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Advertising in IG Living
IG Living magazine brings together patients, advocates and caregivers in the immune globulin (IG) community. IG Living, ISSN 1949-4548, published bi-monthly, is a community service provided by FFF Enterprises, 44000 Winchester Road, Temecula, CA 92590, (800) 843-7477 x1362, fax (951) 699-9655. Subscriptions to IG Living are free, and readers may subscribe at IGLiving.com or by calling (800) 843-7477 x1351. The opinions expressed in IG Living are those of the authors alone and do not represent the opinions, policies or positions of FFF Enterprises, the Board of Directors, the IG Living Advisory Board or editorial staff. This material is provided for general information only. FFF Enterprises does not give medical advice or engage in the practice of medicine. FFF Enterprises under no circumstances recommends any particular treatment for any individual and in all cases recommends individuals consult with a physician before pursuing any course of treatment.

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Patient Empowerment Is Essential to Outcomes

AS AN INTEGRAL part of their medical team, patients must act as a proponent of their care by asking questions and taking charge of their health. According to Kevin Pho, MD, primary care physician and founder of KevinMD, “It’s important for doctors and other medical providers to listen to the most important member of the healthcare team, the patient. After all, there is no bigger stakeholder. Involving the patient in the decision-making process is essential to both better the patient outcome and improve patient experience.”

Cynthia Perry, author of the article “How to Be Your Own Healthcare CEO,” knows this all too well. As a patient with common variable immunodeficiency and multiple other conditions and a teacher of healthcare classes, one of which is titled “Tales of a Professional Patient: Navigating the Healthcare System with Chronic Illness, Grace and Humor,” she modeled this article on the class she teaches. Her step-by-step business plan outlines what she calls the healthcare management process, at the core of which is communicating effectively. Steps include setting treatment goals, hiring and firing healthcare providers, researching options, prioritizing objectives, managing risk and reporting progress, all of which can be accomplished in any order at any time. Patients are encouraged to follow this practice to make it more likely they receive the care they need.

As patients grow older, taking charge of their care becomes paramount — especially if they plan to remain at home. Indeed, a recent survey shows nine out of 10 seniors, the majority of whom have a chronic illness, prefer to stay at home rather than transition to a senior living care facility. But, as we explain in our article “Aging in Place,” planning is key to staying in the familiar home environment during the senior years. This includes making modifications to the home, getting finances in order for long-term care and other medical needs, arranging for help to ensure medication compliance and safety, finding modes for transportation to doctor appointments and other social outings, staying engaged with others and taking advantage of technology such as smartphone apps, computers and assistive technology devices. The host of suggestions in this article can help with planning.

Finally, being a proponent of one’s care also means considering alternative treatment options. For chronically ill patients, help with pain management is often needed. And, considering the dangers associated with today’s opioid epidemic, complementary therapies offer nonaddictive solutions. In our article “Complementary Therapies for Managing Chronic Pain,” we explain how these types of therapies are effective. Of course, with any type of therapy, personal preference will determine which one is best for each individual.

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

Ronale Tucker Rhodes, MS
Filing for SSDI

By Abbie Cornett

PATIENTS OFTEN contact me for advice when they are considering filing for Social Security Disability Insurance (SSDI). In many instances, they have put off filing for SSDI longer than they should have, and they have reached the point where they can no longer work. Many times, they have delayed filing because they see it as a sign of giving up or they are embarrassed because they can no longer work.

When patients admit they feel embarrassed, the first thing I tell them is there is no shame in claiming something they earned! Nobody expects to have to file for disability; on the contrary, almost everyone expects to be able to work until retirement. Clearly, it’s important for people to understand that SSDI is a benefit they have earned by working.

To be eligible for SSDI benefits, individuals must have an earnings record that shows they have worked at least five of the last 10 years, or 20 out of the 40 quarters before they became disabled. This is known as quarters of coverage or credits. For individuals under 30 years old, the requirements are somewhat different since they have not been in the workforce as long.

For those thinking about filing for SSDI, it’s important to understand what criteria need to be met. To receive benefits, individuals must be found disabled. The law defines disability as an inability to perform any substantial gainful activity by reason of any medically determinable physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last for a continuous period of not less than 12 months. When evaluating a claim, Social Security Administration takes into account the severity of the claimant’s condition(s), age, education, past work experience, transferable skills and whether the individual is able to perform any other substantial gainful activity. To succeed in obtaining benefits, the individual must have a severe impairment that is supported by medically acceptable clinical and laboratory findings.

Individuals should have answers to five questions that determine SSDI eligibility:

- Are they working?
- Is their condition severe?
- Is their condition found in the list of disability impairments?
- Can they work as they did previously?
- Can they perform any other type of work?

When patients tell me they are considering filing for SSDI, I advise them to be prepared to be denied! Denial of an initial application is not unusual. If it is denied, a letter will be sent explaining why and how to appeal the decision. An appeal must be filed within 60 days of the date the disapproval letter is received.

Those with a chronic illness who think they may have to file for disability shouldn’t wait until they can no longer work. Filing for SSDI is a long process. Patients should get their paperwork together as soon as possible, and make sure all the information is gathered before filing. The first step is for patients to talk to their doctors to make sure they agree they are disabled. Physician input is an important part of the process. Then, all clinical data and medical records should be compiled, and any work restrictions or accommodations their employer has provided should be documented.

While the disability process is often lengthy, and SSDI may not be awarded on the first filing, those who appeal their claims following a denial will typically stand a very good chance of eventually qualifying. Perseverance is key!

Feel free to contact me with questions about filing for SSDI.

ABBIE CORNETT is the patient advocate for IG Living magazine. She can be reached at patient advocate@igliving.com or (800) 843-7477 x1366.

References


My daughter had aseptic meningitis several times with her IVIG infusions. We’ve slowed the infusion down to take about 11 hours. We premedicate. She gets IV fluids before and after. And she drinks IV hydration that we buy off of Amazon. Not sure which one of the above therapies worked, but intravenous IG (IVIG) has been the only thing that has beat down my disease after 20-plus years of misery.

— Dave S

I’ve had it twice, and I’ve had milder events, and it isn’t fun at all. I have had to have the infusion rate slowed, so I’ve gone from 80 grams over two days to four days. I get fluids before and after, tons of premedications to the point of hardly being able to hold my eyes open, but intravenous IG (IVIG) has been the only thing that has beat down my disease after 20-plus years of misery.

— Becki L

Has your immune globulin (IG) treatment resulted in aseptic meningitis?

Do you worry about antibiotic-resistant microbes?

It is hard not to worry! I am always thinking there will be one infection I will get that an antibiotic will not help. Especially in the winter, my anxiety level goes up.

— Jenny G

Absolutely! I have one child with serious allergies to several of the core [antibiotics], and then my “zebra” spent eight months fighting a sinus infection that was antibiotic-resistant.

— Dana S-S

I am because there [are only] a select few I can take. I’m so scared I will end up with no cure.

— Sarah R

Have you suffered depression?

No, I have not. And I have been through a lot of major health issues that have almost taken my life. I have had to make major adjustments with my family, friends and doctors. I have had to learn to say no, which can be extremely difficult. I surround myself with people who understand my health situation. And if they don’t, then I cannot be a part of their lives. Sometimes life is tough and, yes, I wish it was not. I allow myself a day for a pity party, and then I bounce back.

— Judy S

Yes, I have. When I am slipping into a depression, my brain tells me that this will not help me manage my health issues. Sometimes, I can turn the thought process around and sometimes not. I am extremely blessed with the network of family and friends that I have, and it seems they step in and either have the right thing to say to change my thinking or just say nothing and love me through it. I am so blessed.

— Jenny G
**ASK THE EXPERTS**

**Abbie** » Our experts were unable to find anything conclusive regarding the restoration of IgG levels. While they did find a couple of articles discussing long-term immunosuppression following rituximab (Rituxan), the articles do not state whether B cells will repopulate. However, they did find that patients with low IgG or low IgM levels prior to Rituxan and/or concomitant treatment with cyclophosphamide are more likely to have longer-term B-cell depletion.

A few studies have hypothesized that bovine colostrum may be helpful in specific instances/clinical conditions (mainly diarrhea from enteric microbial infections); however, I was unable to find any conclusive studies in peer-reviewed journals. There is one study published in the journal *Nutrition* (nutritionj.biomedcentral.com/articles/10.1186/s12937-015-0010-7) that showed IgG survived exposure to gastric juices. I would suggest discussing this article with your immunologist.

**Question » Can Low IgG Levels Caused by Treatment for Lymphoma Be Restored?**

After six months of maintenance Rituxan for follicular lymphoma, I have low IgG levels for which I have been treated every month for nine years with immune globulin replacement therapy. Is there any work being done to permanently repair the low IgG levels? Does bovine colostrum show any promise?

**Leslie** » Cladribine does cause a reduction in both T cells and B cells, so it would make sense you would have low IgG levels around the time of chemotherapy. While we were unable to locate articles that discuss the long-term reduction of B cells secondary to the use of cladribine, there is a lot of literature on the long-term effects of rituximab (a similar treatment). Therefore, it is possible cladribine has similar effects.

**Question » Does Chemotherapy Cause Long-Term Low IgG Levels?**

After being treated with chemotherapy (cladribine) for hairy cell leukemia, my IgG levels have not returned to normal. For the past five years since chemotherapy, I have had to be treated with intravenous immune globulin every two to three months. Is this a normal response after a course of cladribine?

**Dr. Harville** » There is no formal written recommendation for the prescription of antibiotics for CVID patients after dental procedures. Prescribing is sometimes based on the perceived severity of the antibody deficiency, and it is in particular based on previous issues. For a patient who is on replacement immune globulin therapy without recurrent infections, no previous dental-related problems and no risk for developing infection of an implanted foreign body (heart valve, artificial hip, etc.), antibiotic prophylaxis may not be necessary.

However, to be on the safe side, I recommend taking 2 grams of amoxicillin within one hour of the procedure. This is not based on any immunodeficiency evidence, but on evidence of persons with heart valve disease who are at risk for endocarditis.

**Question » Are Antibiotics Necessary for CVID Patients After Dental Procedures?**

I have common variable immunodeficiency, and every time I go to the dentist, I have to be placed on an antibiotic afterward no matter what procedure was done. Is this necessary?

**Have a question?** Email us at editor@IGLiving.com. Your information will remain confidential unless permission is given.

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DiGeorge Syndrome: Thymus and Parathyroid Gland Development

By Terry O. Harville, MD, PhD

In previous issues, we discussed features of DiGeorge syndrome (DGS) and partial DGS (PDGS) resulting from the consequences of improper timing of the sequence of events during early phases of embryonic development. The cardinal features of DGS/PDGS are 1) abnormal facies, 2) cardiac malformations, 3) hypocalcemia due to hypoparathyroidism and 4) immunodeficiency. In this issue, we will begin discussion of hypoparathyroidism and the immunodeficiency features of DGS/PDGS that manifest as a result of improper timing during parathyroid gland and thymus development.

By the fourth week of gestation during normal early embryonic development, pharyngeal clefts (also known as gill slits) become

Figure A. Features in the Neck Region of the Embryo at Approximately the Fourth Week of Gestation
What will develop into the head is at the top left, and the rest of the body is in the lower right. The main four pharyngeal clefts and pouches are depicted. The pharyngeal clefts are commonly called gill slits because, in lower species, they will develop into the gills of amphibians and fish. And, interestingly, all higher organisms develop similarly, which is known as the recapitulation of ontogeny, defined as an individual organism’s development of successive stages resembling the series of ancestral types from which it has descended.

Figure B. Features in the Neck Region of the Embryo After the Fourth Week of Gestation
What will develop into the head is at the top left, and the rest of the body is in the lower right. The main four pharyngeal clefts and pouches are depicted, showing their growth toward the midline.

