such as poor dental health, gum disease, or frequent cavities?</b></p>                                                                                                                                                                                                       | <input type="checkbox"/> |
| <p><b>Have you had multiple bone breaks or fractures from even small bumps or everyday activities, or that were slow to heal?</b></p>                                                                                                                                                                                     | <input type="checkbox"/> |
| <p><b>Compared to people your age that you know, do you feel that pain or discomfort makes your daily activities harder to manage?</b><br/> <i>(like stiffness, aching, or discomfort that makes activities like climbing stairs, carrying groceries, doing household chores, or commuting more challenging)</i></p>      | <input type="checkbox"/> |
| <p><b>Does it feel like you experience muscle weakness, shaking, or your muscles giving out more easily than for other people you know?</b><br/> <i>(like standing up without support, legs feeling unsteady, arms tiring quickly when holding or lifting items, or needing to use your arms to push yourself up)</i></p> | <input type="checkbox"/> |
| <p><b>Are you frequently tired and/or avoiding plans or activities because of how you're feeling physically or emotionally?</b><br/> <i>(like canceling plans, calling out of work, or skipping social activities because of low energy, fatigue, or emotional strain)</i></p>                                            | <input type="checkbox"/> |
| <p><b>Have you had difficulty focusing, keeping track of tasks, or following conversations?</b><br/> <i>(like easily losing the train of thought, needing to reread or rewatch things to stay focused, or feeling mentally foggy)</i></p>                                                                                 | <input type="checkbox"/> |

## Childhood reflection

Many symptoms of HPP may first appear or be noticed only in childhood. Think back to when you were young and check anything that describes your experience.

|                                                                                                                                                  |                          |
|--------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| <b>Did you lose baby teeth unusually early and/or with roots still attached?</b>                                                                 | <input type="checkbox"/> |
| <b>Were you told you did not meet early developmental milestones at the expected ages, like crawling, walking, or other physical milestones?</b> | <input type="checkbox"/> |
| <b>Do you feel like you had difficulty keeping up with other children physically during activities like play or sports?</b>                      | <input type="checkbox"/> |
| <b>Did you have a history of bones forming differently (bowed legs or unusual skull shape), breaking easily, or being slow to heal?</b>          | <input type="checkbox"/> |

## Doctor's observations

Check anything a doctor has noted in your medical records or discussed with you.

|                                                                                                                                                                                                  |                          |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| <b>Have you had blood tests showing low alkaline phosphatase (ALP)?</b><br><i>(It is sometimes listed in labs as "alk phos" or similar)</i>                                                      | <input type="checkbox"/> |
| <b>Have you had kidney issues, such as kidney stones or calcium buildup?</b>                                                                                                                     | <input type="checkbox"/> |
| <b>Have you ever been evaluated for or diagnosed with another condition that didn't fully explain your symptoms?</b><br><i>(like osteoporosis, fibromyalgia, arthritis, gout, or pseudogout)</i> | <input type="checkbox"/> |

Use what you've checked here to help guide your discussion with a doctor. Turn the page to explore HPP symptoms that can be harder to describe and easier to miss.



The following pages take a deeper look at possible hard-to-describe symptoms of HPP that can affect your daily life.

# *Could HPP be responsible for how you feel?*

As you go through the rest of this tool, take a moment to think about how your body and mind feel day to day. Remember, some symptoms may have been part of daily life for so long that they feel “normal” and have caused habits to shift over time.

**Sharing these experiences with your doctor can help them connect the dots.**

**[Click here](#) or scan to learn more about the ways HPP can impact the body.**





## **Muscle Weakness**

- Muscles that feel weak or tire easily



## **Pain**

- Bone pain
- Muscle pain
- Joint pain
- Nerve pain
- Headaches



## **Fatigue**

- Low energy
- Trouble sleeping
- Feeling tired even after rest



## **Mind & Mood**

- Brain fog or difficulty focusing
- Headaches
- Feelings of anxiety
- Depression
- Mood swings

**People living with HPP may experience a wide range of symptoms—from muscles and bones to overall physical and mental well-being.**

**Because symptoms of HPP can show up differently for each person, some may be harder to communicate or recognize. Explore the following pages to reflect on your own experiences.**

