

The Importance of Planning

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The hardest requests for assistance that I receive from IBD patients are the ones to which I have to respond that it is too late—too late to find insurance for a grown child who no longer is eligible under her parents' health insurance plan; too late to take Family & Medical Leave to avoid loss of a job; too late to get a school to accommodate a child with a disability because there was no section 504 plan in place.

Patients, caregivers, and parents of school-aged children with IBD should think of all the things that can and will happen *before* they do

in order to avail themselves of the maximum protection afforded by law. Of course, not everything an IBD patient deals with can be planned for, but certain things can. When planning is possible, you should make every effort to ensure that you won't be blindsided.

When Your Child with IBD is Too Old to Be On Your Health Insurance Plan

All health insurance plans that allow coverage of dependents terminate coverage when the dependent reaches a certain age. Typically, the age is in the early 20s, but in some cases, it is tied to the time when your child is a full-time student. If you don't know how long your child can remain on your plan, my first advice is to find out. Then, plan for it.

If your child is going from school to a job in which she has full health insurance coverage effective immediately, then you needn't make other arrangements. However, that is becoming less and less the norm. Chances are there will be a waiting period during which your child's new insurance will not cover her pre-existing IBD, or perhaps your child will not be well enough to be a full-time student. Indeed, perhaps your health care plan will not cover your child over age 18 even if she is in school. If you wait, there will be a gap in coverage. Not only can that be expensive because of the cost of medical care, but it can allow a new insurer to invoke a pre-existing condition exclusion that otherwise would be prohibited.

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Under federal law, if you go from one employer-based group health plan to another, there cannot be a pre-existing condition exclusion. However, that applies only if you do not have a break in coverage of more than 63 days. That means there cannot be more than 63 days from the time your child's coverage under your plan ends and the time when her new plan begins. How to fill the gap? COBRA.

Although most of us think of COBRA as a bridge from one employer-based health insurance plan to another, it also applies when your child becomes too old to be covered under your plan. COBRA allows you (or your child) to continue your insurance for your child for 18 months (or longer if she is disabled at the time she becomes eligible for COBRA). You or your child will have to pay the premium, but that will be far less expensive than an unplanned hospi-

talization if you allow the insurance to lapse.

So your first line of defense is COBRA. Even if your child has a plan available at school, you will find that those plans generally offer less expansive coverage than what is available through your employer-based group plan. You may choose to use COBRA for as long as the law allows, even if there is an option offered to students. The only time you won't have the option to choose COBRA over an alternative is when your child moves into a job that also offers health insurance. Typically, insurers see employer-based group health insurance as primary, and you cannot have two primary insurers at once. Thus, if your child takes a job that offers health insurance, typically, you must let the COBRA lapse. There are two exceptions to this general rule. First, I always overlap for a month, keeping my COBRA

until I know for sure that my new insurance is in place. This is not a problem unless you try to file a claim under your COBRA policy that the other insurance would have paid, and your COBRA insurer finds out that there is other coverage. The reason I keep my COBRA is so I can file a claim under my new policy and ensure that it is paid before I let go of my COBRA coverage. I don't run into a problem because, once my new policy kicks in, even though I pay the COBRA premium for another month, I don't use it unless the new policy turns out not to cover what I need.

Second, if your child is not going from one employer-based group insurance to another with fewer than 63 days' break in coverage, your child's new insurance may not cover her pre-existing IBD for six months to a year. In that case, I suggest that you hold on to your COBRA policy

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and use it for IBD-related claims. Your COBRA policy becomes secondary; you can use it only when your primary insurance does not cover something. Indeed, it may take a bit of a fight to retain both policies since both are employer-based and, thus, typically primary insurance. However, most likely, this fight won't arise because you will be dealing with two different insurers. Although this is an expensive option because it means paying two premiums, it is far less expensive than a week's stay in a hospital for Crohn's-related medical care.

If your child will not have the option of a new employer-based health insurance plan, it is even more important to know what alternatives exist. The answers will differ from one state to the next, so the best I can do here is to give you an outline of what to look for.

First, many states have high-risk pools. If you have a copy of *Know Your Rights: A Handbook for Patients with Chronic Illness*, see Appendix E for a list of high-risk pools and contact information for each state's pool. Or you can start by calling your state's Insurance Department. Most high-risk pools are administered by the State Insurance Department, so they should be able to tell you where to obtain more information on your State's plan. If you have Internet access and search for "high-risk pools," you will find lists of available pools in the various states.

High-risk pools are not the answer for everyone. First, not all states have them. Second, the quality of these plans varies from state to state. Believe it or not, although these plans are designed for people

with chronic illnesses, some of them have a six- or 12-month pre-existing condition exclusion. Some are very expensive, and some do not provide very good coverage. Pay particular attention to prescription drug benefits, which often are limited. The fact that your state has a high-risk pool does not necessarily mean that you've found a workable solution. You have to investigate your state's plan in order to determine whether it will be of value to your child.

