Coping Strategies
Connecting with Others for Help

Tools for Dealing with the “Diagnosis”

When Is It Time to See a Therapist?

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Addressing Emotional Health

Individuals with chronic illness know that the hardest part of living with an incurable illness is typically not the physical pain but the emotional pain. It’s possible to learn to tolerate the physical pain. But the feelings that come with the emotional pain — anger, fear, loss, depression — can be overwhelming. In this issue of IG Living, we focus on a variety of strategies that could help patients accept and adapt to the emotional turmoil illness inflicts on the psyche.

We begin with our article “Dealing with a Chronic Illness Diagnosis,” which discusses the various types of coping patterns and strategies patients and their caregivers can use to create a more positive outlook. While it takes practice, patients can employ tactics to change distorted thoughts and take steps to ensure their lives aren’t labeled by their disease. Physicians can help, too, by recognizing a patient’s personality type and interacting in a manner that can be most helpful.

Many self-help strategies for coping with illness are available, but mental health counselor Stephanie Lauer shares her favorite in her article “Using Dialectical Behavior Therapy Skills to Cope with Chronic Illness.” Specifically, she describes four DBT skills patients can use to 1) stop fighting their illness and accept it, 2) make themselves feel better, 3) take a different action than normal when faced with a difficult situation and 4) better communicate with friends and families.

Sometimes, though, consultation with a specialist educated to deal with emotional issues is needed. Emotions can range from grief to a vicious cycle of depression. But, it is possible to heal emotional pain and suffering with the help of a therapist. Our article “Is It Time to See a Therapist?” outlines the different types of chronic illness therapy, as well as the professions trained to lead these sessions. And, patients shouldn’t be reluctant to seek help due to financial constraints. Insurance plans often cover therapy, but if not, other options are available.

Help can also come by way of practical assistance. Simply getting a helping hand so that patients can focus on their physical and emotional health can greatly help to ease the burden of chronic illness. Enter the role of the patient advocate. This emerging healthcare occupation is explored in our article “Paving the Way for Healing: The Role of the Patient Advocate.” It’s surprising how many tasks patient advocates can perform. From helping with understanding diagnosis and treatment, to scheduling appointments, performing needed research and resolving doctor and insurance conflicts, help is available. But, as with anything else, due diligence is advised when choosing an advocate.

As always, I hope you gain insight from the information presented and enjoy this edition of IG Living.

R onale Tucker Rhodes, MS
Proposed Medicare Part B Reimbursement Policy: The Unintended Consequence

By Abbie Cornett

WHEN POLICYMAKERS set about fixing a perceived problem, they frequently look at it from what is known as the “10,000 foot view.” This means they are viewing the problem from a “big picture” perspective. But, the folly of making revisions based on this perspective is that many details aren’t taken into consideration. This omission can cause especially troublesome results when approaching a perceived problem in a system as large and complicated as healthcare. If recent history is any indicator, the first thing policymakers need to take into account when looking at making a change in healthcare is that no change comes without unintended consequences. Indeed, ill-considered change can dramatically affect access to healthcare and patients’ well-being.

History has shown that altering reimbursement can have a negative effect on access to treatment.

In recent months, a number of policy changes have been placed under consideration that could greatly affect the lives of people with chronic illnesses and life-threatening diseases. The most recent is a demonstration project conducted across many providers may stop providing certain medications. These changes come without unintended consequences based on this perspective is that fixing a perceived problem in a system as large and complicated as healthcare. If recent history is any indicator, the first thing policymakers need to take into account when looking at making a change in healthcare is that no change comes without unintended consequences. Indeed, ill-considered change can dramatically affect access to healthcare and patients’ well-being.

Preserving or enhancing the quality of care provided to Medicare beneficiaries.” The Centers for Medicare and Medicaid Services believes that the current reimbursement rate motivates providers to prescribe more-expensive versus less-expensive drugs. While the intent of the plan, which is to save money, may be desirable, the potential unintended consequence to the most vulnerable patients is not: Many providers may stop providing their most clinically effective lifesaving medications.

Currently, Medicare pays for Part B drugs by reimbursing providers the average sales price (ASP) plus 6 percent. Under the proposed model, providers would be reimbursed ASP plus 2 percent plus an additional flat fee of $16.80 per drug per day. But when outpatient setting may be forced into care in a hospital setting.

History has shown that altering reimbursement can have a negative effect on access to treatment. When the Medicare Modernization Act of 2003 altered Part B drug reimbursement from average wholesale price to ASP, patients had difficulty finding physicians who could afford to treat them with intravenous immune globulin (IG). When their physicians could not recover the costs of IG therapy, patients were forced to forgo treatment or seek it in a more costly hospital setting.

Before any further action is taken on the proposed Medicare Part B reimbursement policy, policymakers need to address these real concerns of patients and physicians. Otherwise, history will repeat itself, and the unintended consequence of trying to save money will result in patients failing to receive the medicines they need to live.

As the patient advocate for IG Living magazine, I will continue to keep you updated on this and other issues that may affect your access to care.

References

ABBIE CORNETT is the patient advocate for IG Living magazine. She can be reached at patience@igliving.com or (800) 843-7477 x1366.
There are no drug interactions between Coumadin and immune globulin (IG); however, one of the risks of IG therapy is the potential to cause blood clots. You need to make sure the physician who has prescribed your IG is aware of the blood clot and that you have started taking Coumadin. You also need to inform the healthcare provider who is administering your infusion that you have a blood clot and are currently taking Coumadin.

Michelle: Typically, patients with CIDP see improvement after one to three courses of IVIG therapy. If you are not seeing improvement, and in fact are declining, you need to follow up with your physician as soon as possible to discuss discontinuing IVIG and to determine what the next step in therapy should be. There are many options that may improve your symptoms. Steroids are but one treatment option; other immunosuppressive agents such as CellCept (mycophenolate mofetil), Imuran (azathioprine), methotrexate (Trexall, Rheumatrex) or Rituxan (rituximab) may also work. Some physicians may also try plasmapheresis.

Also, there are many causes and types of neuropathy. If you are not responding to IVIG, your physician may want to run additional tests to determine if there is another cause for your neuropathy.

Michelle: I have been diagnosed with chronic inflammatory demyelinating polyneuropathy and will be receiving intravenous immune globulin (IVIG) treatment at an infusion center. I am on Social Security Disability and have Medicare Part A and Part B, but no supplemental insurance at this time. Since open enrollment for supplemental insurance isn’t until October, I need to know what costs I will be responsible for.

It is best to discuss the cost of treatment with the infusion center prior to starting therapy so you will know the amount you will be expected to pay.

Leslie: Medicare Part B does pay for IVIG administration in either a physician’s office or a hospital outpatient infusion center. Coverage is based on meeting the criteria outlined in a published LCD (local coverage determination). As long as the clinical documentation from a physician supports the LCD criteria, Medicare Part B will pay for 80 percent of the cost, with the patient being responsible for the remaining 20 percent (typically covered by a supplemental or Medigap plan). Without a supplemental plan, the 20 percent is the patient’s responsibility.

Michelle: I have chronic inflammatory demyelinating polyneuropathy (CIDP) and have had eight intravenous immune globulin (IVIG) infusions with no apparent improvement. In fact, my condition (leg weakness) is getting worse. Should I continue with IVIG therapy or go with the dreaded steroid therapy?

Leslie: There are no drug interactions between Coumadin and immune globulin (IG); however, one of the risks of IG therapy is the potential to cause blood clots. You need to make sure the physician who has prescribed your IG is aware of the blood clot and that you have started taking Coumadin. You also need to inform the healthcare provider who is administering your infusion that you have a blood clot and are currently taking Coumadin.

Have a question? Email us at editor@IGLiving.com. Or, submit your question on our Ask the Experts page on the IG Living website at www.igliving.com/life-with-ig/ask-the-experts.html. Your information will remain confidential unless permission is given.

Michelle Greer, RN, is senior vice president of sales at NuFACTOR Specialty Pharmacy.

Leslie J. Vaughan, RPh, is senior vice president of clinical programs at NuFACTOR Specialty Pharmacy.
Where do you infuse?

After two initial hospital-based infusions (to watch for reactions), I’ve had all of my infusions at home. It’s a much better experience. It’s more comfortable, and I get to develop a one-on-one relationship with the nurse, rather than a different nurse each time who is helping multiple other patients at the same time. Also, after seeing the cost difference, it seems like a responsible way to counter the rising cost of healthcare services.

— C Moore

Do you suffer from fatigue?

Yes, especially when I am having a flare of fever. After a flare that lasts more than four days in a row, the fatigue really builds.

— D Konrad

Sometimes, I tell people I am sick and tired of being sick and tired. I know many of you feel the same way.

— J Gardner

Yes, and I try to fight it and clean. Then, I go to bed very early. Sometimes, I can’t fight it. My 10-year-old daughter is the same way. She has had common variable immunodeficiency (CVID) for five years. I say to my hubby: I am having a CVID tired day. He already knows before I tell him.

— PM Burton

How do you feel about biosimilars?

I am not comfortable with the unknown.

— J Gardner

I agree, scared. If it ain’t broke, don’t fix it. I’d bet there’s greed involved on several levels.

— PS Byers

I think biosimilars are dangerously being demanded by insurance companies. No one reacts the same way to similar medications. I do best with Gammagard SD, which has the lowest profile of IgA. Others cause much worse side effects. Another problem is not being able to order specific IG products. I used to get my infusions in the hospital and was forced to use whatever its formulary was that month.

— I Filitti

Biosimilars are less-costly imitations of biologics, but they are not exactly identical to them.

I hate the idea. I ran into this problem some years back. We all kind of had our own outside support group. After everyone got their new product, they came back in for their next infusion and said they had gotten hives from the cheaper product, and they switched everyone back to their original product. The head pharmacist was [upset with] all of us and actually came and argued with me during my infusion when I wasn’t feeling well and would not stop yelling at me until I asked my nurse to call security. The pharmacist left. Funny — a doctor and nurse gave us the idea.

— D Sprayberry

By Terry O. Harville, MD, PhD

Previously, we discussed how disruption of the timing of developmental events in an embryo can result in the incorrect formation of structures, causing the features of DiGeorge syndrome (DGS) or partial DGS. And, many of the problems DGS patients experience such as recurrent infections, bone issues and gastrointestinal (GI) problems are a result of these malformed physical features.

For instance, when the trachea and esophagus do not form correctly, aspiration into the lungs can result in respiratory disease; therefore, it is recommended that reflux precautions be taken for all DGS patients. When the timing is off during the formation of the Eustachian tubes, nasal passages and sinuses, they may not drain properly and consequently become readily infected and re-infected. Even if the thymus is functioning normally, with normal T lymphocyte production, children with DGS features may have chronic ear or sinus infections due to lack of appropriate physical development in these areas. For example, the Eustachian tubes may be very narrow and slanted in a direction other than normal, resulting in improper drainage. In these cases, the cause of chronic/recurrent ear infections is physical and not due to an immune deficiency. Insertion of tubes may be required in these children’s eardrums to help with drainage to reduce infections. It’s likely these children may require daily antibiotics to reduce infections, at least until they have grown enough in size to overcome the original malposition to allow for better drainage of the Eustachian tubes.

Incorrect position and growth of tissues are not limited to the head and neck regions in DGS. Midline development may also be affected such as the heart and blood vessels in the chest, which will be discussed in more detail in a future issue. In addition, some patients with DGS may have abnormal development of some of the bones of the spine. Depending on what went awry during development, some extent of scoliosis may occur. Also, the ribs may not develop appropriately, resulting in incorrect articulation with the spine or unexpected branching in the front of the chest. The breastbone may be affected as well. While most of these bone irregularities do not result in significant problems, more intervention may occasionally be required to deal with the scoliosis or incorrect articulations of the ribs.

Incorrect development of muscle tissue in the esophagus (due to the parts failing to join together as expected) can extend downward, resulting in swallowing difficulties. During normal development, the GI tract begins as a long tube (from the mouth to the anus). As the esophagus, stomach, small intestine and large intestine begin to develop, parts of the small intestine become even more specialized to carry out specific digestive functions. While this is occurring, the GI tract becomes longer, and to maintain the areas in their specific respective parts of the chest and abdomen, the intestines have to rotate and twist themselves in a specific fashion. As previously discussed, the timing during the stages of formation is also under the control of the neural crest cells. Therefore, if the timing is off, the GI tract may not fully form, the specific sections may not end up in the correct areas of the chest and abdomen, and the intestines may not rotate and twist in the correct manner to allow for normal digestive function.

Incorrect position and growth of tissues are not limited to the head and neck regions in DGS.

In summary, even if there are no significant thymus problems and no immunodeficiency, a patient with DGS can have recurrent infections due to malposition of the Eustachian tubes, and also may have problems with the spine, ribs and GI tract. Unfortunately, gastroesophageal reflux is likely to ensue and require medical intervention to prevent complications.

We will continue with more discussion of these issues next time.