Muscle Weakness

|                                                                                                                                                                                           | No                       | Rarely                   | Sometimes                | Almost always            |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Have you had to change how you approach everyday tasks or avoid certain activities because your muscles feel weak or tire quickly?                                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| On some days, does your muscle strength feel sufficient for daily activities, while on other days even light activities feel harder than usual?                                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel weak or tired muscles make you struggle with common tasks like climbing stairs, carrying groceries, or caring for yourself and family more than it seems for others you know? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Does muscle weakness limit how far or how long you can walk or stay active?                                                                                                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Does it feel like you struggle or take longer than most people you know to stand from a sitting position?                                                                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel weak or slow to get moving in the morning, and does it take time for your body to feel stronger or steadier?                                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| When you were younger, did it feel like you had a hard time keeping up with others your age because you would feel weak or tire quickly?                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Helpful to share with your doctor

Muscle weakness with HPP can vary day to day—manageable on some days and harder on others. **Now, take a moment to think about how strongly muscle weakness impacts your daily life.**

|                            |                                               |                                             |                                                                  |                                                           |
|----------------------------|-----------------------------------------------|---------------------------------------------|------------------------------------------------------------------|-----------------------------------------------------------|
| On your <b>best</b> days:  | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |
| On your <b>worst</b> days: | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |

If muscle weakness has impacted your life, describe specific ways and how often it occurs:



“

When the boys were about 2 months old, we started to notice the weight difference. Josiah was a little bit smaller than Elijah.”

**Elizabeth**

CAREGIVER OF SON LIVING WITH HPP

**For many people, muscle weakness can show up as muscles that tire quickly, lose power, or make everyday moments harder than they should be. This may happen even while doing things that don't require more effort.**



“

**If you need to slow down, or there is an activity you don't want to do because you're afraid you're going to get hurt, you need to be able to tell your family and friends that.”**

**Brian**

LIVING WITH HPP

**Pain in HPP is not always strong or constant. It may also show up as stiffness, tenderness, aching, discomfort, or small moments of pressure. Everyone experiences pain differently.**

# Pain (muscles, joints, or bones)

|                                                                                                                        | No                       | Rarely                   | Sometimes                | Almost always            |
|------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Have you had to change how you move or adjust your approach to everyday tasks because of pain?                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you experience ongoing or recurring joint pain, stiffness, or swelling that affects your daily activities?          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you struggle with common tasks like climbing stairs, carrying groceries, or caring for yourself and family members? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Does pain limit how far/long you can walk or stay active?                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Does it feel like you struggle or take longer than most people you know to stand from a sitting position?              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you avoid certain activities because they feel too physically difficult, or you worry you might get hurt?           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have you missed events or activities because pain made it difficult to participate?                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Does pain make it hard for you to fall asleep or stay asleep?                                                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have you had sharp side or back pain that was linked to kidney issues?                                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## Helpful to share with your doctor

Pain in HPP can be unpredictable. It may feel manageable on some days and much harder on others. **Now, take a moment to think about how strongly pain impacts your daily life:**

|                            |                                               |                                             |                                                                  |                                                           |
|----------------------------|-----------------------------------------------|---------------------------------------------|------------------------------------------------------------------|-----------------------------------------------------------|
| On your <b>best</b> days:  | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |
| On your <b>worst</b> days: | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |

If pain has impacted your life, describe specific ways and how often it occurs:

# Fatigue

|                                                                                                                              | No                       | Rarely                   | Sometimes                | Almost always            |
|------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Do you feel low energy during the day or feel you need more breaks than others you know to get through work or school?       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do everyday tasks feel harder to manage when your energy is low?                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you avoid certain activities because they feel like they take more energy out of you than others you know?                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you plan your days carefully because being active one day can leave you more exhausted than it seems like it should?      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you struggle to keep up with your kids, family, friends, or work because it feels like you tire more easily than they do? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel tired even after a full night of sleep?                                                                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## Helpful to share with your doctor

Fatigue with HPP can vary day to day. Some days feel manageable, while others feel more exhausting. **Now, take a moment to think about how strongly fatigue impacts your daily life:**

|                            |                                               |                                             |                                                                  |                                                           |
|----------------------------|-----------------------------------------------|---------------------------------------------|------------------------------------------------------------------|-----------------------------------------------------------|
| On your <b>best</b> days:  | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |
| On your <b>worst</b> days: | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |

If fatigue has impacted your life, describe specific ways and how often it occurs:



