

NAVIGATING THROUGH ADOLESCENCE

There is no disputing that being a teenager is tough and navigating through adolescence presents a novel set of challenges. During this time, it is not uncommon to feel different from friends and classmates. When a chronic disease, like IBD, gets thrown into the mix of emotional and physical changes, this could be a very difficult time in a child's life. Approximately 15% of all cases of IBD are diagnosed before the age of 18. Moreover, the adolescent age group remains the fastest growing group of new diagnosis of all ages to present with symptoms compatible with IBD. When presenting during teenage years, outside of the classic gastrointestinal symptoms, there are a few key signs and symptoms that both patients and physicians must pay attention to and address in a timely manner. Puberty is the most dynamic phase of growth in childhood and so when IBD presents during this time, both growth and pubertal development can be significantly delayed by ongoing, active and under treated disease.

Growth and pubertal delay

Maintaining adequate nutrition, minimizing inflammation and maximizing treatment *off* of corticosteroids remains an integral part of managing the potential growth stunting effects of IBD, more specifically Crohn's disease affecting the small intestine where nutrients are absorbed. On occasion, growth and pubertal delay is the only presenting sign of IBD and can precede any GI symptoms. Growth failure is secondary to malnutrition with decreased intake contributing significantly. Other factors such as increased losses through diarrhea, malabsorption of nutrients, psychosocial factors and medication effects can certainly impact an individual's nutritional state. When growth delay is present, it is important to discuss with your doctors about getting the calories needed to catch up on any lost ground and to help grow to your genetic potential. Often supplemental nutrition is the key to getting those important additional calories. On rare occasions we need to use temporary tube feeding to provide the additional calories. Persistent inflammation in the face of IBD can also impact the maintenance of bones. Teens acquire their peak bone mass during adolescence so eating healthy will help bones remain healthy and receive enough calcium and vitamin D. A consultation with an endocrinologist, who is an expert on bones and growth, can be very helpful to address these key issues of adolescence.

Emotional challenges

IBD can be very challenging emotionally. Depression and anxiety at the time of diagnosis is not uncommonly seen in teenagers. This is similar to what is seen in other chronic diseases diagnosed during adolescence and so teens with IBD are not alone in this fight. When the gastrointestinal symptoms are better, children often feel better emotionally as well. However, anxiety of not knowing what the future holds can certainly affect mood long term and it is important to address the emotional well being of teens at the same time as the physical well being. Food, in particular, is commonly anxiety provoking and presents a struggle for patients and caregivers. Adherence to medications is also a common problem. The number of pills and how often in the day they need to be taken impacts the ability to be consistent with medications. Because this is so common and forgetting or not taking medications can impact the disease symptoms, it is very

important to be honest with your doctor so that he or she can find ways, by reducing pill count or number of times in a day the medications need to be taken, to help patients remember to take their medications. It is important to discuss with both family members and healthcare professional the emotional impact of the disease.

Transition of care

The transition from pediatric to adult medical care of patients with IBD can be difficult for the child and care givers. Clinicians must be sensitive to this transition and the barriers it may present. The following are certain traits needed to make a successful transition of care and allow for the ability to navigate through the adult healthcare milieu. Communication is critical in order for the child and caregiver to anticipate the new roles each member will play in this transition. The process of transition should be gradual and if the process is delayed the transition may be less successful as the time to prepare and anticipate change has been limited. Family members need to relinquish responsibility and the weaning process should begin fairly early in adolescence so that when the time comes to meet with an adult gastroenterologist the patient and caregiver are prepared. In preparation patients may want to put a portfolio together whereby key documents can be brought to their visit to minimize duplication of history taking and perhaps procedures and tests. Examples would include medical summaries, procedure reports, surgical reports, medication history, recent laboratory results and health insurance information.

SUMMARY:

- IBD is commonly diagnosed during adolescence
- IBD can impact growth and pubertal development
- It is important to discuss with both family members and healthcare professionals the emotional impact of the disease.
- Transition from pediatric care to adult care is important and should start early
- Communication is important and can help teens navigate through adolescence