Terry O. Harville, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences and a consultant for immunodeficiencies, autoimmunities and transplantation.
IN THE NEWS

Research

New Health Economic Study Is Launched for PIs

Baxalta, the University of Sheffield in England and the International Patient Organisation for Primary Immunodeficiencies (IPOPI) have partnered to launch a health economic study that will assess the major factors contributing to the burden of treatment for patients managing primary immunodeficiencies (PIs). The first phase of the study, which will use a PI-specific validated instrument to assess the burden of treatment designed by the University of Sheffield, will be conducted among PI patients in 11 countries, including Canada, Denmark, France, Germany, Italy, the Netherlands, Norway, Poland, Sweden, the United Kingdom and the United States. Results from the study will be used to educate and raise awareness among policymakers, healthcare professionals, healthcare providers and patients about the burden of treatment for PI, and to identify means to help reduce that burden. Initial results will be reported later in 2016.

“We believe that choosing the right treatment for a person living with PI has a major impact on quality of life,” said Johan Prevot, executive director of IPOPI. “We recognize the importance of better understanding treatment burden, which includes the time, physical and psychological effort of those living with PI and their caregivers expend in treating and managing their condition. Our hope is that this study will shed light on these issues and provide us with robust data to advocate for better access to individualized treatments for PI patients.”

Research

Study Finds Influenza Vaccine Protective in CVID Patients

Because humoral vaccine response in patients with common variable immunodeficiency (CVID) is frequently impaired and T cell vaccine response in CVID patients and other patients with antibody deficiency is poor, researchers studied the antibody and T cell immune response of patients with CVID and antibody deficiency to the 2013-2014 influenza vaccine. In the study, eight patients with CVID, eight patients with unclassified antibody deficiency and nine healthy controls were vaccinated with a single dose of nonadjuvanted seasonal influenza vaccine. Before vaccination and three weeks after vaccination, antibody titers against the strains A/California/7/2009, A/Texas/50/2012 and B/Massachusetts/02/2012 included in the vaccine were measured by hemagglutination inhibition testing. Additionally, vaccine-specific T cell cytokine response was determined by stimulation with the complete vaccine in vitro.

Results showed that all of the healthy controls responded to vaccination with serum antibody titers. Only one of eight CVID patients and four of eight patients with unclassified antibody deficiency showed a response against at least one of the three vaccines. However, seven of eight CVID patients and six of eight patients with unclassified antibody deficiency had similar frequencies of vaccine-induced IFN-γ, TNF-α and IL-2 producing CD40L+T cells as the healthy control group. As such, the researchers concluded that most CVID and unclassified antibody deficiency patients benefit from seasonal influenza vaccine by mounting a cellular response.


Medicines

BPL Submits BLS for Gammaplex 10%

Bio Products Laboratory (BPL) has submitted a biologics license supplement (BLS) to the U.S. Food and Drug Administration for the use of Gammaplex 10% (immune globulin intravenous, human) in patients with primary immunodeficiencies (PIs). The submission is based on a two-phase, crossover bioequivalence study between the 10% immune globulin (IG) treatment being investigated and BPL’s approved Gammaplex 5% IG treatment. This study is the first time that a 5% and a 10% IG therapy have been directly compared in a registration trial in patients with PI. “We’re excited by the study results and meeting this submission milestone,” said Eric Wolford, PharmD, vice president of global medical for BPL. “Conducting innovative research to bring patients with primary immunodeficiencies the potential for another therapeutic option required significant effort from BPL researchers and investigative sites.”
Grants

CSL Awards LEAD Grants in Support of Rare Disease Advocacy

CSL Behring has awarded its latest round of LEAD grants in support of advocacy work by patient groups that tackle complex legislative and public policy issues. This year’s grant recipients are the Immune Deficiency Foundation (IDF), Tennessee Hemophilia and Bleeding Disorders Foundation (THBDF), Hemophilia Foundation of Southern California (HFSC) and Gateway Hemophilia Association (GHA) in Missouri.

IDF will use its grant to help fund the Creating Advocates, Enhancing Access pilot program in Florida and Indiana, which is designed to help IDF develop strong grassroots initiatives on behalf of patients with immune deficiencies in those states. THBDF was awarded a grant to build a state advocacy program and train volunteers in advance of their first Legislative Day in Nashville. And, both HFSC and GHA were awarded grants to help support teen advocacy programs that provide advocacy training for teenagers.

“As an established and growing global biotherapies leader with a history and focus in treatments for rare and serious conditions, we understand the challenges that patients with rare diseases face every day,” said Dennis Jackman, CSL Behring’s senior vice president for global healthcare policy and external affairs. “Access to care should not be one of them, which is why CSL Behring’s role as an advocacy leader is so important to us. We will continue to work to enhance the capacity and ability of patient groups to inform and impact public policy decisions, and ensure access to therapies and services.”

Since 2008, CSL Behring has awarded 59 LEAD grants totaling $764,000 to patient advocacy organizations.

Grants

Missing Genetic Link Identified in CVID

In the largest genetic study to date of common variable immunodeficiency (CVID), scientists have identified a gene that may be a “missing link” in the disease. In the study, scientists searched for genetic differences between 778 patients with CVID and 11,000 control patients, all from the U.S., U.K., Germany, Sweden and Norway, using the ImmunoChip, a genotyping tool customized to detect hundreds of thousands of single-nucleotide polymorphisms already associated with 12 immune-related diseases. The study confirmed the discovery in 2011 that CVID is linked to the human leukocyte antigen (HLA)-related gene region on chromosome 16p13.13. The CLEC16A gene region offers a compelling target for understanding CVID because, in the study, the researchers showed that mice with reduced activity in the corresponding animal gene had lower levels of B cells, the immune cells that are depleted in CVID.

In addition, the study found that the newly identified gene plays a key role in autoimmune diseases such as type 1 diabetes, rheumatoid arthritis and allergies. At least 25 percent of CVID patients have autoimmune disorders. Previous genetic studies found that changes in CLEC16A raised the risk of type 1 diabetes, inflammatory bowel disease and other autoimmune disorders.

“The biological mechanisms that cause disease symptoms in CVID are still unclear,” said Hakon Hakonarson, MD, PhD, director of the Center for Applied Genomics at The Children’s Hospital of Philadelphia, “but this study may suggest that altered function in CLEC16A and its associated proteins may represent a ‘missing link’ between immunodeficiency and autoimmunity in CVID. This may offer new opportunities for eventually designing more effective treatments.”

Autoimmune Corner

Research

Study Suggests IVIG Is Beneficial for Treating GI Involvement in SSc

A recent study shows that intravenous immune globulin (IVIG) therapy is beneficial for gastrointestinal involvement (GI) in systemic sclerosis (SSc). In the study, 15 SSc patients with overlap polymyositis who remained active and unresponsive to conventional disease-modifying agents and who subsequently received IVIG were identified. Patients’ mean duration of IVIG treatment was 2.3 years with treatment frequency ranging from every six weeks to every four months. Assessments included validated questionnaires for GI symptoms, the Medical Research Council sum score for muscle strength and modified Rodnan skin score. Serial measurements were undertaken at baseline prior to the first IVIG treatment and post-treatment in the most recent assessment. Results showed that compared with baseline, there was a significant reduction in gastroesophageal reflux frequency and intensity mean scores. In addition, there was significant improvement in the GI tract 2.0 score from a baseline mean score of 1.07 to 0.60, and there was regression in markers of muscle disease with a reduction in the mean Medical Research Council sum score and the median creatine kinase level. Therefore, the researchers concluded that IVIG may be a helpful adjunctive therapy in the amelioration of some key clinical aspects in refractory SSc.


Research

Study to Investigate If Antibody Plays a Role in Sjögren’s Syndrome

A new study led by University of Buffalo (UB) oral biology researcher Jill Kramer will re-examine whether IgM, a protective type of antibody that researchers have believed plays an insignificant role in Sjögren’s syndrome, is pathogenic (capable of causing disease). The goal is to gain a better understanding of IgM’s effect on Sjögren’s and other autoimmune diseases such as rheumatoid arthritis and lupus.

“Analysis of the Source and Significance of IgM in Sjögren’s Syndrome” is one of several studies funded through a $16 million Clinical and Translational Science Award provided to UB from the National Institutes of Health to quicken the delivery of new drugs, diagnostics and medical devices to patients. Kramer will administer IgM to mice (which lack the ability to produce their own antibodies) with Sjögren’s syndrome to examine whether they develop symptoms related to the disease. A separate set of mice will receive IgG, another type of antibody that is harmful in many autoimmune diseases, including Sjögren’s.

According to Kramer, IgG is produced primarily to attack bacteria and other pathogens, whereas IgM functions as the body’s garbage man, helping to clean up cellular debris and reduce inflammation before a stronger response with IgG is triggered. More Sjögren’s syndrome-related research has focused on IgG because of its harmful nature in autoimmunity. But recent studies have found that those diagnosed with Sjögren’s produce a high amount of IgM, suggesting that the antibody plays a greater role than originally believed. By testing how IgM affects salivary function in mice, it can be determined whether the antibody is harmful or released as part of a protective measure, which could aid in the development of medicine and other treatments.

“You can lament what is lost to you, whether it’s opportunity, a person or your health, but clinging to anger is no way to experience life.” — Rebecca Zook in “Life Lessons,” excerpted from Chronic Inspiration.

Download a daily dose of inspiration with this heartfelt compilation of writings on life with chronic illness. From coping strategies and parenting tips to “from the trenches” advice on dealing with family and friends who simply don’t get it, these personal stories are sure to uplift, challenge and inspire. Honest and candid, Chronic Inspiration: Heartfelt Perspectives on Life with Chronic Illness gives voice to those who refuse to let their diagnosis define who they are or what they can accomplish.

“For the patient community, this was invaluable. When I downloaded it, I knew this would be something I would refer to over and over again.”

— Jenny Gardner

Chronic Inspiration can be purchased on iTunes, Amazon and Barnes and Noble.com
**CHRONIC LYMPHOCYTIC** leukemia (CLL) is a form of blood cell cancer that can impact healthy B-cell production, which may increase the risk of infection. Patients with CLL are often treated with intravenous immune globulin (IVIG) replacement therapy in conjunction with other forms of treatment. In fact, CLL is one of the few U.S. Food and Drug Administration (FDA)-approved indications for Gammagard SD, an IVIG therapy.

**Understanding CLL**

Leukemia is cancer that originates in blood-forming tissue characterized by the uncontrolled growth of blood cells that are produced in the bone marrow. In healthy bone marrow, blood stem cells mature over time and become either myeloid stem cells or lymphoid stem cells. Lymphoid stem cells transform into lymphoblast cells and then either B lymphocytes, T lymphocytes or natural killer cells. B lymphocytes bind to antigens, and with the help of T lymphocytes, transform into plasma cells that secrete antibodies to destroy antigens. Key to protecting individuals from bacterial infections, this humoral immunity is impaired in patients with leukemia. In the bone marrow of patients with leukemia, cancerous blood cells form and, in essence, crowd out the healthy blood cells, interfering with their normal function.

There are several types of leukemia (Table 1) categorized according to which blood cells are affected, and whether the disease is acute or chronic. While leukemia occurs in both adults and children, the most common type — CLL, a white blood cell cancer — occurs mostly in adults. In fact, more than 75 percent of people newly diagnosed with CLL are over the age of 50, and men make up the majority. CLL can occur in teenagers and, occasionally, in children, but it is rare.

In CLL, there is an overproduction of lymphocytes that never fully mature and, thus, do not function as they should. In addition, these cells remain viable and multiply, whereas normal lymphocytes die. The result is impaired antibody production, leaving the person at risk for infection.

CLL is usually one of the slower progressing types of leukemia, and many

**Table 1. Types of Leukemia**

<table>
<thead>
<tr>
<th>Type</th>
<th>Cells Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute lymphoblastic leukemia</td>
<td>Overproduction of lymphoblasts</td>
</tr>
<tr>
<td>Acute myeloid leukemia</td>
<td>Abnormal production of myeloblasts</td>
</tr>
<tr>
<td>Chronic lymphocytic leukemia</td>
<td>Overproduction of lymphocytes</td>
</tr>
<tr>
<td>Chronic myelogenous leukemia</td>
<td>Overproduction of white cells</td>
</tr>
</tbody>
</table>

**Figure 1. Rai Staging System**

<table>
<thead>
<tr>
<th>Stage</th>
<th>CLL Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>Absolute lymphocytosis (&gt;15,000/mm3) without adenopathy, hepatosplenomegaly, anemia, or thrombocytopenia.</td>
</tr>
<tr>
<td>Stage I</td>
<td>Absolute lymphocytosis with lymphadenopathy without hepatosplenomegaly, anemia or thrombocytopenia.</td>
</tr>
<tr>
<td>Stage II</td>
<td>Absolute lymphocytosis with either hepatomegaly or splenomegaly with or without lymphadenopathy.</td>
</tr>
<tr>
<td>Stage III</td>
<td>Absolute lymphocytosis and anemia (hemoglobin &lt;11 g/dL) with or without lymphadenopathy, hepatomegaly or splenomegaly.</td>
</tr>
<tr>
<td>Stage IV</td>
<td>Absolute lymphocytosis and thrombocytopenia (&lt;100,000/mm3) with or without lymphadenopathy, hepatomegaly, splenomegaly or anemia.</td>
</tr>
</tbody>
</table>

Source: www.cancer.gov/types/leukemia/hp/cll-treatment-pdq#link/_10_toc
people don’t experience symptoms for quite some time. In fact, the first sign of CLL may be an increased white blood count during routine blood work. Symptoms usually begin with frequent infections and/or fever, night sweats, fatigue and enlarged yet painless lymph nodes. There can also be pain in the left upper abdomen that may be due to an enlarged spleen.