Figure C. Features in the Neck Region of the Embryo Some Time After the Fourth Week of Gestation, But Well Before the 12th Week of Gestation
What will develop into the head is at the top left, and the rest of the body is in the lower right. The first pharyngeal arches are developing into the mandibles. The first pharyngeal clefts are developing into the outer ears and part of the ear canals. The first pharyngeal pouches are developing into the remainder of the ear canals, middle ears and Eustachian tubes. The second pharyngeal pouches develop into the tonsils that are found on either side of the back of the mouth at the throat. Parts of the third and fourth pharyngeal pouches migrate to the superior lobes, and the third pharyngeal pouches migrate to the inferior lobes (Figure E). The thymus develops from the third pharyngeal pouches, which are comprised of normal skin in which the layers become inverted in relationship with the normal skin layers covering the body.
present in the region that will become the neck. Pharyngeal clefts are on either side of this region, and the developing thyroid gland is in the middle of this region (Figure A). Protruding inside each pharyngeal cleft is a pharyngeal pouch (Figures A, B and C). Also during this period, the pouches elongate with parts of the third and fourth pharyngeal pouches from both sides attaching to the thyroid gland (Figures B, C and E). These will become the parathyroid glands. Interestingly, due to the manner in which the embryo is growing and how the tissue is moving, the fourth pharyngeal pouch remnant migrates to the inferior lobes of the thyroid gland (toward the feet), below where they were originally located. And, the third pharyngeal pouch remnant migrates to the superior lobes of the thyroid gland (toward the head), above where they were originally located. In conditions when the timing is off, the parathyroid glands do not position correctly within the thyroid gland and will not function appropriately, which can result in reduced serum calcium levels (hypocalcemia due to hypoparathyroidism).

While these events are occurring, the first pharyngeal arch is developing into the mandible (lower jaw) (Figures A, B and C). This can result in the small chin and elfin-like face commonly present in DGS/PDGS, with the first pharyngeal cleft becoming the outer ear and part of the ear canal. In DGS/PDGS, the ears may be low-set, with the top part of the earlobe becoming somewhat pointed and notched. Thus, the improper timing of events is responsible for the abnormal facies. The first pharyngeal pouch develops into the remainder of the ear canal, middle ear and Eustachian tubes. But, in DGS/PDGS, this anatomy can be malpositioned, contributing to ear infection problems.

Thymus development begins about the fourth week of gestation and ends by about the 12th week. During that time, the third pharyngeal pouches grow (Figures A, B and C). They meet in the middle (Figure B) and separate from the outer skin of the neck region (Figure C). The cells lining the inside of the third pharyngeal pouch are actually made of the outer layer of skin (Figures D and E). Thus, when the pouch separates from the outer neck region, what was the outside skin of the body becomes the inside of the developing thymus, and the normal inner layers of skin form the outside boundary of the thymus (Figures D and E).

In the next issue, we will continue the discussion of abnormal development of the thymus in DGS/PDGS.

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**Figure D. Third Pharyngeal Pouch**
The third pharyngeal pouch develops into the thymus. Depicted is the right lobe development. The left lobe will be developing simultaneously, with eventual fusion with the right lobe in the middle. Since the pouch is an indentation of the skin, the inside of the pouch is composed of the outer layer of the skin. After the developing thymus buds off from the skin, what was originally the outer layer of skin is now inside of the thymus, and the outer part of the thymus is a boundary created by the inner layers of the normal skin. Thus, the thymus looks just like skin, but it has been inverted.

**Figure E. Third and Fourth Pharyngeal Pouches — Thymus and Parathyroid Glands**
This depiction is of the final development of the parathyroid glands positioned in the thyroid gland lobes and the thymus. Due to the migration of the cells and tissues, parts of the fourth pharyngeal pouches become the superior parathyroid glands and, conversely, parts of the third pharyngeal pouches become the inferior parathyroid glands. There are normally four parathyroid glands, one each from the left and right and third and fourth pharyngeal pouches. The thymus forms from the infolding of the skin of the third pharyngeal pouches, which eventually fuses in the midline. During this process, the outer layer of normal skin becomes the inner portion of the thymus, and the outer boundary of the thymus forms from the inner layers of the normal skin. As a result, the thymus looks like inverted skin.
SMALL FIBER neuropathy (SFN), a type of peripheral neuropathy (PN), is a fairly common chronic condition that can develop at any age, with the disease most prevalent in the elderly. While its prevalence is unknown, an estimated 15 million to 20 million people in the U.S. over age 40 have some type of PN. To date, there is no cure for SFN, and very few treatments are effective in reversing the neuropathy. Recently, there is a growing interest in using intravenous immune globulin (IVIG) due to some small reports showing positive results.

What Is SFN?
Smaller fibers result from damage to the small unmyelinated peripheral nerve fibers found in the skin, peripheral nerves and internal organs. Therefore, the symptoms vary depending on which small nerve fibers are affected. In the skin and peripheral nerves, symptoms can cause sensory disruption, including severe pain, burning, tingling and numbness, that can lead to functional impairment, including problems walking, stairclimbing, use of upper extremities and other interference with activities of daily living. Symptoms usually begin subtly with sensory disturbances in the feet and move upward in a stocking distribution. Eventually, the upper extremities may become affected as the neuropathy advances with sensory disturbances in the hands, moving upward in a glove-like manner.

When small fibers of internal organs are affected, dysfunction with the autonomic nervous system can occur. The autonomic nervous system controls organs and systems that are self-regulated such as digestion, heart rate and blood pressure. People with SFN who have autonomic disturbances can experience severe gastrointestinal (GI) problems, including nausea and vomiting, and unexpected drops in blood pressure and heart rate that can lead to fainting.

Causes of SFN
SFN is believed to be associated with many medical and autoimmune conditions; however, prediabetes and diabetes are most often the causes. Indeed, it is believed almost half of diabetics suffer from some form of SFN.

An underlying cause of SFN can be identified more than 50 percent of the time. While there are many different causes (Table 1), prediabetes and diabetes make up approximately 30 percent of known cases. In many cases, the cause is idiopathic (unknown).

Diagnosing SFN
As with any neuropathy, an electromyography, or EMG, (used to measure muscle activity) and nerve conduction studies (measuring speed and strength of nerve impulses) are routine. Because these nerve fibers are so small, the abnormalities cannot be seen on nerve conduction studies. The preferred method of diagnosis is a skin biopsy that measures small nerve fiber density. Autonomic dysfunction is tested by assessing heart rate, blood pressure, breathing and GI function in response to activities such as positional changes and deep breathing. Blood is also analyzed to look for diseases that are associated with SFN. Another aid to diagnosis is quantitative sensory testing, which assesses damage to the small nerve endings and detects thermal sensation, pain and vibration.

Treating SFN
Treatment for SFN includes treating the underlying cause if known. For example, if the cause is diabetes, maintaining proper blood sugar through diet, exercise and insulin therapy is essential. Treatment also includes simultaneously managing symptoms that arise from SFN. Pain is one of the more challenging symptoms to manage. It can begin with a feeling like sand in the shoe, cold or pins and needles. But, it can increase to burning or shooting that can be brought on by touch or temperature change. Pain is managed with anticonvulsants, antidepressants, in some cases opioids, and nonpharmacologic treatments. However, few studies show efficacy of pain management in SFN, which can be very challenging for physicians and frustrating for patients, especially when the cause is unknown.

Causes of SFN
- Alcoholism
- Celiac disease
- Chemotherapy
- Diabetes and other glucose dysregulation syndromes
- HIV
- Lupus
- Neurotoxic medications
- Paraneoplastic syndromes
- Sarcoidosis
- Sjögren’s syndrome
- Thyroid dysfunction
- Vitamin B12 deficiency
Many patients never experience complete relief.

IVIG treatment is being prescribed by some physicians when the cause is suspected to be autoimmune. In a study conducted by the Mayo Clinic in which patients with chronic GI dysmotility and a positive antinuclear antibody test were treated with IVIG, 74 percent showed improvement in GI function in both subjective reporting and objective testing.5 IVIG has also been successfully used to treat ataxic sensory neuropathy associated with Sjögren’s syndrome. Some case studies of IVIG in people with Sjögren’s who have SFN showed a reduction in painful symptoms.

Some practitioners believe there is an immune response that could be a cause of some cases of idiopathic SFN. To assess this, a clinical trial is currently taking place in the Netherlands in which researchers are looking at the efficacy of IVIG. The currently recruiting randomized, double-blind, placebo-controlled study is testing four courses of treatment, three weeks apart, compared with a placebo, to alleviate pain.6

Most recently, a small study was conducted to assess the safety and efficacy of “apparently autoimmune small fiber polyneuropathy (aaSFPN). The researchers hypothesized that small-fiber-targeting autoimmune diseases akin to Guillain-Barré and chronic inflammatory demyelinating polyneuropathy, for which IVIG is often prescribed off-label, could be a cause of aaSFPN. The study included 55 patients with aaSFPN in whom 27 patients had systemic autoimmune disorders, 20 percent had prior organ-specific autoimmune illness and 80 percent had abnormal blood-test markers of autoimmunity — but none had diabetes or other known cause of neuropathy. After being treated with IVIG for an average of 28 months, 77 percent of patients responded to treatment, with pain dropping on average from 6.3 to 5.2 on a 10-point scale. Their internal organ function also improved. The researchers concluded the study provides proof-of-concept evidence that IVIG is safe and effective for rigorously selected SFN patients with autoimmune causality, providing rationale for more trials.7

While these small studies and case reports show some efficacy of IVIG in treating SFN, there is little data overall to support treatment, which makes it very difficult for this therapy to be covered by insurance. Some plans refuse to cover IVIG treatment due to lack of evidence; however, some will consider a short course of treatment to assess response after the prescribing physician completes a peer-to-peer review with a physician at the insurance company.

**Outlook**

SFN remains a confounding disease with its cause understood in only 50 percent of cases. There is no cure, and few treatments are effective in reducing its severely painful symptoms. It’s hoped that research will make greater inroads into both understanding more about the disease and finding treatments such as IVIG that can provide patients some relief.

“Small fiber neuropathy is a devastating condition that is frequently unrecognized or misdiagnosed,” said Roy Freeman, MD, director of the Center for Autonomic and Peripheral Nerve Disorders at Beth Israel Deaconess Medical Center in Boston. “There are no approved symptomatic or disease-modifying treatments. There is an urgent need for randomized, blinded, placebo-controlled trials to test the clinical features of this disorder.”

**MICHELLE GREER, RN**, is senior vice president of sales for NuFACTOR Specialty Pharmacy.

**References**


Research

New Study Planned to Determine Lowest Dose of Chemotherapy Needed for SCID Bone Marrow Transplant

Researchers from Children’s Center for Cancer and Blood Diseases and Children’s Hospital Los Angeles (CHLA) and Boston Children’s Hospital have been awarded nearly $9 million from the National Institute of Allergy and Infectious Disease to study the lowest dose of chemotherapy needed for babies with severe combined immunodeficiency (SCID) undergoing bone marrow transplant, the standard treatment for SCID. The goal is to restore the immune system safely and effectively with less toxicity than the higher dose regimens currently in use.

The trial will be randomized for babies to receive a low or moderate dose of busulfan, a type of chemotherapy that acts to suppress the immune system in preparation for the transplant. The investigators propose that a bone marrow transplant can be performed successfully in SCID patients without the higher dose of busulfan typically used due to the patients’ lack of functional T cells. “Our goal is to decrease the possible long-term effects from chemotherapy by determining the lowest doses needed to ensure T- and B-cell function in these infants, restoring normal immune systems that can last throughout their lives,” said Michael Pulsipher, MD, who is chair of the Pediatric Blood and Marrow Transplantation Consortium, section head of bone marrow transplant at CHLA and professor of pediatrics at the Keck School of Medicine at the University of Southern California.


Insurance

IDF Publishes Findings of ACA Impact on PI Patients

In November, the Immune Deficiency Foundation (IDF) published results of its survey on the impact the Patient Protection and Affordable Care Act (ACA), which became law in March 2010, has had on people with primary immunodeficiency diseases (PI).

The findings from the series of web-based surveys of persons with PI in IDF’s database in 2014, 2015 and 2016 are available at www.primaryimmune.org/insurancesurveys. On the site are four fact sheets covering health insurance and access to care, quality of care, affordability of care and public policy impacts. In addition, the survey background, methodology, questionnaires and a PowerPoint presentation are available in the About the Surveys section.

