

Former patient provides a voice for the voiceless

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Jess Newport is a member of the Duke HomeCare & Hospice Patient and Family Advisor Council.

Jess Newport first came to Duke 11 years ago for a double lung transplant. The Florida native lives with cystic fibrosis and when her local hospital's transplant list was too long, she researched other facilities and came across Duke's program.

"Duke is one of the top transplant centers in the world," said Newport. "I went from on the list to transplant in 37 days. The program was so amazing. It makes sense to me that people come from all over the world to go to Duke."

Newport moved back to Florida after recovery. However, two years after her transplant, she was being hospitalized every few months because of pancreatitis, which is a chronic inflammation of the pancreas that leads to severe pain. The hospital in Florida thought she was just seeking pain medication. So, Newport started flying back to Durham to be hospitalized at Duke instead. She ultimately decided to move to Durham permanently.

After moving, Newport saw a post on Facebook asking for patients to join one of Duke's [Patient and Family Advisor Councils \(https://www.hsq.dukehealth.org/pfac-organization/\)](https://www.hsq.dukehealth.org/pfac-organization/) (PFAC). These groups seek patient and family member input to improve the overall patient experience. She joined the Duke HomeCare & Hospice (DHCH) PFAC in 2016.

"I wasn't sure about joining the hospice group but thought I understood the end-of-life perspective and trying to make the best of medical situations," said Newport. "My personal experience with chronic pain gives me a glimpse into the dying process."

According to **Kellie Brockman**, director of business development for DHCH, "Jess brings openness and transparency about her own experiences as a patient. She's been with the group since its inception and has grown into a co-chair who leads our meetings including PFAC priorities and strategies to achieve priorities."

Since joining the PFAC group, Newport has been a part of a number of projects. The one she is most proud of is a booklet for hospice patients who can't verbally communicate. It features pictures and words that the patient can point to in order to tell others how they are feeling or items they need around the house like adjusting the TV volume. She's proud this will directly impact current patients on hospice.

"The group gives a voice to the patient and family experience that we as clinicians sometimes overlook," said **Benita Pope**, director of patient care with DHCH. "Their input makes us step back and see where we may have blinders."

"This has been an extremely rewarding experience for me," said Newport. "Unlike other PFAC groups, there aren't any patients in the hospice PFAC group. They are family and friends of patients who have been on hospice, or those that may have insight into the patient perspective. We're speaking on the patient's behalf. We put our own feelings aside and provide a voice for patients who can't voice themselves."