If CLL is suspected, testing will include blood work and, possibly, a bone marrow biopsy. The test results are used to stage CLL, most commonly using the Rai staging system (Figure 1). Once the stage of CLL is confirmed, treatment can be determined. Treatment can range from routine monitoring for changes in blood values to chemotherapy, targeted drug therapy and bone marrow transplant. In the earlier stages, since CLL is typically slow to progress, observation may be all that is required. Indeed, it has been shown that early initiation of chemotherapy fails to show benefit in CLL; instead, it may increase mortality.

How IVIG Helps to Prevent Infections

Some people with CLL don’t produce enough antibodies (immunoglobulins, or IgG) to fight infection, which can lead to repeated lung and/or sinus infections. Therefore, CLL patients are monitored for signs and symptoms of infection, and IgG levels can be checked with a blood test to determine whether IVIG therapy should be started.

The initiation of treatment with IVIG therapy differs from clinician to clinician. While some cancer centers and hematology/oncology physicians will wait until IgG levels drop below a certain range, some initiate treatment with or without low levels to prevent infections. IVIG therapy is often given once a month at first, but may be needed less often based on antibody levels.

Research has shown that IVIG is effective in preventing infections in CLL patients. In a 2009 meta-analysis of nine trials, researchers assessed treatment of CLL and multiple myeloma patients with polyvalent IVIG versus a control group with primary outcomes of all-cause mortality and major infections. They found that while no survival benefit could be demonstrated, there was a significant decrease in the occurrence of major infections and a significant reduction in clinically documented infections.1

Another crossover study found that low-dose IVIG therapy was just as effective as high-dose IVIG therapy. In the study, 42 CLL patients with hypogammaglobulinemia (IgG levels less than 600 mg/dL) and/or a history of at least one episode of severe infection in the six months preceding inclusion in the study were randomly allocated to receive either an infusion of 300 mg/kg IVIG every four weeks for six months or no treatment. They were then switched to observation or IVIG for another 12 months, and then received IVIG or no therapy for an additional six months. Results showed a significantly lower incidence of infectious episodes during IVIG prophylaxis in 30 patients who completed the six-month period of either observation or IVIG therapy, as well as the 17 patients who completed 12 months of either observation or IVIG prophylaxis.2

A Preventive Treatment

Lack of proper B cell function is one reason why CLL patients experience frequent infections, which is one of many complications of the disease. While not all physicians recommend IVIG therapy to prevent these infections, it has been shown to be a successful preventive treatment.2

MICHELLE GREER, RN, is senior vice president of sales for NuFACTO R Specialty Pharmacy.
EMILEE A. THOMAS, MPH, PA-C, is a physician assistant with the CLL Research Center at New York Presbyterian/Weill Cornell Medicine.

References
Dealing with a Chronic Illness Diagnosis

Together, patients and their caregivers can play a role in coping with chronic disease to keep it from defining the individual.

By Meredith Whitmore
MAYBE THE DIAGNOSIS is primary immunodeficiency. Maybe it’s multiple sclerosis (MS) or peripheral neuropathy. Whatever the chronic, life-changing illness is, the difficulty of dealing with medications, treatment, pain or even multiple surgeries and disability evokes an avalanche of emotions and questions in patients. Physicians, too, are affected because they must find and tailor ways to help their patients cope. The Centers for Disease Control and Prevention reports that in 2012, about half of all adults in the United States — 117 million people — had one or more chronic health conditions. Considering that staggering statistic, developing coping skills for dealing with long-term illness is more crucial than ever.

How patients deal with their diagnosis depends largely on how they have dealt with various other stressors before they became sick. If, for example, they were previously able to successfully navigate troubles such as family turmoil, car accidents and other tense situations, the chances are more likely they will be reasonably adept at handling their new and often more limited lifestyle. But even the most “skilled” sufferer, faced with a grinding, long-term condition, can be taxed in ways well beyond what they have been prepared to handle. As months or years wear on, disease can deteriorate even the strongest of psyches. According to Drs. Kathleen Franco and Tatiana Falcone, psychiatrists at the Cleveland Clinic, “Even generally high-functioning persons can regress in the face of life-threatening illness. Such regression can resemble the behavior of a dependent child or an angry adolescent.” In other words, the best patients are likely to need help when dealing with a medical crisis. As such, physicians and other providers must teach coping strategies, and patients, in turn, must do the hard work of incorporating them into their treatment plans and lives. There are no quick fixes.

Typical Coping Patterns
For some patients and healthcare providers, simply having an overview of various types of personalities and how they typically respond to medical treatment/illness is helpful. In Table 1, Drs. Franco and Falcone highlight the patient personality types originally outlined in the text Psychiatry and Medical Practice in

<table>
<thead>
<tr>
<th>Personality Type</th>
<th>Patients who…</th>
<th>Often feel…</th>
<th>Are helped by physicians who…</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dependent</td>
<td>Ask a lot of questions; make it hard for the doctor to end the conversation or leave the room</td>
<td>Afraid that physicians won’t care for them or find them worthy</td>
<td>Offer regular, brief sessions; set tactful limits that reassure the patient</td>
</tr>
<tr>
<td>Obsessive</td>
<td>Are insistent; are detail-oriented</td>
<td>Angry when they can’t control their illness, the medical staff and the schedule</td>
<td>Offer detailed explanations; provide choices whenever possible; try to use patient input collaboratively</td>
</tr>
<tr>
<td>Narcissistic</td>
<td>Are self-centered; criticize others; believe no one is qualified</td>
<td>Fearful, threatened and vulnerable</td>
<td>Avoid confrontation, but emphasize that they deserve the best care; keep them informed</td>
</tr>
<tr>
<td>Suffering victim</td>
<td>Always have symptoms and request much attention; might not follow recommendations</td>
<td>Suffering is their role; illness punishes them (and sometimes physicians) but hopes doctor will keep trying</td>
<td>Provide regular visits, no matter how varying the complaints; encourage them to “suffer” through treatments</td>
</tr>
<tr>
<td>Paranoid</td>
<td>Do not trust; refuse to participate in plans; threaten to sign out of the hospital against medical advice</td>
<td>They are being taken advantage of by others or purposefully neglected or harmed</td>
<td>Stay calm; don’t argue; offer understanding of their position; make clear recommendations</td>
</tr>
<tr>
<td>Histrionic</td>
<td>Are flirtatious; want to call the doctor by his or her first name</td>
<td>They want to be special in the eyes of the physician; illness will invalidate them or make them unattractive</td>
<td>Encourage the patient to verbalize concerns; set boundaries for the relationship; remain courteous and objective</td>
</tr>
<tr>
<td>Schizoid</td>
<td>Are very lonely; tend to avoid medical care</td>
<td>Doctors are invading their privacy</td>
<td>Engage them in helping to make medical decisions</td>
</tr>
</tbody>
</table>

Table 1. Patient Personality Types
Patients may see their own demeanors or attitudes in these descriptions and possibly gain more insight into their behavior. And, physicians may better understand how to work successfully with a variety of patients and their specific needs. “Recognition of the different patterns helps to inform caregiver responses that, if tailored appropriately, will be perceived as supportive rather than confrontational,” they note.

Patients’ reactions to their diagnosis also depend on how they view the illness itself. For example, if patients believe that the illness will end up taking their lives, their resistance to stress and ability to endure treatment will be notably hindered. If patients believe that, no matter what they do, they cannot improve their health, they are more likely to succumb to helplessness and worsen their illness. Understandably, healthcare providers who can help their patients learn as much as possible about their illness, reassuring, teaching and guiding them to a more positive outlook, can be very helpful.

HOW PATIENTS DEAL WITH THEIR DIAGNOSIS DEPENDS LARGELY ON HOW THEY HAVE DEALT WITH VARIOUS OTHER STRESSORS BEFORE THEY BECAME SICK.

Strategies to Succeed Mentally and Emotionally

According to Dr. Franco, the healthy “mental constructs,” or toolbox of strategies, required to deal with long-term illness can be honed, though it is a process requiring dedication. One such construct includes putting the illness in a different light. “Instead of saying, ‘Oh, my MS is going to get worse,’” she says, “the patient might say, ‘You know, nobody knows whether I’m going to have this course or that course of MS, and I am going to assume that I am going to get better. There are certain things that I can do to help myself. So I am going to choose to stay active and not wait for the illness to take over my body.’” In this way, she says, the patient develops proficiencies in dealing with fear and other negative emotions.

Many patients need coaching to develop such tactics. “Psychotherapy and cognitive behavioral therapy are especially helpful,” says Dr. Franco. “[Cognitive behavioral therapy] is when you recognize a distorted thought, and you understand that distorted thought is changing your mood. If you take that distorted thought out and put a more objective thought in, you can cope, whether it’s with arthritis, or MS or a cardiac condition. Believing that you can get better, and believing that some distorted thoughts you might have can be corrected, will help an individual tremendously. But patients have to practice that.”

While Dr. Franco says that working with a therapist is perhaps the best way to develop coping strategies, since they are specially trained in such areas, there are also less-involved ways to help oneself. “I use one particular book with my students, and it’s called Feeling Good,” she explains. “The author [Dr. David Burns] has a manual out that has the individual write in their interpretations, and they learn how to identify their own distorted thoughts. Through that, they learn how to be more objective and how to handle their own self-reflections. Or maybe to handle a difficult conversation with a person, or a lot of different things about when distorted thoughts might come in and what to do about them. That [book] is high on my list because it teaches people to believe that they can make things different.”

Another strategy Dr. Franco encourages is exercise. Regular exercise fights mood disorders, depression, anxiety and a host of other draining emotions, she says. The exercise doesn’t need to be exhausting to be beneficial. Even a walk or two around the block is something that can be helpful to one’s outlook and body. In addition, she says, a healthy diet is crucial, depending on what a patient’s nutritive needs are. One dietary aspect is certain, however: “A person who resorts to fast foods and carbohydrates can feel overwhelmed and be brought down [mentally and physically] as their blood sugars fluctuate. So a healthy, plant-based diet, with some protein, would be an excellent addition [to a person’s list of strategies].”

A Potential Step Backward

Sometimes, as an illness endures and perseverance subsides, it’s possible for some people to begin to conflate their condition with their identity. That is, they label themselves and their life according to their disease. While labels are helpful to identify problems, they do not need to define any person or situation. According to Dr. Franco, the suffering victim personality can be especially problematic in this regard. “Some patients can fall into
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— Marcia Boyle
President and Founder, Immune Deficiency Foundation

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self-pity,” she says. “[Their disease] becomes their identity. They can’t see anything else that’s worthwhile about themselves, except that someone might take pity on them. They want to be cared for. They want to be loved. They want to be appreciated for other things [than their illness], but they don’t know what those other things are anymore. Sometimes it takes either a therapist or a friend or someone else who gets them to take a look at other things. I’ve had patients who behaved that way, but who have been able to come out of it. They have been able to get themselves back to college and take classes or look for a career. But such recovery is hard work. And whenever such a patient makes a gesture of trying to escape that mentality, it’s important to praise them for trying.”

Dr. Franco also explains that to help such a patient, whether it’s a friend or loved one, a person must approach gently. “Some of them can hear and listen to what you say, and others may not be able to,” she explains. “If you have a good enough relationship with the person, and you believe that there’s more to them than their illness, help them to find or remember something they can do well, whether it’s music or drawing or teaching a child to read. There could be a million different things that can give them self-w orth apart from the illness. When they focus on the illness, though, they often drive people away, but don’t understand why that’s happening. They become a martyr, and they intensify their efforts [to garner attention] because that’s what they’ve practiced — that’s what has brought them closer to people in the past. But they only have a plan A, so they have to learn other things about themselves that they can appreciate.”

Dr. Franco encourages friends and family members of struggling patients to reach out to the person. She suggests asking them to join an activity they would enjoy. It could be a walk in the park or a volunteer event at which they could help others — anything that the patient doesn’t normally do. Stretch them as far as they will allow in terms of pleasant experiences that are out of their usual routine.

Physicians can also help patients by determining what sources of emotional encouragement they already have and urging them to stay involved with these people or activities. Such sources of reassurance could include a church congregation, friends, family members or colleagues, or a hobby or event. “High social to stay involved with these people or activities. Such sources of reassurance could include a church congregation, friends, family members or colleagues, or a hobby or event. “Social contact is associated with longer survival in women with breast cancer.” In addition, they say, it’s been demonstrated that “functional and social benefits for patients with rheumatoid arthritis lasted up to five years after an intensive nine-day multidisciplinary program that included education, gym exercises, use of devices, counseling, dietetics and discussion of social assistance.”

SOMETIMES, AS AN ILLNESS ENDURES AND PERSEVERANCE SUBSIDES, IT’S POSSIBLE FOR SOME PEOPLE TO BEGIN TO CONFLATE THEIR CONDITION WITH THEIR IDENTITY.

Working to Implement a Plan Together

The role in helping a patient with chronic illness to cope differs but can be equally important for physicians, caregivers, friends or loved ones; they can help to devise and implement the strategies patients need to thrive in the face of difficulty. Patients trying to cope with their conditions need to remember that there is much more to them than their illness; they should not reduce their complexity and experiences to one thing that has the potential to negatively influence their life. A disease does not define an individual. Patients can control what is within their ability to control and learn how to recognize distorted thoughts and combat them with objectivity. And, they can let others help.

