



# How To Be Your Own Advocate



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Fibromyalgia is a chronic condition involving multiple symptoms and comorbidities. The road to diagnosis is difficult as fibromyalgia is greatly misunderstood. Even though more individuals are being formally diagnosed, people with fibromyalgia are being ignored, or overlooked by friends, family, insurance companies, employers and healthcare providers. It is important that you take an active role in managing your health by learning how to be your own advocate.



You have the ability to stand up for yourself. Though you might occasionally need assistance, doing so can strengthen you and enhance your self-esteem.

Three parts of self advocacy is to know yourself, your needs and getting what you need.



# **SELF-ADVOCACY IS THE ACT OF:**

- Representing and speaking up for yourself to ensure your needs, rights, and interests are recognized and met.
- It involves understanding your own needs
- Communicating your needs effectively
- Taking responsibility for making decisions that affect your life
- Empowering yourself and finding your voice when people are not paying attention to your needs
- Fighting for your personal rights and/or against personal discrimination
- Speaking, acting and/or deciding for yourself what is right for you
- Acquiring knowledge to make informed decisions regarding your needs
- Expressing effectively to others about fibromyalgia and how it impacts you as an individual



# STEPS TO BECOMING YOUR OWN ADVOCATE:

- **Believe In Yourself and Your Abilities.** You deserve to prioritize self-care and assert your rights. Trust your understanding of your body, recognizing when you are experiencing a flare or reacting to medications
- **Give Yourself Permission to Self-Advocate.** Speaking up for yourself may not always be easy, but you have the power within you to be an effective advocate. Embrace it and learn to use it!



- **Know Your Rights.** You deserve to be treated with dignity and respect. Familiarize yourself with the Fibromyalgia Patients' Bill of Rights.

- **Research** your options and ask questions when necessary.
- **Be concise and clear** when expressing your needs and accommodation requests. Communicate any challenges or concerns. Don't expect people to automatically know what you need, you have to make a request.



# STEPS TO BECOMING YOUR OWN ADVOCATE:

- **Self- Care** is critical to maintain good mental and physical health. When you are doing a lot of advocating, take time for yourself to do things you enjoy and to recharge your batteries. Prioritizing self-care also means setting boundaries and saying no to things that drain your energy or cause stress.
- **Understand Your Illness.** Educate yourself about fibromyalgia and keep abreast of new research and/or changes to government legislation affecting you and your illness.
- **Write things down and prepare for any situation in advance.** This is particularly important if you find yourself in a situation that lacks support.



# STEPS TO BECOMING YOUR OWN ADVOCATE:

- **Build a Strong Support Network** for yourself and your caregivers. Surround yourself with family, friends, and support groups who understand and empathize with your condition. Having a reliable support system can provide emotional relief and practical advice. Shared experiences can make you feel less isolated. Having a strong support network can help you navigate challenging situations and help you become a stronger advocate for yourself. Have people who make you feel good about yourself and support you in your support network. Seek out mentors or advocates who can help you achieve your goals, like minded people. These people don't have to have fibromyalgia, they can be advocates for their own conditions but it really helps to have these people around.



# STEPS TO BECOMING YOUR OWN ADVOCATE:

- **Practice being assertive.** Assertiveness involves being clear, direct, and respectful when communicating with others. While practicing assertiveness can be uncomfortable, it helps in advocating for oneself more effectively. It's important to know the difference between assertive and aggressive behavior. One way to build the skill of assertiveness is by practicing in small ways in less intense environments. For example, ask someone you feel safe with to prepare your meal in a way you prefer, different from their usual method. The worst that can happen is they say no. Gradually build on this by increasing the asks to strangers, such as requesting a discount on a purchase. Again, the worst they can say is no.



# STEPS TO BECOMING YOUR OWN ADVOCATE:

- **Learn from mistakes.** Mistakes are a natural part of the learning process. Instead of dwelling on them, use them as an opportunity to grow and learn. Analyze what went wrong and what can be done differently next time. This approach will help in becoming a more effective self-advocate over time. It's common to feel angry or upset and shut down after making a mistake. Instead of being self-critical, consider why the situation elicited such a strong emotional response. This reflection can help in developing a more resolved and calm response in future interactions.
- **Celebrate successes.** It's important to recognize that not every effort will be a success, or it may not feel like one. Reflect on accomplishments and take pride in them. Use these successes as motivation to continue moving forward.



# CONCLUSION

In conclusion, being your own advocate is essential for ensuring that your needs and preferences are respected and met. By equipping yourself with knowledge, confidently communicating your boundaries, and making informed decisions, you take control of your life and well-being. Self-advocacy empowers you to navigate various situations with clarity and confidence, fostering a healthier, more fulfilling life. Remember, your voice matters—use it to advocate for yourself and create the life you deserve.

