

Advocating for Yourself

Advocating for Yourself: Ichthyosis Care in Hospitals and Nursing Homes

Being admitted to a hospital or moving into a nursing home can bring new challenges for anyone — and for people with ichthyosis, it can mean making sure your skin care needs are clearly understood and met.

This guide helps you **advocate for your care**, educate healthcare providers, and stay comfortable and safe during your stay.

Why Advocacy Matters

Ichthyosis is rare, and many healthcare professionals may not be familiar with it. Your condition, daily routines, and skin needs may not be part of standard hospital or nursing home care.

By clearly explaining your needs and having a plan, you can help ensure:

- Your **skin is properly moisturized and protected**
 - **Bathing routines** are handled correctly
 - **Medications and treatments** are appropriate
 - **Comfort and dignity** are maintained throughout your stay
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Before Admission or Move

1. Prepare a Personal Care Plan

Write down key information about your skin and care routine:

- Type of ichthyosis (if known)
- Daily skin care steps (bathing, products, moisturizers)
- Frequency and preferred timing (for example, “apply ointment twice a day”)
- Allergies or sensitivities to products or medications
- Notes on temperature regulation or clothing preferences

Keep a printed copy with you and provide one to your care team.

2. Bring Your Own Products

Hospitals and nursing homes may not have the specific products you use.

- Pack your **moisturizers, cleansers, and shampoo** in labeled containers.
- Ask your doctor to include your products in your official care plan so staff can apply them.

3. Identify an Advocate

If possible, ask a **family member or caregiver** to serve as your advocate. They can help:

- Explain your condition to staff
- Ensure daily care routines are followed

- Speak up if something doesn't feel right

During Your Stay

1. Educate Your Care Team

Introduce yourself and your condition. You might say:

"I have a rare genetic skin condition called ichthyosis. My skin doesn't shed normally, so I need daily moisturizing and gentle bathing to stay comfortable and avoid infection."

Offer to share a short information sheet (FIRST can provide printable resources) or direct staff to firstskinfoundation.org.

2. Speak Up About Your Needs

You have the right to request care that supports your health and comfort.

Communicate respectfully but clearly about:

- The **type and amount of moisturizer** needed
- **Frequency of bathing and skin care**
- The importance of **room temperature control** (some people with ichthyosis can't sweat normally)
- Avoiding **harsh soaps or scrubbing**

3. Monitor Your Skin

Check daily for signs of:

- Cracks or open areas
- Infection (redness, swelling, pain)
- Discomfort from dryness or tightness

Alert staff right away if something changes.

4. Prevent Complications

Hospital environments can dry the skin due to air conditioning or low humidity.

- Ask for a **humidifier** if allowed.
- Stay **hydrated** and keep moisturizer nearby.
- Wear **loose, soft clothing** to prevent irritation.

In Nursing Homes or Long-Term Care Settings

1. Establish Routine Care

Make sure skin care is part of your **daily care plan** and charted by staff.

Ask for consistency — ideally the same caregivers should help with bathing and moisturizing when possible.

2. Communicate Regularly

Check in with the care team or charge nurse to ensure your skin care plan is being followed.

If you notice changes in your skin or comfort, bring them up promptly.

3. Educate and Empower Staff

Offer short, simple education:

“Regular moisturizing keeps my skin healthy and prevents infection. It’s not cosmetic — it’s medical care.”

Encourage caregivers to contact your dermatologist or FIRST if they have questions.

If You Face Challenges

If your skin care needs are not being met:

- Speak first to your **nurse or caregiver**
- If unresolved, ask for the **charge nurse or patient advocate**
- In hospitals, you can request a **care plan meeting**
- In nursing homes, contact the **director of nursing** or **ombudsman**

Document concerns in writing if needed.

Resources

- **FIRST Ichthyosis Care Sheets** – Printable guides for healthcare professionals
 - **Patient and Family Support Network** – Connect with others who’ve navigated hospital or long-term care settings
 - **Hospital Advocacy Tips** – www.firstskinfoundation.org
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Key Takeaway

You are the expert on your own skin.

By preparing ahead, communicating clearly, and advocating for yourself or your loved one, you can ensure that your ichthyosis care is respected and supported - wherever you are.

This Adult Toolkit Resource brought to you by:



This information is provided as a service to patients and parents of patients who have ichthyosis. It is not intended to supplement appropriate medical care, but instead to complement that care with guidance in practical issues facing patients and parents. Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, Board of Medical Editors, nor Foundation staff and officials endorse any treatments or products reported here. All issues pertaining to the care of patients with ichthyosis should be discussed with a dermatologist experienced in the treatment of their skin disorder.



Foundation for
Ichthyosis & Related
Skin Types

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

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