



Foundation for Ichthyosis & Related Skin Types, Inc.®

Coping with Ichthyosis Supporting Your Emotional Wellbeing

1. **Advocate for yourself and don't let ichthyosis define you.** Living with a chronic illness like ichthyosis can present many challenges. Try to focus on *what you can do* (even if it means making some changes), instead of what you can't do. Many people say they are able to live a fulfilling life with ichthyosis. Engage in activities that bring your life meaning – on a personal, emotional and spiritual level.
2. **Don't feel obligated to explain your condition to other people.** People will react to seeing you or your child; it's only human. Your skin may look and feel different, but everyone is special in their own way and it's helpful to remember that everyone has something they are dealing with. Try not to take it personally and you may even use it as a chance to educate others.
3. **Tune into and talk about your emotional health.** Living with a chronic condition can be stressful. But depression and anxiety can quickly derail efforts to optimally manage and treat your condition – or care for a child. It can also affect our relationships. If you've felt unusually down, depressed, or you don't feel like engaging in activities that usually bring you joy, tell your health care provider. You might benefit from treatment, including talking with a mental health professional.
4. **Create a circle of support.** Know who you can count on to help lift your spirits. Be sure to connect with other people and families with your type of ichthyosis to be able to share stories and lean on each other for support.
5. **Start a gratitude journal.** Write down one thing you are grateful for at the end of each day. There is science that shows gratitude can improve our emotional and physical health and focuses our mind on the good in our lives.
6. **Be mindful.** Look for ways to lower stress and be focused on the present. For example, practicing moments of quiet reflection, deep breathing or yoga.
7. **Find ways to manage stress.** For example, exercise helps to boost the body's feel-good hormones and we generally feel better about ourselves when we are active. Be sure to find activities that work for you and avoid the heat of the day if you're outside. There may be other activities that are calming for you; for example, knitting, reading, listening to music, volunteering or cooking.
8. **Keep your wits about you.** It's important to stay positive as best you can. Some people living with ichthyosis share that they have found ways to lighten their load a bit through humor. It's best to let the affected person lead the way and show you what they are comfortable joking about.
9. **If you have a child with ichthyosis, engage the school to help encourage understanding and inclusion.** Many children report being teased or left out. Meet with the school's counselors to come up with a plan to support him or her.
10. **Tap into other resources.** For kids, Camp Discovery offers children living with skin disease a one-of-a-kind, fun experience. For more information, visit <https://www.aad.org/public/public-health/camp-discovery>.

It's OK to have big emotions – fear, guilt, anger, anxiety about the future. But don't let them take over and interfere with your ability to move forward.



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PO Box 1067, Lansdale, PA 19446-0687

Phone: 800-545-3286

Website: www.firstskinfoundation.org

Email: info@firstskinfoundation.org

Improve lives and seek cures for those affected by ichthyosis and related skin types.

January 2023