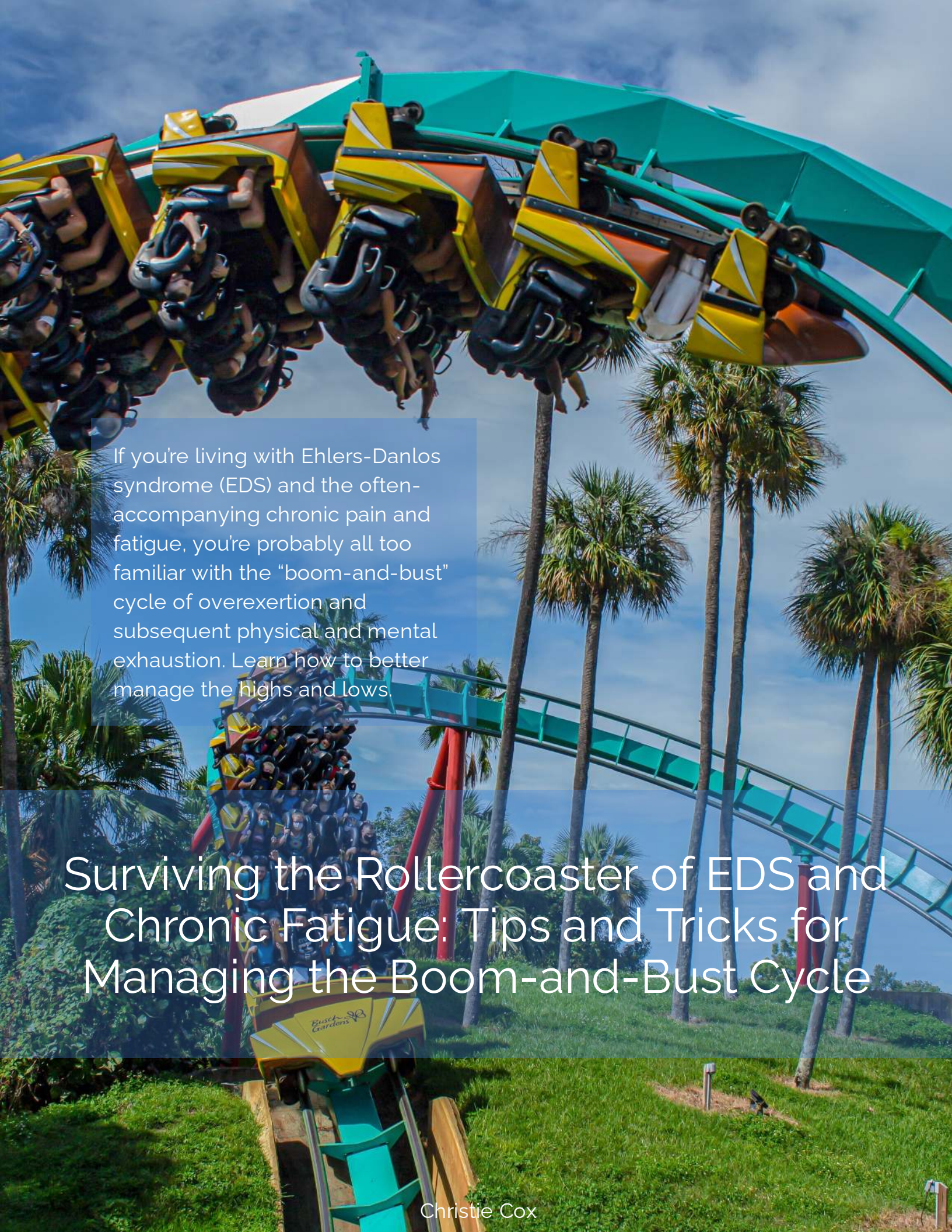


A vibrant roller coaster scene featuring yellow and orange cars with teal tracks. The cars are suspended from a large teal structure, and the track curves upwards. Tall palm trees are visible in the background under a clear blue sky. The roller coaster cars are filled with people, and the overall atmosphere is one of excitement and adventure.