IDF hopes the data will help better inform policymakers about the experiences of those in the PI community as healthcare reform continues to evolve. The foundation is also creating a similar site for its 2017 National Patient Survey that was recently sent to select households.
Research

GSK’s Strimvelis Given Recommendation to Treat ADA-SCID in England

England’s National Institute for Health and Care Excellence (NICE) has published draft guidance recommending GlaxoSmithKline’s Strimvelis as an option for treating adenoid deaminase deficiency-severe combined immunodeficiency (ADA-SCID) when no suitable matched related stem cell donor is available. With Strimvelis gene therapy, the patient’s bone marrow cells are removed and modified outside of the body to produce working ADA enzyme, and then reintroduced via an infusion drip into a vein. Current treatment for the condition is a stem cell transplant, which can restore the immune system but carries a risk of mortality and graft-versus-host disease; however, a matched stem cell donor is often difficult to find.

According to NICE, the Strimvelis treatment is administered usually only once, and the effects are thought to be lifelong. The treatment can be administered only at a hospital in Milan, Italy. “Strimvelis represents an important development in the treatment of ADA-SCID, offering the potential to cure the immune aspects of the condition and avoid some of the disadvantages of current treatments,” said professor Carole Longson, director of the centre for health technology assessment at NICE. “This means that children born with ADA-SCID will now have a better chance of being able to lead as near normal a life as possible, going to school, mixing with friends, free from the constant threat of getting a potentially life-threatening infection.”


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Important Safety Information

Hizentra treats various forms of primary immunodeficiency (PI) in patients age 2 and over.

**WARNING:** Thrombosis (blood clotting) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

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.

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 hyperprolinemia (too much proline 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.
Are you a person with PI who takes Hizentra? Do you care for someone who does?

Voice2Voice®

Voice2Voice gives you an opportunity to connect with others who have been in your shoes. Dealing with PI can be a challenge, and knowing someone who truly understands what you’re going through can mean a lot.*

It’s good to know you’re not alone.

Sign up at voice2voice4pi.com

You may also call 1-877-355-IGIQ (4447)
Monday–Friday, 8 AM to 8 PM ET

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 boxed warning and patient product information, please visit Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

*Voice2Voice advocates are not healthcare professionals or medical experts. For medical questions, please contact your physician. Voice2Voice advocates are compensated by CSL Behring LLC for their time and/or expenses.

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use HIZENTRA safely and effectively. See full prescribing information for HIZENTRA.

WARNING: THROMBOSIS

See full prescribing information for complete boxed warning.

- 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.

INDICATIONS AND USAGE

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.

DOSAGE AND ADMINISTRATION

For subcutaneous infusion only.

Administer at regular intervals from daily up to every two weeks (biweekly).

Initial U.S. Approval: 2010

Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid

-----DOSE FORMS AND STRENGTHS-----

0.2 g per mL (20%) protein solution for subcutaneous injection

-----CONTRAINDICATIONS-----

- Anaphylactic or severe systemic reaction to human immune globulin or components of Hizentra, such as polysorbate 80
- Hyperprolinemia (type I or II) (Hizentra contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

-----WARNINGS AND PRECAUTIONS-----

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including Hizentra.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- Hizentra is made from human plasma and may contain infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

-----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.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

-----DRUG INTERACTIONS-----

The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.

-----USE IN SPECIFIC POPULATIONS-----

- Pediatric: No specific dose requirements are necessary to achieve the desired serum IgG levels.
Autoimmune Corner

Research

Experimental Drug Shows Promising Results for Treating MS

Ocrelizumab, which is under review by the U.S. Food and Drug Administration (FDA) for approval to treat primary progressive and relapsing multiple sclerosis (MS), has shown positive results in three Phase III trials. In one trial, 488 patients with primary progressive MS were randomly assigned to receive ocrelizumab and 244 received a placebo. On average, patients remained in the study for nearly three years. Overall, the rates of adverse events were similar in both groups, but at 12 weeks, 32.9 percent of the ocrelizumab group had confirmed disability progression versus 39.3 percent with a placebo. At 24 weeks, 29.6 percent of the ocrelizumab patients had confirmed disability progression compared with 35.7 percent with the placebo. In two other studies, patients with relapsing forms of MS given ocrelizumab showed lower rates of disease activity and progression compared to patients receiving Interferon beta 1a, a standard MS treatment.


Research

Scientists Link Chronic Fatigue Syndrome with Immune System Imbalance

Researchers at Stanford University, Palo Alto, Calif., have found blood levels of immune molecules that cause flulike symptoms such as fever and fatigue track the severity of symptoms in people who have received a diagnosis of chronic fatigue syndrome (CFS). In the study, they analyzed the blood of 192 people who had met one of the established criteria for CFS, also called myalgic encephalomyelitis (ME), and 392 healthy individuals, and found the levels of 17 cytokines, substances produced by immune cells in response to infection, correlated with disease severity. Cytokine levels were higher in patients with the severest symptoms than in patients with milder symptoms or healthy people. In patients with the mildest symptoms, cytokine levels were lower than in healthy people, and in patients with moderate symptoms, they were comparable to individuals with no disease. Of the 17 immune molecules, the vast majority are known to stimulate inflammation and produce flulike symptoms. “I found it surprising that so many cytokines are altered in the patients,” said Mark Davis, an immunologist at Stanford University. “It seems like the disease is leaving no cytokine untouched.”

However, they also found that a few cytokines didn’t correlate with disease severity. Specifically, they found that the blood level of TGF-β, a cytokine that is involved in biological processes such as inflammation and cancer, was higher in CFS/ME patients, regardless of the severity of symptoms, than in healthy people. And, the blood levels of resistin, a hormone produced by immune cells, were lower in patients compared with individuals with no disease. Nevertheless, researchers say the study is a “tremendous step forward.” It is hoped these results will provide insight into the cause of CFS/ME.

How to Be Your Own Healthcare CEO

This step-by-step business plan will help patients manage their chronic illness and get the care they need.

By Cynthia Perry
HEALTHCARE IN THE U.S. is changing. Today, the norms are 15-minute patient appointments and an ever-increasing documentation burden for physicians. Primary care providers likely care for more than 1,000 patients, spend more than six hours a week on paperwork and are overextended or at capacity, with no time to see additional patients. Insurance reimbursement for patient care is getting more and more complicated, and physician burnout is real. And, while it would be ideal if patients had a provider who played quarterback on their healthcare team, the reality is that role is increasingly falling to patients.

Yet, despite these challenges, it is possible to receive excellent care. By acting as CEO of their healthcare, patients can successfully improve their odds of getting the care they need. All that is required is to take the time to properly prepare for the 15 minutes they will likely get with their providers.

The Healthcare Management Process

Good CEOs adhere to a business plan. And, this should be the case for patients, too. As CEO of their healthcare, patients should view managing their care as a business endeavor, which includes the following steps:

• Setting treatment goals
• Hiring (and firing) healthcare providers
• Researching treatment options
• Prioritizing objectives
• Managing treatment risk
• Reporting progress back to providers

Figure 1 illustrates the healthcare management process. Note that the lines in this diagram are nondirectional, indicating the steps can be completed in either direction. The steps could even be viewed as a web in which any step could be completed in any order, and as often as needed.

Communicate Effectively

Throughout each step of the process, effective communication between patients and healthcare providers is critical. As a basis for good communication, patients and providers need to build a rapport with one other. For instance, no matter how sick they feel, patients can try to smile, and both parties can make an attempt to find something they have in common. It is also important for patients to thank their providers in person, via email, with cards or by giving good ratings on surveys and Internet sites.

Patients can facilitate good communication by organizing their medical records. This includes gathering records important to their diagnoses (tests, imaging, blood work, surgical records and doctor notes), and using these to create a medical summary of information such as current providers, diagnoses, surgeries, tests, medications and anything else their healthcare providers need to know. This way, valuable appointment time won’t be wasted communicating medical background information. Instead, appointment time can be focused on current medical needs.

Finally, patients should be direct in their requests for tests or referrals, and providers should offer clear answers in return.

Set Treatment Goals

Before meeting with providers, patients need to decide on their treatment goals. Some doctors start a visit by asking, “What can I do for you today?” This open-ended question is designed to focus the appointment. As Yogi Berra said, “If you don’t know where you’re going, you’ll end up someplace else.” Some sample treatment goals patients could set include:

• Optimally managing a chronic condition
• Looking for a healthcare provider who will prescribe a minimum of medications
• Seeking opinions for a new approach
• Finding a cure for a diagnosis or condition

Figure 1. The Healthcare Management Process
Hire and Fire Healthcare Providers

With many insurance plans, patients are only able to see providers in their network. Once these are identified, patients can search for the best fit. Some ways to start the search include:

- Asking their primary care provider and other providers for recommendations
- Talking to family and friends
- Reading local media reports of doctor rankings
- Using websites such as Healthgrades and Yelp
- Visiting providers’ websites to find out about their care philosophy, education, research interests, etc.

Once potential providers have been identified, patients can “speed date” these candidates until they find the best match. When meeting new providers, patients should bring their medical summary along with a printed list that includes treatment goals and any acute and chronic issues they want the provider to manage. They should discuss how they would like to partner with the provider, and the best way to get urgent care, if needed. If patients feel the provider is a good fit for them, they should ask the provider if they are willing to take them as a patient. Sometimes, a provider won’t want to take on a complex patient and will state that outright. And, sometimes, they will refer patients to another provider as a subtle way of saying they don’t want to treat the patient.

Regardless of how patients and the provider feel about the appointment, patients should always thank the provider for his or her time. If the provider wasn’t a good fit for any reason, patients shouldn’t feel bad about moving on to the next one. The goal is to look for long-term partnerships for their healthcare. In some cases, for very complex and rare conditions, the best match may be out of state and/or out of the insurance network. Under very special circumstances, patients can successfully argue to have out-of-network providers covered as in-network.

Occasionally, patients may need to “fire” a healthcare provider. Circumstances under which patients might need to do this include when the provider:

- Has a style that doesn’t match the patient’s
- Won’t listen
- Isn’t taking concerns seriously
- Won’t answer questions
- Doesn’t treat the patient as a partner in his or her care
- Isn’t making the patient better, or the patient has lost confidence
- Is giving referrals that aren’t working for the patient
- Has billing or office staff issues

When patients fire a provider, they should find another one first, whenever possible, so there is no gap in treatment. They should retrieve their medical records to give to the new provider and cease seeing the previous provider. There is no need to explain anything to the previous provider if they don’t want to, but they can write a succinct and professional letter.

Research Options

When providers decide how to proceed in treating patients’ conditions, they may present options. In addition, well-meaning friends and family may offer their perspectives, opinions and experiences. These can often be helpful because there may be options not widely prescribed or still in clinical trial from which they could benefit.

While patients with complex medical conditions often conduct their own Internet research to help them decide how to proceed, healthcare providers are much more likely to put credence in well-designed research studies. Figure 2 shows the levels of evidence of research studies (the bottom of the pyramid is the lowest level and...
the top is the highest level). Randomized trials with some participants receiving a therapy and others receiving a placebo are the gold standard in medical research. In general, the larger the study size, the more reliable results are deemed. Even more rigorous than a single randomized trial, though, is a systematic review of multiple studies. What healthcare providers are least likely to accept, even if published in a reputable medical journal, is an expert opinion with no case studies, controls or trials.

Prioritize Objectives

Providers are paid using a complex formula that includes work expenses (by diagnosis), practice expenses and malpractice insurance expenses (rate-adjusted for area of country). Medicare sets payment rates that private insurance generally follow; however, private insurance plans usually pay more than Medicare. For these reasons, most providers limit appointment times and the number of issues they will address with patients in a single appointment. A study of 392 videotaped patient visits showed an average 15.7-minute visit with an average of 5.3 minutes of patient talk time and 5.2 minutes of physician talk time. While many patients with multiple chronic conditions try to address everything at once, neither primary care doctors nor specialists can address all of a complex patient’s issues at once. Therefore, it is important for patients to triage their conditions by determining which they feel are most important to address, and which can wait for future appointments.

Patients also need to prioritize their objectives. To do this, they should create an agenda to guide the discussion during the appointment. Once at the appointment, they can give one copy of the agenda to the provider and keep one for themselves. The agenda should include items such as:

- Treatment goals and/or goals of appointment
- Questions they want to ask
- New or changing symptoms
- A list of other providers they have seen and their recommendations and prescriptions
- A summary of any research patients want to discuss
- Tests or referrals desired
- Prescription refills needed

Manage Risk

Patients have the right to make their own medical decisions. However, insurance companies also determine whether treatments are medically necessary and safe and effective for a diagnosed condition before agreeing to pay for them. As such, patients must consider many factors before deciding on a treatment plan:

- Insurance coverage and expense
- Goals of treatment
- Quality of life versus possible side effects
- Stage of life
- Possible risks versus expected benefits

While patients can decline a recommended treatment, doctors can terminate their relationship with a patient for noncompliance. If patients choose to be noncompliant, it is very important they discuss the reasons with their provider. If the patient and provider can’t agree on a treatment plan, the patient may want to find a provider with a care philosophy more in line with their treatment goals.

