**Coping with Rare Disease Tips**

**1**

**Get the answers you need.** Everyone needs help dealing with a rare or serious illness, but you also have to be ready to be your own strongest advocate. Ask questions, seek out opinions, and become as knowledgeable as you can about your condition. Coping is very hard to do alone, but it does begin with you.[[1]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-1)

* Having an undiagnosed rare illness can be particularly stressful. Co-workers, friends, and even medical professionals may be skeptical or unsupportive if your illness is not made “real” through diagnosis.[[2]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-2)
* If you are dealing with an undiagnosed illness, never doubt its reality and never stop seeking answers. Seek out organizations that deal with undiagnosed illnesses for information, advice, and support.
* If and when your illness is diagnosed, don’t be afraid to seek a second or third opinion. Rare illnesses are easy to miss and easy to misidentify. Being thorough is not the same as being in denial, and does not interfere with coping.

**2**

**Seek answers and a supportive community online.** You can make the argument that the internet has been a literal lifesaver for many people facing rare illnesses, by providing them with information, treatment advice, community support, and hope. People with rare illnesses often become “power users” of the internet, developing expertise in finding and evaluating information, and networking with others facing the same challenges.[[3]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-3)[[4]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-4)

* As with everything else on the internet, you need to use your best judgment in determining what information and communities are legitimate and trustworthy. You may want to start your search by utilizing the links and contacts provided by established organizations like the National Organization for Rare Disorders (NORD).[[5]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-5)
* Prioritize online information about your rare illness that comes from medical or academic journals, government agencies, and recognized healthcare organizations. Steer clear of unsubstantiated claims and websites that are trying to sell you something.

**3**

**Connect with others facing the same condition.** While the internet makes it much easier to find and connect with rare illness communities, you may also be able to find support groups in your area as well. Whenever possible, seek out support groups (online or physical) comprised of people facing the same rare disorder as you. You’ll probably be surprised how many other people are out there.

* You’ll probably find out quickly that “rare” does not mean you are all alone. Just because you do not know anyone else with your illness does not mean there are not thousands of other people going through the same thing as you. In the U.S., a “rare illness” is generally defined as one that affects fewer than 200,000 people in the country. In total, some 30 million Americans live with at least one rare illness.[[6]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-6)
* Rare illnesses are prevalent enough that the rarest day on the calendar — February 29th, or “leap day” — has been unofficially declared “Rare Disease Day.” The goal of the event is to raise awareness and funds. Of course, you don’t have to (and shouldn’t) wait for one day every four years to seek out information and provide support for rare illnesses.[[7]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-7)

**4**

**Cope with your illness as an ongoing process.** The initial bewilderment at an undiagnosed illness or the shock of a rare disease diagnosis can unleash a flood of emotions and a wide range of responses. As time passes, you will need to develop coping strategies that work for you, and adjust and revise them as your needs and circumstances change.[[8]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-8)

* Coping with a rare illness or anything else is not a start-to-finish task. You never “finish” coping, you get better at doing it. Prepare for plenty of ups-and-downs when it comes to dealing with something as stressful as a rare illness.
* In fact, effective [stress reduction techniques](http://www.wikihow.com/Relieve-Stress) like meditation, visualization, yoga, aromatherapy, or just exercising, listening to music, or tidying up a bit can help with coping.
* Journaling is another effective way to cope with your anxieties and fears. Writing helps you to identify, analyze, and let go of emotional “baggage” that may be weighing you down.[[9]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-9)

**5**

**Lean on people you trust to help you cope.** You’re going to have good days and bad days in dealing with your rare illness. On the bad days, whether the causes are physical or emotional, lean on family, friends, support groups, professional counselors, and other people you trust to help see you through and continue the coping process.