MEREDITH WHITMORE is an English professor and freelance journalist in the Northwest.

References
Paving the Way for Healing: The Role of the Patient Advocate

By Dana Henry

You’ve probably heard the saying: “Be your own advocate.” But, sometimes, that’s easier said than done. Trying to wrangle all aspects of a complicated health issue can leave patients feeling frustrated, discouraged and drained. If that’s the case, a patient advocate might be just the ticket.

FINDING THE RESOURCES and care one needs to deal with a challenging medical condition can be difficult. It may require getting a second opinion, coordinating with several specialists, having numerous tests or procedures, coordinating follow-up appointments, weighing different treatment options, spending time in the hospital and juggling complex treatment plans. Just reading that list can be a little overwhelming. It’s easy to see how actually working through all those steps can become a full-time job and can keep patients from focusing on their health and well-being. And, that’s where patient advocates come in. Their role is to assist patients so they can focus on what matters: their health.

What Do Patient Advocates Do?

A patient advocate is someone who can help patients navigate their healthcare journey in myriad ways. Professional patient advocates work with hospitals, insurance companies and drug manufacturers, as well as independently as private patient advocates. Lay advocates don’t have formal training but can nonetheless be invaluable. They are often the friends and family members of those living with serious health issues. This article mainly deals with professional patient advocates. (Find tips for working with lay advocates in the sidebar titled “Four Ways to Recruit and Support Lay Advocates.”)
The Agency for Healthcare Research and Quality defines a health advocate as someone who can ask questions, record information and speak up for patients so they can better understand their condition and get the care they need. However, an advocate’s role can be much wider ranging (Table 1). The National Patient Safety Foundation defines a patient advocate as a “supporter, believer, sponsor, promoter, campaigner, backer or spokesperson.” An advocate can also focus on a narrower range of services, such as those who specialize in medical billing.

In the Journal of Medical Ethics, Lisa Schwartz writes that an advocate can help patients translate their desires into a cogent treatment plan and can help steer medical teams in the directions patients prefer. But, there are many other reasons for patient advocacy, Schwartz says, adding that there are also caveats, including ensuring the advocate can clearly understand patients’ needs and can represent those needs without distortion. The demand for patient advocates is evident. In 2007, CNN listed patient advocacy as one of seven positions poised for growth. In 2010, the Institute for Change Partners in Care Foundation identified patient navigation/advocacy as one of six emerging healthcare occupations that have the potential to keep people healthier and lower healthcare costs.

Finding a Professional Patient Advocate

There are many reasons patients may want to work with a professional advocate. “Volunteers can be wonderful, and the price may be right, but they often don’t have the experience you need to be sure you’re getting the best care you can get,” says Trisha Torrey, who works as a writer, speaker and private patient advocate. Here are three ways to find different types of advocates.

Insurance. Patients who are insured can check their health insurance benefits. Large employers often provide advocate services such as Health Advocate, the nation’s biggest employee-based advocacy firm. Some Blue Cross and Blue Shield plans, for example, offer free advocate programs to help patients and their families with complex healthcare issues. Services offered through these programs include obtaining pre-authorizations and prior approvals, speaking to medical staff with a patient or on a patient’s behalf, suggesting community resources and resolving billing issues.

Online directories. Several websites offer directories of private patient advocates. These include AdvoConnection (advoconnection.com) and the National Association of Health Advocacy Consultants (nahac.memberlodge.com/directory).

Table 1. Types of Assistance a Patient Advocate May Offer

| • Arrange transportation        |
| • Ask questions about next steps with regard to diagnosis and treatment |
| • Compile or update vitamin, supplement and medicine lists |
| • Discuss recommended health services |
| • Explain benefits |
| • Explain medical jargon |
| • File paperwork and assist with insurance matters |
| • Find support groups and other community services |
| • Get pre-authorizations and prior approvals |
| • Give the patient and family members emotional support |
| • Help with delays in getting tests, treatment or information |
| • Help the patient follow treatment instructions |
| • Help the patient get copies of relevant medical records |
| • Locate doctors and specialists |
| • Make sure the patient and family members know the facts about the patient’s condition and care |
| • Manage physician referrals |
| • Navigate healthcare networks |
| • Recommend health and wellness programs |
| • Research treatment options, procedures, doctors and hospitals |
| • Resolve hospital and doctor/provider billing issues |
| • Respond to requests and concerns 24/7 or during set hours |
| • Schedule appointments |

Torrey also recommends patients search for phrases such as “health advocate” and “patient advocate,” along with the name of the area where they live to find advocates in their vicinity. Many advocates will have websites or LinkedIn profiles so patients can get a sense of the services they offer and the fees they charge.
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If you are at high risk of thrombosis, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor you for signs of thrombosis and hyperviscosity. Always drink sufficient fluids before administration.

Please see additional Important Safety Information on reverse side and brief summary of full prescribing information for Hizentra, including boxed warning, on adjacent page.


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Tell your doctor if you have had a serious reaction to other immune globulin medicines or have been told you also have a deficiency of the immunoglobulin called IgA, as you might not be able to take Hizentra. You should not take Hizentra if you know you have hyperprolactinemia (too much prolactin in your blood).

Infuse Hizentra under your skin only; do not inject into a blood vessel.

Allergic reactions can occur with Hizentra. If your doctor suspects you are having a bad allergic reaction or are going into shock, treatment will be discontinued. Immediately tell your doctor or go to the emergency room if you have signs of such a reaction, including hives, trouble breathing, wheezing; dizziness, or fainting.

Tell your doctor about any side effects that concern you. Immediately report symptoms that could indicate a blood clot, including pain and/or swelling of an arm or leg with warmth over affected area; discoloration in arm or leg; unexplained shortness of breath; chest pain or discomfort that worsens with deep breathing; unexplained rapid pulse; and numbness or weakness on one side of the body. Your doctor will also monitor symptoms that could indicate hemolysis (destruction of red blood cells), and other potentially serious reactions that have been seen with Ig treatment, including aseptic meningitis syndrome (brain swelling); kidney problems; and transfusion-related acute lung injury.

The most common drug-related adverse reactions in the clinical trial for Hizentra were swelling, pain, redness, heat or itching at the site of injection; headache; back pain; diarrhea; tiredness; cough; rash; itching; nausea and vomiting.

Hizentra is made from components of human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent, cannot be completely eliminated.

Before being treated with Hizentra, inform your doctor if you are pregnant, nursing or plan to become pregnant. Vaccines (such as measles, mumps and rubella) might not work well if you are using Hizentra. Before receiving any vaccine, tell the healthcare professional you are being treated with Hizentra.

Please see brief summary of full prescribing information for Hizentra on adjacent page. For full prescribing information, including box warning and patient product information, please visit Hizentra.com.

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- Thrombosis may occur with immune globulin products, including Hizentra. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.
- For patients at risk of thrombosis, administer Hizentra at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

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Hizentra is an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated for the treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

DOSE AND ADMINISTRATION

For subcutaneous infusion only. Do not inject into a blood vessel. Administer at regular intervals from daily up to every two weeks (biweekly).

**Dosage (2.2)**

Before switching to Hizentra, obtain the patient’s serum IgG trough level to guide subsequent dose adjustments.

- **Weekly**: Start Hizentra 1 week after last IGIV infusion
  - Initial weekly dose = \( \text{Previous IgIV dose (in grams)} \times 1.37 \)
  - No. of weeks between IGIV doses.
- **Biweekly**: Start Hizentra 1 or 2 weeks after the last IGIV infusion or 1 week after the last weekly Hizentra/IGSC infusion. Administer twice the calculated weekly dose.
- **Frequent dosing (2 to 7 times per week)**: Start Hizentra 1 week after the last IGIV or Hizentra/IGSC infusion. Divide the calculated weekly dose by the desired number of times per week.
- **Adjust the dose** based on clinical response and serum IgG trough levels.

**Administration**

- Infusion sites – 1 to 4 injection sites simultaneously, with at least 2 inches between sites.

<table>
<thead>
<tr>
<th>Infusion Parameters</th>
<th>Infusion Number</th>
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<tbody>
<tr>
<td>Volume (mL/site)</td>
<td>1(^{st})</td>
</tr>
<tr>
<td>Rate (mL/hr/site)</td>
<td>15</td>
</tr>
</tbody>
</table>

* As tolerated

ADVERSE REACTIONS

The most common adverse reactions observed in ≥5% of study subjects were local reactions (i.e., swelling, redness, heat, pain, and itching at the injection site), headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, rash, pruritus, vomiting, abdominal pain (upper), migraine, and pain.

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**USE IN SPECIFIC POPULATIONS**

- **Pregnancy**: No human or animal data. Use only if clearly needed.
- **Pediatric**: No specific dose requirements are necessary to achieve the desired serum IgG levels.
subcutaneous immune globulin, have programs in which fellow patients share their own experiences with their treatment, answer nonmedical questions, connect patients with resources and offer encouragement. This type of peer advocacy is more limited than the health advocate services insurance companies offer, but it is still valuable and can be used in conjunction with other advocacy services. Some drug manufacturers such as Baxalta also offer nurse advocacy programs for insurance questions, treatment-related questions and educational resources. 10,11

How to Choose a Professional Advocate

Torrey lays out the basic framework for evaluating a patient advocate and advises starting with an interview. “It will be important to you to develop a rapport with your chosen advocate to have confidence in her abilities, to trust her to collaborate with others involved in your care and help you understand your options,” she says. “As you ask these questions, you’ll be able to tell whether she fits your needs.”

Patients should also find out if the advocate candidates have worked with similar cases. They should ask about their credentials, and find out what services they offer to determine if those services are what they’re looking for. They should discuss the time frame and workload, and make sure those are a good match as well. What patients don’t want is to be surprised by any unanticipated charges, so the advocate’s compensation should be discussed, as well as whether pricing is a flat rate or variable depending on the type of work being done. Lastly, references should be checked. “This is perhaps the most important of all the interview questions,” Torrey says. “References are vital.”

Torrey notes, however, that advocates may be reluctant to give out contact information for their clients because of privacy concerns. “If so, ask [the advocate] to provide your name and contact information to other patients who would be willing to speak to her abilities,” Torrey suggests. 12

Researching patient advocates might sound almost as daunting as managing healthcare issues. After all, patients want to work with an advocate so they can do less footwork, not more. Therefore, patients should think of the research and selection process as putting in time up front that will be paid back to them with interest as they move through their medical journey. The payoff will be well worth the effort when their advocate helps them shoulder the burden they would otherwise be carrying alone.

DANA HENRY is a writer and editor in the Kansas City area who specializes in science, medicine and health.

Four Ways to Recruit and Support Lay Advocates

1. Ask people you trust. A lay advocate may see a patient’s medical records and will be privy to personal health information. As such, patients should make sure to choose someone they trust with this information. They don’t want to overhear their advocate talking about their health issues at the water cooler or the next family reunion.

2. Choose those with the chops for the task at hand. The advocate role should be filled as if it were a professional position. In the workplace, employers wouldn’t hire someone to handle their files if they weren’t organized. The same concept applies to advocacy work. Patients shouldn’t ask someone who isn’t a good note-taker to take notes at their appointments. They also shouldn’t expect someone who doesn’t have a solid understanding of medical issues to distill their medical information. Finding the right advocate for the right type of support will make the process easier and more fruitful for everyone involved.

3. Divvy up the work. Too much weight should not be placed on any person’s shoulders. Studies show that family caregivers can suffer from the effects of stress related to supporting their loved ones. The same holds true for those playing the role of advocate. If possible, the responsibility should be spread out among several people. Maybe a family member can go to doctor visits, while a friend can help the patient prepare for appointments. Also, areas of specialty that different advocates can focus on should be considered. This will keep advocates from getting burned out and will help ensure they aren’t stepping on each other’s toes — or the patient’s, for that matter!

4. Remember to say thank you. Advocates are taking time out of their day (sometimes day after day) to help patients with their health and recovery. They should be told on a regular basis how much their support means. A heartfelt thank you or a personalized card can go a long way in showing appreciation.

References
Is It Time to See a Therapist?

A chronic illness diagnosis is physically, mentally and emotionally traumatic. For many patients, seeing a licensed mental health professional can provide needed support, encouragement and coping skills.

By Trudie Mitschang
WHEN IT COMES to a chronic illness diagnosis, what you can’t see can hurt you. With a primary immunodeficiency diagnosis, the physical symptoms are treatable with immune globulin (IG) infusions that allow many patients to lead relatively normal lives. But what about the mental side effects of living with an incurable disease? It’s not uncommon for newly diagnosed individuals to experience feelings of shock, anger, grief, loss and sadness. These feelings may pass with time, but if they are not dealt with effectively, they could lead to an increased risk of developing mentally debilitating conditions like depression and anxiety.

“Everyone gets down or gets the blues now and then. The sign that you could benefit from therapy is that the low mood settles in for two to three weeks without lifting,” says Toni Bernhard, PhD, author of How to Live Well with Chronic Pain and Illness and a frequent contributor to Psychology Today. “Most moods (good and bad ones) come and go like the weather. They change with the changing conditions in our lives. But if you get stuck in a dark mood that doesn’t lift, that’s the time to reach out for help.”

