

## Ulcerative Colitis – Kids and Teens

### How can I make the most of my treatment?

Once you are feeling better, it is important to keep your symptoms from coming back. Although the causes of a relapse (return of symptoms) are unknown, there are some things you can do to help prevent it.

- **Eat a healthy diet.** Each person is different when it comes to diet and ulcerative colitis. Most importantly, follow a healthy and balanced diet with plenty of nutrients and vitamins. Diet does not influence inflammation in the colon in people with ulcerative colitis.
- You may have to **adapt your diet** after surgery by eating smaller and more frequent meals, and avoiding drinking large amounts of fluids.
- **Keep taking your medicine**, even if you start feeling better or if you think it isn't working as well as it used to. Talk to your doctor before making any changes on your own, and remember that treatment may take time to work so don't give up too soon.
- **One common mistake people make is to decide to stop taking their medicine without telling their doctor once their symptoms go away.** Don't make this mistake, as you need to keep taking your medicine to help keep your symptoms from coming back. If you are unsure, check with your doctor.
- **Make sure you understand how your medicine works** and possible side effects to watch out for.
- **Remember to take your medicine every day for best results.** Try setting the alarm on your mobile telephone or wristwatch, or asking your mum or dad to send you a text message as a reminder.
- If something **changes in your life**, such as school, sport, when you have meals, etc., which affects your ability to take your medicine, discuss this with your doctor so any changes in your treatment plan or medication can be made. (For example, if you find you have trouble swallowing pills, ask about other ways you might be able to take your medicine instead.)
- **Get regular exercise:** Most children need 60 minutes of exercise 5 times a week. This includes walking, swimming or bicycling. Find something that you enjoy and invite your friends or family to join in as well.
- **Get plenty of sleep** each and every night. You may want to stay up late reading or watching television, but it is more important to do everything you can to make sure you feel your best the next day. Drink a lot throughout the day. Children should drink 4 to 8 cups of water a day.
- If you have **other health problems**, it is usually okay to take other medicines at the same time as your ulcerative colitis medicine. However, use care with some over-the-counter medications such as aspirin, non-steroidal anti-inflammatory drugs (NSAIDs or paracetamol). If you are unsure, check with your doctor or a pharmacist first.
- **Get help and support** from your family, friends and maybe also other children with Crohn's disease to help ensure that you have someone to turn to when you have questions or need extra help.
- **Stay positive.** Although stress cannot cause ulcerative colitis, it can affect your symptoms. If you are feeling upset, talk to a family member or friend. It may help to see a counsellor for emotional support to help you with your feelings.
- **If you plan to travel**, consider asking your doctor for a letter outlining your medical condition, in case you need to get medical attention in another city or country. You could also ask your doctor write down a brief plan for what to do if you become unwell while you are travelling. Also, be sure to bring your doctor's contact information with you, and plan ahead to find out who to contact or where to go if you have any medical needs while you are travelling. Helpful travel information for some countries is available at the EFCCA website (<http://www.efcca.org>).

### What else can I do?

- **Stoma care:** If you need to have a stoma, perhaps after an ileostomy, the bag (or pouch) must be emptied several times a day. It can, however, be hidden with clothing and is not usually noticeable. Some people worry that there will be a smell from the stoma, but this is not usually a problem. Your doctor or nurse can tell you how to care for your stoma, and tell you

about support groups run by other people who also have stomas to help answer your questions.

- **Support groups:** Joining a support group can help you find other people in your area for education, help and guidance. Many people say that meeting others with similar medical conditions can be very helpful, as well as fun. To find a support group in your country or local area, contact EFCCA (<http://www.efcca.org>).
- **Diary:** In addition to the checklist provided in this guide, you may find it helpful to keep a diary of your symptoms over the period of a month. An example is provided in [Managing Your IBD Day by Day](#).
- **Bone mineral loss:** Ulcerative colitis may be linked to bone mineral loss and hip fracture, possibly due to the use of corticosteroids, avoiding dairy foods, poor nutrition and the inflammation itself. Your doctor may tell you to have your bone density checked regularly with a scanning machine called a DEXA. If bone density is low, treatment may be needed. Additionally, you can take steps to prevent bone loss, including:
  - Regular weight-bearing exercise such as brisk walking, jogging or aerobics
  - Get more calcium and vitamin D, and also possibly vitamin K
  - Consider daily treatment to help stop any inflammation

If you have mild disease, don't worry about the section on stoma care – you will have to have had surgery to have a stoma.