

A Digital Toolkit for
Primary Hyperoxaluria Type 1 (PH1) Caregivers

Practicing Self-Care as a Caregiver

1. Remember to take time for yourself. It's important to take breaks from caregiving to recharge yourself when you can. Maybe you make a date to meet a friend for lunch. Or perhaps you relax with a book or take a long bath. Whatever you do, remember that taking care of your mental and physical health first makes you better prepared to help others.

2. Be gentle with yourself. You may be overwhelmed by the daily challenges of balancing your child's needs with your other responsibilities at home and work. Or maybe you're fearful because PH1 can often be unpredictable. Remember to be patient with yourself as you navigate the ups and downs of your child's PH1 journey.

3. Don't be afraid to ask for help. You don't have to go through this alone — it's OK to seek and accept the support of others. Whether you reach out to friends and family, your health care team or support group, remember there are people who support you.

The Mighty is a safe, supportive community for people facing health challenges as well as the people who care for them. Connect with others who understand what you're going through on themighty.com or by downloading The Mighty app.



Don't forget to drink your water!

Instructions: Fill in a droplet for every cup of water you drink.

Monday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tuesday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wednesday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thursday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Saturday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sunday:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Explaining PH1 to Others

What is Primary Hyperoxaluria Type 1 (PH1)?

Instructions: Fill in this worksheet with the information your child's school teachers and nurses need to better support and understand their medical needs. You can then share a copy with them to start a conversation about your child's PH1.

What is PH1? Primary hyperoxaluria type 1, or PH1, is a rare and serious genetic disease that primarily affects the kidneys. With PH1, your body produces too much oxalate, a waste product that your kidneys typically remove from your body through urine. When you have too much oxalate, it can combine with calcium to form kidney stones and cause other serious kidney damage.

My Child's Strengths:

Share some of your child's strengths around managing their condition.

My Child's Limitations:

Write down any limitations or challenges your child may face at school.

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Accommodations:

Include any special accommodations your child may need for academic or physical education, as well as any dietary accommodations.

Medications:

Write down any medicines that your child will need to take during the school day.

Symptoms To Look Out For:

Share what to do if your child experiences certain symptoms during the school day.
