Voices 4 Youth in Pain

Advocating for Your Child with Chronic Pain – When You Feel Dismissed or Racialized in Health Care Settings

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🌟 Purpose of This Guide

Navigating health care can be especially challenging when your child's pain is not taken seriously — and even more so if you feel your family is being dismissed due to race, ethnicity, or cultural background. This handout offers practical tools and strategies to help you advocate for your child and ensure they receive compassionate, appropriate care.

🌎 1. You Are Not Alone

Racial and ethnic disparities in pain treatment are real and documented. You are not imagining it. Many families share similar experiences.

- **It is not a failure on your part**.
- You know your child best. If something doesn't feel right or your concerns are not being heard, it's okay to speak up.
- Acknowledge this inequality with your child. Help your child advocate for themselves in health care settings.

📝 2. Prepare For Your Child's Appointment

- **Write a list of key concerns and questions.** Write down what your child is experiencing: pain levels, triggers, patterns, and impacts on daily life. **Prepare a list of questions.**
- **Bring pictures, videos, or a pain journal to help validate your concerns.**
- **Practice what you want to say.** Example:
  "We've noticed ongoing pain that's affecting school and sleep. We need help understanding what's going on and how to manage it."
- **Know your rights.** Every patient deserves to be treated with dignity, respect, and compassion — regardless of race or background.
    - **Hospitals may have a "Patient Bill of Rights" that you can reference.** Familiarize yourself with that information. You may be able to find this document on the clinic's website, posted in the clinic, or you may have to ask for a physical copy.

- **Bring Support**. Bring a trusted friend or family member for emotional support.
    - Take notes during the appointment or ask the provider if you can record the conversation.

🗣️ 3. Clear and Effective Communication with Providers

If you feel dismissed, it's okay to redirect the conversation.

- "I hear what you're saying, but we are not feeling heard. Can we slow down and revisit what we shared?"
- "I understand that other factors can contribute to pain, but we would like to investigate this further. Is there a specialist you can refer us to?"
- "I'm concerned that bias may be influencing the care we're receiving. We need our child's pain taken seriously."

If you continue to feel concerned about being dismissed despite attempts to redirect the conversation, encourage documentation of your experience in the medical record.

- "Please document in my child's medical record that you are not looking into this."

Please note that you are legally required to have an interpreter present if you would like or need one present. If you prefer for an interpreter to be in person at your child's appointment, you can call ahead to confirm if an interpreter will be available to be at your appointment. Otherwise, a virtual interpreter is always available.

🩹 4. Monitor Your Child's Treatments

Discuss Potential Treatments, Medications, and Side Effects

- Ask questions about why a certain treatment or medication is being prescribed.
- Request resources and documentation about the suggested treatments to make an informed decision. If there are multiple options for treatment, you do not always have to make a decision right away about which treatment plan you and your child would like follow.
- If your child is being prescribed a medication, ask about potential side effects.
    - "I need more information about the treatments/medications that you are suggesting. Is there more information you can provide to us before we make a decision?"

- "This treatment/medication may not be the best option for my child. Can we explore other options?"
- "Does this medication require a prior authorization and how will your office communicate the completion of this?"

Track Your Child's Treatment and Medication Experience

When a treatment plan decision is made, follow the healthcare provider's instructions, and keep track of whether or not the treatment or medication is helping. Make note of what is working and what is not working. Note any side effects to medication that your child is experiencing.

- This can be a **continuation of your child's pain journal.**

Advocate When Treatment Changes are Needed

Monitoring your child's treatments and medications can help indicate when a change is needed.

- If your child's pain is not improving, consider checking-in with your child's healthcare provider to discuss other options.
  - "Unfortunately, this treatment is not improving my child's pain symptoms. Can we discuss other options for treatment?"
- If your child is experiencing side effects to a medication, reach out to your child's healthcare provider to express your concern.
  - "My child is experiencing the following symptoms from this medication. Can we discuss how we can help alleviate these side effects?"

💬 4. Educate Yourself and Healthcare Providers

Your pediatrician or health care provider may not know that chronic pain is a real condition that affects a lot of children and adolescents.

- Provide resources to your healthcare provider to help them self-educate about chronic pain. See a few resources below:
  - United States Association for the Study of Pain
  - US Pain Foundation
  - Meg Foundation
- Pediatric pain specialists do exist, and ask for a referral to those providers.
- You and your child are the experts in your child's symptoms.
- Educating yourself about pediatric chronic pain can help inform your and your child's decisions about medical care.

📣 5. Advocate with Confidence

- Ask for a referral to a **pain specialist**, **mental health provider**, or **pediatrician experienced with chronic pain**.
- Know that you have the right to:
    - **Ask for a second opinion.**
    - **Request a different provider.**
    - **Request a copy of your medical records.**
    - **Consider sharing your experience with the clinic or hospital's patient advocate.** Keeping records of your appointments and notes from your visits will be helpful.

🤝 6. Build a Support Network

Advocating can be difficult and stressful. Build relationships with others who are going through something similar.

Support Resources:

- Pediatric Pain Warrior Program: A US Pain Foundation Program offering support and resources for children with chronic pain and their families. Resources include retreats, workshops, events, etc.
- The Comfortability: A program designed to provide kids and parents/caregivers tools to manage chronic pain symptoms. Resources include workshops as well as peer support for teens and parents/caregivers.

💔 Final Thoughts

You are not alone. Many parents of color have had to fight harder to be heard in health care. You are a powerful advocate for your child — your voice matters, and your child's pain deserves real care and respect.