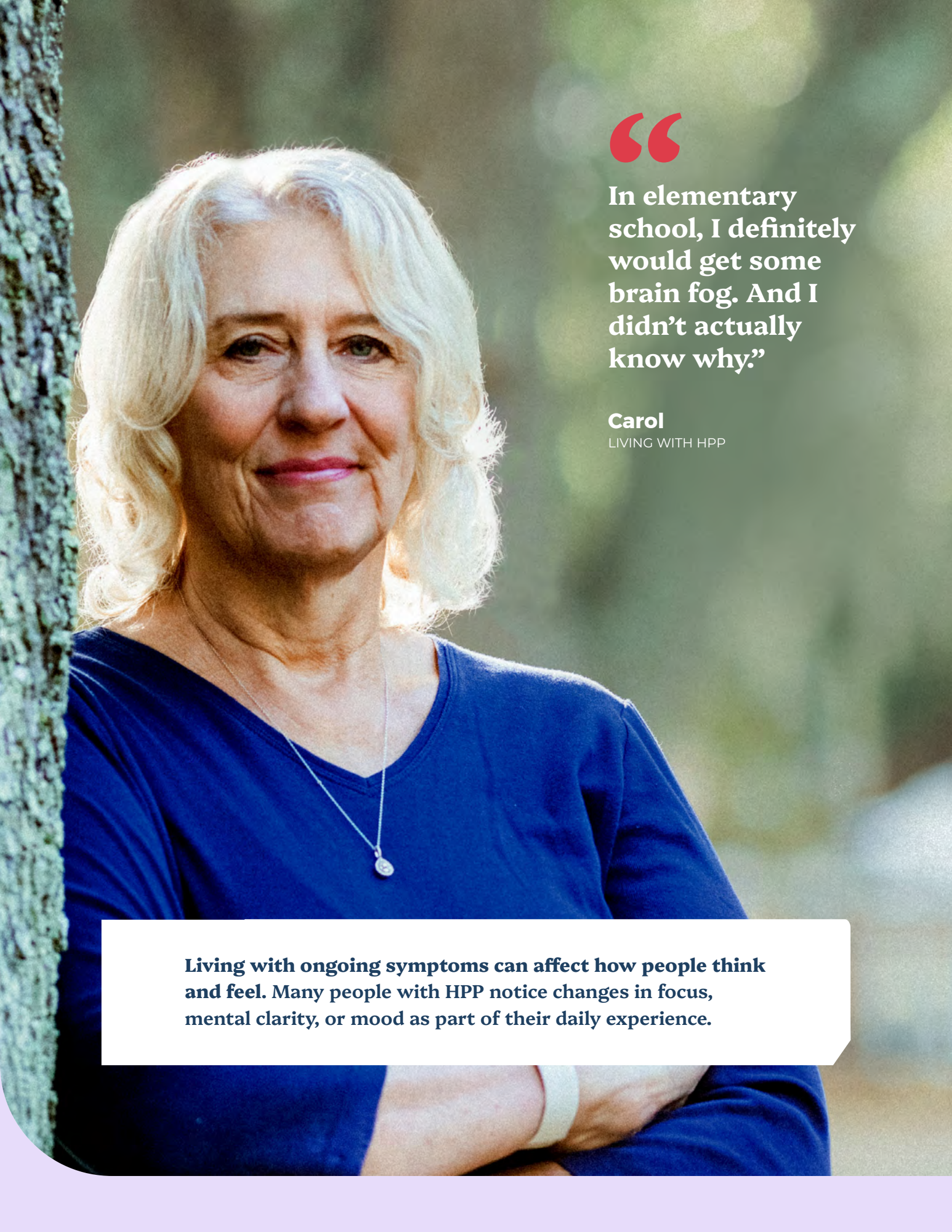
“

As an adult, the first thing I started noticing was the unusual fatigue and the headaches that put me in bed. The fatigue was awful. I could barely get through the workday.”

**Cindy**

LIVING WITH HPP

**Fatigue can be part of HPP.** It can be difficult to explain how HPP fatigue is different from “normal tiredness,” but it can show up as low energy, trouble sleeping, or feeling tired even after rest. Many people also find that they become more tired from physical activity than others.



