

Interstitial Cystitis: A Primer for Nutrition Educators

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Author: Confident Choices: Customizing the Interstitial Cystitis Diet



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Interstitial Cystitis (IC) is a puzzling bladder disorder that is characterized by “urinary frequency, urgency, nocturia, and suprapubic (bladder and/or pelvic) pressure and/or pain in the absence of any identifiable cause, such as a bacterial infection.” (1) Research has yet to discover a distinct cause, and diagnosis may take months or years as physicians rule out other urinary tract disease such as infection or cancer, frustrating patients and clinicians alike. Examination of the bladder wall by cystoscopy, generally done under anesthesia, often reveals inflammation and ulcerations, but absence of such evidence does not exclude diagnosis if the patient presents with clinical symptoms. Although IC can become disabling in some cases, treatment can effectively increase the quality of life of a patient. Treatment plans are individualized for each patient, and success, even a remission, may be attained by combining lifestyle changes, medications, and dietary modification.

Challenges of Dietary Intervention in IC

Despite the fact that there is no scientific evidence linking diet to IC, the effects of particular foods on interstitial cystitis have been observed for decades by patients and doctors. In fact, a 2004 online survey by the Interstitial Cystitis Association recorded that 91% of patients with IC report that their symptoms are affected by foods, beverages, and dietary supplements, and 84% report symptoms reduced by changing some aspect of their diet. (2) At diagnosis, patients often receive one of several, confusing “good food/bad food” lists and are seldom referred to a dietitian. Unfortunately, the simplicity of a good food/bad food list belies practical observations that different foods (including various quantities of the same food) may or may not increase symptoms in individual IC patients. Some researchers explain this phenomenon by differentiating foods either as allergenic to the bladder or as bladder irritants. Complicating matters, it may take months of trial and error to develop an overall treatment plan that is effective for an individual. Patients may become depressed, anxious, and distraught as hope for relief and remission are challenged repeatedly. Despite these obstacles, dietary modification is a low-risk treatment with potentially huge benefits to an IC patient. Dietitians are in a unique position to aid IC patients on their journey to healing.

Using an Elimination Diet

Applying an elimination diet in conjunction with a voiding diary is often the first step in discovering food triggers for IC patients. First, a patient must do a weeklong voiding diary before they begin manipulating their diet. Documentation can be cumbersome, but is necessary to determine accurately the effects of dietary intervention. Patients may use a simple notebook or personal calendar to document day, time, symptoms, and volume of urine voided; or they may use a form provided in this module that was developed by the Interstitial Cystitis Network.(3) Then, the dietitian should evaluate the patient’s motivation to undergo a lengthy discovery process coupled with his or her motivation to change in order to determine which type of elimination diet will work best.

The “simple exclusion diet” taught in this module may be all that is needed for most patients to determine if a suspect food is affecting their IC symptoms. With guidance from a

dietitian, a patient will eliminate suspect foods and wait for symptoms to diminish. Then, by adding those foods back slowly one by one, and assessing the recurrence of symptoms, an individualized list of foods to avoid is developed.

For patients who feel as though all foods cause them symptoms, the “empirical diet” may provide better results. Beginning with the “safe” foods generally recommended for IC patients, and eliminating the foods that most IC patients have trouble with, a patient can add foods back in one at a time, or one food group at a time. The skills learned in the application of the simple exclusion diet can be adapted for use when implementing the empirical elimination diet.

The most drastic method to determine food triggers for an IC patient is the “few foods diet.” In this scenario, rather than use IC “safe” foods as the starting point, the patient builds a basic diet using foods that the patient identifies as least likely to personally cause them trouble. As in previous methods, the patient adds foods back slowly while documenting symptoms in a voiding diary. If symptoms increase, the food is eliminated again. One by one, a personalized list of trigger foods is developed. In addition to whole foods and food groups, a dietitian may help the patient investigate reactions to additives and preservatives, including the addition of vitamins to products. Food may also have different affects on people in raw and cooked forms. Finally, IC patients may experience different symptoms from food at various stages of the disease. In fact, after treatment, many IC patients find that they can add back some foods in small quantities.

Just as important as dietary guidance, the dietitian can provide an emotionally stable link in treatment for the IC patient. The average IC patient sees seven doctors before diagnosis. Medical treatments are often experimental and may take months of trials before assessing the benefits, if any, of an individual treatment. Patients’ personal lives may become challenging as they try to explain a disease that affects personal body functions to their family and friends. Many IC patients have been told for years that the disease and the pain is “all in their head.” By providing nutrition information, and guidance in food elimination, a dietitian is in a unique position to help the IC patient overcome the struggles of their disease, replacing them with messages of hope and healing.

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2. *Your Opinion Counts! ICA Survey: IC and Diet—Results*. Interstitial Cystitis Association. Retrieved June 23, 2004 from Interstitial Cystitis Association website:
<http://www.ichelp.com/youropinion/Survey-Diet-Results.html>
3. Osborn, J. (Ed.). (2003). *Elimination Diet Strategies*. Retrieved January 13, 2004, from Interstitial Cystitis Network Web site:
<http://www.ic-network.com/handbook/eliminationdiets.html>

Resources

1. Confident Choices: Nutrition and Lifestyle Education for Interstitial Cystitis and Overactive Bladder Patients: www.NutraConsults.com/confidentchoices.html
2. Interstitial Cystitis Network: <http://www.ic-network.com/>
3. Interstitial Cystitis Association: <http://ichelp.org>
4. National Institutes of Health:
<http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/>
5. The National Women's Health Information Center:
<http://www.4woman.gov/faq/intcyst.pdf>