Report Progress

After treatment goals have been established and a plan is in place, it is important for patients to report progress back to their providers. Many smartphone apps can help patients track symptoms, some that are good for overall health issues and some that are created for specific health issues such as diabetes, headaches or chronic pain. Apps, which are available for both Apple and Android platforms, are described and rated in the app stores.

Those with chronic health issues might benefit from making appointments every three to six months with their primary care provider. These visits, which should be outside of sick appointments and regular checkups, are a good time to review progress with specialists, medications and side effects, and how they are holding up under the stress of dealing with health issues. Providers, especially primary care providers, are also often open to email communications for updates between appointments.

It’s Up to the Patient

In today’s healthcare environment, providers must care for more patients than is desirable to make their practices financially viable. Because patients know their bodies and health histories better than anyone else, it’s up to them to take the time to act as CEO of their healthcare by managing their health with a disciplined process and approaching their providers as partners. By doing so, they are more certain to get excellent care.

CYNTHIA PERRY worked in the medical device field for eight years, interviewing doctors and conducting market research and strategic planning. She now writes articles and teaches classes focused on healthcare. Cynthia has been diagnosed with multiple chronic conditions and is a breast cancer survivor.

References

The growing international trend to remain at home during the senior years is gaining ground — even for those with a chronic illness.

By Abbie Cornett and Ronale Tucker Rhodes, MS

The silver tsunami is here, and it includes those with a chronic illness. The silver tsunami refers to the growing aging population. By 2020, the number of seniors (those over age 65) will outnumber children younger than 5 years of age. And, within 25 years, the number of seniors will have doubled. Baby boomers are, of course, a major contributor to this, but so too are advances in medicine that are helping people live longer — even those with a chronic illness.

According to a report by the American Association of Retired Persons (AARP) Public Policy Institute and the National Conference of State Legislatures, nine out of 10 seniors say the most important aspect of aging well is the ability to age in place. What’s more, 80 percent believe they will stay in their homes until they die. Even among those older adults who require day-to-day assistance of some kind, 82 percent prefer to stay at home.

Aging in place is defined as the ability to stay in one’s home and community safely, independently and comfortably regardless of age, income or ability. The goal of aging in place is to live where one chooses and get any needed help for as long as possible, while maintaining and even improving quality of life.
Why Age in Place?
Dorothy said it best when she clicked together the heels of her ruby red slippers and said: “There is no place like home.” One of the most important reasons seniors want to remain at home is the comfort of a familiar environment. They want to stay in close proximity to family and friends and where their memories and emotional attachments are.

Even more importantly, aging in place gives seniors control over their independence, quality of life and dignity. According to a study conducted in 2000, “adults aging in place exhibited better levels of cognition, better functioning in daily living activities, decreased levels of depression and lower levels of incontinence compared to older adults aging in nursing home settings.”

And, it’s not just seniors who benefit from aging in place. Policymakers and local leaders are recognizing the benefits of providing services that allow people to stay in their homes and communities. “To society, it costs a lot less for someone to age in their home than to go into a care facility,” says Marty Bell of the National Aging in Place Council.

Increasingly, more options are being offered to assist seniors with aging in place. One is known as Naturally Occurring Retirement Communities (NORCs), where healthcare and social services are brought to neighborhoods that have a large aging population. Other communities are using the “village” concept to provide services and support, such as transportation, home repair and social activities, to seniors living in the neighborhood for a membership fee. According to a report by Rutgers School of Social Work, the annual membership fee for a single member costs $430, on average, and most villages offer a discount to members with financial need.

Seniors are also opting to share their homes with someone who can provide help with home maintenance, errands and other chores in exchange for below-market rent. A benefit of this arrangement is that it offers companionship, says Kirby Dunn, of HomeShare Vermont, a company that has been setting up home-share matches for 30 years.

Planning for Aging in Place
The key to aging in place is creating a plan as early as possible that focuses on quality of life and covers the home, finances, medical care, transportation, and social and technological needs. Importantly, individuals need to make plans for staying in the home before they are facing serious problems. Indeed, the only problems that may not be able to be fixed while aging in place are the ones that haven’t been planned for.

Housing. Most people buy their homes with little or no consideration about whether they will be safe to live in as they age. But, seniors intending to age in place need to consider future modifications such as grab bars for showers or tubs, raised toilets, widened doorways, nonslip floors, chairlifts for stairwells and ramps, easily accessible outlets and door handles and medical alert systems (see AARP’s Most Common Home Modifications for Older Adults). Home inspectors can recommend corrections and adaptations to the home to improve maneuverability, accessibility and safety. The International Association of Certified Home Inspectors has an extensive checklist available for seniors who are considering remodeling their homes to age in place (www.nachi.org/aging-in-place.htm).

Finances. While aging in place is inarguably less expensive than care facilities, finances must still be taken into account.

Medicare will pay for in-home care, including home healthcare that provides someone to help with personal care tasks, but Medicare is only a short-term solution for long-term care. Therefore, other available options must be investigated. Medicaid is generally the long-term care solution. Medicaid’s Home and Community Based Services (HCBS) waiver program is designed to pay for many services that would be impossible for seniors to afford on their own. The HCBS program provides for homemaking, personal care and even adult day healthcare services.

Seniors who are veterans are eligible for a number of services, from homemaker/home healthcare services to adult day care and hospice options. To seniors’ advantage, Veteran’s Affairs programs provide more individual discretion about how funds are used than many government programs.

AARP’s Most Common Home Modifications for Older Adults
- Safety features such as nonslip floor surfaces (80 percent)
- Bathroom aids such as grab bars (79 percent)
- A personal alert system that allows people to call for help in emergencies (79 percent)
- Entrance without steps (77 percent)
- Wider doorways (65 percent)
- Lever-handled doorknobs (54 percent)
- Higher electrical outlets (46 percent)
- Lower electrical switches (38 percent)
Other sources of financial assistance include state assistance programs that can help to make modifications to the home or pay for long-term care; private insurance options that will help pay for in-home care, cover the cost of durable medical equipment and, with a doctor’s order, may include some of the equipment needed to live safely in the home; local nonprofit assistance programs that can help make home modifications; and long-term care insurance policies to help pay for a variety of long-term care options, including home care, assisted living care or a nursing home stay, as well as pay expenses for adult day care, care coordination and other services.

For homeowners, a reverse mortgage can cover needed expenses. With a reverse mortgage, there is no monthly payment; the amount comes due when the homeowner moves out of the home, passes away or moves away from the property for more than a year.7

At some point, seniors are going to be unable to take care of their own finances. Before that happens, the following questions should be answered:

- How will long-term care be paid?
- Who will manage financial affairs?
- Who will be responsible for the individual’s personal care such as medical decisions, where they will live, in-home assistance, etc.?
- Who will manage the individual’s assets so that a spouse or loved one receives care?
- How will the estate be handled, and who will carry out the individual’s wishes?

Medical care. One of the most important things seniors can do if they want to live at home is to stay engaged with their primary care physician. While residents living in assisted living and nursing homes get help taking medications and monitoring results, those who stay at home need to find ways to remember to take their medications and stay in touch with doctors about possible side effects and needed changes.7 In addition, a doctor or pharmacist should review medicines — both prescription and over-the-counter — to see if any might interfere with aging in place.

For those with significant health conditions, the care component can oftentimes be the most costly when choosing to age in place. While many have family and friends who can assist, others must hire caregivers to provide medical and nonmedical assistance, which could cost as much as $10,000 to $15,000 a month.10 This is why planning ahead is so essential for putting resources such as long-term care in place.

Transportation. Only 1.2 percent of seniors use public transportation on a daily basis, with most relying on friends and family for rides to go to doctor appointments, social events, church services, etc. According to Katherine Freund, president and executive director of ITNAmerica, a consulting firm in Portland, Maine, women live an extra 10 years on average between the time they stop driving and pass away, while men live an extra six years. So, to avoid being homebound, seniors aging in place must look at reliable transportation methods, especially if there are no family and friends to assist.

While taxis, Uber and Lyft can be good methods of transportation, many seniors don’t feel safe using them. Fortunately, other ride services are available in many locations. For instance, ITNAmerica (ITN stands for independent transportation network) has helped form senior transportation networks in 26 communities in 21 states. In each of these, a nonprofit organization has been established to oversee and administer the volunteer transportation service, with funds coming from donations and member dues that riders pay. An example of this is in Charleston, S.C., where the transportation service averages 25 rides a day, utilizing mostly senior volunteer drivers. To use the service, seniors pay an annual membership fee of $50, and each ride costs $4, plus $1.45 per mile (on average, $12 one way). Rather than exchange money with the driver, the money is put into a personal ITN account that is deducted after each ride, and no tipping is permitted.11

There are also senior transport and rideshare services staffed by volunteers and sponsored by community, religious or nonprofit organizations, which offer free transportation to those who qualify. Some limit the number of rides provided to any one person each month, and most require advance notice for scheduling. These can be located either in the local telephone book under senior services, by phoning local religious groups or through the nearest Area Agency on Aging.
For those who need transportation to a clinic or hospital, services are offered based on availability, with most requiring scheduling several days to a week in advance. These can be found by contacting the particular clinic or hospital in which the patient will be receiving care.

Lastly, local Veterans Health Administrations offer limited transportation services to those receiving care, with a limited number of daily pickups, usually originating from central spots within the community. Advance reservations are required, and most facilities don’t allow family members or friends to ride along. These can be found by contacting the particular veteran’s facility through the U.S. Department of Veterans Affairs.  

Socialization. With 28 percent of Americans over age 65 living alone, the possibility of social isolation when aging in place that can lead to depression must be taken seriously. Social isolation often happens when there is lack of communication with other people. To combat this, seniors are encouraged to volunteer their time at schools, hospitals, libraries, soup kitchens, churches and local charities; find and enjoy a hobby with others such as playing cards, scrapbooking or playing bingo; schedule regularly weekly times to meet with friends and family; and attend church.  

If seniors are unwilling to do any of these things, an alternative option is to hire a companion or caregiver who can visit several times a week. In addition, local Area Agencies on Aging can often recommend volunteers who will stop by or call to keep seniors company or talk about any problems they are having.  

Technology. Interestingly, technology can address many concerns about aging in place, including social isolation, maintaining independence and confronting healthcare challenges. While many overlook the usefulness of technology for seniors due to its unfamiliarity, the Pew Research Center reports 42 percent of adults 65 and older own smartphones today (compared with just 18 percent in 2013), and 67 percent of today’s seniors use the Internet.  