Assessing the Benefits of Therapy

According to Johns Hopkins University, more than 145 million people — or nearly half of all Americans — live with a chronic condition. That number is projected to increase by more than 1 percent each year through 2030, resulting in a chronically ill population of an estimated 171 million.1 And for many of those individuals, the physical challenges are only the beginning. Following the diagnosis of a chronic illness or development of a disability, necessary lifestyle changes may make individuals feel stressed, resentful or overwhelmed. The emotions are real and often misunderstood by family and close friends. The support of a therapist or other mental health professional is often beneficial as individuals begin to adapt and cope with their “new normal.”

Mental health professionals are trained to help people normalize overwhelming emotions, provide creative ways to address and resolve troubling feelings, and offer ongoing support and encouragement. For example, a person recently affected by illness or disability may find it challenging to maintain a view of their identity that is separate from the illness itself. A therapist can help that person come to terms with the illness as something distinct from who they are as an individual, and help them establish healthy views on how they define themselves post-diagnosis.

“Learning to live with a chronic illness has several stages,” says Becky Crusoe, PsyD, a mental health professional in Westlake Village, Calif. “First, there are the endless efforts to find someone who can tell you what is wrong. Then, once you are finally accurately diagnosed, there is a usually long period of learning about your condition, grieving and coming to terms with what the illness means for your life.”

As a therapist who has dedicated a significant segment of her practice to helping patients with chronic illness, Dr. Crusoe says many people avoid seeing a therapist because they don’t see the point; after all, a therapist can’t cure the illness. “While it is true I can’t cure the physical side of the ailment that individuals are dealing with, there is hope for healing from the emotional pain and suffering,” she says. “We can work on identifying inner resources and coping skills. We can talk about the impact illness has on family relationships, and explore ways to help friends and family better understand what is happening. We can also look at how the illness is affecting a person’s connection to life and future goals.”

THE SUPPORT OF A THERAPIST OR OTHER MENTAL HEALTH PROFESSIONAL IS OFTEN BENEFICIAL AS INDIVIDUALS BEGIN TO ADAPT AND COPE WITH THEIR “NEW NORMAL.”

Types of Chronic Illness Therapy

Chronic illness influences the lives of everyone in the family, not just the person who is sick. Roles and routines change. The demands of caregiving must be negotiated. Family members’ emotions may seem to be on a continuous roller-coaster ride. Some families and couples grow closer, while others pull apart. According to the American Association for Marriage and Family Therapy,2 there are several areas of therapy and intervention that can be helpful to those coping with chronic illness:

• Family therapy. Sometimes it is valuable for the whole family to meet with a qualified marriage and family therapist. During sessions, the therapist may work on communication skills and assist with problem-solving. Family therapy sessions may also include medical professionals who are involved with providing
treatment plans. This provides an opportunity for clarification of treatment expectations and goals.

- **Multifamily group psychotherapy.** Meeting with other families who are also dealing with chronic illness can help individuals to see they are not alone. These family group meetings may include an educational component, as well as discussion and problem-solving.

- **Individual assessment and treatment.** Individuals with chronic illness who are experiencing symptoms of depression or anxiety likely need private, one-on-one counseling, appropriate medication and, when recommended, ongoing individual therapy in conjunction with family therapy.

- **Support and psychotherapy groups.** Many organizations offer support groups that focus on specific illnesses. While these groups are not a replacement for individual therapy, they can help individuals connect with others who share in their struggle.

### If individuals are in the early stages of learning to live with chronic illness, feelings of grief and loss are common and very normal.

When working with an individual therapist, grief counseling may also come into play. If individuals are in the early stages of learning to live with chronic illness, feelings of grief and loss are common and very normal. They may see it as a loss of independence, youth or freedom. As with any loss, the stages of grief cannot be rushed and will be different for everyone. A licensed therapist with grief counseling skills can help individuals navigate this unfamiliar emotional terrain so that they can move forward with their lives. “When faced with a diagnosis, some people see it as a challenge and will fight to conquer the limitations that they are now met with,” says Dr. Crusoe. “Others will want to ensure that they’re doing everything they can to maintain the best health possible. Either way, knowledge is power, and a therapist can help you clarify emotions and gain perspective.”

### Psychiatrist, Psychologist or Therapist: What’s the Difference?

Individuals considering getting mental health treatment for the first time might be confused by the different types of help available. The most common types of credentials within the mental health field fall into three basic categories:

- **Psychiatrists** are medical doctors who have specialized in the field of psychiatry and are able to prescribe medication. Psychiatrists treat patients by talking with them, as well as by prescribing medication.

- **A psychologist** is a clinician who holds a doctorate in psychology (PsyD) or a doctorate of philosophy in psychology (PhD). A psychologist treats patients by talking with them, but does not prescribe medication. If medication is needed, a psychologist will refer the patient to a physician such as a psychiatrist or a primary care physician.

- **Licensed mental health counselors** (LMHCs) or therapists hold master’s degrees in counseling. They have completed two years of graduate training and one to two years of work experience under supervision. LMHCs provide counseling to individuals, families and groups. They, too, will partner with a psychiatrist if they feel medication is recommended.

The most significant differences between the various types of mental health professionals are areas of expertise, education and experience. Most qualified mental health professionals will refer a patient to another professional if the specific type of treatment needed is outside their scope of practice. Determining which type of mental health professional is best for each individual will depend on the specific issues they are struggling with and whether or not medication is a recommended part of the treatment plan.

### Paying for Therapy and Counseling

With skyrocketing costs of healthcare, pursuing therapy can seem like more of a luxury than a necessity, especially for those dealing with the high cost of IG therapy. But individuals shouldn’t rule it out; many insurance companies provide limited coverage for psychotherapy. Depending on the plan, though, some types of mental health professionals might not be covered, and individuals may need a referral from their primary care physician.

Also, some therapists do not accept insurance, only payment directly from the patient. In these instances, these therapists will sometimes accept sliding scale payments for which patients pay what they can afford for each session. If individuals feel a particular therapist could be a good fit, they shouldn’t be afraid to ask
what arrangements can be made. Community-based services can be considered, too. Senior centers, family service agencies and mental health clinics are good places to start. Many offer affordable options, including sliding scale payments.

**Dealing with the Big “D” — Is It Depression?**

Depression has often been referred to as a normal reaction to an abnormal situation. It comes as no surprise, then, that depression is the most common complication of almost all chronic or serious medical conditions.

In the general population, the risk of experiencing symptoms of depression is generally 10 percent to 25 percent for women and 5 percent to 12 percent for men. However, those with chronic illnesses face a much higher risk, as much as 25 percent to 33 percent, regardless of gender.¹ The sad reality is that depression often results in physical changes within the body that can worsen a medical condition, creating a vicious cycle: Chronic illness can bring on bouts of depression, which, in turn, can lead to a run-down physical condition that interferes with successful treatment of the chronic condition.

Elvira Aletta, PhD, a clinical psychologist who has personally struggled with chronic illness and depression, says that after processing the grief and loss associated with an illness diagnosis, taking some type of proactive steps can help patients keep grief from morphing into depression. For many, that can mean taking small steps and setting realistic goals. “If someone is so depressed that they stay in bed all day, a good goal for them is to get up and take a shower,” she says. “For another person who’s also depressed but makes it to work, their goal might be to engage in one pleasurable activity per day. Some people berate themselves because taking a shower is a seemingly trivial target. But remember that it leads to another step, which leads to another step. All these steps are simply the building blocks to getting better.”

Additional tips include:

- Try not to isolate oneself. Individuals should reach out to family and friends. If they don’t have a solid support system, they can take steps to build one.
- Learn as much as possible about the condition. Knowledge is power when it comes to getting the best treatment and keeping a sense of independence.
- Make sure there is medical support from trusted experts who can be talked to openly about concerns.
- If it is suspected that the medication is causing depression, it should be discussed with a doctor.
- Keep doing things that are enjoyable. This will keep individuals connected, as well as boost their self-confidence.

- If individuals think they are depressed, they shouldn’t wait to get help.

When depressive symptoms are related to physical illness or the side effects of medication, individuals may want to speak with their doctor about adjusting or changing the medication or dosage. It’s also important to note that while therapy alone can help people develop the mental fortitude needed to cope with a diagnosis of chronic illness, more than 80 percent of people battling depression can be effectively treated using medicine, psychotherapy or a combination of both. If a doctor does prescribe antidepressants, individuals should be sure to work closely with all of their physicians and their pharmacist to avoid unwanted or dangerous drug interactions.

**Depression is the most common complication of almost all chronic or serious medical conditions.**

Making the decision to seek mental health services can be difficult. For some, there remains a stigma attached to seeking help from a therapist; the myth remains that getting counseling is a sign of weakness or that therapy is only for “crazy people.” In reality, asking for help when it’s needed is a sign of strength and maturity. No matter where individuals are in their journey as people living with chronic illness, it’s important to remind themselves that simply because the negative and upsetting emotions they may be feeling are normal, that does not mean they have to learn to cope with them on their own. Finding a qualified therapist can provide long-lasting benefits that go beyond symptom relief. Therapy can give them the tools they need for building the life they want for themselves, and the coping skills required for whatever difficulties may lie ahead.

**TRUDIE MITSCHANG** is a contributing writer for IG Living magazine.

**References**

Using Dialectical Behavior Therapy Skills to Cope with Chronic Illness

THOSE OF US with chronic illness are constantly trying to find ways to cope with something that just will not go away. Let’s face it, chronic illness is here for the long run, which leaves us with three options: 1) feel miserable about it, 2) feel better about it or 3) accept it. I admit that I am often stuck with the first option! And, while the second option sounds great, it’s not realistic. That leaves us with the third option: accepting our condition for what it is. This is where using dialectical behavior therapy (DBT) skills can help.

Four DBT Skills

The term “acceptance” doesn’t always conjure up happy emotions. But, this is because, oftentimes, individuals incorrectly define what acceptance really means. Acceptance is not giving up. It is not agreeing with the situation. And, it is not pretending to be happy about something difficult. Acceptance is staying in the here and now while acknowledging that we cannot change what is happening so we might as well stop fighting it. One core DBT skill is called radical acceptance, which means completely accepting something for what it is, bad or good. It’s completely accepting reality. Once we stop fighting something we cannot change, we can finally begin to find some peace.

Another DBT skill is called IMPROVE. This skill can be especially beneficial if used daily in whole or even in part. IMPROVE stands for imagery, meaning, prayer, relaxation, once a day do something you are good at, vacation and encouragement. Imagery is a popular concept right now, so you may have a good idea of what some imagery tasks could be. For me, coloring mandalas is fun (adult coloring is the thing to do right now!). Meaning could translate into trying to find meaning out of the not-so-good things that happen. Most of us know what prayer is, but if you do not pray, time in nature could be a great alternative. Relaxation does not have to be a day at the spa, but could be a few minutes to yourself just chilling out on the couch. Once a day, do something you are good at: Whatever is fine! Perhaps you are an awesome cook or are good at repairing things? Vacation is similar to relaxation; it could be a 10-minute vacation doing something you don’t normally get to do such as a walk around the block or even a

By Stephanie Lauer, MHC
bubble bath. Finally, encouragement could mean being your own cheerleader. Hey, someone needs to do it!

My favorite DBT skill is an easy one called opposite action (O2a). While this is self-explanatory, it is also met with the most resistance. I am not suggesting you should go out and run a mile when you are feeling ill. Instead, try to identify how you are feeling and the actions you normally take when you are feeling that way. For example, I often get upset after having a conversation with a loved one or friend who makes light of my situation or gives unsolicited advice. I usually withdraw when this happens. With opposite action, I would do the opposite and interact. I might post on a support group what happened, or call someone who I know could offer a bit of support. Opposite action might also include pushing myself to do some cleaning or take a brief walk. Again, do what you can. Only you know what your limits are. Sometimes you might need to just rest.

We all know how difficult it can be to communicate with friends and families about our needs and wants. There is one DBT skill in particular that can really help us to communicate our needs to others. DEAR MAN stands for describe, express, assert, reinforce, mindful, appear confident and negotiate. Although this sounds cheesy and simple, it can be effective. In essence, it means to describe only the facts of a situation before using feeling words, and to be assertive while also being mindful of what others might be feeling. Many of us get into the habit of apologizing for needing something. While apologies are sometimes needed, they can also be overused. Part of appearing confident is not apologizing when we don’t need to. This can be a tough habit to break, but it does work when help is needed.

Start Here, But Branch Out
These four DBT skills can be very helpful, but there are a lot more DBT skills out there. A simple Google search will turn them up. As with other skills, these will take some practice to get used to. So, start using your new skills today. I look forward to hearing about how they work!

STEPHANIE LAUER, MHG, is a 28-year-old from Long Island, N.Y., who recently graduated with a master’s degree in clinical mental health counseling. She has been living with common variable immunodeficiency and other chronic illnesses since she was a child.
Food Choices

By Mindy Hermann, MBA, RDN

Dietary approaches can often reduce and lessen the GI issues faced by individuals with immunodeficiencies and autoimmune conditions.

PEOPLE WITH PRIMARY immunodeficiencies and autoimmune disorders often experience gastrointestinal (GI) issues. Some of these can be relatively minor and inconvenient, while others can be quite severe and debilitating.

