

Adults with eosinophilic gastrointestinal disorders face many unique problems. Chronic illness can affect employment, insurance (health, disability and life), inter-personal relationships and family.

Family and friends may not understand that 'just a little' of an unsafe food CAN hurt you. Holidays, parties and family gatherings are often food-focused, particularly for adults. There is no need to miss out on holiday and other celebrations that are focused on food. Attend anyway, and engage in cheery conversation!

Frequently Asked Questions

How can I survive food-focused social outings?

Arriving with a full stomach can help you resist the temptation to eat potentially unsafe foods. You should always bring some 'safe' food with you just in case you do get hungry. If you are hungry, you may be tempted to cheat. However, if you bring some 'safe' food that you can eat (fruit, special cookie, sandwich etc) you may avoid this potential hazard. For some, food gatherings are a test of will power for keeping true to your diet. "Don't leave home with out your safe food!"

Can I eat at a restaurant and not have problems?

Cross-contamination is a concern whether at a restaurant, or at a friend's house. No matter how hard you try to explain, it's often difficult for someone else to comprehend just how sensitive you are, and what it really means to avoid cross-contamination issues. However, do not let that stop you from going out to dinner with friends. Most friends get together to have a fun time with each other. Join in the lively conversation, and do not worry about not eating. Really, no one will mind.

If you really want to eat with the gang, there are a number of ways to eat safely. If you know which restaurant you are going to, call in advance, but do not call during a busy time. Calling in mid-afternoon between lunch and dinner is a great time. Ask to talk to the chef (or restaurant manager) and discuss your issues. Most restaurants really do want to help you, and it is much easier to explain your needs when you can get the full attention of the staff.

If you are still not comfortable about having the restaurant cook your food, just bring your own food and ask them to prepare it for you (microwaving is easy!). If the restaurant is close by, you might want to stop off at a slow time and give them your food. Then when you arrive, just tell the waiter you are the one with the 'special' meal, and most people will never know that you made your meal yourself. Bringing your own food will definitely go a long way in making you feel like part of the group.

How can I cook for my family?

Cook a meal that celebrates the kind of food you can eat. Alternatively, let unaffected family members participate in food preparation, while you take on other chores. For

most of us, our diets are still varied enough that most people will not notice that we prepare a 'restricted' meal. Family members with unlimited diets can learn to either cook for themselves or eat meals from the restricted diet 'menu'.

Help! I'm having a party - How can I entertain guests with my limitations?

Most people with EGID still have a varied menu. Just serve up the things you can eat – most people will never know the difference. Another way to approach entertaining is to have a food-free activity like games, outdoor events, a visit to a museum, or even taking a small hike. For an outdoor activity, most people will bring their own food or purchase a snack.

Traveling can be challenging. Do you have any suggestions for eating on the road?

For day or short excursions, bringing your own food or calling your destination in advance for availability of special foods is the safest bet. Most restaurants are willing to reheat a meal that you have brought for yourself. If you require formula and specialty food items, they can often be ordered and mailed ahead of time to your destination. That way you will have room in your luggage for clothes!

Depending on your food restrictions, try staying at a hotel that has a kitchen in the room. Residence Inn, Extended Stay America, and Summerfield Inn are some examples. That way, you are not dependant upon eating in a restaurant all the time. If you are looking for a wonderful vacation, you can often rent a house in a great location. Again, the goal is to find ways to ease the food issues while traveling.

Is EGID serious enough that I need a Medic-Alert™ identification (or similar)?

A Medic-Alert medallion or bracelet to alert emergency workers can inform medical technicians of your unique medical situation - otherwise they may give you medicine containing gluten, lactose, or other food-derivatives. Medication allergies should also appear on the bracelet.

This disease seems to be ruling my life, how can I change that?

Don't let the disease rule your life or make you depressed. There are so many things in life other than food! If you cannot eat out due to allergy concerns, invest in a nice picnic basket and regularly go for picnics with your family or friends. For social gatherings, go to interactive museums, bowling, art museums, miniature golfing, and other activities that do not involve eating

Preparing your special food in advance or in large quantities and freezing will allow you to spend less time on food preparation, enabling you to focus on more important aspects of life.

How do I find a physician that understands my problems?

Transition from a pediatric to an adult physician can be particularly stressful. Not all adult gastroenterologists have a lot of experience with EGID or food related issues.

Researching doctors well ahead of the transition time will pay off in the long run. This advice applies prior to relocating to another city, or a change in insurance plans.

Some typical questions to ask when looking for a new doctor: What area of gastroenterology do they specialize in? How many patients with EGID has this doctor cared for? Are they willing to learn? Do they have a nutritionist they work closely with?

The reality is that the search for an adult GI that you feel comfortable with may take some time. Dealing with a chronic illness requires a strong doctor-patient relationship, so it is worth looking and waiting for the right doctor you can work with. It is important that you can develop mutual trust and a partnership in dealing with this illness.

I find I am frequently stressed and depressed because of my chronic illness. Is there help available?

Depression and anxiety are very common in adults coping with chronic illness. The psychological impact of facing a life-long, incurable illness should not be underestimated. If you feel you are having difficulty coping, get help early. Your family physician may be able to refer you to an appropriate specialist who understands the psychological impact of chronic illness. While many psychologists can help you, finding one that specializes in chronic illness may take some legwork. You will find psychologists who specialize in terminal diseases (cancer), but living with a chronic illness requires a treatment strategy.

I can barely juggle my family's needs now, how can I do it while sick?

Patience is a key here. At times, it may take the entire family's support and patience to see through a rough patch. Rest as often as possible to reserve strength. Compliance will help minimize these events. If you do not take care of yourself, you CANNOT take care of others.

Encourage your family to educate themselves about your illness. Leave written instructions on medication dosages and scheduling, food ingredients and label reading. For those dependent on formula or tube feedings, educate your family on care of your tube and feeding pump.

How does EGID disease affect my social life?

Dating can be a rough issue. Suggest activities that are non-food related. Beach, lake, hike, bowling, museums, theater, ice skating - life is full of enjoyable non-food related adventures. Alternatively, learn to accept that others eat- call ahead to the restaurant, prepare ahead of time- or- just enjoy a good conversation while the other person eats.