

# Teens Remain Highly Satisfied with Hemophilia Treatment Center Care



Improving the health, safety, and well-being of adolescents is a national priority. Making sure teens who have bleeding disorders are confident and educated to take care of their own medical needs as they mature is a focus in Hemophilia Treatment

Centers (HTC) nationwide. Parents or guardians are responsible for managing bleeding disorder care for small children including scheduling appointments and infusing factor. But as children with a bleeding disorder grow older, HTCs help teach young adults skills and encourage them to take on these responsibilities.

**Are teens satisfied with how their HTC helps prepare them?** Patient Satisfaction Surveys (PSS) of HTCs can help us find out. A national PSS was conducted in 2015 and 2018. PSS data shows us levels of HTC satisfaction and how they change over time. We looked at the survey results from families

**“I feel my son is being prepared for his transition to adulthood for his bleeding disorder care.”**

Parent of teen with severe hemophilia from Tennessee

with teenagers, as the PSS included two questions specifically asking how well HTCs

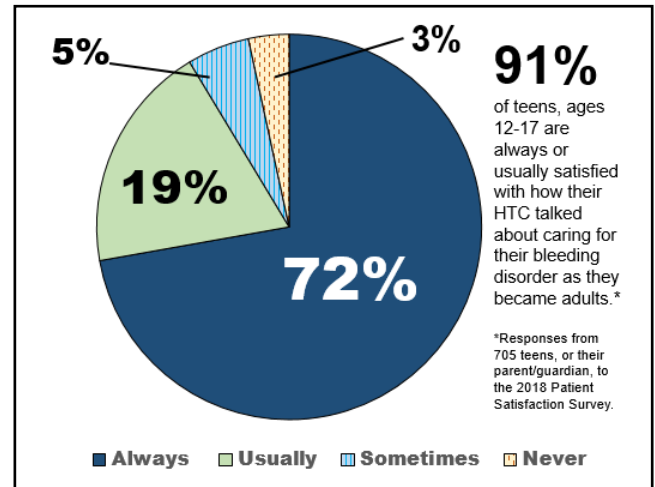
help teenagers prepare to care for themselves independently.

One question asked how satisfied teens were with how their HTC encouraged them to take charge of their own care. The other asked about satisfaction with the way their HTC talked about how to care for their bleeding disorder as they became adults. Over 700 teens age 12-17 (or parents/guardians) from over 130 HTCs across the U.S. answered these ‘teen transition’ questions in 2015 and 2018.

## How satisfied are teens with their HTCs?

Results in both surveys were overall positive: over 90% of teens in both years were always or usually satisfied with how HTC providers talked to them about treating their disorder as they became an adult. In both years, 92% of teens reported being always or usually satisfied with how HTC staff encouraged them to manage their own care.

**What did we learn?** The high levels of “always” and “usually” satisfied teens in both years is evidence that HTCs are consistently doing a very good job helping teens learn to manage their disorder. We also learned that HTCs which only care for people up to age 18 are doing equally well helping teens with transition as those HTCs that care for people of all ages.



Each region, and each center, received their own survey responses, which allows them to see if they improved or not from 2015 to 2018. Reviewing satisfaction over time helps us understand how well HTC efforts are working to prepare teens to manage their bleeding disorders as they become adults.

All HTCs are trying to improve and learn ways to help their teens progress and learn self-care and independence.

Our hope is that with each passing year, more and more teens will always be satisfied with the help their HTCs give, and able to take on the challenge of managing their bleeding disorder as they become adults.

**“I have been doing self-care for a while, and I didn’t need a talk once I turned 12.”**

Teen with severe hemophilia from Massachusetts

Asking the teens themselves about their experience adds powerful understanding about how HTCs are of value to the bleeding disorders community. You can learn more about the survey results at [www.htcsurvey.com](http://www.htcsurvey.com).