

Setting Goals and Managing Expectations for Chronic Illness

These guidelines are intended to help patients reach their goals without disappointing expectations.

By Surayyah Morris



CHRONIC ILLNESS IS like tug-of-war, walking a tightrope blindfolded and treading water in the middle of the Atlantic during hurricane season. Every move you make may have a different result each time. Consistency is a luxury. Your body and mind are fragile, and you want to keep them in the best condition possible. The goal is to prevent a vicious cycle of taking two steps forward and 10 steps back. Sometimes, to your surprise, you'll take two steps forward and then sprint to the finish line unscathed.

Setting goals is a great way to manage daily activities that affect physical and mental health and life in general. When you have a chronic illness, having defined goals gives you something to work toward while allowing you to reflect on what does and doesn't work for managing your condition. Following is some goal-setting guidance.

Goals Should Be SMART

A starting point for setting goals is to use the acronym SMART, which stands for specific, measurable, attainable, realistic and time-based.

Specific: If you can answer the five W's (who, what, when, where, why), you're off to a great start. Be as detailed as possible when outlining the plan you want to accomplish.

Measurable: This is where the "H" comes in. How much? How little? How do you know when you've reached the desired outcome? You'll want a way to quantify your progress.

Attainable: In what ways will you be able to work toward this goal? Are there any tools or people to help you?

Realistic: Anything is possible, but is your goal really something you can accomplish with the resources available to you?

Time-based: What is a reasonable length of time to achieve your goal? Organize short-term and long-term goals into days, weeks and months if necessary.

Goals Should Be Intentional

Be sure to consider how you will accomplish your goals. For instance, if you want to show your doctor you are serious about adjusting your treatment, present him or her with new research data. If you want to hang out with friends more often, reach out to them first. If you want to decrease the amount of exposure to infections, be proactive in maintaining a clean and safe environment. Ensure you start with small goals, and work your way to more challenging ones. Also, consider starting with only one goal, because having too many easily becomes overwhelming.

Tackling Expectations

After you've developed your SMART goals, it's time to manage your expectations. Setting expectations too high can lead to disappointment if the goals aren't reached. On the other hand, setting expectations too low creates a negative mindset with hopes that the outcome is better than expected, leading to further disappointment if the outcome is unfavorable. Sometimes, the fear of exhaustion, pain and sickness prevents us from doing anything at all. Yet, even with a chronic illness, something is better than nothing. In either instance, it is important to keep things in perspective.

The following are a few tips to encourage good results when setting goals and managing expectations.

Start low and go slow. Moderation is key. Take baby steps. There is nothing worse than getting overexcited to do something and, soon after beginning, you crash. Ease into the activity you are working toward. If you need to get moving, start walking in five-minute increments to build up stamina. If gravity isn't your friend, water aerobics is a wonderful alternative. Yoga is also an option that gives more energy than it takes. On good days, it is easy to feel on top of the world, leading to a day full of activity and tasks that aren't part of your normal routine. You have to do everything you can while you're feeling OK, right? Wrong! Be cautious with your physical activity so overexertion doesn't land you in unfavorable pain or injury in the days to follow.

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Take notes. Slowly increase the amount you do each day, and keep a mental note or journal of your activity and record the following: 1) activity, 2) length of time spent performing that activity and 3) how you feel before and after the activity. When you keep track of what you are doing and how you feel afterward, you can adjust accordingly for next time. If you feel better (or not worse) afterward and the next day, you

should continue at that pace and make small increases in activity each day or week until you feel like you've reached your goal. If you feel worse afterward, take a break from the activity until you recover, and then try again with a little less effort to avoid overexerting yourself. It also helps to jot down any specifics such as weather, medications taken or tools needed for relief during and after your activity. You may not even have to modify your activity. You can change your environment to make it more comfortable whether it's moving from outdoor to indoor, taking breaks or going hands-free by using wireless devices. If you know your limitations, respect them. When in doubt, rest. You will save energy and reduce the physical and emotional stress of the crash-and-burn by listening to what your body and mind are asking of you.

