Special problems

Osteoporosis

Over half of all patients with inflammatory bowel diseases suffer from reduced bone mineral content. While such bone loss can be mild or severe, both forms respond to drug treatment. Patients' bone density should be measured especially in cases of long-term administration of cortisone preparations. Bone density is measured using radiologic methods that expose the patient to relatively low doses of radiation. Therapy in mild forms of bone loss consists of the administration of vitamin D and calcium. More severe bone loss may require the use of other drugs (bisphosphonates). These drugs directly inhibit bone destruction but are associated with a higher rate of side effects than vitamin D and calcium.

Inflammatory bowel diseases during childhood

It would appear that the frequency of Crohn's disease in children is increasing. Thus, children and adolescents should be just as carefully examined and treated as adults. An additional problem in these young patients is the fact that both the chronic bowel inflammation and, in some cases, the necessary drugs may result in disturbances of physical development. In such cases, as well as in patients who do not respond to drug treatment, surgery must be considered. This will at least temporarily remove the site of inflammation. Children by nature are more greatly affected than are adults by psychic stress. They also suffer more profoundly under the effects of chronic diseases and therefore should be seen by a child psychiatrist as early as possible after first diagnosis. More so than with adults, it is advisable that the treatment of inflammatory bowel diseases in children should be conducted in cooperation between the child's family doctor and a clinical center.

The risk of cancer

The well-informed patient understands that the danger of cancer is associated with any chronic inflammation that persists for a long period of time. What does this mean, however, for patients with ulcerative colitis or Crohn's disease?

Studies have shown that there is an increased risk of cancer in patients with ulcerative colitis in whom the entire colon is affected and in whom the disease starts early and has persisted for more than 10 years. For this reason, all patients who have suffered from ulcerative colitis for longer than 10 years should undergo endoscopic examination of the

colon at least every two years. This is the only way to detect the early signs of malignant degeneration, such as dysplasia. If discovered in time, the development of colon cancer can be prevented by surgically removing the colon (a so called colectomy, see treatment ulcerative colitis). However, since several stages of dysplasia are known, a colectomy might not be always necessary. This has to be discussed with the treating physician on an individual basis. The risk of cancer is significantly lower in Crohn's disease. However, when only the colon is affected, colonoscopy should be performed every two years in patients whose disease has persisted more than 10 years.

Psychic stress

The realization that you have been diagnosed with a chronic disease and will be confronted with it and its associated problems for many years to come naturally affects your personal sense of intactness and psychic constitution in a very profound way. What can you do in order to better cope with these problems?

Rule number one: You must confront your disease, then come to terms with it and accept it. You have the advantage of recognizing your disease, an advantage not shared by many other people. Coping with such a disease has its purpose and can be a source of enhanced self-confirmation and worth.

Rule number two: You must not let your illness control you. Those who lose courage suffer the most from their disease. You must actively confront your disease and live a normal life – despite and even because of your disease. All means of actively confronting your disease are open to you. First and foremost, of course, are rational medical treatment and drugs. However, other alternatives – again, after consultation with your doctor to prevent undesired consequences – are preferable to losing heart and doing nothing. Disease attacks the individual as a whole. All therapeutic measures must therefore also treat the person as a whole.

You are not alone in your disease. Coping with a chronic or other long-lasting illness can be made much easier by talking about it and its problems with others suffering from the same disease. Patient associations have been formed in many towns and countries. In the USA this is the Crohn's and Colitis Foundation of America (CCFA).

Disability and career

You are unable to work during the active phase of your disease. This is equally true for inflammatory bowel diseases as for any other disease and applies to every profession or line of work. Because of the typical chronic, episodic course of the disease, you must be prepared, whatever your work, for short, disease-related periods of disability. However, job re-training or giving up a career are only necessary in a few individual cases. Under certain circumstances, such as after major abdominal surgery, the presence of fistulae or in patients whose disease has not responded adequately to medical treatment, heavy physical work is not advisable. Such patients, however, can normally perform other jobs involving only light physical activity or that can be performed in seated position.