Indeed, technology is giving seniors more confidence in their ability to live alone. This includes Bluetooth, cellular connectivity via mobile phones, smartphone monitoring apps and sophisticated computers. Devices can check medication, monitor Alzheimer’s wandering, activity in the home, falls and real-time health information. “We’ve entered the era of low-cost, miniaturized, technological capabilities that enable smarter caregiving and greater independence,” says Laurie Orlov, an aging-in-place technology analyst. In fact, the current $2 billion industry is expected to rise to $30 billion by 2020. Unfortunately, the government and insurance companies aren’t yet paying for many of these devices. “While Medicaid may reimburse for some aging-in-place technologies, Medicare, unfortunately, does not,” says Majd Alwan, executive director of the nonprofit Leading Age Center for Aging Services Technologies. But, that hasn’t stopped the boom in new devices, as more and more seniors

### Aging in Place-Related Websites

- **Administration on Aging** is the federal agency within the Department of Health and Human Services that advocates for older Americans, provides home- and community-based care, and provides funds for services and programs at the state and local level: [www.aoa.gov](http://www.aoa.gov)

- **Aging in Place Initiative**, a collaboration between N4A and Partners for Livable Communities, is an 18-month commitment with eight selected communities providing technical assistance to enable older adults to age in place: [api.n4a.org/index.htm](http://api.n4a.org/index.htm)

- **The AdvantAGE Initiative** is based on a survey taken by older adults in 10 U.S. communities to assess their needs and concerns about growing older and aging in place: [www.vnsny.org/advantage](http://www.vnsny.org/advantage)

- **American Association of Retired Persons** (AARP) is a non-profit, nonpartisan membership organization for people 50 years and older that advocates for its members on issues ranging from prescription medication to home improvement to current legislation: [www.aarp.org](http://www.aarp.org)

- **Communities for a Lifetime** is an initiative of 73 towns, cities and counties in the state of Florida to strengthen relationships between local aging organizations and community partners to make civic improvements in the areas of housing, transportation, healthcare and efficient use of natural resources: [www.communitiesforalifetime.org](http://www.communitiesforalifetime.org)

- **The National Aging in Place Council** is a senior support network founded on the belief that an overwhelming majority of older Americans want to remain in their homes for as long as possible, but lack awareness of home and community-based services that make independent living possible: [www.ageinplace.org](http://www.ageinplace.org)

- **National Association of Area Agencies on Aging** is the leading voice on aging issues for Area Agencies on Aging across the country and a champion for Title VI-Native American aging programs: [www.N4A.org](http://www.N4A.org)
embracing the lifestyle choices they offer. Here are some examples: 

- MedMinder (www.medminder.com): A digital pill dispenser that looks like a regular seven-day model that is locked until its time for medication. A caregiver fills the medicine tray, remotely programs the schedule that beeps when its time for the medication to be taken, and monitors to see whether the user has complied.

- Philips Lifeline with AutoAlert (www.lifelinesys.com/content): A personal help button for home use that is worn around the neck or wrist and can detect when a person has fallen. When this happens, the person is connected to the response center.

- GrandCare Systems (www.grandcare.com): A multipurpose system that tracks daily activity, has medical monitoring (glucose, oxygen, blood pressure, weight) and can display diets, discharge plans, exercises, etc. An interactive touch screen lets the person watch videos, view family or Facebook photos, listen to music, play games, read the news and video chat with family.

- GreatCall 5Star Urgent Response (www.greatcall.com/fivestar_urgent_response): A mobile personal emergency response system that uses GPS technology to allow CPR-trained agents to find the location and assess the situation.

For those with significant health conditions, the care component can oftentimes be the most costly when choosing to age in place.

Assistive tech (AT) can also be very beneficial. AT, defined as “any item, piece of equipment, software program or product system that is used to increase, maintain or improve the functional capabilities of persons with disabilities,” allows seniors to compensate for disabilities such as loss of vision, hearing and movement. For instance, there are tablets designed to help them stay connected with family that are distant or in times of power outages or other emergencies. Tablets can also be used to participate in social groups or hobbies that may be limited due to disability. Another example is a connected home, which allows devices to be controlled using an Internet connection and apps via smartphones or smart televisions, that can address safety issues such as monitoring the opening and closing of doors or windows.

The Chronic Illness Factor

Having a chronic illness doesn’t mean seniors can’t age in place. But, they do need to be actively involved in their own care. It’s estimated between 95 percent and 99 percent of chronic illness care is given by the person who has the illness. On a day-to-day basis, these patients are in charge of their own health, and the daily decisions they make have a huge impact on their outcomes and quality of life. That doesn’t mean, though, that they should rely solely on themselves. Rather, they need to stay engaged with their physicians. The National Institute on Aging recommends seniors discuss their illness with their physicians to determine how their chronic illness may impact their ability to age in place and what additional steps may be needed.

Most importantly, successful aging in place depends on good planning that is done early — long before seniors need help. This means making necessary changes to living environments, ensuring finances are in order, arranging for proper medical care and insurance, researching transportation sources, staying as social as possible and taking advantage of technological tools to stay connected and safe.

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References


Understanding Chronic Mucocutaneous Candidiasis

This collection of disorders that cause cutaneous and fungal infections has just recently become better understood, but diagnosis still remains a challenge.

By Bob Geng, MD

Patients with significant defects in cellular immunity have long been recognized to be susceptible to a variety of mucosal and systemic fungal infections. These include patients with primary combined immune deficiencies and cellular immunodeficiency syndromes who may present with both cutaneous and systemic fungal infections, one of which is chronic mucocutaneous candidiasis (CMCC).

The clinical phenomenon of CMCC has been recognized for decades, but the underlying mechanisms that lead to the disease have not been well understood until recently. Clinically, patients with CMCC present with chronic Candida infections of the nails, skin and mucous membranes. The most common species of Candida found in CMCC is Candida albicans. Some of the most recognized cases of CMCC have defined genetic causes,
some of which are associated with deficiencies in the innate immune system and defects of the TH17 pathway of adaptive cellular mucosal immunity. In addition to susceptibility to Candida infections, CMCC patients also often present with autoimmune endocrine and hematologic complications.

**The most well-defined genetic defect associated with CMCC is the autoimmune regulator deficiency.**

### Specific Known Genetic Defects

In general, antifungal immunity is achieved through pattern recognition receptors of the innate immune system and T helper cells that help to defend the mucosal membranes and skin. Unlike receptors on T cells or immunoglobulin, the innate pattern recognition receptors are not specific to individual types or species of fungi to which the body is exposed; instead, they recognize general conserved features of all fungi organisms. The group of T helper cells involved in antifungal immunity and defense of the mucosal membranes and skin are the TH17 cells, which derive their name from their involvement in the production of a cell signaling molecule called IL-17. Defects that alter the normal number or function of TH17 cells or alter the expression of IL-17 will lead to impaired immunity against fungi, as well as decreased ability for the body to defend the mucous membranes and skin.

The most well-defined genetic defect associated with CMCC is the autoimmune regulator (AIRE) deficiency. AIRE accounts for most of CMCC cases in certain populations (Sardinians and Finns), but only a minority of cases of CMCC in the general population. Around 50 different mutations have been discovered thus far on this gene leading to CMCC. This specific defect leads to CMCC because AIRE, under normal conditions, prevents the proliferation of autoimmune T cells. During the process of T-cell development and maturation, those with receptors that recognize self are not allowed to expand to prevent the development of autoimmune disease. Normal functioning of AIRE is what allows this selection against autoimmunity to occur. Therefore, when AIRE is abnormal, these autoimmune T cells are allowed to expand and travel to the rest of the body. One of the manifestations of this autoimmunity is the impairment of the TH17 system. There is evidence that some of these autoimmune T cells induce B cells to produce antibodies that block the normal function of IL-17 and IL-22 (another cell-signaling molecule that is involved in the TH17 system). This impairment leads to a functional deficiency of the TH17 system’s ability to defend against Candida infections.

In addition to the impact against the TH17 system due to AIRE deficiency, other forms of autoimmunity can occur such as in the endocrine system. The endocrine system is responsible for the production of various hormones essential for a body’s healthy functioning. This is why patients with CMCC from the AIRE mutation can often develop hypoparathyroidism and adrenal failure. Patients with hypoparathyroidism can develop severely low calcium levels and low magnesium levels in the blood, and occasionally other endocrine disorders such as hypothyroidism, type 1 diabetes, growth hormone deficiency and decreases in the sex hormones. Collectively, both CMCC and endocrine abnormalities are called the autoimmune polyendocrinopathy candidiasis ectodermal dystrophy or the autoimmune polyendocrine syndrome type 1. It is often challenging to make this diagnosis since different features of the condition may occur in different individuals at different times in their lives. The first signs and symptoms may occur during infancy, but they can develop as late as young adulthood. Therefore, in patients with features of CMCC and endocrine defects, it is important to have a low threshold to suspect AIRE mutation.

Other known defects of the TH17 system associated with CMCC include gain-of-function mutations of the signal transducer and activator of transcription 1 (STAT1), as well as mutations directly on the IL-17 receptor. STAT1 actually leads to a functional decrease of IL-17 and IL-22 leading to a relatively impaired TH17 response, thus decreasing the defense against Candida. Unlike the AIRE mutations, these defects do not appear to directly result in autoimmune diseases of the endocrine system.

One well-described defect in the innate immune system leading to CMCC is Dectin-1 deficiency. Components of Candida are recognized by various pattern-recognition receptors (toll-like-receptors 2 and 4 and mannose binding receptors). Dectin-1 works with these receptors to enhance production of cell-signaling molecules to defend against Candida infections. Therefore, deficiencies in Dectin-1 will lead to an impairment
of anti-Candida immunity. Again, similar to most forms of CMCC, patients with Dectin-1 do not develop systemic invasive Candida infections, and are susceptible only to Candida infections in the skin and mucous membranes. Another more recently described defect in the innate immune system is a specific mutation of the toll-like-receptor 3 (TLR3) that leads to features of CMCC. In addition, since TLR3 is very important in antiviral immunity, these patients also develop severe viral infections and chronic lung disease, some degree of autoimmunity involving the endocrine system and low blood cell counts.

Since antifungal immunity is a complex process, many other conditions will lead to susceptibility of both mucosal/cutaneous candidiasis and more serious invasive disease. Secondary immunodeficiencies such as HIV, poorly controlled diabetes or medication-induced immunodeficiency due to prolonged use of steroids can all increase the risk of developing fungal infections. Other primary immunodeficiency syndromes such as severe combined immunodeficiency, hyper-IgE syndrome and other forms of combined cellular and humoral immunodeficiency can all lead to some degree of fungal infection. However, all these conditions have other clinical signs and symptoms that make them distinct from CMCC. Furthermore, it is important to distinguish these other conditions from CMCC since they have specific treatments, as well as potential susceptibility to more invasive systemic fungal infections.

**Laboratory Evaluation**

Diagnosis of CMCC is largely clinical, based on signs and symptoms of presentation. The only definitive laboratory diagnosis is based on genetic testing to detect specific known genetic defects associated with CMCC. However, there are some features of CMCC that may be found in standard immunologic testing. One of the more common laboratory findings in CMCC is the abnormality in both T-cell count and response to Candida antigen. In the usual cellular immune panel ordered for immunodeficiency evaluation, the T-cell numbers and T-cell proliferation may be reduced following Candida stimulation. Some patients may also demonstrate humoral immunity with decreased level of circulating immunoglobulin. This hypogammaglobulinemia could be manifested in a lower level of total IgG or in IgG subclasses, as well as functional defect seen as decreased response following vaccination with polysaccharide antigens (a selective antibody deficiency type of presentation). Testing for specific IgG to Candida is not helpful in the diagnosis of CMCC.

**Treatment**

Candidiasis is generally treated with azole antifungals. For some patients, only acute therapy is needed when infections occur. However, for others who have more recurrent disease, prophylactic therapy is necessary to prevent occurrences. One of the most commonly used agents is fluconazole, which is well-tolerated and cost-effective. If patients develop resistance to fluconazole or develop infection despite chronic suppression therapy with fluconazole, other agents may be used. Voriconazole, itraconazole and posaconazole are other more potent agents that may be prescribed. In addition to antifungals, it is important to address endocrine deficiencies. For patients with hypoparathyroidism, serum calcium and magnesium levels need to be monitored and replaced if they are low. Lastly, some CMCC patients, depending on the specific genetic defect, may also have varying degrees of upper- and lower-airway infections, as well as laboratory signs of antibody deficiency, which may require immune globulin replacement therapy.

**Diagnosis of CMCC is largely clinical, based on signs and symptoms of presentation.**

**A Collection of Disorders**

CMCC are a collection of disorders that share features of chronic Candida infections in the skin and mucous membranes. Some patients with CMCC have a clearly defined genetic defect. Aside from the candidiasis, depending on their specific underlying genetic defect, many patients have other clinical features such as endocrine disorders and susceptibility to respiratory infections. Due to the heterogeneity of presentation, variable age of presentation and lack of readily available confirmatory laboratory evaluations other than genetic testing, recognition and diagnosis often are delayed and remain a challenge.

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Complementary Therapies for Managing Chronic Pain

Fueled by recent news coverage focusing on opioid addiction, a heightened awareness of the dangers of overmedicating has led many to revisit the benefits of complementary therapies to manage chronic pain.