If you're living with Ehlers-Danlos syndrome (EDS) and the often-accompanying chronic pain and fatigue, you're probably all too familiar with the "boom-and-bust" cycle of overexertion and subsequent physical and mental exhaustion. Learn how to better manage the highs and lows.

Surviving the Rollercoaster of EDS and Chronic Fatigue: Tips and Tricks for Managing the Boom-and-Bust Cycle

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When you're doing okay, it can feel like a high, a return to normalcy even. It is hard to figure out the level of functioning that is going to allow you to get things done without making your symptoms send you into another flare. It's a tiny little fine line between doing too much and too little. You know, the one, when good days come around, meaning that your pain is low, you have energy, and you are ready to function; it can feel like you're at an amusement park as a kid again! Woohoo! It's so easy to 'make the most' of this good day, trying to squeeze everything in that you haven't been able to do for a while. You try to do as much as you can during those "ups," but you inadvertently do too much, making your symptoms flare and leaving you worse than you've been for a while. This is the boom-and-bust cycle, and the rollercoaster begins.

If you're living with Ehlers-Danlos syndrome (EDS) and the often-accompanying chronic pain and fatigue, you're probably all too familiar with the "boom-and-bust" cycle of overexertion and subsequent physical and mental exhaustion. We've all been there – you have a burst of energy and decide to tackle that long-neglected to-do list, only to crash and burn (literally) a few hours later. It's super frustrating! Frankly, it blows my mind and my mood why this happens. It's so overwhelming not to be able to do simple things and to finally really learn – where is the balance between rest and everyday activity?

We often feel like we're on a wild rollercoaster ride, never knowing when the next dip or turn is around the corner (ready to make us nauseous). It seems like there's always something going on! This aspect may be the common bond we all struggle with despite our various diagnoses, capabilities, and differences. Our volunteer team would love to write an article to tell you exactly how to manage it, but it's a struggle every day for us too. We do not have an easy answer for you. If there was only an app or magic formula to help us figure out pacing before it's too late! But don't despair – we've curated a few simple strategies and tactics to help you manage the boom-and-bust cycle and a few steps to practice pacing to avoid the super highs and lows and curves around the bend.

Why is this important, you ask? If this cycle continues, your good days will become less frequent and much shorter, and your flares will become more regular, much longer, and more severe. Even though you may think you're making the most of the time you have with a good "brain and body doesn't hurt day," but you're actually feeding into this vicious cycle and making your chronic pain worse. Try to have an open mind as you read the suggestions below. And who knows, maybe you'll even be able to find a way to see the highs and lows in a new way to potentially enjoy the crazy ride! As with anything, it takes a great deal of practice and patience.

What is pacing, and how can it help?

So you're supposed to do some exercise or household chores and not avoid activity, but you're also supposed not to do too much? The solution to this dilemma is pacing. The term 'pacing yourself' means that you take things a step at a time, ensuring you get adequate rest and won't push past your limits. Here are a few basic tips on ways to do that with EDS.