“

**In elementary school, I definitely would get some brain fog. And I didn't actually know why.”**

**Carol**

LIVING WITH HPP

**Living with ongoing symptoms can affect how people think and feel. Many people with HPP notice changes in focus, mental clarity, or mood as part of their daily experience.**

# Mind & Mood

Not all mind and mood symptoms may be caused by HPP, but it is important to talk to your doctor about them.

|                                                                                    | No                       | Rarely                   | Sometimes                | Almost always            |
|------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Do you experience brain fog that makes it harder to think clearly?                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you have trouble focusing or keeping up with conversations, meetings, or tasks? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you experience headaches that impact your daily routines?                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel anxious, on edge, or overwhelmed?                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel depressed or struggle to enjoy things you normally like?               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you notice mood swings that affect how you move through the day?                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## Helpful to share with your doctor

Mind and mood symptoms can vary from day to day. Some days you may feel clear and steady, while other days focusing may feel harder. **Now, take a moment to think about how strongly mind and mood symptoms impact your daily life:**

|                            |                                               |                                             |                                                                  |                                                           |
|----------------------------|-----------------------------------------------|---------------------------------------------|------------------------------------------------------------------|-----------------------------------------------------------|
| On your <b>best</b> days:  | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |
| On your <b>worst</b> days: | I don't notice it<br><input type="checkbox"/> | It's manageable<br><input type="checkbox"/> | It's not easy, but I push through it<br><input type="checkbox"/> | It's very difficult to manage<br><input type="checkbox"/> |

**If issues with your mind or mood have impacted your life, describe specific instances and how often they occur:**

# Signs in *your family*

## **HPP can be passed down through families.**

Noticing patterns among biological relatives may help your doctor understand your overall health picture. This is not meant to diagnose your family members, just to give your doctor helpful context.

### **HPP may impact different family members in different ways**

- HPP symptoms can range from physical to cognitive or emotional, and from visible to less noticeable, even among people in the same family
- HPP can be progressive, so it's important to share your experience with your doctor
- HPP is a lifelong condition that is passed down through families
- A relative may have HPP and not know it or recognize any of the symptoms
- A relative may have been diagnosed with a condition that can resemble HPP, like fibromyalgia, osteoporosis, arthritis, gout, or pseudogout

**Think about your biological family.** Have you seen any of these symptoms in family members related by blood?

*Check anything that applies:*

|                                                                     |                          |
|---------------------------------------------------------------------|--------------------------|
| <b>Someone was diagnosed with HPP</b>                               | <input type="checkbox"/> |
| <b>Chronic pain</b>                                                 | <input type="checkbox"/> |
| <b>Frequent physical weakness</b>                                   | <input type="checkbox"/> |
| <b>Unusual tiredness or feeling easily worn out</b>                 | <input type="checkbox"/> |
| <b>Frequent bone breaks or fractures</b>                            | <input type="checkbox"/> |
| <b>Bone or joint injuries that have been slow to heal</b>           | <input type="checkbox"/> |
| <b>Kidney stones or calcium buildup in the kidneys</b>              | <input type="checkbox"/> |
| <b>Avoiding physical activity or slowing down during activities</b> | <input type="checkbox"/> |
| <b>Frequent dental issues or cavities</b>                           | <input type="checkbox"/> |

***You've taken an important step***  
by reflecting on these experiences

**Next, use what you've noticed to prepare a quick summary to help guide a conversation with your doctor.**

# Your *health* summary

By now, you've done some important reflection on your health. Use this page to summarize the key points to prepare for a focused, productive conversation with your doctor.

## What symptoms are the most prominent?

*List the symptoms that feel most noticeable, frequent, or disruptive.*

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## How do these symptoms affect daily life?

*Briefly describe how each symptom impacts everyday activities (like fatigue affecting work or social plans, pain limiting movement, or difficulty focusing at work).*

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## Are there any patterns or changes you've noticed?

*Use this space to note anything that stands out, including symptoms that have become more frequent, harder to manage, or new symptoms that have appeared over time.*

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## What else feels important to discuss with your doctor?

*Use this space to note any questions, concerns, or topics you would like help understanding or addressing next.*

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**Sharing key symptoms, impacts, and patterns you've noticed can help your doctor determine next steps, so bring this guide to your next visit.**

**Click here or scan to learn  
more about living with HPP.**



<https://qr.short.az/r/cvneuacyl6yqfb>

**Click here or scan for more  
information about how to have  
the best doctor's visit possible.**



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