

Fact Sheet



National
Scleroderma
Foundation

How to Handle a Bathroom Emergency

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Why do people living with scleroderma need a “bathroom card”?

Sometimes, people with scleroderma experience an overwhelming urge to defecate. That’s because your disease can reduce your rectal capacity. It’s truly a “bathroom emergency,” because these embarrassing episodes can happen at any time, and sometimes, you have explosive diarrhea too.

Why should I carry this card at all times?

When Ally, a young woman with Crohn’s disease, was a teenager, she was denied bathroom access at a major retailer with no public restroom. Ally asked to use the employee restroom, but she was denied and subsequently soiled herself. Ally and her mom made it their goal to make bathroom accessibility a law.

The Restroom Access Act, known as Ally’s Law, is in effect in several states. However, there is no federal law that guarantees access to a restroom for people with medical conditions that cause bathroom emergencies. You can use this card in states both with and without Ally’s Law to request bathroom access due to your scleroderma.

If I’m in a state that hasn’t enacted Ally’s Law, could I still be denied bathroom access?

Unfortunately, yes. But you will find that most people are understanding when they see your card. Even though you urgently need to use the bathroom, stay calm and courteous. Look them in the eye and let them know you’re serious. It’s likely that they will let you use their restroom.

What else can I do when I feel the urgent need to go?

If you feel an urge to defecate, try to “freeze, squeeze, and breathe”:

- Stand still
- Tighten your pelvic floor muscles
- Relax and tighten these muscles over and over
- Breathe steadily and deeply
- Try to distract your thoughts to gain more time to get to a bathroom
- To “freeze” your bodily function response, bend your knees slightly to relax your thigh muscles as you squeeze the pelvic floor muscles, especially focusing your squeeze on the anal sphincter.



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Scleroderma, which means *hard skin*, is a chronic disease that can damage internal organs, including the **gastrointestinal tract**, lungs, heart, kidneys, and esophagus, in addition to causing thickening and tightening of the skin. Scleroderma occurs three to four times more often in women than men. Symptoms vary from mild to severe. For most, the disease has a dramatic impact on daily life, but for some, it is life-threatening. Medications sometimes help, but there is no cure. Research seeks to discover the cause, understand the mechanism, and overcome scleroderma forever.

PLEASE, I CAN'T WAIT!

I have a medical condition and urgently need to use the bathroom.
Thank you for your understanding.

Many people with **systemic scleroderma** experience symptoms that involve the GI tract and limited bladder capacity. Because of these issues, immediate access to a bathroom is necessary and appreciated.



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