HOW TO HANDLE A BATHROOM EMERGENCY

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Q Why is a “bathroom card” helpful for people living with scleroderma?

A Sometimes people with scleroderma will experience an overwhelming urge to defecate accompanied by explosive diarrhea. In some cases the rectal capacity is decreased due to the disease. That situation is indeed what is often called a “bathroom emergency.”

Q Why should I carry this card at all times?

A As a teenager Ally, a young lady with Crohn’s Disease, was denied bathroom access at a major retailer with no public restroom. Ally asked to use the employee restroom, 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. As yet there is no federal law addressing this important issue. The card below can be used in states with and without Ally’s Law.

Q Can I still be denied bathroom access in states where there is no Ally’s Law?

A Unfortunately, yes, but you will find many people to be understanding when they see your card. As badly as you need to get to the bathroom, stay calm and courteous (looking at them with pleading puppy dog eyes helps, too). Chances are they will let you use their restroom.

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

A When the urge begins to overwhelm you try to “freeze, squeeze, and breathe.” Urge suppression by standing still, tightening your pelvic floor muscles, relaxing and tightening over and over while you deep breathe and try to distract yourself can frequently buy you more time as you get to the bathroom. When you freeze, you should bend your needs slightly to relax your thigh muscles as you squeeze the pelvic floor muscles, especially focusing your squeeze on the anal sphincter.
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. For some, it is life-threatening. Although medications sometimes help, there is no cure.

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.