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1. **Be realistic with your goals:** First things first, it's important to set realistic goals for yourself. No, you probably can't clean the entire house in one day (although if you can, kudos to you! You're basically a superhero.) Instead, break larger goals into smaller, achievable tasks. For example, instead of trying to clean the entire house in one day, consider cleaning one room per day or per week. This will help you avoid overexertion and reduce the risk of [post-exertional malaise](#) (PEM). As the coaster rounds the bend for the last loop-de-loop, brace yourself for the full stop ahead.
2. **Practice good self-care:** Sounds too easy but taking care of yourself is essential for managing EDS, other chronic illnesses, and ongoing fatigue. Oh, if it were that easy! But start with the basics for your body, such as prioritizing rest/sleep, eating a healthy diet that won't inflame your system, and making time to engage in activities that bring relaxation and joy. Yes, this means finding the time to do something that makes your heart sing. Also, try to set aside time for relaxation techniques such as deep breathing, progressive muscle relaxation, or mindfulness meditation. And don't forget to treat yourself every once in a while – it's okay to indulge in that tasty yummy or tune out to your favorite TV show binge session. Just don't go overboard – balance is key!
3. **Use pacing techniques:** Pacing techniques, such as the "[spoon theory](#)," can be incredibly helpful for managing energy levels and preventing overexertion. This involves breaking activities into smaller chunks and taking breaks as needed to allow for rest and recovery. Sounds easy enough, right? UGH-NO!! You kinda need to plan to do this successfully to know which spoons you want to save for what matters most. For example, if you're planning on running a few necessary errands or shopping, consider breaking it up into smaller chunks, such as going to the grocery store one day and doing another errand the next day but not back to back. Or, if you're planning on working on a project, take breaks (and set an alarm if you have to) every hour to remind yourself to stop and rest and recharge. Think of it like a marathon, not a sprint – if you spend too much energy at the beginning, you won't last the whole 26.2 miles, and you won't be able to finish. The same principle applies to everyday activities. [Read more tips on pacing in our [The Six Steps of Proper Pacing](#) article.]
4. **Seek out support:** It can be very helpful to connect with others who have similar conditions, whether through in-person support groups or online communities. Use the search feature on www.chronicpainpartners.com to locate an EDS support group near you. Sharing experiences and advice with others can provide valuable support and a sense of community – plus, you'll get that much-needed validation that you are not crazy dealing with all of this! It may also be helpful to seek out the support of a mental health professional, such as a therapist or counselor, to help manage feelings of loneliness, frustration, and other emotions such as grief and loss. We all had expectations that seem halted due to our illness. It's critical to connect with others, so you know in your heart that you're not alone in this journey and there are people who can help you along the way if only to listen while you vent.

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5. **Work with your healthcare team:** It's important to work with a healthcare team that is knowledgeable about your conditions and can help you develop a personalized treatment plan. Contact local support groups to locate knowledgeable providers, as this is key. This may include a primary care physician, specialist, physical therapist, and mental health professional. Try to reframe a doctor visit like this... don't be afraid to advocate for yourself and ask for the support and resources you need. Your healthcare team is there to help you, even when they don't understand, so make sure to take advantage of the expertise and guidance they can provide. Remember, you are paying them for a service, and you are the customer despite how their gaslighting might leave you feeling. Be respectful but prepare in advance your priorities and get what you came for. We all deserve it!
6. **Keep a symptom diary:** Maintaining a symptom diary can be incredibly helpful for tracking your symptoms and identifying patterns that may be contributing to the boom-and-bust cycle, especially with persistent brain fog and forgetfulness. Writing it down in a planner or digital device and including information such as the intensity and duration of symptoms, triggers that may worsen symptoms, and any medications or treatments that may be helpful when you're in a pain flare. A symptom diary can also be a useful tool for communicating with your healthcare team. Doctors love data, so use it to tell your story and bring it to your next appointment, as it provides a clear record of your symptoms and how you have been managing them. They can help you identify patterns you may not see or cannot recall in the swirl of multi-systemic issues. Consider using a journal, an app, or an online tool to track your symptoms – whatever works best for you. If the last few years taught us anything, it's that those without a plan will struggle to survive – let alone thrive – when the unexpected happens.

Managing EDS and chronic fatigue and pain can be really challenging, but with the right strategies and support, you can find ways to live better with these conditions. It's important to remember that everyone is different, and what works for one person may not work for another. It may take some trial and error to find the strategies and approaches that are most helpful for managing the boom-and-bust cycle. It will take time to learn and practice pacing successfully. But don't give up – you got this! And who knows, maybe you'll even discover some new tricks and techniques along the way. If so, share in the comments. Just remember to take it one day at a time and give yourself some grace – you're doing the best you can, and that's all anyone can ask for. Chronic illness may be a rollercoaster, but we can learn to enjoy the ride by finding balance. After all, as long as we're not on a rollercoaster with a faulty safety bar, we can handle anything life throws our way because we are warriors!

More reading: ["The Spoon Theory" by Christine Miserandino](#) is a popular essay that provides a helpful metaphor for understanding the concept of pacing and managing energy levels. If you haven't read it already – it's a must!