

# New national study finds Crohn's disease diagnosis difficult to obtain and life altering

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In a new national survey of Crohn's disease patients, Health Union reveals that it was not uncommon for patients to see multiple healthcare professionals (HCPs), have numerous office visits, and endure multiple diagnostic tests before receiving a diagnosis. Results demonstrate an impact on such things as the ability to work or exercise, but also on overall quality of life and social activities. Respondents wished more people understood the disease and its impact.

Crohn's disease is a [chronic inflammatory disease](#) of the digestive tract affecting about 780,000 people in the U.S. Typical symptoms include [abdominal pain](#), diarrhea, weight loss, and fever. In addition, as an inflammatory disease, Crohn's can have symptoms outside of the [digestive tract](#) affecting the joints, skin, eyes, and liver.

The exact cause of Crohn's is unknown. It is believed that it may be an autoimmune reaction - the immune system overreacts and attacks the body's healthy cells. The survey shows that 45% of respondents had a family member with an autoimmune disease other than Crohn's. Forty-two percent had a family member also diagnosed with an inflammatory bowel disease, such as Crohn's or ulcerative colitis. Various stimuli, such as a bacteria or virus, can be responsible for triggering the immune system reaction.

Crohn's disease is often life altering and 22.5% of respondents experienced their first symptoms before the age of 15. Seventy-eight percent say that Crohn's at least sometimes impacts their ability to work

and over half report that it often or always negatively impacts their overall quality of life. "I wish people would become more educated about Crohn's Disease," says Paul Richman, [CrohnsDisease.com](http://CrohnsDisease.com) patient contributor. "If everyone was more well-read about Crohn's, they would understand how it affects people's lives in every way. They would realize how many people are affected by it, and how hard it is to keep friendships and relationships because of the embarrassing impact it has on our daily lives and routines."

In addition to gastrointestinal issues, 85% of respondents experience complications, with the most prevalent being:

- arthritis/swollen joints (60%),
- malnutrition/nutritional difficulties (37%), and
- anemia (36%).

Crohn's proves very difficult to diagnose with 44% of respondents needing 10 or more office visits and 59% seeing three or more HCPs. More than 3/4 started off with a moderate to severe Crohn's diagnosis.

On a more positive note, once diagnosed, patients actively pursue treatment and are generally happy with their medical care. Eighty-seven percent began treatment immediately or within one month of diagnosis and 95% are under the care of an HCP. Over 3/4 are satisfied with their HCP, with those unsatisfied most often wanting more empathy and education/communication. Patients found HCPs most valuable for monitoring progression, treatment suggestions, and education.

"When it comes to Crohn's, health care providers can do a lot more than just provide treatment. Openly discussing the unsavory aspects of this condition is really important as many patients feel they can't talk to their friends/family. This is why a site like [CrohnsDisease.com](http://CrohnsDisease.com) is so important. It provides the open, non-judgmental support so necessary for

management," says Tim Armand, president and co-founder of Health Union.

Just as diagnosing Crohn's is difficult, so is symptom management. Less than three percent of respondents were not experiencing symptoms and those with symptoms experienced an average of seven, with 68% citing fatigue/low energy as the most difficult to manage. One quarter have never been in remission and those who have been experienced remission for less than three years. Almost 3/4 experience flares every few months, if not more often. The primary trigger was stress, followed by greasy foods and raw fruits and vegetables.

Finding the right treatment is difficult. More than half of respondents have been on their current treatment plan less than two years and about 70% may be changing in the next year. The most common treatment is biologics. Sixty percent would be interested in participating in a clinical trial.

"Inflammatory Bowel Disease is incredibly difficult to live with and not very well understood by the public. It does make me feel good to know that some pharmaceutical companies and doctors are working hard for the first time ever to collaborate with patient advocates to improve quality of care for those suffering from this debilitating disease. This helps to mitigate some of the unique challenges faced by IBD patients," said CrohnsDisease.com patient contributor Marisa Lauren-Troy.

The Crohn's Disease in America survey was conducted online October 29, 2015, to January 10, 2016, with 2,018 respondents who were diagnosed with Crohn's disease and a resident of the U.S. or U.S. citizen living abroad. More details about the survey are available on request.

**More information:** [crohnsdisease.com/graphics/in- ... isease-america-2016/](http://crohnsdisease.com/graphics/in-...isease-america-2016/)

Provided by Health Union

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