

Kathy Bates joins other lymphedema advocates at the steps of the Lincoln Memorial in Washington, DC.

# Kathy Bates is figuring out how to live with lymphedema

MedlinePlus magazine caught up with the actress to see how she's been managing her diagnosis

nen award-winning actress Kathy Bates was featured on the cover of NIH MedlinePlus magazine in 2016, she spoke about her experience with lymphedema following her breast cancer surgery and her advocacy for those with lymphatic diseases as a national spokesperson for the Lymphatic Education & Research

Network. NIH MedlinePlus magazine recently caught up with her to learn more about her lymphedema journey.

#### How are you doing?

My lymphedema (LE) is under control. I've lost about 80 pounds over the last few years, which has helped a lot with the swelling in my arms, but I still wear my

compression sleeves if I'm flying or if I'm doing strenuous tasks. I like to be self-sufficient, so before I know it, my arms are inflamed and painful. However, I'm luckier than most who have LE. I can afford the doctor's visits, compression garments, and therapy. Many people can't.

## "Other people's stares may hurt at first, but they have no power to define us as people. We **have** lymphedema. We're not lymphedema."

– Kathy Bates

#### How did the pandemic impact you?

Like many, I was in guarantine for almost two years. My niece brought me food and helped me take care of the house. She took care of the whole family. I don't know what we would have done without her. I managed to keep my weight off, which was a miracle. I worked very hard at it.

#### What do you do to maintain your health and energy?

I try to pace myself so I don't get too stressed. If I can stop rushing, relax my shoulders, straighten my spine, breathe deeply, and focus on each little moment of completing a task, I have more confidence in my ability to live with LE. The pandemic forced me to slow down.

I also started raising miniature and full-size violets. I found working with plants, digging my hands into bags of soil... it centers me. I love coming downstairs in the morning to see the new buds. My little dog is jealous that they get attention before she gets her breakfast!

#### Looking back over the course of your experience with lymphedema, what is your message to others who have been diagnosed more recently?

That's a very difficult question to answer. To give someone meaningful comfort without physical connection is hard. The platitudes like "don't lose hope" or "try not to get depressed" seem so cliche. For the day-to-day

battle, I would advise gathering the courage to get out and live your life no matter the severity of your disease. Going out in public wearing a compression garment, especially when people aren't educated about LE, can sometimes be more painful than the disease itself. However, hiding at home and living a sedentary life will only make things worse for your body and brain. As my other niece says, "Motion is lotion." Other people's stares may hurt at first, but they have no power to define us as people. We have lymphedema. We're not lymphedema. Reclaim your life. Get used to being in public so you can live your life to the fullest. Most of all, don't withdraw from your family and friends. Keep them close. We're all dealing with something, especially these days.



Kathy Bates testifies before Congress as an advocate for those with lymphatic diseases.

#### Has there been progress made through your advocacy?

Absolutely! NIH is working on a new, broader way of advancing lymphatics science and research by establishing a National Commission on Lymphatic Diseases. And NIH is now creating research categories specifically for lymphedema and for lymphatic diseases. Those of us with lymphedema have succeeded in making our case and being recognized, but there is still work to be done to get us to our ultimate goals of new treatments and eventual cures.

### More than **1 million** poeple in the U.S. have lymphedema.

SOURCE: National Heart, Lung, and **Blood Institute** 

#### What are you doing in your entertainment career now? Any plans for new shows or movies?

Last June, I had an opportunity to do a lovely role in the film adaptation of Judy Blume's acclaimed novel, "Are You There God? It's Me, Margaret," which will be released in September. I'm getting ready to fly to Dublin to do a film with Maggie Smith and Laura Linney. I've been working with a dialect coach for the past few weeks to perfect the working-class Irish dialect. I love poetry and literature, and I think Irish writers are the greatest who ever laid a pen to paper. Also, my middle name is Doyle. My great-great-grandfather came from Dublin during the Irish Potato Famine, so in a way, I'm going home.