The broad GI symptoms that accompany immunodeficiencies and autoimmune disorders are not well understood. To better identify the most common issues, a group of researchers looked at the medical files of 50 immunodeficient patients with GI
symptoms. They found that nearly all of them had chronic diarrhea and over half had trouble digesting and absorbing certain nutrients. This malabsorption may have resulted from and/or caused deterioration of the microscopic fingers in the intestine, called villi, that absorb nutrients. Many of the immunodeficient patients also had chronic gastritis, a long-term inflammation of the lining of the stomach and/or intestine that can be accompanied by abdominal pain, nausea and vomiting. In a different study, abdominal pain and vomiting were the most common GI symptoms in people with lupus. The lupus patients studied also developed more intestinal infections.

Following are common GI symptoms and possible dietary approaches. Importantly, food usually is not the cause, nor is it the primary or only treatment. Furthermore, the causes of GI symptoms can be related. However, in many cases, certain foods can be avoided or incorporated to help reduce or eliminate GI issues. All GI symptoms should be reviewed with a physician or qualified medical professional before making any diet changes.

**Bloating and Gas**

Most people, whether immunodeficient or with an intact immune system, experience periodic or frequent bloating and abdominal gas. Some of the most common culprits include carbonated beverages, swallowing air while eating, foods known to be gassy (Table 1) or fatty foods, especially for people who have trouble digesting and absorbing fat as a result of their disease or history of abdominal surgery. Sometimes, gas accompanies abdominal conditions that are more prevalent among people with immunodeficiencies such as irritable bowel syndrome, Crohn’s disease, changes in or overgrowth of intestinal bacteria, intestinal blockage and malabsorption, as well as intolerances to gluten and/or lactose.

The best strategies to manage gas when more serious causes have been ruled out include limiting or avoiding gas-producing foods, limiting fat and eliminating carbonated beverages.

**Constipation**

Constipation — fewer than three bowel movements a week — may be less common among people with immunodeficiencies, whose condition and side effects tend to be associated instead with loose stools. In addition to food causes such as eating too little fiber, constipation can be caused by certain medications, as well as intestinal narrowing or blockage, colon or rectal cancer, certain hormone-related diseases or neurological issues that affect the colon and rectum.

Changes that may help relieve constipation include eating more fiber from foods such as beans, fruits, vegetables and whole grains, and increasing physical activity.

**Diarrhea**

People with diarrhea have frequent, loose, watery bowel movements, sometimes accompanied by cramps. Some have diarrhea all the time, while others may cycle between normal bowel movements, constipation and diarrhea. Several illnesses can contribute to diarrhea, including Crohn’s disease, ulcerative colitis and irritable bowel syndrome. Among the numerous other causes are antibiotics, bacterial or viral infections, medications, lactose intolerance, gluten intolerance and fat malabsorption.

Ideally, treatment for diarrhea should start with identifying the cause(s), which may or may not include foods.

**Table 1. Typically Gassy Foods**

- Beans and peas (legumes)
- Vegetables in the cabbage family (broccoli, Brussels sprouts, cabbage, cauliflower)
- Vegetables in the onion family (onions, garlic, leeks, green onions)
- Spinach and leafy greens
- Mushrooms
- Certain fruits (apples, peaches, pears, dried fruit)
- Bran and whole grains
- Sugar alcohol sweeteners (sorbitol, mannitol, xylitol)
Managing Gut Bacteria

Much attention today is on the bacterial cultures in the intestinal tract called the microbiome. A healthy gastrointestinal tract contains billions of bacteria that benefit the body by breaking down food the body cannot digest, crowding out harmful bacteria, preventing harmful bacteria from entering the body through the GI tract, and releasing compounds that help the colon function normally. Intestinal bacteria also affect the body’s immune system. One research group suggests that improving the types and amounts of intestinal bacteria could lessen the symptoms of certain autoimmune diseases, including celiac disease, and aid the treatment of such diseases as rheumatoid arthritis.

A healthy microbiome depends on two elements: probiotics and prebiotics. Probiotics are strains of bacteria with functions that benefit health. Traditional yogurt bacteria, for example, break down lactose (milk sugar) to make it more digestible and give yogurt its characteristic tart flavor. Many yogurt varieties have additional cultures with other benefits. Probiotics also are widely available in supplement form. Probiotic bacteria are not native to the GI tract and must continue to be taken to confer benefits.

Prebiotics are certain types of fiber that feed the bacteria in the colon. Research suggests that the prebiotics chicory root fiber, inulin, fructooligosaccharides and others may help boost immunity by stimulating gut-associated lymphoid tissues by nourishing beneficial bacteria. Preliminary animal studies also show that the combination of prebiotics and probiotics may lessen the severity of chronic inflammatory bowel diseases such as Crohn’s disease and ulcerative colitis. Prebiotics offer additional benefits, including improved stool frequency, volume and consistency. Yogurts, nut and snack bars, and other foods may contain added prebiotic fibers, often in the form of inulin. Jerusalem artichokes, garlic, onions, asparagus and bananas contain prebiotic fibers, which also are available as a supplement. Patients should consult with a health professional before considering probiotics and prebiotics.

Small intestinal bacterial overgrowth (SIBO) is an infection of the small intestine that is caused by infiltration of bacteria from the large intestine. It can worsen the symptoms of irritable bowel syndrome and Crohn’s disease, as well as contribute to gas, bloating, abdominal pain, diarrhea and constipation. SIBO often accompanies autoimmune diseases and can cause nutrient malabsorption. Antibiotics are the most effective treatment, along with correction of any nutrition deficiencies that are identified by the doctor or health professional.

Resources for Patients

- The Monash University Low FODMAP Diet (Version 1.6) [Mobile Application Software]: itunes.apple.com/au/app/monash-university-low-fodmap/id586149216?mt=8
- Low FODMAP Central: www.nestlehealthscience.us/lowfodmap
- Mayo Clinic: www.mayoclinic.org/patient-care-and-health-information
- WebMD Digestive Disorders Health Center: www.webmd.com/digestive-disorders/features/5-things-digestive-problems

Lactose Intolerance

Many adults, including those with a compromised GI tract, lose the ability to digest lactose, the carbohydrate in milk. Disease-related damage to intestinal villi prevents them from producing the enzyme needed for lactose breakdown. The end result is gas, bloating, gurgling and, often, diarrhea. Testing for lactose intolerance is easy if not a bit uncomfortable. It is done by drinking a glass of skim milk by itself and paying attention to any symptoms; discomfort suggests lactose intolerance.

In addition to lactose-free products such as milk and cottage cheese, lactase enzyme tablets are widely available. Some people with lactose intolerance can eat cheese and yogurt because they have much less lactose than milk.

Celiac Disease

Celiac disease is an autoimmune response to gluten, a protein in wheat, rye and barley. It appears to be more common in individuals with immunodeficiencies and may exacerbate certain symptoms. People with true celiac disease rather than an allergy or sensitivity to wheat respond adversely to even the smallest amounts of gluten. This damages the intestinal villi, leading to malabsorption of many nutrients. When celiac is suspected, blood tests and an intestinal biopsy must confirm the diagnosis.

A strict gluten-free diet is the only known treatment for celiac disease. Individuals with celiac disease should work closely with a registered dietitian nutritionist to learn which foods are likely to contain gluten and which terms to look for on food package labels.
FODMAPs are specific types of carbohydrates that can be poorly absorbed and cause digestive discomfort.

Examples of High FODMAP Foods and Ingredients

- **Fermentable**
  - Fructans / GOS: wheat, rye, onions, garlic, artichokes, inulin, baked beans, red kidney beans, cashews
  - Lactose: milk, yogurt, ice cream, pudding, custard
  - Excess Fructose: high fructose corn syrup, honey, apricot, mango, watermelon
  - Sorbitol / Mannitol: sugar-free products, blackberries, apples, pears, peaches, cauliflower, mushrooms, snow peas

- **Oligosaccharides**
  - Inulin: onions, garlic, artichokes
  - Fructans: wheat, rye, barley
  - Galactooligosaccharides: onions, garlic

- **Disaccharides**
  - Lactose: milk, yogurt, ice cream, pudding, custard

- **Monosaccharides**
  - Excess Fructose: high fructose corn syrup, honey, apricot, mango, watermelon

- **Polyols**
  - Sorbitol / Mannitol: sugar-free products, blackberries, apples, pears, peaches, cauliflower, mushrooms, snow peas

FODMAPs are found in a wide variety of food groups.

**Low FODMAP Diet 101**

The low FODMAP diet has two phases, starting first with a strict elimination of high FODMAP foods for a period of 2 to 6 weeks. The second phase involves systematically reintroducing specific FODMAPs into the diet to help identify which specific FODMAPs trigger digestive discomfort in each individual. Both phases should be conducted with the guidance of a physician and a registered dietitian with expertise in FODMAPs.

**Low FODMAP Diet Resources**

- www.lowFODMAPcentral.com
- www.med.monash.edu.au/eccs/gastro/fodmap
- blog.katescarlata.com

*Please visit a healthcare professional to learn if the low FODMAP diet is right for you.

**FODMAPs**

A low FODMAPs diet (Figure 1) could be considered if celiac disease, SIBO and other causes have been ruled out, but GI symptoms persist. FODMAPs (fermentable oligo-, di-, and monosaccharides and polyols) are found in particular fruits, vegetables, dairy products, nuts, sweeteners and other foods. Several of the foods that are limited on a low FODMAP diet are the same ones that are described as prebiotics.

Kate Scarlata, a Massachusetts-based dietitian who specializes in the low FODMAP diet and digestive health conditions, suggests that the low FODMAPs diet requires consultation with a dietitian because its restrictions can be both stringent and nuanced and require advanced skills in label reading. The diet also can be nutritionally unbalanced unless carefully planned.

**Crohn’s Disease**

Crohn’s disease is accompanied by inflammation of the bowel. Symptoms can include abdominal pain and cramping, diarrhea, malabsorption and malnutrition, and loss of appetite. The disease is not caused by or treated with diet.

People with Crohn’s should work with a doctor, dietitian or other health professional to identify foods that are tolerated best.

**Sleuthing Out a Solution**

Individuals with GI problems related to their immunodeficiency should identify which foods are well-tolerated and which cause problems. This may require working with a dietitian or other health professional on a strict “elimination” diet that cuts out potentially problematic foods — wheat and related grains, certain vegetables and fruits, soy and other legumes, dairy products, high FODMAPs foods and fatty foods — for a period of time and then adds back foods one by one, waiting several days between each introduction. This type of diet is best used in consultation with a health professional for guidance and instruction on when to add back which foods, which foods and ingredients appear to cause problems, and how to read labels to avoid them. A carefully maintained food diary is essential for identifying problematic foods and monitoring symptoms. The ultimate goal is to narrow down the list of foods to avoid and create a diet that is nutritionally balanced and well-tolerated.

**MINDY HERMANN, MBA, RDN**, is a food and nutrition writer and communications consultant in metropolitan New York.

Sources available upon request.
LET’S TALK

Julie Fetch was finally diagnosed with CVID after years of being labeled a Munchausen syndrome patient because doctors believed she was “making herself sick.”

PROFILE: Julie Fetch

By Trudie Mitschang

Trudie: You were diagnosed over 14 years ago. Tell us about the years leading up to the diagnosis.

Julie: My journey to diagnosis took over 20 years. I was in and out of the hospital with odd infections. Even as a young child, I had frequent sinus infections, ear infections, bronchitis and pneumonia, and they could not figure out what was wrong or why I was getting so sick. But it wasn’t until I had an unexplained severe run-in with chickenpox at age 15 that my condition began spiraling downward.

Trudie: When did you learn you had CVID?

Julie: I was diagnosed as an inpatient in the intensive care unit with sepsis and endocarditis. Finally, a doctor new on my case decided to check my antibody levels. My IgG was 88, whereas, a normal low range is about 500. A short time later, I was diagnosed with CVID. Thankfully, I was started on IVIG as soon as possible. After being sick for so long, it was a relief to get a diagnosis and confirm that it was not all in my head.

Trudie: Before your diagnosis, you said people thought you had Munchausen. Tell us about that.

Julie: Since none of the doctors I saw knew what was wrong with me, I developed that label over time within the medical community. Whenever I had odd infections, they accused me of “making myself sick.” One time, I woke up from a procedure with a “sitter” in my room who told me I could not be left alone for fear I might harm myself. Needless to say, I was very upset and fired the doctor who was overseeing my case. Unfortunately, that was not the only time I was accused of having Munchausen.

Trudie: How are you since the diagnosis?

Julie: I am significantly better! I have to get my IVIG fairly frequently because I developed other health problems such as hemolytic anemia that causes my body to destroy its own blood, which has led to the need for a series of blood transfusions. Thankfully, it’s been five years since I’ve needed a blood transfusion. Of course, like all PI patients, I still get sick easily, and it takes me longer to recover from illnesses. I have learned to live around this

SINCE HER DIAGNOSIS of common variable immunodeficiency (CVID) 14 years ago, Julie Fetch has gone from frustrated patient to hands-on political advocate. In 2010, Fetch and several other patients met with legislators in Washington, D.C., a move that led to the sponsorship of House Bill HR 2002, the Medicare Patient IVIG Access Act. This April, Fetch was in D.C. again, speaking out regarding the Medicare Part B cost-cutting proposal that could adversely impact patients’ access to lifesaving and life-enhancing Medicare Part B-covered therapies such as intravenous immune globulin (IVIG). The busy single mom also volunteers as a speaker who talks with other primary immunodeficiency (PI) patients and plasma donors. Her message? “You’re not alone out there. You have to have a good attitude.”
with lifestyle changes that help me avoid infection. For instance, during flu season, I limit my grocery shopping during peak hours to avoid being around people who could be contagious. And, I’m a big fan of hand sanitizers!

