

TAKING CHARGE OF YOUR HEALTH CARE

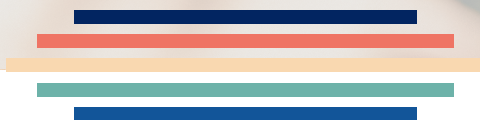


A YOUNG ADULT'S GUIDE TO LIVING WITH CHRONIC PAIN





From Pediatric to Adult Pain Care: What's Changing and Why It Matters



The Big Picture

Moving from pediatric to adult health care is a big step—especially when you live with chronic pain. You may be starting college or a job, or gaining independence while living at home. You're learning to advocate for yourself, choose providers, manage appointments, and make treatment decisions. It's a lot, but you're not alone. This guide helps you build confidence, own your care, and find hope and purpose, even with pain.





What's Different About Adult Care?

PEDIATRIC CARE

Mostly led by parents or guardians

Focus on growth & development

Smaller, more connected care teams

Same provider for many years

ADULT CARE

You lead your own care

Focus on independence & managing your health long-term

Larger, less-coordinated network of providers

You may see more specialists and change doctors more often

Tip: Feeling nervous is normal. Transition is a process—take it step by step.

Your Health, Your Responsibility

In most states, at age 18, you're legally in charge of your health care:

- You make your own decisions.
- Providers and insurance companies can't talk to your parents or guardians without your permission.
- You'll likely switch from pediatricians who helped coordinate your care to adult providers expecting more independence.

It's a big change, but with the right tools, you've got this.



Preparing for a Successful Transition

Get Organized

Ask your providers for a portable medical summary with:

- Diagnoses
- Treatments
- Medications and allergies
- Imaging and test results
- Emergency plan

Create a medical binder or digital file with:

- Insurance info
- Doctor contacts
- Emergency contacts
- Symptom and medication trackers

Use clear, specific words to describe your pain.

Try words like: *throbbing, stabbing, dull, burning, aching*, or anything else that fits how it feels to you.



Example: "I get a sharp, stabbing pain in my lower back when I stand too long."

Understand & Describe Your Pain

Clear communication helps providers take you seriously. Practice describing:

- Where your pain is, and when it hurts
- What helps or worsens your pain
- Impact on daily life (sleep, school, activities, relationships)
- Patterns or triggers

Note: Some providers prefer that you bring a printed copy of any information you'd like to share with them.

Pro tip: Use "I" statements to advocate for yourself.

"I've noticed my pain gets worse when I sit for a while."

"I'm a little nervous about trying this medication—can we talk about the side effects?"

BUILD A CARE TEAM THAT GETS YOU

Start preparing for the transition six months before leaving pediatric care. Ask for referrals to:

- Adult primary care doctors
- Pain specialists
- Mental health providers
- Physical or occupational therapists
- Adult specialists for any conditions currently managed by pediatric providers

Call new referrals to ask:

- Experience with young adults with chronic pain?
- Types of insurance accepted?
- Taking new patients?
- Waitlist time?

TAKE CONTROL OF DAY-TO-DAY CARE

Know your new responsibilities:

- Schedule and track appointments (use calendars, apps, reminders).
- Know medication doses, side effects, refill schedules, and pharmacy location.
- Understand insurance basics: cards, prior authorizations, deductibles, copays, explanations of benefits (EOBs).
- Know when and how to get referrals.

Common Challenges & Tips

CHALLENGE

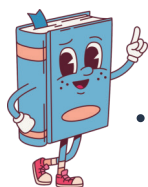
Insurance confusion
Nervous to discuss symptoms
Forgetting details
Feeling dismissed
Going alone to appointments

TIP

Use Healthcare.gov or call insurer
Practice what to say; write a script
Use apps, notebooks, trackers
Bring records or a support person
Ask someone trusted to join virtually or in person



Navigating Life With Pain as a Young Adult



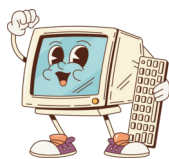
IN COLLEGE?

- Register with campus health services early.
- Connect with disability services for accommodations (extra test time, attendance flexibility, priority scheduling, housing modifications). You have the right to request accommodations under the Americans with Disabilities Act (ADA).
- Ask about mental health support on campus.



IN A NEW CITY?

- Find providers in your insurance network and schedule specialist appointments ASAP.
- Find a pharmacy near you, and share it with new providers.
- Look into telehealth for specialist visits.
- Explore local or online support groups.



AT WORK?

- Know your rights under the Americans with Disabilities Act (ADA) to request accommodations (flexible schedules, ergonomic tools, breaks).
- If switching to a new employer-sponsored health insurance plan, communicate as needed with the insurer or HR to understand your coverage and how your care is affected.



LIVING AT HOME?

- Take the lead on your care. Schedule appointments, speak directly with providers, organize your medical records and meds.
- Set boundaries around privacy and medical decisions.
- Plan for future independence by researching adult providers now and, depending on your age, transition to those providers even while living at home.
- Communicate how pain affects your daily life and what support is helpful.