* When you need help, ask for it. When you need someone to talk to, find a good listener — someone who is willing to simply be there for you.[[10]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-10)
* NORD also offers a substantial list of links to helpful resources, many of which address getting assistance in coping with a rare illness.[[11]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-11)

**Part 2:**

**1**

**Become an expert and an advocate for your illness.** Knowledge is power when dealing with a rare illness. You need to be able to trust in the experience and skills of your medical team, but at the same time become an informed advocate for your own care. Legitimate, medically-sound internet resources are a good starting point for learning as much as possible about your rare illness.[[12]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-12)[[13]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-13)

* The old saying “the squeaky wheel gets the grease” is appropriate when dealing with rare illnesses. Become a champion for raising awareness and funds — both charitable and research-oriented — for the cause. Being actively involved in improving the lives of those facing your condition can provide you with a sense of ownership and power over your rare illness.

**2**

**Investigate potential clinical trials.** The clinical trials website run by the U.S. National Institutes of Health provides information on over 200,000 current studies, so a little research may turn up trials that are relevant to your rare illness. Search the databases, identify possible trials, and see if you may be eligible to participate.[[14]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-14)

* Never stop seeking new treatment options for your rare illness. This doesn’t mean you have to sign up for every trial and try every new medication — just make sure you arm yourself with the most up-to-date resources so you can make informed decisions about how to manage your disease.

**3**

**Consider genetic counseling as warranted by your situation.** Depending upon the nature of your rare disorder, you may be concerned about the possibility of loved ones — and especially children you have or may someday have — contracting the illness as well. Genetic counseling can offer you realistic assessments of such likelihoods so that you can make informed life decisions.[[15]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-15)

* If you are dealing with the question of whether to have children due to the risk of passing on a severe and/or rare disorder, empower yourself with as much information as possible. While it’s a decision that needs to be made with your heart as much as your head, use the information you can derive from genetic counseling to influence both of these decision-making zones.

**4**

**Seek help with financial and insurance issues.** Dealing with a rare illness can be an expensive proposition, even if you have health insurance. Some insurers may be hesitant to offer adequate financial support for rare conditions, but that doesn’t mean you are out of options. Once again, it is up to you to be your own fiercest advocate.

* If you are being denied adequate coverage, contact officials within the insurance company as well as (in the U.S.) your state insurance commissioner. NORD even offers a form letter you can personalize and use.[[16]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-16)
* Organizations like NORD may also offer or be able to direct you to patient assistance programs that can help you with your financial difficulties when facing a rare illness.[[17]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-17)

**Part 3:**

**1**

**Expect stress and grieving on your part.** If you have a child or other loved one dealing with an undiagnosed or diagnosed rare illness, you will be deeply affected by it as well. You might experience shock, denial, and other common stages of grief, and will almost certainly be facing a great deal of stress. You will need to learn to cope in your own way, as does the person with the actual illness.[[18]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-18)

* Many of the same coping mechanisms that may help the person with the disease might also be useful for you. Educate yourself about the illness, find support groups, advocate for increased awareness and financing, and take other such steps that enable you to accept the reality of the situation while rejecting that you are powerless to do anything about it.

**2**

**Care for yourself so you can help the ill person.** People caring for sick loved ones are frequently over-stressed, sleep-deprived, lacking in regular exercise, and tempted to seek temporary relief in unhealthy choices like junk food, tobacco, and excessive alcohol consumption. Remember that if your own health falters, however, you will be unable to provide the level of care and support you want to give to the person facing the rare illness.[[19]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-19)

* You simply have to set aside some time for yourself to sleep, exercise, eat healthy, engage in stress-reduction activities, and do things that make you happy. This is not selfishness or wasted time; it is a necessary component of coping with a challenging situation and of providing the best care you can.
* You can step away from the illness briefly, even if the person suffering from it cannot. Don’t feel guilty; instead, use it as an opportunity to recharge and get back into the fight with renewed energy and purpose.

**3**

**Support and speak up for the person and his or her illness.** Some people, due perhaps to age or the severity of the condition, simply cannot be their own informed advocate when it comes to rare illnesses. When this is the case, you can step up and be a champion for your loved one.[[20]](http://www.wikihow.com/Cope-with-a-Rare-Illness#_note-20)

* Consider becoming an advocate for other people facing rare illnesses who may not have loved ones who can speak up for them. Make use of the expertise and experience you’ve acquired. If you’re looking for a way to cope with a rare illness, getting involved in a manner that may potentially benefit thousands of other people is certainly a worthwhile method to try.