**Trudie:** What inspired you to get into advocacy work?

**Julie:** I wanted to help others with this illness avoid the long road to diagnosis that I experienced. I live in a rural area in Michigan, where not many doctors know about PI. I want to help educate people, give back and make a difference.

**Trudie:** What is your volunteer role with the Immune Deficiency Foundation (IDF)?

**Julie:** I am involved in the Peer Support Program, which helps patients know they are not alone, despite having a rare disease. I also work on legislative issues for IDF.

**Trudie:** What brought you to Washington, D.C., for the recent Medicare Part B discussion?

**Julie:** This was actually my sixth trip to Washington, D.C., with IDF. My role is to represent patients by telling legislators my story. Putting a face on rare disease is a really important part of advocacy. In April, when I was there for the Medicare Part B proposal hearing, it was very personal for me. The part that really concerns me is the portion of the bill that groups patients by ZIP code and dictates what type of treatment they can and cannot have, either IVIG or subcutaneous IG (SCIG). This bill would touch me personally because I can’t do SCIG for various health reasons. This is not a bill that only affects PI patients; either cancer patients and diabetics would also be impacted.

**Trudie:** You’ve been featured in some IG promotional ads. How did that come about?

**Julie:** My favorite immunology nurse now works for an IG manufacturer, and I was contacted by them to participate in a training video. It was a lot of fun to be involved with the marketing side of things!

**Trudie:** What has been the most challenging part of your chronic illness journey?

**Julie:** The most challenging obstacle I’ve faced was when I adopted my son. I’m a single mom, and I had to prove to the court that I had enough support from extended family to help me if I got sick. Another big challenge has been getting friends and family to understand that if I am sick and cancel plans, it’s because I just can’t risk being around sick people. Sadly, I have lost some friends who did not want to accept my limitations.

**Trudie:** What advice do you have for other patients?

**Julie:** My best advice is know that you’re not alone out there. Even though it can be very difficult at times, try to live life to the fullest, and don’t let CVID take your life and independence away. Also, advocate for yourself or have a friend help you. It’s very important for patients to feel empowered and have a say in their own medical care.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.
PATIENT PERSPECTIVE

It Takes a Village

By Stacey Philpot

WE’VE ALL BEEN there: It’s a mere 24 hours before the big event — our best friend’s wedding, our parents’ 50th anniversary party, our oldest child’s senior banquet or maybe our youngest’s first day of preschool — and yet our bodies remain on strike. We survey the items left unchecked on the “to-do” list and determine there is only one thing truly left to do: Call in reinforcements.

For me, it was my oldest son’s 16th birthday, and we’d planned a teenager’s delight, complete with a live DJ, 20-foot water slide, photo booth and 40 guests. There were luau-style decorations to be hung, errands to run and a house to clean. Unfortunately, we also had one major dilemma: I couldn’t get out of bed. I don’t mean I was feeling a little sluggish or irritable. I mean I absolutely couldn’t remove myself from the bed, not even to bathe myself. So I did the only thing I could do: I called in reinforcements.

My husband helped me bathe, and a dear friend dried my hair. Another friend made the cupcakes, while her daughter ran the vacuum. There were three different trips to the store by three different people. My kids set up tables outside and periodically snuck in to give me hugs. The doctor called in rescue meds. And me? I cried. Yes, I shed some tears of frustration. Why was this body constantly thwarting me? But, primarily, the beauty of it all overcame me. I was overcome with gratitude.

So often I hear others who battle chronic illnesses and rare diseases express what I’ve been thinking: “But, I don’t want to be a burden. I don’t want anyone to have to help me.” Days like my son’s party remind me of the importance of community. They remind me that needing someone isn’t weakness; it’s humanity. None of us are as independent as we think we are. And, what if independence isn’t all it’s cracked up to be, anyway?

Isn’t there beauty to be found in rallying together around a common cause? In crying: “We’re in this together!”? Isn’t there something soul-stirring about being supported, met with help and love in your time of need? We all need help sometimes; there’s no shame in it. But since most of our friends and family aren’t mind readers, we have to speak up. We have to let others in. We have to be vocal and honest about what we need and when we need it. This may be humbling in the beginning and might require some practice, but that’s OK. Didn’t our moms always tell us “practice makes perfect”?

And what about those seasons in life when you seem to have somehow been separated from your village? You’ve thought and thought, but not a single person comes to mind that you might ask for help. Maybe you’ve been too sick to leave the house, or you’ve just recently moved to a neighborhood. Now, it’s crunch time, hours before your son’s graduation or your husband’s surprise party, and you have no village to call upon.

I’ve been there, too. Villages come in many shapes and sizes. You may find them online in a support group, in the line at the grocery store or sitting next to you at a religious service. The members of your village may be neighbors who came over to complain about the length of your grass, but left a member of the tribe. They may be the funny nurse at the doctor’s office, the cousin of your co-worker or your college roommate. Whoever they are, wherever you find them, remember it takes a village. And there’s no shame in that.

STACEY PHILPOT is an author, gooiball and avid reader. You can find her blog at chronically whole.com, where she shares her journey of making the most of a life touched by common variable immunodeficiency, Lyme disease and rheumatoid arthritis.
Before You Cross That Career Off Your List

By Ilana Jacqueline

IN SEVENTH GRADE, my business elective teacher gave our class an assignment. “Three careers,” she said. “I want you to think of three realistic careers you want to have in the future.” So, later that night, I took a poster and divided it up into three sections that read: PUBLISHER | JOURNALIST | TEACHER.

I was a kid. I wouldn’t be diagnosed with an immune deficiency for another five or six years. Even though all of my symptoms were present since birth (and, at certain points, severe), no one ever told me I wouldn’t be capable of doing any of these jobs one day. In fact, every doctor I’d ever seen had agreed that, one day, I would grow out of my allergies and infections. I could put whatever I wanted on that poster. It was mine to fill.

During my last year of high school, when my body was at its least capable, I realized I couldn’t finish out a full day of school as a student; how would I ever be able to take care of a class every day as a teacher? I crossed that career off my list.

That year, I also received my first pair of press passes to a presidential debate. I was so excited to go. I had my tape recorder and my notepad. Being in the frenetic hub of the media room, watching major networks and their anchors prepare to go live on air or online, was almost comatose from fatigue. The debate had barely started. Another career crossed off my list.

I clung to the hope that maybe a nice desk at a publishing company had my name on it. But when the time came to apply, I found the majority of these positions required a move away from my support system and doctors to the city. Suddenly, that poster I’d made all those years ago seemed so much more ambitious than I’d ever imagined. I always believed that I would grow up and grow out of my disease. I had just assumed my career would follow suit.

It isn’t easy, but I have found there are ways to have a career despite the severity of my disease. I’m so grateful to live in a time when my laptop connects me to everyone from my closest friends to the VPs of Fortune 500 companies. I’ve been working as a freelance writer and journalist for many years now — researching, interviewing, submitting work and networking entirely from home or a hospital.

While teaching in a normal classroom will never be a fit for me with my unpredictable symptoms, I still do a lot of teaching. Webinars, articles and videos allow me to connect with others who want to learn — even those who are too sick to be in the classroom.

Working from home, independently, I allow myself to give my best effort whenever it occurs. At 9 a.m. on Monday, I may be drowning in brain fog. But, at 2 a.m. on Saturday, I might find the most clarity to do my work. Having the ability to manage my own schedule, tools of interaction, pace and environment has made any career a possibility for me.

We can earn our degrees online, search and apply for jobs online and even do interviews via Skype. Group management tools like Basecamp and Salesforce have made working with large corporate teams as a contractor a simple process. (It also doesn’t hurt to have an online portfolio or business card page to share with new contacts.) So, whether you want to be a fashion designer or a journalist, an IT tech or a marketing manager, the poster is yours to fill.

ILANA JACQUELINE is a 26-year-old dysautonomia and primary immune deficiency disease patient from South Florida. She’s been writing professionally since 2004 on everything from health and wellness to celebrities and beauty. Her blog www.letsfeelbetter.com is both a personal collection of anecdotes about life with chronic illness, as well as a resource for patients of all ages.
Connecting Chronically Ill Children with Others

By Jessica Leigh Johnson

Parents of Chronically Ill children know the reassurance that comes from connecting with other adults who have kids with chronic illness. Until I found my X-linked agammaglobulinemia (XLA) Facebook group, I felt helpless and alone whenever one of my boys got sick or developed a new and unusual symptom. Now that I’m part of a group of individuals facing similar situations, I don’t know what I ever did without them. Whenever life seems out of control, this group is my only connection to sanity. How could my friends with healthy children possibly understand my panic when I hear that the Zika virus may be a bigger threat than we first thought (and when I consider selling my house in mosquito-infested Minnesota and moving to Sweden)? But I know that my fellow XLA moms online will be quick to respond to my fears with an “I hear you” or “I totally get it.”

If this camaraderie helps parents like me survive the trials and face the unknowns of daily life with chronically ill kids, it just makes sense that the children themselves need that same kind of encouragement from someone who understands — someone who has “been there.” All children need to feel like they belong. But, the need to belong can be exaggerated when children suffer from chronic illness. Connecting chronically ill children to one another is a great way to help them feel “normal,” especially when their diagnosis and symptoms might tell them otherwise.

The question is: How do we, as parents, connect our chronically ill children with others who know what they’re going through? This can be especially difficult when children have a rare disease.

Internet. Thankfully, our world is connected by the Internet, which gives this generation of children an advantage that others before didn’t have. With just a few mouse clicks, parents can join online communities such as Facebook groups, or follow blogs dedicated to their children’s specific condition. A simple shout-out such as “Hey, does anyone live in my area?” can connect parents to others in their community who are seeking the same thing — someone who understands. Once a friendship is established, parents can arrange play dates for younger children or family outings where their kids can meet others in their city or state who have the same condition. As always, take caution when using the Internet to meet people, and be sure to monitor any of your children’s online activities.

Specialists. Additionally, parents may not need to look further than their children’s hospital or specialist’s clinic to find a connection. Most major hospitals and clinics can provide information on local support groups for parents, families and children affected by the same illness.

Summer camps. A great way for children to connect with other kids like them is by attending a summer camp geared toward a specific illness or condition. At a camp where daily activities are centered around being active and enjoying the outdoors, these kids may find that they not only share the same condition, but also enjoy similar activities and have common interests. The Federation for Children with Special Needs has a summer camp listing at fcsn.org/camps for children with a variety of conditions, including asthma, cancer, diabetes, metabolic conditions, epilepsy and chronic illness. In addition, the American Camp Association’s website also lists camps for children with physical and/or mental challenges at www.acacamps.org.

Immune Deficiency Foundation (IDF). An invaluable resource for both children with primary immunodeficiency (PI) and their parents, IDF has numerous events scheduled throughout the year where...
parents and children can connect and network with other families facing similar situations.

For teens living with PI, IDF has created a social networking group called IDF Common Ground, an online community that gives them the opportunity to share their feelings and experiences about their diagnosis through group forum posts and chat room conversations, as well as videos and pictures. In this safe online environment, teens can discuss a variety of topics centered around their daily life and the challenges of living with PI such as positive and negative experiences with immune therapy and issues they might face at school.

The IDF Peer Support program can also assist parents in connecting their children with someone who may share the same diagnosis or live nearby. The program gives patients, parents and caregivers the opportunity to interact with an IDF volunteer who shares a similar relationship to PI. Parents requesting support for their children or teens are networked with volunteers who are parents and have children in similar age groups. They then determine the best way for their children to communicate. All volunteers undergo training and background checks.

Another unique opportunity for older children with PI to meet others is by attending one of the two IDF Teen Escape weekends. Designed as a getaway exclusively for teens ages 12 years through 18 years who have been diagnosed with PI, these weekends promote and nurture friendships and provide attendees with entertaining and educational activities, while parents attend sessions that focus on their own issues and concerns. According to IDF, the weekends can be life-changing, empowering experiences for teens with PI where they can make lifelong connections.

Parents and their children can also attend IDF Family Conference Days and IDF Retreats held throughout the country that offer programs for youth ages 6 months to 18 years. These events help patients and their families learn more about living with PI while connecting with others and having fun.

If this camaraderie helps parents like me survive the trials and face the unknowns of daily life with chronically ill kids, it just makes sense that the children themselves need that same kind of encouragement from someone who understands.

IDF’s National Conference is held every other year to bring together individuals from all sectors of the PI community. It is the world’s largest gathering of families affected by PI. At this conference, families meet each other and get the latest information from medical experts while enjoying social events. Youth programs geared toward children ages 6 months to 18 years are offered to provide fun, educational activities for those diagnosed with PI. They help children understand their primary immunodeficiency disease and connect often-isolated youth with peers who are facing similar circumstances.