By Amy Scanlin, MS

**CHRONIC PAIN**, defined as lasting three to six months and longer, can be devastating for those who suffer from it. From growing financial costs, to loss of mobility and productivity at work and home, and psychological and family stress, the implications for those impacted are staggering. An analysis of data from the 2012 National Health Interview Survey found an estimated 25.3 million U.S. adults, or 11.2 percent of the population, had pain every day for the preceding three months, and nearly 40 million adults had severe pain.¹

“Pain is the most common reason for seeking medical care,” explains Wendy J. Weber, ND, PhD, MPH, acting deputy director for the National Center for Complementary and Integrative Health (NCCIH) and branch chief for the Clinical Research in Complementary and Integrative Health Branch, part of the National Institutes of Health (NIH) Pain Consortium. “It’s also the most common reason why people turn to complementary and integrative health approaches.”
While complementary therapies are not new, there is a resurgence in popularity thanks to a trend toward a more holistic approach to care, findings at multiple research centers of evidence-based proof of their effectiveness, anecdotal success from friends and blogs and, of course, curiosity about whether something as seemingly simple as breathing can have a positive effect on one’s health. “Physician care guidelines are starting to include complementary health approaches when the evidence base is strong that they may provide benefit and are less likely to cause harm than other available treatments,” says Dr. Weber. “For example, the American College of Physicians’ treatment guidelines for acute, subacute and chronic back pain recommends the use of several complementary health approaches as first- and second-line treatment for these conditions.”

Chronic vs. Acute Pain

What is chronic pain, and how does it differ from acute pain? One way it differs is where it resides in the brain. Acute, or temporary, pain appears in areas of the brain associated with damaged tissue that caused the pain, whereas chronic pain resides in the prefrontal cortex and limbic system where memories, emotions and feelings of pleasure reside. One theory about how chronic pain develops is that continuous signals of pain to and from the brain cause anatomical changes and begin to “wear down” nerve pathways on which they travel to the point that one continually senses pain. In essence, although the body has healed, the pain signals continue. It has even been suggested that chronic pain may reprogram how genes in the immune system work.²

As with opioids, complementary therapies such as meditation, relaxation and yoga provide relief by deadening the sensations of pain. It is believed that pain needs an audience, and when the brain is unable to focus on pain, a person no longer feels it, or feels less of it. Complementary therapies can retrain the body and mind to refocus away from the pain.

Many find comfort by adding complementary therapies to their routine. Although the combination of types of therapies and possible pharma interventions differ from person to person, the ultimate goal is improved quality of life and reduced pain levels. How that happens is very individualistic. “What works depends on the individual,” explains Penney Cowan, founder and chief executive officer of the American Chronic Pain Association. “Their needs, what is offered and available to them, their personal motivation, their support at home. We talk a lot about personalized medicine, and healing is not one-dimensional.”

Movement Therapies

Overwhelmingly, most who suffer from chronic pain are encouraged to keep active within their pain limits and to strengthen, stretch and improve their cardiovascular systems. While working through the pain of movement, at least initially, may seem counterintuitive, a lack of mobility leads to weaker and tighter muscles making movement even less comfortable. Cardiovascularly, the health risks of not exercising are equitable across the board — chronic pain or not. Inactivity compounds many problems and increases pain and health risks in the long run.

With movement therapy, healthcare providers conduct an initial health assessment, and then encourage individuals to take a multitiered approach. Individuals learn what types of movements are encouraged, how to perform them safely and why they are beneficial. Knowledge is power, and understanding their importance provides an extra incentive to keep going on tough days.

As with opioids, complementary therapies such as meditation, relaxation and yoga provide relief by deadening the sensations of pain.
class, which will allow them to offer modified movements as necessary.

It is common to feel new discomforts when starting an activity, and those with chronic pain may feel them more intensely. As such, some may be tempted to cease activities before the real benefits kick in. If this occurs, individuals should speak with a healthcare professional, physical therapist or exercise professional trained in working with those who have chronic pain to understand if new pain is a normal, short-term result of the exercise; simple stiffness that can be corrected with improved range of motion; or something else such as a compensatory movement (i.e., inadvertently favoring one side of the body to protect the other), which leads to new types of pain or pain in new areas.

**Movement therapy can take many forms, from simple walking to aquatic exercise and mind-body movements such as tai chi and yoga.**

**Passive Therapies**

The brain can also be retrained to reduce focus on pain with passive techniques that require no physical energy expenditure and that can create new, pain-free pathways for nerve impulses to travel through.

Meditation, particularly mindful meditation, has been shown in numerous studies to have a positive impact in lessening chronic pain by as much as 60 percent to 90 percent, and this is true of both seasoned and beginning meditation practitioners. By slowing down the mind and focusing on something as simple as breathing, individuals can alter pathways that send pain signals to the brain, as well as alter memories of that pain. Mindful meditation is also helpful in relieving the anxiety and depression that often accompany chronic pain. There are many ways to practice meditation, either solo or in a group setting, and many different types of it. When starting out, it is important for individuals to remember the mind will wander, and that is OK. When it does, individuals can bring the focus back to the breath, mantra, guided imagery, etc. With time and practice, focusing becomes easier, and the benefits are even greater. Many meditation apps, CDs and classes are available.

Virtual reality is also being studied as a method for managing chronic pain. Though fairly new, it is being successfully used in a number of settings, and results are lasting, in some cases, as long as 48 hours. One such virtual reality game is SnowWorld. Although it was originally designed to help with acute pain, some patients with chronic pain are also finding relief. Much like the principles of yoga and mindful meditation, it helps individuals to refocus away from pain with an analgesic effect that eliminates pain’s audience. According to researchers, the more “into” the game an individual is, the better the result. Because the technology is so new, there are no long-term studies to demonstrate effectiveness, but there is hope for continued good results over the long term. It wouldn’t be unreasonable to speculate that some may find similar distractions and benefits while playing other virtual reality games. For instance, the game Tetris was found to lessen the effects of post-traumatic stress disorder by distracting from the trauma.

Other passive modalities can also help. “Spinal manipulation and massage appear to be as effective as other therapies commonly used for chronic low-back pain, such as physical therapy, exercise and standard medical care,” says Dr. Weber. Performed by chiropractors, osteopaths and physical therapists, spinal manipulation involves a variety of techniques, depending on the practitioner, and has been recommended since 2007 by the American College of Physicians and the American Pain Society as one of several treatment options to consider when pain does not improve with self-care. Individuals interested in spinal manipulation can ask their healthcare provider for recommendations and should always seek a board-certified practitioner.

**Emotional and Social Support as Therapy**

Equally important as physical pain is the emotional pain that can accompany it, as is the feeling of isolation as pain limits individuals’ ability to enjoy leisure and professional endeavors. “We identify ourselves by what we can accomplish in a day, and pain takes that away. That’s depressing,” says Cowan. “It takes away our ability to function; it prevents us from doing activities we love.” Even family members of those with chronic pain face these challenges, adds Cowan. They have all the same experiences, except for the pain, and they need validation, too.

The challenge of treating chronic pain along with anxiety or depression is often met with a combination of complementary and psychological therapies. Cognitive behavioral therapy
(CBT), a form of psychotherapy that treats problems and boosts happiness by modifying dysfunctional emotions, behaviors and thoughts, is the most widely used psychological intervention for chronic pain. And, CBT’s acceptance and commitment therapy (ACT) approach, which uses the insights of mindfulness training, is showing particular success. Those who participate in ACT tend to have more psychological flexibility and are more engaged with managing their pain therapy, resulting in less pain-related anxiety, depression and social isolation.6

Again, seeking a referral to a mental health specialist from a healthcare provider can help to find someone who is a good fit. Other options may be found through departments of public health, places of worship and referrals from friends.

The Hard and Anecdotal Science

Just because something is complementary or trendy doesn’t mean it is safe and effective for all. Medications, health status and pregnancy are just a few factors that can influence which type of therapy individuals should try and how effective it will be. Close coordination with a healthcare provider, physical therapist, personal trainer and/or counselor will help to ensure that whatever therapies are tried, the road to improvement will be safe and effective.

The NCCIH has been studying integrative health approaches since 1998, both at its NIH intramural laboratories in Bethesda, Md., and through research grants funded around the country, that aim to build an evidence base for the effectiveness and safety of complementary approaches for chronic pain management.

Some conditions for which complementary therapies are showing promising results are:7

• Fibromyalgia: Tai chi, yoga and mindfulness have potential therapeutic benefit; however it is still uncertain if the same can be said for acupuncture.
• Osteoarthritis in the knee: Tai chi is showing promise.
• Severe headaches and migraines: Relaxation techniques are showing effectiveness.
• Low-back pain: Tai chi, acupuncture, spinal manipulation and massage may provide benefit.

Personal preference is often the first consideration when deciding which complementary therapy to try, says Dr. Weber, although she hopes future research will help guide that decision-making process. “Discussing options with your healthcare provider is important to make sure that the approach you want to try is safe for you,” she explains. “Giving a provider a full picture of what you do to manage your health will help ensure coordinated and safe care. Ask the practitioner if they have experience working with your pain condition, and find out about their training and experience. Overall, it’s important to learn about the complementary health approach or product being considered — especially the scientific evidence of its safety and whether it works.”

The challenge of treating chronic pain along with anxiety or depression is often met with a combination of complementary and psychological therapies.

How does one know if it’s working? It takes time, and “working” will mean different things for different people. “If you have been sitting in a chair for a couple of years, it will take a while to get back,” says Cowan. “Everyone is looking for a formula, but give something a chance.” If it doesn’t seem like it’s working, she adds, individuals should talk to a provider to see what else can be done.

Although there are too many complementary options to cover in this article, the take-home message is no matter what method is tried, treating the whole person is what will ultimately lessen chronic pain. Getting back out and enjoying life is not a quick fix, it is a long-term, active solution that must be tended to diligently and carefully.

AMY SCANLIN, MS, is a freelance writer specializing in medical and fitness issues.

References
LET’S TALK

PROFILE:
Julian Vilaranda

By Trudie Mitschang

Trudie: Were there any health events leading up to Julian’s symptoms?

Amelia: In August 2012, during a summer vacation in Cuba, Julian caught a serious case of impetigo on his nose. Upon returning home, we visited the doctor because the infection wasn’t going away. Unfortunately, he was only treated with a topical cream and not an antibiotic. With time, the infection went away only to return at least monthly. Julian also seemed to develop seasonal allergies, often complaining about itchy eyes, and his nose would get congested, causing sinus issues. We now believe impetigo caused by strep bacteria might have been the trigger to his misdirected immune response.

Trudie: What was Julian’s initial diagnosis?

Amelia: We visited the family doctor for the first time in March 2015 for the OCD symptoms. The doctor performed a routine check-up and said that maybe OCD was just part of his personality. We left the office with no recommendation or treatment plan. That same week, Julian’s symptoms skyrocketed. His anxiety level was through the roof, and he began to have horrible intrusive thoughts. At times, he would hit his head on the floor in desperation. That’s when I requested a referral.

Trudie: What happened next?

Amelia: The next doctor diagnosed him with anxiety and prescribed a very low dose of fluoxetine (Prozac, Sarafem). Upon hearing this medicine could cause him to become aggressive, Julian refused to take it. So, instead, we tried a natural product called LTO3, and it did calm him down, but not as much as we hoped. His anxiety kept increasing, he became terrified of going to school, and he became desperate and said he no longer wanted to live like this. The first time I heard my baby say these words, it was like knives stabbing me in the heart. I called Chatham-Kent Children’s Services, and a crisis social worker detected we were dealing with more than a mental illness. She told us we needed to take our son to the emergency room (ER) immediately.

Trudie: When was Julian diagnosed with PANDAS?

Amelia: After our trip to the ER, we were referred to Wendy Edwards, MD, who saw us the next day. She was the first to diagnose PANDAS.

Trudie: What was Julian’s treatment plan?

Amelia: He was prescribed azithromycin and a very low dose of fluoxetine, and he experienced symptom relief almost immediately. He was on antibiotics for a couple of months, initially on a treatment dose and then prophylactically. He finished the school year successfully and did so well that, halfway through the summer, I took him off antibiotics to give his body a break. In retrospect, that was probably my biggest mistake.
**Trudie:** When did things get worse?