Build a Personal Pain Management Plan



A well-rounded approach to managing chronic pain often includes a mix of tools and strategies tailored to your unique needs. Consider incorporating:

- **Medications:** Over-the-counter (OTC) pain relievers, prescription medications, supplements or nutraceuticals (e.g., magnesium, turmeric), and CBD or medical cannabis.
- **Restorative or Integrative Therapies:** Physical therapy, occupational therapy, acupuncture, massage, and other integrative approaches.
- **Behavioral Approaches:** Therapies like cognitive behavioral therapy (CBT) or acceptance and commitment therapy (ACT), psychiatric treatment, and mindfulness-based practices.
- **Lifestyle Adjustments:** Sleep hygiene, activity pacing, balanced nutrition, gentle movement (such as yoga or stretching), and stress management techniques.
- **Assistive Devices:** Braces, orthotics, ergonomic tools, mobility aids (e.g., canes, walkers, wheelchairs), and hot/cold therapy devices. (Consult with your health care providers first!)
- **Self-Management:** Track your symptoms, set realistic goals, and plan activities in accordance with your pain and needs.
- **Support Systems:** Engage with support groups (online or in-person) and build a team that supports your journey.

REMEMBER: MENTAL HEALTH MATTERS

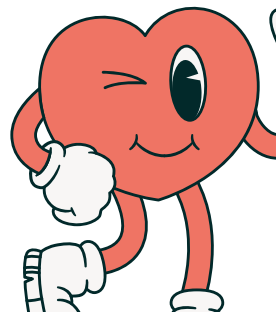
Pain doesn't just affect your body—it impacts your mood, sleep, relationships, and overall quality of life. It's OK to seek support:

- Connect with a therapist who understands chronic pain or offers trauma-informed care.
- Explore coping strategies, mindfulness, and other mental health tools to help manage the emotional toll of pain.
- Join a free U.S. Pain Foundation peer support group to connect in a judgment-free zone with others who get it (visit painconnection.org).

ADVOCATING FOR YOURSELF

Self-advocacy is a skill that improves with practice.

- Prepare a short summary of your condition for new providers, professors, employers, or anyone else you may want to share it with.
- Speak up about your needs:
 - “Can we meet somewhere with comfortable seating?”
 - “I need to stretch every 30 minutes to manage my symptoms.”



A decorative graphic consisting of a 4x8 grid of squares. The squares alternate between a light beige color and a reddish-brown color in a checkerboard pattern, starting with a light beige square in the top-left corner.



- Call your provider or go to urgent care or the emergency room if your pain spikes or becomes intolerable.
- Share your diagnosis, meds, and history, and bring another person to help advocate for you if needed.

- Call or text **988** for the Suicide & Crisis Lifeline (24/7) if you need immediate support or help.
- Reach out to a therapist or counselor for ongoing mental health support and coping strategies.

IT'S BRAVE TO ASK FOR HELP.
YOU MATTER.
YOUR PAIN IS REAL.

Thriving with Pain



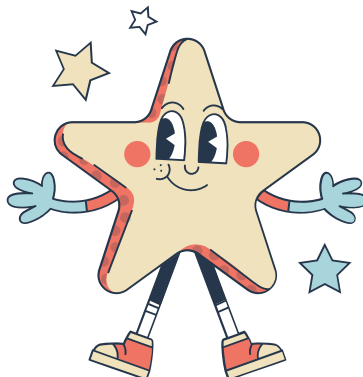
Chronic pain may be part of your story, but it doesn't define you. You are much more than your pain—and now is the time to work on building the kind of life you're excited to live.

TIPS FOR LIVING WELL

- Pace yourself—balance rest and activity.
- Set realistic goals—focus on progress over perfection.
- Find people who listen to and believe you.
- Own your identity—you're more than your diagnosis.
- Advocate—your voice matters in your care and beyond.

SELF-CHECKLIST: ARE YOU READY?

- I understand my diagnosis, the medications or supplements I take, and my treatment plan.
- I can explain my symptoms and how pain affects my daily life.
- I know how to schedule doctor's appointments and request medication refills.
- I have at least one person I trust and can talk to about my health.
- I make time for self-care (including rest, movement, balanced eating, and mental health).
- I've created a pain management toolbox with strategies that help me feel better.
- I have a plan for tough days—including who to call, what helps, and how to stay safe.





Final Thoughts: You've Got This

You're juggling big changes, new responsibilities, and managing pain. That takes real strength and courage. Remember, you're not alone. There's a whole community that understands what you're going through—and we're here to support you however you need.

This educational booklet was created with support from Vertex Pharmaceuticals. The U.S. Pain Foundation independently developed the content without sponsor review. The information provided is for educational purposes only and is not intended as professional medical advice, diagnosis, or treatment. The U.S. Pain Foundation does not endorse any specific treatments or approaches. For personalized medical advice or concerns, please consult your health care professional.



U.S. PAIN FOUNDATION



The U.S. Pain Foundation is a national nonprofit organization dedicated to supporting people who live with chronic illnesses or serious injuries that cause pain—along with their families, caregivers, and health care providers.

Our mission is to empower, educate, connect, and advocate so that no one has to face pain alone. And everything we offer is free for patients and their communities.

Learn more or get involved: uspainfoundation.org