Childhood is a time of growth and self-discovery, and a time for friendships to take root and blossom. Unfortunately, chronically ill children may feel isolated, different and even burdensome. But they don’t have to feel like they’re the only ones living with their specific illness. As the saying goes, there is strength in numbers. Together, chronically ill kids can share their experiences in order to feel understood, supported and accepted. No one knows what your children are going through like other children with the same condition. When connected with others who are facing the same disease, they can receive social and moral support that might make life just a little bit easier.

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References
**CHRONIC ILLNESS** often comes with a host of other debilitating health issues, including chronic pain and fatigue. Unfortunately, those living the vicious cycle — treatment options designed to make them feel better that, instead, produce side effects making them feel worse — know that finding a regimen that actually works requires constant trial and error. Enter the role of complementary and alternative medicine (CAM).

**Understanding CAM**

CAM is a broad category of diagnostic and therapeutic disciplines that are typically used in conjunction with conventional medicine. An example of a complementary therapy might be the use of aromatherapy to help lessen discomfort or nausea from chemotherapy. An alternative therapy example might be a specific nutritional plan used in place of chemotherapy. Although “complementary and alternative” is often used as a single category, it can be useful to make a distinction between the two terms, especially since some therapies may fall into both categories. The U.S. National Center for Complementary and Integrative Health (NCCIH) uses this distinction:

- **When a nonmainstream practice is used together with conventional medicine, it’s considered “complementary.”**
- **When a nonmainstream practice is used instead of conventional medicine, it’s considered “alternative.”**

One of the reasons CAM is considered controversial is because the therapies are usually not taught or commonly used in Western medical schools or hospitals. Despite the controversy, anecdotal evidence within various patient populations suggests that many of these therapies can be helpful. For example, there is evidence that osteopathy, chiropractic and acupuncture are effective for treating lower back pain. Other popular CAM therapies include homeopathy, herbalism and aromatherapy.

**Finding a CAM Practitioner**

Before beginning any complementary or alternative therapy, patients should discuss their plans with their primary care provider and/or specialist. Some CAM therapies (especially herbal supplements) can interfere with the effectiveness of prescription medications patients are already taking and, in some cases, may cause dangerous interactions. For example, the popular herb St. John’s wort can reduce the effectiveness of birth control pills, as well as drugs for cancer and HIV.

Once a CAM practitioner is found, it’s a good idea for patients to schedule a consultation to gather information about their qualifications. Here is a short list to get started:

- What is the cost of treatment?
- How long will the treatment last?
- Are there any people who should not use this treatment?
- What side effects might the treatment cause?
- Is there anything that should be done to prepare for treatment?
- What system is in place for dealing with complaints about treatment or service?
- Does the practitioner have documented proof of qualifications, memberships, education and/or training?

**Staying Safe**

As with any medical product or treatment, there can be risks with CAM approaches. These risks depend on the specific product or practice. When deciding to use a practice provided by a complementary health practitioner, patients should be sure to choose one carefully, much as they would do when choosing a healthcare provider. Also, they should be sure to inform all of their healthcare providers, including their pharmacist, about any complementary approaches to ensure coordinated and safe care.

More information on choosing a practitioner or product can be found at the NCCIH at [www.nccih.nih.gov](http://www.nccih.nih.gov).

**TRUDIE MITSCHANG** is a contributing writer for *IG Living* magazine.
Go Under the Needle
Acupuncture has long been recognized as an effective treatment for chronic pain, including back and neck pain, degenerative joint disease, chronic headaches, pelvic pain, chemo side effects, and even depression and anxiety. To find a qualified acupuncturist, the American Association of Acupuncture and Oriental Medicine is a national membership organization of acupuncturists and Oriental medicine practitioners and supporters in the U.S. [www.aaaomonline.org](http://www.aaaomonline.org)

Get Adjusted
Chiropractic is a branch of healing arts based upon the belief that good health depends upon a normally functioning nervous system (especially the spine and the nerves extending from the spine). Chiropractic comes from the Greek word Chiropraktikos, meaning “effective treatment by hand.” Many insurance plans cover a limited number of visits with providers in-network. A list of chiropractors can be found in the U.S. Chiropractic Directory. [www.uschirodirectory.com](http://www.uschirodirectory.com)

Get Happy
The Happy Wraps Herbal Neck Wrap and Eye Mask contains soothing lavender infusions that can be microwaved and refrigerated to provide relief for tension, neck stiffness and back pain. It can be used cold to relieve migraines and sinus pain. $19.95; [Amazon.com](http://Amazon.com)

Air Quality Control
The Premium Cool Mist Ultrasonic Humidifier helps alleviate dry cough, irritated sinuses, itchy eyes and dry skin by adding needed moisture to the air of a home to help people sleep better, breathe better and feel better. It can also be used for aromatherapy by adding essential oils. A built-in seven-color LED night light is designed to create a calming and comforting atmosphere. $39.99; [Amazon.com](http://Amazon.com)

Whole Body Care
Osteopathy is a form of drug-free noninvasive manual medicine that focuses on total body health by treating and strengthening the musculoskeletal framework, which includes the joints, muscles and spine. Its aim is to positively affect the body’s nervous, circulatory and lymphatic systems. This therapy takes a holistic (whole body) approach to healthcare, concentrating on treating the problem area, while using manual techniques to balance all the systems of the body. A qualified practitioner can be found at the American Osteopathic Association. [www.osteopathic.org](http://www.osteopathic.org)
The Autoimmune Connection: Essential Information for Women on Diagnosis, Treatment, and Getting On with Your Life
Authors: Rita Baron-Faust and Jill Buyon
Publisher: McGraw-Hill Education

The Autoimmune Connection explains the links between autoimmune diseases and offers up-to-date information on diagnosis, treatments and risks for women with one or more autoimmune disease such as lupus, rheumatoid arthritis or Crohn’s disease. Readers will learn how to sort out vague and seemingly unrelated early signs and symptoms; which diagnostic tests they may need and what the results can mean; how autoimmune diseases and treatments can affect them at different stages of life; what new treatments and therapies are on the horizon; and where to find the proper specialist and how to navigate the healthcare system.

Autoimmune Disease: Discover the Symptoms & Treatment of Chronic Pain & Genetic Disease (Psoriasis, Anti Inflammatory, Arthritis, Fibromyalgia, Multiple Sclerosis, Symptoms, Celiac Book 1)
Author: Mary Patterson
Publisher: Amazon Digital Services

In Autoimmune Disease: Discover The Symptoms & Treatment of Chronic Pain & Genetic Disease, Mary Patterson explains the scientific background and root causes of autoimmune diseases so readers know exactly what they’re dealing with. Covered are the basic processes underlying autoimmunity and which symptoms individuals should look for in themselves and their loved ones. Details are provided on a number of autoimmune diseases, including thyroid gland disorders, rheumatoid arthritis, systemic lupus erythematosus, multiple sclerosis, type 1 diabetes mellitus and celiac disease.

new and useful reading

Primary Immunodeficiency Disorders
Authors: Manisha Madkaikar Mukesh Desai and Zinet Currimbhoy
Publisher: Free E-Books

This is a new book released in May written by doctors at the Division of Immunology at the Bai Jerbai Wadia Hospital for Children in India, where primary immunodeficiency (PI) is in its infancy. The book was written to increase the level of awareness and knowledge on this topic in India and other countries. It includes a definition of PI, how to suspect a PI, how to establish normal laboratory values to evaluate immune-compromised infants and children, and an analysis of clinically obtained data.

Autoimmune Diseases Pocket Guide: Full Illustrated 2016
Editor: HC-HealthComm
Publisher: HC-HealthComm

Crohn’s disease, psoriasis and rheumatoid arthritis are related immune-mediated inflammatory diseases for which there is no cure. Other associated diseases include ankylosing spondylitis, juvenile idiopathic arthritis and psoriatic arthritis. This pocket guide provides an overview of the possible etiologies, pathophysiology and environmental factors underlying these conditions. Summaries of internationally recognized diagnosis and management guidelines aimed at remission and improving patient outcomes and quality of life are provided. In addition, recent advances in the treatment of these immune-mediated inflammatory diseases, particularly the development of novel biologics and individualized treatment strategies, are explored.
For a more comprehensive list of resources, visit the Resources page at IGLiving.com.

**Ataxia Telangiectasia (A-T)**
- **WEBSITES**
  - A-T Children’s Project: www.atcp.org

**Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)**
- **WEBSITES**
  - GBS/CIDP Foundation International: www.gbs-cidp.org
  - The Foundation for Peripheral Neuropathy: www.foundationfornpn.com

**Evans Syndrome**
- **ONLINE PEER SUPPORT**
  - Evans Syndrome Research and Support Group: www.evanssyndrome.org

**Guillain-Barré Syndrome (GBS)**
- **WEBSITES**
  - GBS/CIDP Foundation International: www.gbs-cidp.org
  - The Foundation for Peripheral Neuropathy: www.foundationfornpn.com
  - GBS/CIDP Foundation International Discussion Forums: forum.gbs-cidp.org/forum/main-forum

**Idiopathic Thrombocytopenic Purpura (ITP)**
- **WEBSITES**
  - ITP Support Association – UK: www.itpsupport.org.uk
  - Platelet Disorder Support Association: www.pdsa.org

**Kawasaki Disease**
- **WEBSITES**
  - American Heart Association: www.heart.org/HEARTORG/Conditions/More/CardiovascularConditions/Childhood/Kawasaki-Disease_UCM_308777_Article.jsp#T1T2bopPWE0
  - Kawasaki Disease Foundation: www.kdfoundation.org
  - KidsHealth: kidshealth.org/parent/medical/heart/kawasaki.html

**Mitochondrial Disease**
- **WEBSITES**
  - United Mitochondrial Disease Foundation: www.umdf.org
  - MitoAction: www.mitoaction.org

**Multifocal Motor Neuropathy (MMN)**
- **WEBSITES**
  - The Foundation for Peripheral Neuropathy: www.foundationfornpn.com

**Multiple Sclerosis (MS)**
- **WEBSITES**
  - All About Multiple Sclerosis: www.msci.org
  - Multiple Sclerosis Association of America: www.msaa.org
  - Multiple Sclerosis Foundation: www.msfocus.org
  - National Multiple Sclerosis Society: www.nationalmssociety.org
  - ONLINE PEER SUPPORT
    - Friends with MS: www.FriendsWithMS.com
    - MSWorld’s Chat and Message Board: www.msworld.org

**Myasthenia Gravis (MG)**
- **WEBSITES AND CHAT ROOMS**
  - Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org
  - ONLINE PEER SUPPORT
    - Genetic Alliance: www.geneticalliance.org

**Myositis**
- **WEBSITES**
  - The Myositis Association: www.myositis.org
  - International Myositis Assessment and Clinical Studies Group: www.mias.org
  - ONLINE PEER SUPPORT
    - Juvenile Myositis Family Support Network: www.curejm.org
    - The Cure JM Foundation: www.curejm.org
    - Myositis Association Community Forum: myositiscommunityforum.nmg.com
    - Myositis Support Group – UK: www.myositis.org.uk

**Peripheral Neuropathy (PN)**
- **WEBSITES**
  - Neuropathy Action Foundation: www.neuropathyaction.org
  - Western Neuropathy Association: www.pnhelp.org
  - Texas Chapter of the Neuropathy Association: www.handsfeetheart.org
  - The Foundation for Peripheral Neuropathy: www.foundationfornpn.com

**Primary Immune Deficiency Disease (PI)**
- **WEBSITES**
  - Immune Deficiency Foundation: www.primaryimmunedeficiency.org
  - Jeffrey Modell Foundation: www.info4pi.org
  - The National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov/Pages/index.aspx
  - American Academy of Allergy, Asthma & Immunology: www.aaaai.org
  - International Patient Organisation for Primary Immunodeficiencies (IPOD) — UK: www.ipopi.org
  - New England Primary Immunodeficiency Network: www.nein.org
  - Rainbow Allergy-Immunology: www.uhhospitals.org/rainbow/services/allergy-immunology
  - ONLINE PEER SUPPORT
    - IDF Common Ground: www.idfcommonground.org
    - IDF Discussion Forum: idffriends.org/forum
    - IDF Friends: idffriends.org
    - Jeffrey Modell Foundation Facebook Page: www.facebook.com/JMFworld
    - Michigan Immunodeficiency Foundation: www.facebook.com/groups/108048062584350

**Scleroderma**
- **WEBSITES**
  - Scleroderma Foundation: www.scleroderma.org
  - Scleroderma Research Foundation: www.srfcure.org
  - Johns Hopkins Scleroderma Center: www.hopkinsscleroderma.org
  - ONLINE PEER SUPPORT
    - International Scleroderma Network: www.sclero.org/support/forums/a-to-z.html

**Stiff Person Syndrome (SPS)**
- **WEBSITES**
  - American Autoimmune Related Diseases Association Inc.: www.aarda.org
  - Genetic Alliance: www.geneticaalliance.org
  - Living with Stiff Person Syndrome (personal account): www.livingwithspss.com
  - Stiff Person Syndrome: www.stiffpersons.net

**Pemphigus and Pemphigoid**
- **WEBSITES**
  - The International Pemphigus and Pemphigoid Foundation: www.pemphigus.org
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