The other option is a "guaranteed issue" policy. Insurance companies issue these policies because some states require them to do so if they wish to do business in those states. If you live in one of these states, your State Insurance Department should be able to provide a list of insurers that have guaranteed issue policies. However, the only "guarantee" is that there is a plan; there is no guarantee that it is affordable or provides good coverage. Like high-risk pools, guaranteed issue policies can be very expensive and/or not provide very good coverage. Again, you must research what is available in your state.

As you can see, all of this takes a lot of research and a lot of time. One excellent source that I use a lot is www.healthinsuranceinfo.net, a Georgetown University Web site that has a summary of what is available in each state. You can choose your state and easily determine whether there is a high-risk pool or guaranteed issue plan; however, you still will have to track down the details of the available plans on your own. Planning for the inevitable will allow you the time to do all the necessary research and find the best solution for your family.

Planning For Work Absences

Another area where planning is critical is in the context of work. Whether you are a working patient or a working caregiver of an IBD patient, you can count on some absences during the year. Absences can run from a surgery and recuperation period to a two-day absence every eight weeks for Remicade® infusions. Regardless of the length or frequency of absences, under the Americans with Disabilities Act, you can be fired for absenteeism, even if you are absent due to a chronic illness. How can you avoid being fired? The answer is to take leave under the Family & Medical Leave Act (FMLA).

The FMLA provides up to 12 weeks of unpaid leave time in a 12-month period for employers with 50 or more employees. Some states have less restrictive laws, providing FMLA leave for smaller employers and/or for longer periods of time. The catch, though, is that you have to request FMLA leave in advance; you can't wait until it looks like you are about to get fired because you have missed a lot of work. Once you have FMLA leave, you cannot be fired for using it. This is the only protection against job termination due to absenteeism of which I am aware.



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Every person who might need FMLA leave should apply for it at the beginning of every year. Some employers will ask you to fill out a form; for others, you just submit a written request in the form of a brief note. You also must provide a medical certification, but you do not have to provide detailed medical records. Your employer has the right to select which of several ways the company will count the 12-month period—it can be the calendar year, the fiscal year, or a rolling 12-month period established by the employer. You should be very aware of how your employer counts the relevant 12 months.

In addition, your employer may make you use your paid sick and vacation leave during an FMLA leave. In general, FMLA leave is unpaid. However, your employer is not required to give you 12 weeks of FMLA leave and an additional two weeks' vacation time. Your employer can require that you apply your paid vacation and sick time to your FMLA leave.

You do not have to wait for a crisis before asking (in writing) for FMLA leave. You can do so at the beginning of the year on the basis that you have a chronic illness and, thus, some absences can be anticipated each year. You may or may not use up your 12 weeks of leave every year. You lose nothing by not using up all of your time.

FMLA leave ensures that you cannot be fired as long as you do not use up more than 12 weeks of leave time. If you plan in advance, you can protect your job; if you don't, you can be fired for absenteeism. Planning is the key.

Section 504 Plans for School-Aged Students with IBD

Finally, all too often, I get calls from parents whose child has made it to final exams, but the child has a flare during exams and the school refuses accommodation because it was not sought earlier in the year. Designing a section 504 plan at the beginning of every school year can protect against this sort of last-minute crisis.

Section 504 of the federal Rehabilitation Act addresses disparities in education faced by children with physical disabilities. The standard for determining if a child is disabled is the same as the test under the Americans with Disabilities Act. Although the courts are by no means unanimous, most children with IBD will be found to be substantially impaired in the major life activity of disposing of bodily waste, which would render them disabled in the eyes of the law.

Although most children with IBD will not need special education services, they may need accommodation due to their disability. For example, they might need “stop the clock testing,” which means that the clock stops when the student goes to the bathroom, and starts again when the student returns to continue work on the exam. These sorts of accommodations are negotiated and put in writing in the form of a section 504 plan.

Two CCFA member families recently approached me about creating a “template” section 504 plan for children with IBD. I worked on the template with those two families, along with a social worker at the IBD Center at Boston's Children's Hospital and two psychologists at NYU who are experts in chronic disease. The template is available upon

request from either CCFA or Advocacy for Patients. If you would like it, please email me at patient_advocate@sbcglobal.net and I will send it to you. Please note that it is intended to cover the universe of issues that might face children with IBD. No one student should need the entire template as his or her actual section 504 Plan.

Once Again

Whether you're concerned about a gap in insurance coverage for your child or yourself, an extended leave from work, or that your child gets the best education possible, the best advice remains the same: plan ahead. Resolving many of these issues will take persistence and patience, no matter how early you start, but the more time you allow for the process, the greater your chance of reaching an acceptable resolution. More information on all of these topics and more, is available in *Know Your Rights: A Handbook for Patients with Chronic Illness*, available at www.ccfa.org/store. ■

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