Beyond the physical. Other ways to manage expectations extend beyond physical activity. These same concepts apply with learning, parenting and personal life. Learning issues such as trouble concentrating can be improved with brain games. Set a goal to play 15 minutes of brain games daily. If parenting is becoming a bit much, see if grandparents can take the kids every other weekend. In your personal life, let go of the need to always follow routines and check off long to-do lists. Consistency is great, but not if it isn't keeping you mentally intact. Create and follow your routine the best you can, but if you are unable to follow it exactly, do not be discouraged. Find a way to adapt to the change that has

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occurred or move on to something else, expecting that you will still reach the desired outcome, just a little more slowly. Rest if you need it. For your mental and emotional health, take a day to dump your brain of all things stressful and focus on yourself. Do not clean, work or worry about anything that doesn't make you happy and relaxed. Mental health days are good for clarity and allow you to reset from the chaos of life.

What to Expect

Managing expectations with a chronic illness is as easy as riding that indoor roller coaster when it's really dark. You have no idea where you are in space, you don't know what drop or turn is coming next and you don't know how long you have until the end. It can be frustrating when things don't happen the way you expected, or better yet, the way they were supposed to. Expectations shift based on many factors that you typically don't have control over. Some may find it easier not to have any expectations at all. Not having expectations relieves you of disappointment (and may save you a conniption fit or two). But, realistically, it's kind of difficult not to presume, assume or suppose, especially when it comes to your health. That being said, here are a few times when having defined expectations is absolutely necessary:

1) *Setting goals.* You should always have at least this one expectation when setting goals: Expect to reach your goals and/or learn from the process. Be SMART and have perseverance.

2) *Doctor appointments.* You should attend with the expectation that you will leave with answers, whether or not they are the answers you want. Expect your doctor to refer you to someone who can help if he or she is unable to do so. Have a checklist of things you need to discuss at each appointment. Place the most important and time-sensitive requests at the top of the list to ensure those things are completed before moving on to anything else, even if it means not addressing the less-important items on your list.

3) *Expect tomorrow.* You should always expect to see the next day. No, tomorrow is not promised, but you need something to look forward to. Remain positive given your situation, knowing that you have something to live for. Expect that tomorrow will be another chance to accomplish your goals and make the progress you may not have made today. Tomorrow is a new opportunity to experience an amazing life despite your illness.

Making Health Decisions

Expect there to be a reaction for every action and a consequence for every decision (good or bad). Proactively manage your expectations in order to make responsible decisions when it comes to your health. Do you remember being taught to think before you speak? Along with watching your words, you need to watch your actions. Think before you do. Assess how your activity or action you plan to take

will affect how you feel at three very important times: 1) immediately, 2) at the end of the day and 3) the following day. What you do now *will* affect you later. The goal is to have a positive effect. For instance, let's say you need to try something new and rejuvenating to clear your mind. For some, an hour of yoga may provide this rejuvenating effect. For others, a successful hike to the mountaintop is just as revitalizing. It can be frustrating to not always be able to do what you want, and that is OK. Find something you enjoy and are able to do with success, and keep doing it to provide a sense of independence. Remember to slowly increase and track your progress.

This positive cause-and-effect mindset is also relevant when taking care of business. Don't expect the doctor's office to always follow up with you, but be grateful if they do. Preparing ahead of time will relieve you of troubles on the clerical side of things. Set reminders to refill medications routinely (every 30 days, 90 days, etc.). The effect is you won't run out of medication unexpectedly. If there is an inventory issue or insurance problem, you will know early,

giving you time to rectify the issue before you need more medicine. Schedule follow-up doctor appointments as far out as possible during your first visit. The effect is you won't be scrambling your schedule to fit in untimely slots at the last minute. You may always change the dates later if needed.

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Communication

Being transparent is the easiest way to combat misguided expectations when you have a chronic illness. If your superpower isn't mind reading, then you are better off clearly expressing your ideas, concerns and feelings through effective communication. Ask questions to gain a better understanding or to clarify discrepancies. Be comfortable with sharing your expectations for how you plan to move forward with your treatments, and be open to all feedback. Never feel obligated to leave anything up to chance. Avoid expecting people to tell you everything you need to know; it usually isn't an intentional omission of detail. Effective communication maintains clarity when your health is complicated and relieves assumptions about how you are feeling. It makes caring for one another easy and effortless.

Count It All as Progress

Set some goals, and have a great time working toward them. Taking a few steps back is never defeat; it is still progress. As long as you learn from the setback, you are doing something right. Keep your expectations balanced, and enjoy the process! ■

SURAYYAH MORRIS, PharmD, is an IG patient from Central Florida. As a medication therapy management and pain management specialty pharmacist, she enjoys supporting patients with chronic pain and chronic conditions to help find balance and improve quality of life.