**Amelia:** His health declined rapidly in fall 2016. We immediately put Julian back on antibiotics, but this time, it didn’t work. We added supplements and alternative therapies, but nothing really brought him back to baseline. He became so severe that he could no longer attend school or leave the house. His pediatrician suggested we try an antiviral, and for a short while, he started to feel some relief, but then he would relapse. We started to wonder if one of us was a strep carrier. We all got tested and, sure enough, Jayden was a carrier. Because Julian’s symptoms were so severe, he became suicidal, and his doctor prescribed him 30 days of a steroid taper. The first 15 days were absolutely horrible with rages and increased OCD. As we started to decrease the dose, Julian finally began to show some progress. Since none of the other antibiotics we tried worked for him, we began to suspect his strep was hiding in his gut. His doctor kept him on an antiviral and added rifaximin, an antibiotic that targets only gut bacteria. Jayden was also put on azithromycin and rifampin to get rid of the stubborn strep still hiding somewhere in him. This combination of Jayden’s treatment and Julian’s new antibiotic seemed to be game-changers. He finally started to make progress, but the minute he came in contact with someone sick, he would experience an immediate increase of symptoms.

**Trudie:** When did you first consider IVIG?

**Amelia:** We first considered IVIG over the summer, when he had been house-bound for months. He was getting desperate and losing hope that he would ever get his childhood back, and his pediatrician agreed he was a good candidate for IVIG. Thankfully, he was approved, and the treatment is covered by the Ontario Health Insurance Plan. He had his first infusion in November 2017.

**Trudie:** Tell us about his infusion.

**Amelia:** Julian’s first IVIG treatment took place in our local hospital. He received high-dose IVIG after being well-hydrated for several hours. Half an hour before the infusion, he was given 30 ml of Benadryl to prevent any possible allergic reactions. The first infusion took approximately six hours, and he was kept on IV hydration throughout the night. His second infusion took approximately five hours. Julian did really well and had no side effects other than a mild headache before he left the hospital. The first night home, his headache became a migraine, and we treated him with Advil and lots of hydration.

**Trudie:** What advice do you have for parents who suspect PANDAS?

**Amelia:** If you notice a change of behavior in your children without any apparent reason, seek answers. Visit the doctor’s office and demand testing. I can’t stress enough the importance of knowledge. Knowledge is power! Spend the time doing the research and educating yourself on their illness and treatment choices. I would also recommend journaling everything. It is easy to see progress or regression on different treatments this way. Lastly, remember PANDAS affects the whole child, so forming a team of professionals who are willing to work with you and with each other is extremely important.

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**If you notice a change of behavior in your children without any apparent reason, seek answers.**

**Trudie:** How did he respond to IVIG treatment?

**Amelia:** The very next day, his PANDAS symptoms started to decrease. His OCD wasn’t as severe, and his mood was more stable. He was able to go upstairs to his room without having to come back down and up again. I know it is very early, but we are already seeing glimpses of positive change. The best part is he is noticing these changes himself, and hope for healing is finally coming back to him.

**Trudie:** How have you educated yourself about Julian’s condition?

**Amelia:** I researched everything I could to help me understand the journey we were about to embark on. I joined various Facebook support groups. I attended a screening of the film “My Kid is Not Crazy,” followed by a presentation by Ayla Wilson, ND, a naturopathic doctor treating this condition in Vancouver, B.C., Canada. I watched several You Tube video conferences featuring the top U.S. neurologists and pediatricians treating this illness. I have spent many late nights and full days in front of the computer trying to wrap my brain around the complexity of this illness and the treatment plans available.

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

By Stacy Oliver

I WAS GETTING my infusion of immune globulin again. Every two weeks, my body needs the magic juice to function. The first monthly cycle, it’s two days in a row, and the next cycle, it’s one day (my “bump” dose). And so it goes, like clockwork. It keeps me on an even keel. It’s never a joy to take steroids to combat aseptic meningitis symptoms that I might get, or the massive headache that might cause me to cancel our plans that evening, leading me to a quiet, darkened bedroom hugging my pit bull Lulu after I’ve taken enough meds to put a horse to sleep. No, I was feeling fine. My creativity was flowing, projects were humming along, my home nurse was good company as always, and we had new shows to watch on Netflix. I had even bought corned beef and rye bread to make sandwiches for lunch. Life was pretty good (it usually is when a homemade Reuben sandwich is involved).

I was in my own little world; it was a day of healing, planned out and set aside. That was on a Friday. When I checked Facebook two days later, I found out a childhood friend had unexpectedly passed away that Friday. The exact day I was getting treated to have a productive life, he had a brain aneurysm and was being treated to live. But, he didn’t. It didn’t seem possible; the smiley, tall, strong boy from my youth was gone. It seemed so unreal — upsetting, sad and unfair.

In a split second, tears of joy can easily turn to tears of sadness. One moment, I’m ecstatic for a friend giving birth to a healthy baby, and the next, I’m learning of a devastating hurricane ravaging an entire island of people. One starts to feel a bit guilty. How can I be so happy when there’s so much misery in the world? How can I be having such a good time when bad things are happening around me?

I’m no expert, nor do I profess to be. I am a mere mortal, and a very flawed one at that. But I know this much: This is life. I can hear my mom telling me this when I was a little girl. I would wonder why it was a special day like my birthday, and there would be a horrible murder in my city. I can hear her voice: “This is life.” As a young adult, I’d seen freedom for thousands of people with the fall of the Berlin Wall. Yet, thousands die from drought and famine from various countries every year. My mother’s words echo in my head: “This is life.”

Then, 10 years ago out of the blue, I got my three autoimmune diseases, forever changing my life. I lost friends because I got sick. I had to stop doing activities I loved. I have cried more tears in my life than I ever thought possible. Yet, during those same 10 years, I spent them married to the most wonderful man, I discovered IG Living magazine and now write for it, we bought a house, we enlarged our family from one dog to three, and we’ve traveled to visit loving friends. This is life.

Good with bad. Yin and yang. Dark and light. We can do our best, help where and when we can, be kind to one another and know that our small acts of good add up to a big positive effect. It’s OK to laugh, dance, love and eat cake. There will be hurricanes, horrible crimes, deaths, injustices, major personal setbacks and pain. There are two sides to a coin. There are faces for comedy and tragedy. Both happen at the same time. There’s ugliness and beauty in this world. I used to not believe my mom or really understand her. I believed that if I “controlled” the situation better that maybe the outcome would be different. It took 30 years to realize that isn’t the way to live. Let it go. You can only do so much. You can’t control the world.

I will miss my friend and mourn his death. Yet, I will keep living and be happy for it. I’m scheduling my next infusion, and I’m feeling pretty lucky to be able to do that. This is life.
Doctor Appointments and Transportation Obstacles

By Ilana Jacqueline

IN SOUTH FLORIDA, where I live, if you don’t have a car, you’re not going anywhere. There is virtually no public transportation and, only recently, has Uber started to become more available. Because of the heat, very few people walk or ride their bikes for more than a block. There are very few buses with few stops, no subways and no convenient train stations.

So, when you hear that people in Florida drive crazy, you can rest assured this is an accurate observation. Whether you’re too sick or too old to drive, you don’t have much choice if you need to get to a doctor and can’t find a reliable ride.

This has long been a nightmare for me. With all of my health problems, I prefer not to drive. While I might feel fine when I leave, I can’t predict how exhausted I’ll be when I need to go home. And, with chronic fatigue, I need to limit the length of time I allow myself to drive to avoid losing concentration. I also won’t drive on highways anymore.

Because of this, I have to limit the range of doctors I see. If I need to see a specialist who is in the next town, I have to find a reliable mode of transportation. Enter my mom. Moms are very reliable methods of transportation to and from doctor offices. This is because they love you, want you to be well and know how important it is that you get to your appointments safely.

While moms have their own lives and can also become exhausted, they will rarely hesitate to put these things before your medical needs — which is wonderful and certainly something you can appreciate during an emergency or a short period of illness.

However, for chronic illness patients, the mom solution lacks longevity. And, as with any family member or close friend who constantly offers support, you must take their support sporadically, and ideally find a more independent solution.

I feel very strongly about the saying: “It takes a village.” Those of us with chronic illness can’t rely on a single person to assist us. Support has to be executed by a team — friends, family and neighbors — as well as with money, technology and community.

In 2016, Blue Cross Blue Shield implemented a new initiative. To encourage a cost-effective, preventive plan for good health, the company decided to make sure every patient could get to their scheduled doctor appointment. Using services like Lyft and Uber, it picked up the tab for patients as often as needed. As a result, costs declined, hospital readmission rates fell and healthcare providers reported fewer cancelled appointments. Hopefully, more insurance companies will see the benefits of this and follow suit.

For those who have to rely on their own means of transportation, ride-sharing services are a good value. Though prices vary, they are most often drastically lower in price than a taxi, and certainly less expensive than an ambulance ride. Uber has implemented an excellent handicap-friendly branch of services, including drivers who allow service animals, wheelchair-accessible vans and even Uber-ASSIST, a program that provides vehicles operated by drivers who have obtained independent training from third-party organizations to assist riders into their cars.

Still, there are days when things don’t work out the way you plan. When I’m in a real bind, I’ve often asked my doctors if I can do my appointment over the phone or through Skype. Many have said no. But, a few have been fine with getting an update on my disease management in cases where an exam wasn’t entirely necessary. It never hurts to ask!

ILANA JACQUELINE is a 28-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.letsfeeltbetter.com is both a personal collection of anecdotes about life with chronic illness, as well as a resource for patients of all ages.
**How to Help a Child Deal with Being “Different”**

By Jessica Leigh Johnson

**AT SOME POINT**, every child will feel different — like they don’t fit in. Even adults feel this way at times. But certain aspects of a chronically ill or disabled child’s condition may set him or her apart from others. This is something that cannot be changed, and most likely won’t be outgrown.

My oldest son, who has a primary immunodeficiency disease, also suffers from lung disease and a chronic cough. Although it can be an annoyance to others, he can’t help it. Most of the children in his classes have grown up with him and are used to his cough; hopefully, it has become unnoticeable to them. But, last year, a new student had a class with my son, and the boy was quick to point out that my son must be sick because he coughs all the time. For several days, my son seemed down, and I didn’t know why. Finally, after asking him several times, he told me about the student and how he embarrassed him in front of his friends.

If I’d followed my maternal instincts, I would have marched straight to that kid’s house and yelled: “You have no idea how your careless words have hurt my son! He has lung disease!” But that wouldn’t have helped my son — not in the long run. So, how can parents help, other than following their child around school and threatening anyone who dares to comment on his differences? On the contrary, since he’ll have to deal with his condition for the rest of his life, he’ll need to figure out his own ways of dealing with being different.

**Don’t Minimize the Issue**

If a child has a learning disability or a physical condition that sets him apart from his peers, it’s not helpful for parents to say, “Don’t make such a big a deal out of this. You’re just like everyone else.” Because, really, the child isn’t like everyone else — and that’s not necessarily a bad thing. However, because children don’t have the emotional maturity to put things into proper perspective, their differences seem huge to them. They’ll just feel misunderstood if parents try to minimize that.

Let the child talk it out. Don’t try to make the problem seem like it’s not important, because to him, it is.

**Remind Children Regularly That They Are Loved**

According to James Lehman, a social worker who deals with behaviorally troubled youth, it’s normal for kids to want to be like everyone else. Fitting in gives them a sense of safety and security. So, when they say they don’t fit in, they may also be saying they don’t feel safe. To them, being different means being vulnerable. And, unfortunately, other children tend to single out kids who are different and can be very unkind.

One of the most important things parents can do is tell their different children often how much they love and care about them just the way they are. While they may feel like they don’t fit in with their peers, kids need to know home is a safe place where they’ll always belong. Parents should make a point of reminding their children about their strengths, instead of focusing on weaknesses, and complimenting them when they do something good or when they work hard at something that may come more easily for others. And, always offer plenty of hugs!

**Don’t Overreact; Put the Problem into Perspective**

It’s perfectly acceptable for parents to be concerned when their child is struggling with being different, but it’s too easy for parents to lose their objectivity when their child comes to them and says he is being picked on at school because of it. Parents can feel frightened for their child and powerless to help, or they may be angry,
but they need to be aware their initial response is probably based on a protective instinct, and not always the best response to display in front of the child.

If needed, parents should take five minutes to calm down or talk it through with another adult, but they should not overreact in front of the child. This will only make the child think the problem is really as bad as he thinks it is. Parents should instead acknowledge the issue, validate the child’s feelings and then bring the issue down to its proper size by saying something like: “Yeah, that is tough. What you’re going through happens to kids sometimes, but I’m sorry it’s happening to you. I know it hurts.”