Similar considerations apply to recreation as apply to work and career. All options remain open to you despite your disease. Only in phases of severe inflammation should certain restrictions be placed on your physical activity. With the exception of high-performance sports, physical activity in any form is fully recommended. This is true even in patients undergoing long-term drug treatment. In fact, particularly in patients receiving cortisone preparations, regular exercise of the muscles, joints and bones is highly recommended and may help reduce or prevent some of the side effects of these drugs. It is also normally possible to take vacations in foreign countries. The required vaccinations, however, should be given only after consultation with the physician treating your IBD, though, as a rule, there is no reason not to get them. One special factor is the long-term treatment of Crohn's disease with the antibiotic, metronidazole or with sulfasalazine. Patients receiving this drug should protect themselves from direct sunlight and avoid alcohol.

Sex and partnership

Here, too, no specific restrictions are required. Sexual activity will naturally be reduced during an acute disease flare-up. In females, the body's natural mechanism for conserving its energies and resources may result in interruption of menstruation. The formation of fistulae in patients with Crohn's disease may, in certain cases, affect the internal and external genital organs, resulting in a mechanical restriction of sexual activity. Such fistulae require intensive medical attention and drug therapy. Thus, prompt consultation of a physician is advisable.

Reproduction and genetic factors

In our discussion of the causes of inflammatory bowel diseases, we noted that genetic predisposition probably plays a role in both ulcerative colitis and Crohn's disease. Should this be considered a reason not to have children? The probability of inheriting a predisposition to inflammatory bowel disease is low. Thus, the risk that children of persons with IBD will develop either ulcerative colitis or Crohn's disease is therefore not considered to be very high. This small risk should not deter persons affected by IBD from having children.

Pregnancy

This section is closely related to the last. Is it advisable for women with IBD to become pregnant and should these women attempt to carry pregnancies to term and deliver normally?

In answering these questions, it is important to state at the outset that pregnancy has not been shown to adversely affect the clinical course of either ulcerative colitis or Crohn's disease in any way. Thus, the decision to conceive can be supported in patients who desire children. It is, of course, important to plan the pregnancy, so that it does not occur

during a period of more pronounced disease activity. During pregnancy, patients should be carefully monitored in cooperation between an internist and gynecologist. Should an acute disease flare-up occur during pregnancy, treatment with cortisone and 5-aminosalicylic acid preparations is possible. Careful administration of these drugs will control inflammatory activity without producing side effects in the embryo. Patients undergoing long-term treatment with azathioprine and/or anti-TNF agents (Remicade®, Humira®), however, should use contraception and discuss with their physician if they should stop this drug before becoming pregnant. Female patients treated with methotrexate have to stop the drug at least 3 months before they plan to become pregnant. The two most effective methods of birth control, the pill and the intrauterine device (IUD), are both somewhat controversial in patients with IBD. The best form of contraception must be individually decided, if possible, by an internist and gynecologist working together.

"Ileostomy": the artificial bowel outlet

Newly developed surgical techniques make it possible in many cases of ulcerative colitis to remove the entire colon without permanent creation of an artificial bowel outlet, or "ileostomy" . In fact, a permanent ileostomy is required only in very rare cases. The creation of a temporary ileostomy in patients with ulcerative colitis and Crohn's disease may, however, actually have a beneficial effect on the disease. The ileostomy is usually closed after four to six months. Modern ileostomy appliances make it possible to live a practically normal life, including sports and sexual activity, despite the artificial bowel outlet. Early retirement due to a permanent ileostomy is necessary only in the rarest of cases.

If, however, your disease and its treatment do require the placement of an artificial bowel outlet, you should contact and listen to the experiences of others who have been in your condition. Ileostomy patients have formed associations in many cities and countries. In the triangle this is the Triangler Ostomy Association, which serves the ostomy and J-pouch community (http://www.raleighuoa.org)