When parents talk to their child, they can put things into perspective by reminding him that many other kids have felt out of place, or like they don’t fit in, and yet they’ve made it through. While it may seem huge now, it’s only for a time, and it truly is not the end of the world.

Try Positive Self-Talk

When children struggle with feeling different, parents can help them identify specifically with what is happening, and then suggest positive phrases they can recite in their minds whenever the situation arises. For example, if a child at school is picking on a girl for the way she dresses, parents can say: “It’s not your problem that Emily doesn’t like your clothes. It’s her problem. I know it makes you feel bad, but you’re OK. You’re great just the way you are, and I love you.” The child can turn her parents’ words into her own “self-talk” mantra, which she can recite to herself the next time it happens. Other positive phrases would be: “This is not my problem; it’s her problem,” or “I’m doing the best I can. If she doesn’t like me, there’s nothing I can do about it.” Parents can help coach younger children through this by role-playing these conversations.

Continue to Set Limits and Expectations

This may seem like tough love, but it’s important for children to learn to function appropriately no matter how they feel. Even if children are feeling bad or down, parents need to emphasize that regular responsibilities and tasks still need to be carried out. If a child comes home upset after a bad day at school, parents can say: “Take a few minutes to yourself, but then get started with your homework.” It’s OK for children to feel sad for a time, especially if they’re being picked on, but they still need to fulfill their obligations to the family. Even when they’re feeling this way, they still have to do their homework. They still have to join the family at the table for dinner, clean their room and treat others nicely.

By setting expectations, parents ensure that children continue to be responsible and keep up with the daily tasks of life. Otherwise, they will learn to be crippled by these bad feelings. This skill will benefit children into adulthood, when the stakes are higher and they can’t simply skip a day of work because someone at the office makes them feel bad. While hurt feelings are real and legitimate, it’s important for children to take charge over them. The fact remains: Once children become adults, they’ll have to fulfill their work, family and community obligations no matter how they feel.

Offer to Help

Parents can also bring the situation down to size by offering to help. This gives kids some tangible hope in an overwhelming situation. Help may come in the form of books, online resources or school by having discussions with teachers, administrators or counselors. No matter what, let children know that help is out there, and that they don’t have to deal with this on their own. One of the best things parents can ask their children is: “What would be helpful for you right now?” Also, let them know that it’s always OK to ask for help if they need it.

What if the Child Is Bullied?

Bullying is not acceptable, and today’s schools are working hard to raise awareness about and bring an end to bullying. If the child is being bullied, parents must be proactive with teachers and school administrators. Together, they can work out a plan for what to do if bullying occurs. While the child is in school, his physical and emotional safety is the school’s responsibility.

It’s so hard for parents to watch their children suffer for something they can’t change. When possible, parents should give their children opportunities to shine, express their strengths and do what they’re good at, which takes some of the focus off what makes them different. The most important thing is to equip children with the tools and strategies to deal with these situations on their own, while also offering plenty of love and affirmation.

References


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is a stay-at-home mom and mother of four kids, three of whom have X-linked agammaglobulinemia. She is a member of American Christian Fiction Writers and has written one book about the loss of her son to a primary immunodeficiency.
Exploring the Allure of Aromatherapy

By Trudie Mitschang

WHEN YOU LIVE with primary immunodeficiency (PI), medication regimens and treatment plans are typically deeply rooted in traditional medical science. This is why being offered an alternative treatment like aromatherapy tends to be dismissed at first glance as unhelpful or even silly. But, not so fast. The truth is aromatherapy and essential oils have been used effectively in conjunction with illness and disease for centuries, including during the deadly plague of the Black Death. As the story goes, a small band of marauding thieves seemed immune to the outbreak, and when the King demanded to know their secret, he learned the essential oils they rubbed on their bodies worked medicinally and prophylactically to ward off disease. Fast forward to 2018, when the benefits of essential oils continue to be used for their therapeutic properties, particularly when it comes to common immune disease symptoms and side effects.

What Is Aromatherapy?

Aromatherapy, or essential oil therapy, refers to a range of traditional, alternative or complementary therapies that use essential oils and other aromatic plant compounds. The National Association for Holistic Aromatherapy (NAHA) defines aromatherapy as “the therapeutic application or the medicinal use of aromatic substances (essential oils) for holistic healing.”

A range of essential oils have various degrees of antimicrobial properties, with many offering antiviral, nematicidal, antifungal, insecticidal and antioxidant benefits. These essential oils can be used topically and via inhalation, depending on the symptoms being treated. Keep in mind that aromatherapy is considered a complementary therapy, meaning it is used in conjunction with traditional treatments since it is not a “cure” for disease. Still, there are a number of PI-specific symptoms that may be improved through the use of essential oils and aromatherapy. Here is a list of common concerns and recommended aromatherapy options.

Fatigue. PI patients often lack energy and struggle with symptoms of chronic fatigue. Lemon oil, basil oil and eucalyptus oil can all be used to combat fatigue. Diffuse and inhale or mix with a carrier oil such as jojoba oil and apply to the forehead, heart and chest area. Ratio for mixture is approximately 10 drops of essential oil to one tablespoon of carrier oil.

Headache. Headaches and migraines seem to go hand-in-hand with intravenous immune globulin (IVIG) treatment, and some aromatherapy options can help alleviate headache pain. Peppermint oil has the ability to inhibit muscle contractions and helps stimulate blood flow in the forehead when applied topically. To improve blood circulation, reduce pain and relieve tension, dilute two to three drops of peppermint oil with coconut oil, and rub it into the shoulders, forehead and back of neck. Lavender essential oil induces relaxation and relieves tension and stress. There is also growing evidence that it serves as an effective treatment of neurological conditions. Lavender oil also regulates serotonin levels, which helps minimize pain in the nervous system that can lead to migraine attacks. To use, diffuse five drops of lavender oil and inhale the aroma, or apply lavender oil mixed with a carrier like coconut oil to the back of neck, temples and wrists to relieve tension headaches.

Muscle pain and inflammation. Muscle spasms and pain are common side effects of IVIG treatment. Thyme and rosemary essential oils are very effective for chronic muscle pain. Juniper and wintergreen essential oils are other proven remedies. Blend a few drops with one to two teaspoons of carrier oil, and apply to the affected area followed by a hot compress or heating pad for 30 minutes. Chamomile essential oil contains flavonoids that act as natural relief for joint and muscle pain. Make an anti-inflammatory essential oils blend by combining two drops each of frankincense and chamomile essential oil with two tablespoons of a carrier oil such as jojoba, coconut or almond. Gently apply the mixture to the affected area, and massage until fully absorbed. Essential oils can also be added to bathwater; add one cup of Epsom salts to a full tub with three to five drops of anti-inflammatory oils.

Nausea. Feeling nauseous is another common side effect associated with IVIG. To quell queasiness, try ginger, which is famous for its ability to calm an upset stomach, diarrhea, nausea, motion sickness and more. To use, place several drops of oil in a nebulizing diffuser, and inhale the steam until symptoms subside.

Living with PI can be greatly improved with regular IVIG treatment, but side effects of the treatment and chronic illness can still make life challenging. Aromatherapy is one of many complementary therapies that can safely and effectively improve symptoms and quality of life. However, patients should check with their physician prior to embarking on any alternative therapy or treatment plan.

TRUDIE MITSCHANG is a contributing writer for IG Living magazine.
**Perfumed Pendant**
The Pure Essences stainless steel oil diffuser pendant necklace is made from hypo-allergenic, surgical-grade stainless steel for sensitive skin. To use, simply put three to four drops of essential oil on the provided felt pad for therapeutic benefits throughout the day. $16.99; amazon.com

**Portable Relief**
The innovative Aromacube diffuser can be used at home or when traveling. Simply add 10 to 20 drops of essential or aroma oil blend and enjoy. Oils are not included. $29.99; aromatech.com

**Shopping Guide to Aromatherapy Products**

**Vapor Action**
The classic black Ultrasonic Nebulizer Diffuser provides a continuous gentle mist of essential oil and water blends. It comes with five timer settings and three mist settings. It can be used with any essential oil. $64.99; puritan.com

**Educational Essential**
*Modern Essentials: The Complete Guide to the Therapeutic Use of Essential Oils* offers practical advice for anyone wanting to learn about essential oils and their everyday uses. The easy-to-use format outlines which essential oils to use for hundreds of health conditions, how to safely and effectively apply them, and ways to incorporate oils into daily living. $27.95; aromatools.com

**Colorful Therapy**
This essential oil diffuser by Radha Beauty comes with seven changing colored LED lights to create a restful ambiance in any room. The diffuser uses ultrasonic waves to vaporize water and oil and create a gentle fragrant mist. $17.95; amazon.com

**Energizing Elixirs**
This essential oil kit from NOW Foods Solutions includes four 1/3 fluid ounce (10mL) bottles of energizing oils: lemon, orange, grapefruit and citrus/herb blend. Add to a diffuser, or create a room mister by adding 30 drops to 1 ounce of water in a spray bottle. $16.09; vitacost.com
**The Prince at the Ruined Tower: Time, Uncertainty & Chronic Illness**

Author: Michael D. Lockshin, MD  
Publisher: Custom Databanks Inc.

Dr. Lockshin is a pioneer in solving both the medical and personal healthcare issues for patients with chronic illnesses, having conducted research on autoimmune illnesses, particularly those that affect women such as systemic lupus erythematosus, antiphospholipid antibody syndrome and pregnancy-related problems of these illnesses. In this book, he explores seldom-discussed issues of contemporary medical practice: How should and how do patients, doctors, insurers and administrators respond when diagnoses are uncertain? How do they balance short-term versus long-term goals? Dr. Lockshin explores the notion that it is the doctor’s job to reject dogmatism and instead articulate uncertainty to himself/herself, the patient, the student and the administrative healthcare world.

**Medical and Psychosocial Aspects of Chronic Illness and Disability, 6th Edition**

Authors: Donna Falvo, PhD, and Beverly E. Holland, PhD, RN  
Publisher: Jones & Bartlett Learning

*Medical and Psychosocial Aspects of Chronic Illness, Sixth Edition* is intended to teach students, counselors and other medical professionals working with the chronically ill and disabled how to better understand the manifestations of common chronic illnesses and the disabilities among their clients. The text is designed as a reference for nonmedical professionals and students who have little prior medical knowledge. In addition to basic information regarding physical aspects of each chronic condition, the text addresses psychosocial aspects and the potential functional impact on activities and participation at home, work and employment.

**Chronic Babe 101: How to Craft an Incredible Life Beyond Illness**

Author: Jenni Grover  
Publisher: Orange Grove Media

This course-in-a-book contains 10 lessons in essential areas that women with chronic illness need to craft a life beyond chronic illness and become more than professional patients. Through personal stories, expert interviews, encouraging exercises and hundreds of resources, the author teaches “sick chicks” how to become “total babes!” Lessons include It All Starts with Learning to Practice Acceptance, Learn to Kick Those Bad Habits to the Curb, It’s Time to Turn Around Negative Thinking, Establish Healthy Boundaries to Create Confidence, Learn to Love Your Body Again, Build Your “Team” to Maximize Support, Strengthen Personal Relationships to Weave a Safety Net, Adapt Your Education and Career to Boost Success, Become a Talented Communicator and Get Organized: Tips, Tricks, Tools and Systems.

**You, Pain Free: Break Free of Chronic Pain and Get Your Life Back**

Authors: Jonathan Kuttner and Naomi Kuttner  
Publisher: Independently published

Jonathan Kuttner is a musculoskeletal pain specialist with more than 30 years helping people in chronic pain get their lives back. In this book, he introduces readers to the “6 Keys” model — a process to return the body to its natural pain-free mode. This step-by-step guide teaches the three chronic pain types and how to find out which one a person is (each type needs a very different approach to be treated successfully); how Dr. Kuttner went from daily back pain to pain-free kitesurfing in 12 weeks; techniques for in-the-moment pain relief that can be used anywhere at any time; and how to reprogram the pathways in one’s mind and body to turn down amplified pain.
Download the *IG Living* eBook today—now available for iPad, Nook and Kindle!

“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*.

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“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
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